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Perceptions and treatment of cutaneous leishmaniasis in Suriname

A medical-anthropological perspective



Sahiensshadebie Ramdas

Perceptions and treatment of cutaneous leishmaniasis in Suriname
A medical-anthropological perspective
Sahiensshadebie
Ramdas



**Perceptions and treatment of
cutaneous leishmaniasis in Suriname**

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Dedicated to

**my wonderful mum
my beloved father
my beautiful sisters
my dear brother**

**Biesmawatie Gopal
Ramdas Sewpersad
Urmila, Asha, Indra, Maya
Radjesh**

**Perceptions and treatment of
cutaneous leishmaniasis in Suriname**

A medical-anthropological perspective

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aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
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ten overstaan van een door het college voor promoties
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You can never cross the ocean until you have the courage to lose sight of the shore
(Christopher Colombus)



Source: http://www.kofc.org/en/columbia/detail/2012_06_columbus_interview.html

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List of acronyms (including names of Dutch and Surinamese organizations)

ACD	Active Case Detection
ACT	Amazone Conservation Team
AIDS	Acquired Immunodeficiency Syndrome
AISSR	Amsterdam Institute for Social Science Research
ATV	All Terrain Vehicles
Au	Aucan
BOG	Bureau voor Openbare Gezondheidszorg
BY	Busi Yasi
CL	Cutaneous Leishmaniasis
CMWO	Commissie Medisch Wetenschappelijk Onderzoek
DD	Dermatologische Dienst
EM	Explanatory Model
GDP	Gross Domestic Product
GNI	Gross National Income
HBM	Health Belief Model
HIV	Human Immunodeficiency Virus
IMF	International Monetary Fund
IRIN	UN Office for the coordination of Humanitarian Affairs
IRS	Indoor Residual Spraying
LLINS	Long-lasting Impregnated Nets
MZ	Medische Zending
MSA	Ministry of Social Affairs
NWO – WOTRO	Netherlands Organisation for Scientific Research – WOTRO Science for Global Development
PAHO	Pan-American Health Organization
PELESU	Pentamidine isethionate regimen for cutaneous Leishmaniasis in Suriname
Po	Portuguese
RGD	Regionale Gezondheids Dienst
Sa	Saramaccan
SD	Surinamese Dutch
Sr	Sranan
STINASU	Stichting Natuurbehoud Suriname
SZF	Staats Zieken Fonds
TPB	Theory of Planned Behaviour
Tr	Trio
VL	Visceral Leishmaniasis
WHO	World Health Organization

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Feeling gratitude and not expressing it is like wrapping a present and not giving it
– William Arthur Ward (1921-1994)

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Sahienshadebie Ramdas

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Chapter 1 Introduction

When I started my research about the social and cultural aspects related to the perceptions and treatment of cutaneous leishmaniasis (CL) in Suriname, I never thought I would hear a ‘faeces theory’ about how the illness is caused. During a focus group discussion with five Maroon men – gold diggers and woodcutters – in Boslanti, a village near Brokopondo centrum in a Saramaka Maroon community, I asked the group if they had ever heard of the illness *Busi Yasi* (the local name for CL). Pika, the oldest man in the group, aged 52, who claimed to have 25 years of experience working in the Amazonian woods, replied:

I have seen it [Busi Yasi] on people, yes. What I heard about this illness is that you can contract it if you go into the woods and shit [on the ground] somewhere in certain areas, and if you leave that [shit] without burying it. But if you dig a hole and bury the shit neatly, you will not contract this illness. Thus, if you shit, just like that, wherever you feel like, then you'll get it. I have seen this happening in certain working areas. And this is also what I heard from the elderly.

I was very surprised by this explanation, and at the same time very intrigued: “But what’s the relation between shitting and Busi Yasi?” I asked. Pika replied:

Certain woods do not like it. It is a kind of a *trefu* [allergy] that the bush has. For example, the bush here, around us [gesturing around with his arms], it does not like it when you just come and go shitting just like that. Then you'll get the disease. (...) Thus the things [spirits] that live in the woods, they do not like it.

As I looked around the group, all the men were listening with attention. “Do all of you think the same way about this illness, or have you heard of other causes?” I asked. “Well,” another younger man, Henk, a gold digger, replied,

what I heard, and what my experience – because I have also worked in this jungle for a long time – is that it is [caused by] some kind of leaf, I don't know which one exactly, but my experience is that if such a leaf rubs accidentally against your body, you can get it. But I don't know what leaf exactly it is. (...) it must have some kind of a bacteria or something.

Here Henk provided another disease causation theory, but then continued, in reaction to Pika's story:

I was with fifteen men in a [gold digger's] camp, seven of them got Busi Yasi; however, these seven men had been shitting everywhere, without properly burying their shit, indeed. The rest of us, we dug a hole and buried the shit, we never contracted it. I always dig a hole if I go shitting and I have never contracted the disease.

In previous conversations with other groups of Maroon men in another village, I had heard about dirty water as a cause of Busi Yasi, so I continued: "But what about dirty water? I heard it can cause BY too." John, a 42-year-old Saramacan Maroon gold digger, interpreted my remark as meaning that Busi Yasi could be caused by drinking dirty water. He replied: "I drink all kinds of water, I have never gotten it. As long as the water runs, I drink it, never experienced any problems with it." "No," I corrected, "I meant whether Busi Yasi is caused by entering dirty water or getting it on your body." Pika reacted quickly, "There is no water as dirty as water where gold is being mined; if you come out of that, you look so dirty that nobody would even recognise you. But such a person does not get it. It's all that *shitting around* that brings along this disease with it, woman [referring to me]." Everybody started laughing. "What about you?" I asked 38-year-old Mani, the fourth man in the group. "Do you know this disease?" Mani did not belong to the group of gold diggers working in Boslanti, but he had been working in the bush as a woodcutter and gold digger for about twelve years. "Yes, I heard about this illness," he replied, "I don't even want to take its name in my mouth because I'm so afraid of it; yes, it is a kind of a bacteria illness." In reaction to the 'shit' theory, he continued, "If you shit everywhere, then it is fucked up. It is better if you do the shitting in a righteous way." However, he then provided another explanation:

It is also a matter if you go into the woods and you don't wear any shirt. You'll be sweaty when you come back, you don't wash yourself and then you go lying down like that; you'll get itching and that will cause a sore. People don't like to bathe, that's why they get such diseases. If you come out of the jungle and you get washed, you won't get it.

John reacted:

I tell you, I won't get this illness, because if I come out of the woods, I shower very well. I'm just afraid of it [Busi Yasi], and if I come out of the woods and it itches me somewhere, I start thinking, hey, maybe it's Bus' Yasi, and then I take alcohol and I start burning the place where it's itching. I don't feel any itching anymore, later on, and then I'm relieved. I'm afraid of it.

Pika replied fiercely, "You guys are afraid of it?! I have told you what it is [shitting everywhere without burying it]. A plant, mosquito, itching. I've never gotten it. And I work already 25 years in the bush."

"What do *you* think about it?" I asked, directing the conversation towards Glen, a 31-year-old Saramaka Maroon gold digger and the fifth participant, who had been silent till now. He replied:

I believe what the men tell here [about shitting around]. But I heard others talking about it. And what I experienced is that it is caused by a certain liana, which may not be cut. (...) Nobody knows what kind of liana it is, but if you clean the forest [make it ready for gold digging], then if you cut it and its milk drops on your body, you'll get it. You also have certain things that bite you, and then it itches and you get Bus' Yasi. Look [showing a round shaped mark on his arm], I've got it here, but I

have never taken an injection, I treated it with bush medicines. And up till now my arm looks clean, it did not appear again.

“What did you apply to it?” I asked. “Here?” he answered, showing the sore on his arm,

the battery bar of big batteries, the one you use for the radio or flashlight. You break the battery and take out the black thing. I grated it fine – it should not be rough, but fine – and then I applied it to the sore. It has to pull out the water [wound fluid]. (...) I heard it from a friend of mine, as long as it [the battery bar] sticks to the sore, you don’t have to worry. (...) It is just poison, you have to put in onto the sore, it will kill it. (...) Other people use the turtle skin, they burn it and apply it to the sore. Look, if you get this disease and you make efforts to cure it, you won’t have any troubles.

Pika complemented this by saying:

What I also see is that many people go to the Dermatology Service, they have treatment for it. But indeed, people use these kinds of battery stuff, because you know, this thing, the more you itch it, the bigger it gets. Because it secretes some kind of fluid, if you itch it and the water [wound fluid] flows from one to the other place [showing from his elbow to his pulse], then you’ll get it there as well (...)

“Yes,” the others commented, “it is a very fucked up disease!”

1.1 Obscurity surrounding cutaneous leishmaniasis

From a ‘faeces’ to a ‘liana’ disease causation theory, from chemical treatments or natural products to the use of biomedicine, there are multiple explanations about this one single illness and multiple ways to cure it. Throughout my whole fieldwork period in Suriname, which began in September 2009 and continued for a period of ten months, I heard a rich variety of explanations about what could cause the disease cutaneous leishmaniasis (CL), or *Busi Yasi* as it is called in the Sranan language, the informal national language in Suriname. I collected extensive data among CL patients, as well as among Maroon and Indigenous people living in the hinterland, community members, traditional healers, and gold diggers, about perceptions, knowledge, and beliefs about CL; treatments for the disease: botanical medicines, biomedicines, non-biomedical chemical substances; aspects of stigma surrounding CL; and thoughts on prevention.

The disease cutaneous leishmaniasis is generally unknown in Suriname. It is mostly those living in the hinterland, namely Maroon and Indigenous communities, who are familiar with it. Those working in the hinterland, such as in the gold and lumber sector, also ‘know’ CL. The same counts for people visiting the hinterland for leisure purposes, such as for hunting, fishing, and camping. Vacationers or tourists who go into the woods may contract CL, but for them it is usually an alien disease. Indeed, for many who contract CL, as well as for those who see it on others or hear about it, it is often a mystery. I found it remarkable that nobody really seemed to

know anything exact about CL, such as how it is caused or what medicines are best to cure it. Nevertheless, many had somehow studied the illness from their own experience or that of others, and had found diverse ways to treat it. I was asked many questions during my fieldwork, such as: What is this disease? How is it exactly [biomedically] caused? Is it contagious? How can it be cured? Is it deadly? How can it be prevented? It quickly became clear to me that in Suriname, CL is surrounded by obscurity.

1.2 Framing cutaneous leishmaniasis research in Suriname

CL has never been a priority disease in Suriname. The first CL case in the country was reported in 1911 (Flu 1911). Until today, however, updated incidence numbers for CL are lacking. Epidemiological data is scattered, unstructured, and poorly collected and monitored. In 2008, Van der Meide and colleagues reported a detection rate for CL infections for 2006 of 5.32 to 6.13 CL patients per 1000 inhabitants for the hinterland and 0.64 to 0.74 patients per 1000 inhabitants for the whole country. Conclusions on possible changing incidence rates of CL in Suriname could not be drawn, however, since the detection rates could not be annualised (Van der Meide et al. 2008:195). The last estimations of the annual incidence of CL in Suriname were made between 1979 and 1985, wherein a mean annual incidence of 4.9 per 1000 inhabitants in the hinterland and 0.66 per 1000 for the whole country was reported (Burgus & Hudson 1994). In 2011, almost 300 new cases of CL were registered at the Dermatology Service in Paramaribo (Hu 2013:13). As Hu (2013:13) points out, however, these numbers may be an “underestimation of the true incidence as not all cases are officially reported; e.g. cases seen by general physicians, cases among Brazilian gold diggers, and persons who treat themselves with traditional medicine.”

Detection, treatment, and prevention of CL is, moreover, neither prioritised on a national level in Suriname nor on a global level generally. The World Health Organization (WHO) has acknowledged it as a severely neglected disease, and labelled leishmaniasis as a ‘Category 1’ disease, which covers emerging or uncontrolled diseases (WHO 2004:13). This neglect is imputed to poverty; the disease mostly affects poor people in remote areas and has been of little interest to the pharmaceutical industry since those affected by it usually lack the resources to buy the drugs to treat it (Schneider et al. 2008; WHO 2009:3). Despite the global research carried out to date, much about this disease is still unknown. Areas where information is lacking include: 1) the exact species of parasite involved and the exact type of leishmaniasis they cause; 2) the number of reservoirs (especially zoonotic); 3) treatments without side-effects or with less significant toxicity; and 4) appropriate prevention methods. Due to the global knowledge gap, the increase in the number of affected regions, the sharply rising number of recorded cases (Reyburn et al. 2003; Guernaoui et al. 2005; Guernaoui et al. 2006), outbreaks of epidemics (Pardo et al. 2006), and its major impact on public health and socio-economic activities, CL has currently been placed on the international health research agenda. This is especially so for health organisations involved in research regarding (neglected) tropical diseases.

Departing from this global context, several prominent health, research, and education institutions in the Netherlands and Suriname joined forces to study and combat CL in Suriname. During 2007-2008, they set up a multi-disciplinary research programme entitled 'Leishmaniasis in Suriname'. CL is endemic in Suriname and health professionals report it as an increasing health threat (Burgus & Hudson 1994; Van der Meide et al. 2008; Hu 2013). Congruent to the global picture, mainly poor populations in the interior of Suriname are affected. A leishmaniasis control programme in Suriname has yet to be established and prevention programmes are lacking. Since there is no vaccine against CL, early and accurate diagnosis and effective treatment are the only ways to control it (Hu 2013:15). However, medical doctors have reported that they increasingly experience treatment failure, possibly due to drug resistance against the available first line treatment. They have also reported non-compliance with biomedical treatment as being a huge problem in Suriname (ibid:31).

Taking the CL related problems into account, the **overall aim** of the research programme 'Leishmaniasis in Suriname' was to address all major aspects of leishmaniasis in Suriname through a multidisciplinary approach, consisting of clinical, biological, and anthropological perspectives. My colleague Dr. Ricardo Hu, a dermatologist, carried out *clinical* research that involved a clinical trial 'PELESU', in which two regimes of pentamidine isethionate, the biomedical drug available in Suriname for clinical treatment of CL, was studied. He compared treatment outcomes, side-effects, and drug toxicity, compliance to the treatment, cost effectiveness, and the quality of life of CL patients (see Hu 2013). My other colleague, Alida Kent, a medical biologist, carried out the *biological* part of the research, with the aim of providing better insight into the biology of the disease, namely the infecting *Leishmania* species, vectors and reservoirs, and epidemiology (see Kent 2013). I carried out the *anthropological* part that focused on the social and cultural aspects of CL. Those affected by and vulnerable to the disease were central to my study. How do (lay) perceptions, explanations, treatment preferences, and practices relate to the experience of illness, treatment seeking, and adherence to biomedical treatment? This was the central question that drove my research.

For those who may never have heard of CL before, it may be difficult to grasp what kind of illness it is and the global burden of the disease. For this reason, I think it useful to provide some biomedical background information on CL, including what causes it, the different types of leishmaniasis that exist, and the spread of CL throughout the world.

1.3 Cutaneous leishmaniasis: a biomedical profile

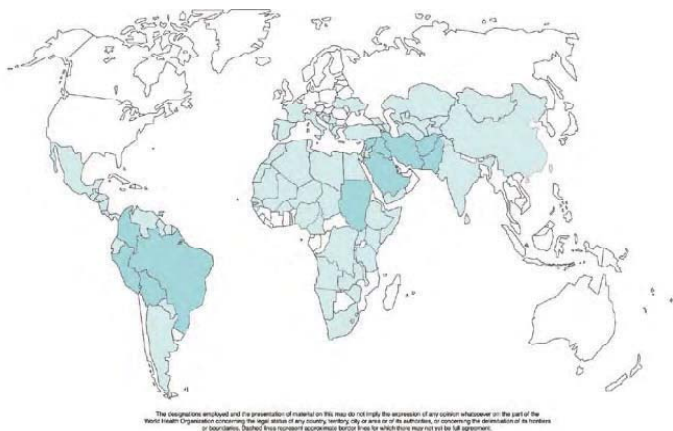
In the biomedical view, leishmaniasis is caused by protozoan *Leishmania* parasites. These parasites are transmitted via infected female phlebotomine sandflies (Diptera: Psychodidae) who feed on infected reservoir hosts (Desjeux 2004; Saliba & Oumeish 1999; Kassi et al. 2008), which can be both human and animal. Leishmaniasis is endemic in 88 countries and 350 million people are at risk; its prevalence is more than 12 million cases per year and disease incidence is more than 2.5 million cases per year (Bailey & Lockwood 2007; Desjeux 2004; WHO 2008). It occurs in tropical and subtropical areas and in southern Europe within

different environmental settings, such as rainforests in the Americas, deserts in western Asia, and in rural and peri-urban areas (Herwaldt 1999:1191).

Once bitten by an infected sandfly, the leishmania parasites can cause chronic infections, with two main clinical presentations: visceral and cutaneous/mucocutaneous. Visceral leishmaniasis (VL) has a multitude of (gradual) clinical features. The most important are swelling of the spleen and liver, recurring and irregular fever, anaemia, pancytopenia (shortage of all types of blood cells), weight loss, and weakness. Symptoms can appear over a period of weeks or even months. The disease is viewed as a silent killer, as it is fatal for almost all untreated cases (Boeleart et al. 2000; Hailu et al. 2005). Mucocutaneous leishmaniasis affects the mucous membranes, especially those of the nose, mouth, and throat. My research focused on cutaneous leishmaniasis, less lethal but nevertheless the second major type of leishmaniasis. Cutaneous leishmaniasis can be caused by at least 14 different species of parasite belonging to the subgenera *Vianna* and *Leishmania* (Silveira et al. 2004:239), and is divided into two major eco-epidemiological entities: anthroponotic CL and zoonotic CL. In anthroponotic forms, the sole source of infection for the sandfly vector are humans; in zoonotic transmission cycles, the reservoirs that maintain and disseminate the *Leishmania* parasites are animals (Desjeux 2001:239). Some currently known zoonotic reservoirs are hyraxes, sylvatic rodents, wild rodents, domestic dogs, sloths, anteaters, opossum, and a variety of forest rodents and marsupials (Bern et al. 2008:3; Kent et al. 2013).

According to the WHO (2007:1), CL is endemic in 82 countries spread over Southwest and Central Asia, the Middle East to Afghanistan, parts of Africa, and South and Central America; see the light coloured areas in Figure 1. Ten countries (see dark coloured areas) harbour more than 90% of the worldwide disease incidence: Afghanistan, Algeria, Iran, Syria, Saudi Arabia, Colombia, Brazil, Bolivia, and Peru (WHO 2007a; Bern et al. 2008; Desjeux 2004). Afghanistan, Syria, and Brazil are the main foci of CL (Pavli & Maltezos 2010).

Figure 1: Map of regions affected by cutaneous leishmaniasis



(Source: WHO 2007a:4)

The most prominent and disfiguring elements of CL are the extensive ulceration and scar formation. Lesions are often painless; they enlarge slowly and ultimately have a central ulceration, often covered with eschar (scab), surrounded by erythematous (redness of the skin), and with an indurated (hardened) border (Aronson et al. 2003). CL is therefore clinically considered “one of the most serious skin diseases in developing countries” (Gonzalez et al. 2008:1) and is often related to stigma.

1.4 Objectives of the study and research questions

In February 2009, a few months after the start of the research in November 2008, the multi-disciplinary research team for the ‘Leishmaniasis in Suriname’ programme held a national conference in Suriname, to which all national stakeholders were invited. Different non-governmental institutions working with Maroon and Indigenous communities in the hinterland, local cultural organisations, community health organisations, educational institutions, and national health professionals took part in the conference, where the three CL projects were presented, and gaps and problems concerning CL in Suriname identified and discussed.

All issues raised regarding the anthropological part of the research were related to health or treatment seeking, stigma, and (non-) compliance to biomedical treatment. How do people perceive and explain CL? What do they call the disease in their community? What do they do when they have the disease? Do they know what they have, and how do they diagnose it? Where do they go if they have the disease? How do they feel about it? These were some of the many questions brought forward during the conference. It became evident that little was known by medical professionals about the ‘social’ and ‘cultural’ side of CL. As a matter of fact, health perceptions and explanations, health seeking behaviour, and stigma relating to CL in Suriname have never been studied; up to now, studies done on CL in Suriname have been mainly from a biomedical perspective (Flu 1911; Burgus & Hudson 1994; Wijers & Linger 1966; Lai A Fat et al. 2002; Van der Meide et al. 2008a; Van der Meide et al. 2008b; Van der Meide et al. 2009; Hu et al. 2012; Hu 2013; Kent 2013).

In the Netherlands, the Royal Tropical Institute (KIT)’s unit for biomedical research, the Academic Medical Centre, and the University of Amsterdam facilitated and supported the ‘Leishmaniasis in Suriname’ programme. In Suriname itself, the Anton de Kom University, the Academic Hospital Paramaribo, the Ministry of Health, the Dermatology Services, the Medical Mission, and the Amazon Conservation Team Suriname were the main facilitating and supporting stakeholders. The programme was funded by the Netherlands Foundation for Scientific Research-WOTRO Science for Global Development (NWO-WOTRO).

The **general aim** of this anthropological research was to study the social and cultural aspects underlying the perceptions and treatment of CL in Suriname, in order to improve the management of CL and to facilitate better communication between patients and health workers. **The specific objectives** were: 1) to study (lay) perceptions, explanatory models, and treatment preferences and practices concerning CL among different ethnic and social groups, as well as among local traditional practitioners; 2) to ascertain overlapping and conflicting views and practices concerning CL treatment and prevention between local healers and biomedical professionals; 3) to assess the influence of stigma on local perceptions

of and treatment seeking for CL; 4) to investigate the socio-cultural and economic aspects affecting non-use of or non-adherence to professional health care regarding CL; and 5) to raise awareness of CL and improve public education about the disease.

Without a doubt, my research spanned a broad, multilevel area of investigation. Departing from the comprehensive central question and the aims of my study, I formulated a set of **sub-questions** that facilitated research and analysis:

1. What are the (lay) perceptions, explanatory models, treatment preferences, and practices concerning CL among CL patients, and among different ethnic and social groups (Maroon, Amerindian, Brazilian gold diggers)?

This sub-question provided the opportunity to look further into the dimensions of health seeking by exploring existing (lay) perceptions, beliefs, explanations, treatment preferences, and practices concerning CL among CL patients, and in the different hinterland communities and among different groups of people. How do CL patients and others in the different communities perceive and explain CL? How do they treat it? What are the common beliefs concerning CL? How is CL diagnosed? What are their thoughts on contamination? Is there a general tendency for self-treatment or a preference for traditional or biomedical health care, and if so, why?

2. How do traditional healers diagnose, explain, and treat CL, and how are the traditional treatments experienced by local people and CL patients?

The idea here was to gain more insight into the perceptions, explanations, beliefs, diagnoses, and treatment methods and practices of traditional healers, and to assess the efficacy of the treatment methods according to CL patients and local people. These insights may contribute to an understanding of the *kind* of diseases or symptoms diagnosed and categorised by traditional healers as CL, and why people experiencing CL may prefer traditional healing over biomedical treatment.

3. Which views or ideas are held by biomedical health practitioners about traditional health practitioners and vice versa regarding treatment and prevention of CL, and how do these perceptions and ideas relate to each other?

The objective of this question was to ascertain overlapping and conflicting views concerning diagnosis, treatment, and prevention of CL between local healers and biomedical professionals, and to bring into perspective the relational context in which these two systems operate in Suriname. Would, for example, a traditional healer recommend biomedical treatment for CL to a patient, and if so, why, when, and in which cases? And the other way around: would medical doctors or health workers recommend traditional healing, and if so, why and in which cases? Is there harmony or conflict between these two health systems in the field and how does this influence treatment seeking?

4. Do people with CL experience stigma, and if so, what type(s) of stigma and how?

In this research, special attention has been paid to the concept of stigma. Other studies conducted in the field of CL have emphasised that the disease causes unaesthetic or aesthetic stigma (Desjeux 2004:10; Bañuls et al. 2007:10), social stigma, and psychological stigma¹ (WHO 2007a:5; WHO 2008:5; Kassi et al. 2008:1). IRIN, the UN office for the coordination of humanitarian affairs, highlighted the impact of social stigma related to CL in Afghanistan, in particular for women, girls, and young men. It reported that women suffering from CL may be treated as outcasts by their community; girls may drop out of school when experiencing CL, especially when on the face, and several men encountered in the study had cancelled their engagements to their fiancée if she became facially disfigured by CL².

Reitingner and colleagues (2005) reported varying levels of exclusion in Afghanistan, “from minor domestic restrictions” (such as not sharing plates, cups, or towels) to severe “physical and emotional isolation” (Reitingner et al. 2005:635), such as not allowing someone with CL to hug your children, not allowing women with CL to breastfeed their babies, or not allowing someone with CL to cook for the family. As a result, people suffering from CL were found to become isolated, since Afghan communities believe that through isolation, further spread of lesions to other family members can be prevented.

In addition to the restriction of social participation of individuals affected by the disease, stigma is further reported as causing or precipitating psychological disorders, as well as emotional pain and suffering (Kassi et al. 2008:1). Social stigmatisation has been found to cause anxiety, depressive symptoms, and decreased body satisfaction and quality of life among CL patients (Yanik et al. 2004:467). Stigma has also been found to cause trauma among people suffering from CL, either by the disfigurement due to the lesions or scars or because of the painful treatment (Reitingner et al. 2005:635).

This third research question therefore provided space to explore the concept of stigma in depth; to determine the existence of stigma related to CL and the *kind* of stigma experienced or perceived in Suriname. Do people with CL actually experience discrimination (enacted stigma) due to the illness? Or do they apply a negative image to themselves, or experience fear of being discriminated against (perceived/internalised/felt stigma)?

5. In case CL stigma is limited or lacking in Suriname, how could this be explained and related to research in other CL affected regions where CL stigma has been described as a major problem?

As I have described above, the existing literature suggests stigma to be a major problem related to CL in affected regions and countries across the world. This sub-question, however, aimed to investigate the opposite situation: to explore possible lack of stigma in Suriname, and how to understand this against the backdrop of globally experienced CL stigma.

¹See web reference number 1.

²See web reference number 2.

6. How could non-use of biomedical health care services or non-adherence to biomedically advised therapies for CL be understood within the wider socio-cultural, economic, and geographical context?

This question sought to provide insight into other aspects that may hamper or facilitate the use of biomedical services and compliance to biomedical treatment. Is there easy access (financial, geographical) to biomedical health services, and how affordable are they? Are medical treatments available in the interior or do patients have to travel to the city? What are the major constraints for adherence to biomedical treatment?

7. How do CL patients, family and community members, traditional healers, and health professionals perceive CL prevention and – according to them – which aspects (in a socio-cultural, economic, environmental context) possibly contribute towards the spread of CL?

This final question looked into the aspect of prevention and provided a chance to generate the perspectives of CL patients, community members, and health authorities on the topic of prevention and spread of the disease. The insights provided here may be helpful for future CL prevention programmes.

1.5 Relevance of the study

My research *firstly* contributes towards increasing knowledge about CL on both a national and international level, since CL is a neglected and therefore under-studied disease. The study provides *new* information and insights about CL to the national (Surinamese) and international health community. *Secondly*, because of the anthropological approach in my study and the emphasis on the emic view of different ethnic and social groups regarding CL, my research contributes a *new kind* of information that may be useful for other affected countries and regions in the world. As mentioned earlier, particularly in Suriname medical anthropological research on health seeking behaviour in relation to CL has never been conducted. *Thirdly*, this study contributes academically to the discussion on the concept of health related stigma. Stigma is often linked to CL, with its strong skin damaging, deforming, and mutilating capabilities. While the concept of stigma is often used by social scientists, clinicians, health workers, and others engaged in health research in general, and with regard to CL studies in particular, this study highlights the caution that such actors must adopt when using it. *Fourthly*, my project is significant for Suriname as it adds value to current health authority initiatives, in both Suriname and the Netherlands, to combat and control leishmaniasis in Suriname. The anthropological angle of my study provides a different yet useful and complementary approach within the larger research programme.

In particular, this study is socially relevant. Since CL is an increasing health problem in Suriname and many aspects are not well understood or studied, there is an evident need for further studies on CL. The study will benefit all people suffering from CL, in particular communities living and working in the interior of Suriname (Maroons, Amer-Indians, Brazilian gold diggers) and medical experts and

organisations involved in providing health care for these communities. Some gold diggers in the hinterland with whom I spoke even expressed their relief: “Finally someone is inquiring about this disease. We *need* to know what it is, what causes it, because it is really bothering us!”

Possible collaboration between traditional healers and biomedical professionals may also be initiated or improved upon. Overall, my study provides practical and valuable in-depth insights, which can be used by health professionals to first and foremost *understand lay perceptions* of the disease, which in turn can be used for effective and early case detection and treatment, guidance of CL patients, and management and prevention of the disease in Suriname.

1.6 Outline of the study

This study reveals a wide range of aspects related to perceptions and treatment seeking in case of CL. Because of its comprehensive character, the study is outlined in a pathway model. The first three chapters (Chapters One, Two, and Three) present the skeleton of the research.

Chapter One provides the necessary introduction: it describes the illness characteristics; its global spread and familiarity within the Surinamese context; the set-up of the ‘Leishmaniasis in Suriname’ programme; the aims, scope, and relevance of the study; and the main questions that drove this study.

Chapter Two sets out the theoretical foundation of the study and discusses the core concepts used, with health seeking, adherence to biomedical treatment, and stigma being the main ones. In addition, a multidimensional pathway model into health seeking is depicted as a ‘route map’, laid out as a series of steps according to which the inquiries have been done.

Chapter Three, on the research methodology, is divided into two parts: the first provides a background about Suriname, its socio-demographic, geographic, and economic profile, and the main national and local stakeholders that facilitated the field research. This section also presents an overview of all research sites, and a sketch of the socio-cultural and geographical environment in which CL is mostly encountered. The second part focuses on the methodology used in the research. It provides insight into how the research was executed, who the target population was, and what methodological issues unfolded during fieldwork.

With the background information concerning the ‘Leishmaniasis in Suriname’ programme given, and with the theoretical and methodological foundation clarified, the next chapters (Four to Ten) form the rest of the body of the research, presenting, analysing, and discussing the research results.

Chapter Four provides in-depth insight into how the illness is perceived by those experiencing it, and describes a variety of explanatory views and lay diagnoses. The red thread through this chapter is how ‘not knowing’ gives rise to a multitude of aetiological explanations.

Chapter Five presents and describes a major trend in health seeking among CL patients: self-treatment. This chapter deals mainly with patients’ self-treatment practices, their advisors, the role of local healers in the treatment of CL, and the large inventory of medicines (bush medicines, biomedicines, non-biomedical

chemicals) used by patients in self-treatment. The quest for the 'right' medicine is also discussed.

Chapter Six delves further into the topic of self-medication, guided by the questions: What characteristics do the different medicines have in common? Are they helpful or harmful? And why are these particular medicines used to cure CL? The reasoning behind the use of such 'suitable' medicine is focused on, and insight is provided into other contexts that impact self-treatment, including the viewpoint of biomedical professionals on self-treatment of CL patients.

Chapter Seven focuses on a next step in the health seeking process: treatment seeking at biomedical health services. In my study, only when self-treatment failed did the majority of CL patients seek biomedical care. Since biomedical treatment involves taking painful injections, the chapter focuses on patients' attitudes towards the injections. The group of patients seeking only biomedical care are also further examined and certain aspects are revealed as possibly contributing to their seeking only biomedical treatment. The chapter furthermore focuses on (non-) adherence to biomedical treatment and shows how different aspects may be related to non-adherence.

Based on the ethnographic material, Chapters Five, Six, and Seven thus illuminate and discuss the health seeking trajectories of CL patients, starting from self-treatment and ending with seeking biomedical care. After the elaboration on the health seeking of CL patients, in Chapter Eight another dimension that is often associated with CL is highlighted: CL related stigma. The different dimensions of stigma are set out and inquiries into CL patients' negative experiences with their illness are analysed. A striking outcome is the near absence of CL stigma. In this chapter, this finding is compared to findings from other research projects looking at CL in different countries, wherein CL related stigma was found to be a grave problem. The relative absence of CL stigma in Suriname is therefore contextualised.

In the ninth chapter, inquiries into CL prevention from a micro (lay, patient) and macro (public health) level perspective are presented and discussed. Relationships between aetiological explanations and the preventive thoughts of CL patients are depicted. Furthermore, in order for CL management to be more effective, the benefits of taking lay perspectives into account, and integrating them into public health prevention programmes, is highlighted.

The results of this comprehensive research come together in the final chapter, which presents the conclusions, in which answers to the research questions are given based on the analysis of the research results. The inquiries into illness perceptions, the quest to cure, stigma, adherence and non-adherence to biomedical treatment, and prevention of CL are presented again in summary. Knowing and not knowing about CL, contradictions in explanations of the illness, contradictions and ambivalence in terms of medical choice, the near absence of stigma, and the practicality of this research are discussed. Based on the output of this study, recommendations are made. These recommendations should guide public health authorities in the design and implementation of purposeful CL education and prevention programmes in Suriname and beyond.

Chapter 2 Sketching the theoretical framework

2.1 A hybrid theoretical position

The fragment presented below of an interview with a CL patient illustrates well the main theoretical ideas present in this research. Pista, a 21-year-old Maroon man, working part-time as a bartender in the heart of the city Paramaribo and part-time as a gold digger in the rainforest, came to the Dermatology Service with a gaping wound on the back of his hand, in search of biomedical treatment after he had already tried many other chemical products to cure his sore. He had even tried Gramoxone, a highly poisonous herbicide manufactured to kill grass and control weeds, in his quest to cure his sore. The use of such harmful products to treat CL is worrisome for health professionals. But as Paul has expressed, “if you wish to help a community improve its health, you must learn to think like the people of that community” (1955:1), or as Green and Thorogood have written:

the best qualitative research starts by asking not what people get wrong, or don't know, or why they behave irrationally, but instead seeks to identify what they *do* know, how they maintain their health, and what the underlying rationality of their behaviour is (2006:20, original emphasis).

So, upon questioning Pista about why he had used such toxic chemicals in an attempt to cure his sore, he explained:

We always have Gramoxone at home, for the grass, but also against mosquitoes. When I saw it, I thought, Gramoxone kills everything. My sore was caused by Busi Yasi [CL]; busi meaning the bush, something of nature. And then I thought, if this [the sore] was caused by something of nature, something that kills everything in nature would probably also kill my sore. I just used one drop of it [Gramoxone], one drop on the sore and with some cotton I rubbed it into the sore. It hurt a lot, a lot! But I left it, and later added one more drop. But it started hurting me too much. In the evening, I tried to clear the thick green substance on top of the sore with a piece of cotton drenched in 70% alcohol, but it hurt me extra. It was burning, biting, pulling, and I just couldn't get rid of the pain. I then put my hand in the freezer, and kept it there for a few minutes. And then the sore started feeling a bit colder. Then I sat down, watched the television a bit and again, as it started hurting extra again, I put my hand in the freezer. I did so some two to three times. I hoped it would help, but it didn't cure my sore (Pista, Ramdas 2010: Dermatology Service)

Pista's story presents an *emic perspective* on treatment seeking; it reveals *his* thoughts and associations about using a certain type of medicine. In my research, emic reflections are strongly present; I focus on the points of view of the participants in my research, *their* ideas and perceptions about CL, and their treatment of it. With this *interpretative approach*, in the thesis I demonstrate how the behaviour of people experiencing CL, and their decisions regarding self-medication, traditional treatment, and non-use of or non-compliance with biomedical treatment, can be understood within their socio-cultural context. In the words of Van der Geest, “...anthropology is not a tool to ‘crack the secret code’. The main motive for studying the ‘lay

perspective' is that what these people think and say has value in itself" (2005:8). The interpretative approach underlines how people make sense of their world, how they *interpret* their world in a way that works for them. Within an interpretative approach, meaning and understanding are central:

Human beings differ in some essential respects from the objects of natural science inquiry. Unlike atoms (or plant or planets), human beings make sense of their place in the world, have views on researchers who are studying them, and behave in ways that are not determined in law-like ways. They are complex, unpredictable and reflect on their behaviour. Therefore ... instead of explaining people and society, research should aim to *understand* human behaviour (Green & Thorogood 2006:12, emphasis added).

Over time, numerous studies in the field of medical anthropology have proven that employing such a perspective can provide a valuable contribution to the enhancement of health. For many national and international aid programmes and disease control strategies, it is often crucial to have knowledge about emic cultural constructions, notions, and explanations of health and disease, since lack thereof may lead to the failure of community health programmes (Nichter 1992; Nichter & Nichter 1998).

While on the one hand I emphasise the importance of (lay) people's perceptions, beliefs, and explanations, on the other hand I do agree with critical anthropologists who draw attention to wider causes and determinants of decision making and treatment seeking. In the case of Pista, for example, several other contexts – economic, environmental, occupational, geographical – contributed to his health seeking behaviour. As Singers has remarked:

explanations that are limited to accounting for health-related issues in terms of the influence of human personalities, culturally constituted motivations and understandings, or even local ecological relationships are inadequate because this distorts and hides the structures of social relationship that unite (in some, often unequal fashion) and influence far-flung individuals, communities and even nations (2004:24).

Health issues should also be viewed within the context of "encompassing political and economic forces – including forces of institutional, national and global scale – that pattern human relationships, shape social behaviours, condition collective experiences, reorder local ecologies, and situate cultural meanings" (Baer et al. 2003:38).

I have therefore integrated my theoretical framework with a *critical perspective*, which I believe strengthens the research in terms of highlighting the different dimensions related to CL and the many forces at work. In light of such a perspective, I have inquired into the socio-economic and geographical factors that co-influence treatment seeking and (non-) compliance to biomedical treatment. With the critical perspective as a *complementary* approach, I have attempted to understand (perceptions and treatment of) CL in Suriname in light of the larger historical, social, economic, environmental, and geographical forces that shape explanatory models and health seeking, pattern social relationships and

vulnerability, and influence experiences of the disease. The distribution of health services and the role of traditional health practitioners versus the position of biomedical health professionals in the field of CL in Suriname have also been investigated.

Both approaches – interpretative and critical – are well known within medical anthropology. But by being *well known*, they do not become less important. On the contrary, especially in my research, both are highly necessary and functional because of the multi-disciplinary, pragmatic, and *exploratory* character of my research. Using middle-ranged theories, which “are often rooted in particular disciplines, and we acquire our knowledge of them through training as nurses, doctors, sociologists, psychologists etc.” (Green & Thorogood 2006:8), I have theoretically built upon concepts – health seeking, adherence, stigma – that have been widely used in different kinds of health research by social scientists in relation to health seeking. My research therefore fits well into the current research arena, and by employing an interpretative approach complemented by a critical perspective, aspects that can improve doctor-patient communication can be pointed out, support groups can be guided, and collaboration with actors both in the biomedical field as well as in the ‘traditional’ healing domain can be facilitated, all in order to manage disease – in this case CL – more effectively. By taking socio-cultural determinants of health and disease into account, and by incorporating a critical perspective towards other determining factors, CL prevention programmes can be carefully planned and successfully launched and maintained. In the following sections, I elaborate further on the main concepts that constitute the theoretical perspective of my research and highlight how they have been used in this study.

2.1.1 Health or treatment seeking

The concept of health or treatment seeking is one of the core concepts used in health research aimed at providing in-depth knowledge and understanding of the whole range of motivations, actions, and behaviours that people cross-culturally have about or in response to diseases and ill health. Although the terminology used by social scientists to define the concept of health or treatment seeking may vary, the different variations nevertheless have more or less the same characteristics, namely that they: 1) regard understandings, perceptions, labels, beliefs, and explanations people have about a certain disease or symptoms of that disease as important; 2) refer to actions or activities undertaken by individuals to find an appropriate treatment or remedy; 3) examine compliance or non-compliance to biomedical treatment; and 4) refer to ideas and practices to maintain health and prevent disease (Foster & Anderson 1978; Kleinman 1980; Helman 2000; Young 1983). Health or treatment seeking thus regards the whole process of thoughts, actions, and behaviours of people in terms of their seeking – or not seeking – treatment for a perceived illness. As such, it fits well as a base theoretical model for this research.

2.1.2 Concise overview of health or treatment seeking models

Over the past five to six decades, several models have been developed to interpret, explain, and even predict health seeking behaviour. Probably the most well known

models used in public health (as outlined by Broslov 2002; Green & Thorogood 2006; Francis et al. 2004; Hardon 2001; Hausmann-Muela et al. 2003; Helman 2002; Mac Kian et al. 2004) are the Health Belief Model (Rosenstock 1966; Harrison et al. 1992), the Theory of Reasoned Action and its later development as the Theory of Planned Behaviour (Ajzen & Fishbein 1980), the 'model of the four As' (Hausmann-Muela et al. 2003), the Health Care Utilisation or Socio-Behavioural Model (Andersen & Newman 1973; Kroeger 1983), the Pathway Model (Kroeger 1983; Good 1987), and the ethnographic Decision Making Model (Weller et al. 1997; Young 1981; Garro 1998).

The Health Belief Model (HBM) and the Theory of Planned Behaviour (TPB) are grounded in social psychology. The HBM was first developed in the 1950s out of the need to explain health behaviour: Why do people take a particular health related action? Why do people, for example, seek a screening test or examination for asymptomatic diseases such as tuberculosis, hypertension, or early cancer? Or why do they use condoms? An important assumption of the HBM is that people can influence their health because they act from the desire not to fall ill or to stay healthy. According to the HBM, a person will take a health related action based on: 1) the belief that his or her health is in jeopardy, or that he or she can have a disease but not yet feel the symptoms (perceived susceptibility); 2) the person's perception of the 'potential seriousness' of the condition in terms of pain, discomfort, time lost from work, economic difficulties, or other outcomes (perceived severity); 3) the person believing, after assessing the circumstances, that a recommended action outweighs the costs and that such an action is possible and within his or her grasp (perceived benefits/barriers); 4) the person's awareness and readiness to be concerned about health issues (general health motivation); and 5) the person receiving certain 'cues to action' (such as media information, education) or a precipitating force (such as symptoms) that strongly influence him or her to undertake action.

The latter two assumptions (points four and five in the list above) have been added over the past three decades, and include the concepts of 'demographic' and 'structural' variables (such as age, class, sex, ethnicity, religion, socio-economics, knowledge, etc.) and 'psychological characteristics' (personality, peer group pressure, etc.), which can to certain and differing extents influence the perceptions of a person (Broslov 2002; Hausmann-Muela et al. 2003:10). The HBM thus focuses on the attitudes and beliefs of individuals and attempts to explain and predict given health related behaviours based on certain belief patterns about recommended health behaviour and the health condition that the behaviour was intended to prevent or control.³

Over the past years, the HBM has been used in diverse health studies covering three broad areas: 1) preventive health behaviours, focused also on health promotion (such as dieting, exercising), (sexual) health risk behaviours (such as not using condoms, smoking), and vaccination and contraception practices; 2) sick role behaviours, referring to compliance to biomedical treatment regimens; and 3) clinic use (Conner & Norman 1996). The HBM has frequently been used in surveys and has proven valuable in providing "interesting and highly relevant findings for health

³See web reference number 3.

promotion” (Hausmann-Muela et al. 2003:10). But it is also criticised for neglecting other determinants of health seeking and lacking consistency in predictions for many behaviours due to its limited scope in terms of predisposing factors (Harrison et al. 1992; Hausmann-Muela et al. 2003).

The other main socio-psychological model is the Theory of Reasoned Action, later renamed the Theory of Planned Behaviour (TPB). This model focuses on predicting whether a person intends to do something by investigating attitudes, subjective norms, and perceived behavioural control (Francis et al. 2004:7). According to the TPB, human action is guided by three considerations: 1) behavioural beliefs, namely beliefs about the likely consequences of a behaviour; 2) normative beliefs about the normative expectations of others; and 3) control beliefs, which are beliefs about the factors present that may facilitate or hamper certain behaviour.⁴ The concept of perceived behavioural control in the TPB was derived from Bandura’s (1977) concept of self-efficacy: whether a person persists in a certain behaviour in different circumstances depends on his/her perception of individual mastery over the behaviour (Mark et al. 2004). Just as with the HBM, the most important assumption of the TPB is that people are rational decision makers who freely control their own behaviour. Motivation, according to this model, is the best predictor of behaviour (Scheerder et al. 2003:52).

The TPB has been very useful in the development of communication strategies, in particular due to its focus on the influence of social networks and peer pressure on health seeking behaviour (Hausmann-Muella et al. 2003:12) and for evaluation studies.⁵ It is especially suitable for projects aimed at bringing about behavioural change through intervention, with aspects of information, education, and communication in general (Scheerder et al. 2003:52), and is, for example, abundantly used in HIV/AIDS research (Hausmann-Muela et al. 2003:12). However, this model too is criticised for being too rationalistic, for its overemphasis on psychological factors, lack of a temporal element, and for the minimal attention given to social variables and structural factors, such as limited access to or availability of resources (Berry 2007:32; Hausmann-Muela et al. 2003:12).

The Health Care Utilisation or Socio-Behavioural Model (Andersen & Newman 1973) was specifically developed to investigate the use of biomedical health services, and later extended to include other health care sectors. It is a prediction model, providing insights by predicting levels of utilisation and describing patterns by focusing on three categories of factors: predisposing factors (i.e. age, gender, religion, education, knowledge about illness, etc.), enabling factors (availability of services, affordability, health insurance, social network support, etc.), and need factors (perception of severity, number of sick days for illness, days in bed, help with care from outside, etc.), all of which influence health behaviour (Hausman-Muela et al. 2003:12-13). This model centres specifically on treatment selection and includes both material and structural factors. It is used in particular for working with statistical data on actual cases (Weller et al. 1997) and “for gaining evidence on the weight of different factors for health service use” (Hausman-Muela et al. 2003:13).

⁴See web reference number 4.

⁵See web reference number 5.

Kroeger (1983) elaborated on this model, combining most of Andersen's categories of factors into a single category of 'independent variables', with so-called 'dependent variables' "reflecting the availability of different resources of health care, to predict individual choice of health care resource" (Stekelenburg 2004:80). This model, known as the Determinant Model, outlines a set of determinants that are associated with the choice for different kinds of health service, and is based on a more biomedical and quantitative approach. It has been found to be useful due to the variety of factors organised into categories, which elaborate on how and why interventions or therapeutic options (or the lack thereof) are (not) feasible, and it has also been found to establish correlations with good predictability; however, it does not specify how and why different factors affect therapeutic selection (Weller et al. 1997).

Kroeger (1983) also identified the Pathway Model, a more anthropological approach to health seeking that describes the steps of the health seeking process, from recognition of the symptoms to the use of a particular health service. The Pathway Model uses primarily qualitative research methods to concentrate on the sequence of steps in health seeking behaviour and to investigate the social and cultural factors that affect this sequence (Ward et al. 1997:23). This model of health seeking is thus more descriptive, in which health seeking is depicted as a dynamic process. Both Kroeger (1983:148) and Loue (1999:69) mention the models of Suchman (1965), Fabrega (1972), Chrisman (1977), and Igun (1979), all of which explain the health seeking process, as examples of pathway models. In all pathway models, different key steps (such as recognition of symptoms, decision making, use of health systems, evaluation of the outcome, and reinterpretation of illness) are broadly investigated and aspects or factors determining the course of treatment path are sequentially brought into view; though some researchers do stress that not all of the identified steps need always to occur, and also that they need not be sequential in their occurrence (Chrisman 1977). In pathway models, health seeking is depicted as a dynamic process and the importance of 'significant others' in the process is often emphasised (Good 1987; Janzen 1987; Kleinman 1980). Such models are viewed as very useful and complementary to other quantitative health research models (Ward 1997:23).

Another model, rooted in the General Comment on the Right to Health as adopted in 2000 by the UN Committee on Economic, Social, and Cultural rights (WHO 2007b) and widely used by health researchers (such as medical geographers, anthropologists, and epidemiologists) emphasises the dimensions of access to health care services that influence the course of health seeking (Obrist et al. 2007:e308; Hausmann-Muela et al. 2003:14). According to this model, which is often referred to as 'the model of the four As' (Hausmann-Muela et al. 2003:14), access to health care becomes an important issue to be investigated once illness is recognised and treatment seeking initiated (Obrist et al. 2007:e308). In this model, five elements of access to health care are emphasised, namely availability, accessibility, affordability, adequacy, and acceptability (ibid); note that Obrist and colleagues (2007) add a fifth A – Adequacy – to the original four as outlined by Hausmann-Muela and colleagues (2003). *Availability* refers to existing health services and goods, and whether they meet clients' needs. Questions to be asked in this regard are: What types of services exist? Which organisations offer these services? Are there enough skilled personnel? Are there enough supplies to cover

demand? *Accessibility* refers to the geographical distribution of health facilities in relation to the living areas of users, means of transportation, roads, and time and financial costs regarding transportation. *Affordability* refers to treatment costs, the ability of clients to pay health care costs, health insurance coverage, etc. *Adequacy* looks at the organisation of health care in terms of meeting clients' expectations: How are services organised? Do facilities' opening hours match the working schedules of clients? Are facilities clean and well kept? Finally, *acceptability* refers to whether the characteristics of providers match those of clients. Do, for example, the information, explanations, and treatment provided take local illness concepts and social values into account? Do patients feel welcome and do they have trust in the competence and personality of health workers? This model is predominantly used to identify key potential 'barriers' to adequate treatment seeking or provision (Hausman-Muela et al. 2003:14), and to understand health seeking within a socio-economic context (Obrist et al. 2007:e308).

The last in the group of health seeking models are ethnographic decision making models. These models are viewed as predictive (Hausman-Muela et al. 2003:17; Matthews 1987:55) and "seek to understand what people do when faced with illness and typically attempt to account for actions taken to deal with illness" (Garro 1998:318). Well known examples of such models are those of Young (1981) and Garro (1998), who investigated treatment choice in Pichataro, Mexico, and found four criteria relevant for treatment choice: 1) gravity of the illness; 2) knowledge of appropriate home remedies; 3) faith or confidence in the effectiveness of the home remedy for a given illness; and 4) the expense of treatment and availability of resources. Weller and colleagues (1997) also identified three main criteria for treatment choice in a Guatemalan community: 1) severity of the illness; 2) economic resources; and 3) prior experience with the illness. Ethnographic decision making models tend to follow a sequential method. First there is an ethnographic assessment, in which key factors as pointed out by a community are noted. This is followed by the creation of hypothetical scenarios or vignettes by the researchers, which are presented to respondents. The responses to these scenarios or vignettes are then quantified into percentages, and predictive statements or conclusions are made. Finally, data are compared with actual cases to test the predictability of the model (Hausman-Muela et al. 2003:17).

2.1.3 Building further on a multidimensional pathway model for health seeking

Many of the abovementioned health seeking models are viewed as prediction models, while some are designed to provide causal explanations. Such models are, however, often criticised as being too rationalistic, suggesting that people are – or should be – very logical in the choices they make for treatment. This contradicts certain statements that ill people make when seeking treatment or certain decisions that they take that are not solely based on rational reasoning. As Crandon-Malamud (1991:33) has pointed out, illness also provides a means to position oneself socially, culturally, and politically.

In this study, I have used a combination of certain health seeking models to direct my research. I emphasise, however, that my aim was not to predict health seeking behaviour, but rather to contextualise, analyse, and provide understanding

of the complex process of health or treatment seeking among people with CL, through the viewpoint(s) of the different actors related to and involved in the process. With a qualitative approach, I provide insight into the underlying motivations and explanations regarding health or treatment seeking, which can be understood well within the multidimensional context of people dealing with CL in their daily lives.

Based on the above described characteristics and scope of the main health seeking models widely used in health research, and taking the nature of my research (including the research questions and methods) into account, I found the pathway models to be the most advantageous. Given that I used a qualitative methodology in my research, and based on the exploratory nature of my study, the HBM, TPB, Health Care Utilisation Model or Socio-Behavioural Model, and Ethnographic Decision Making Models were not suitable.

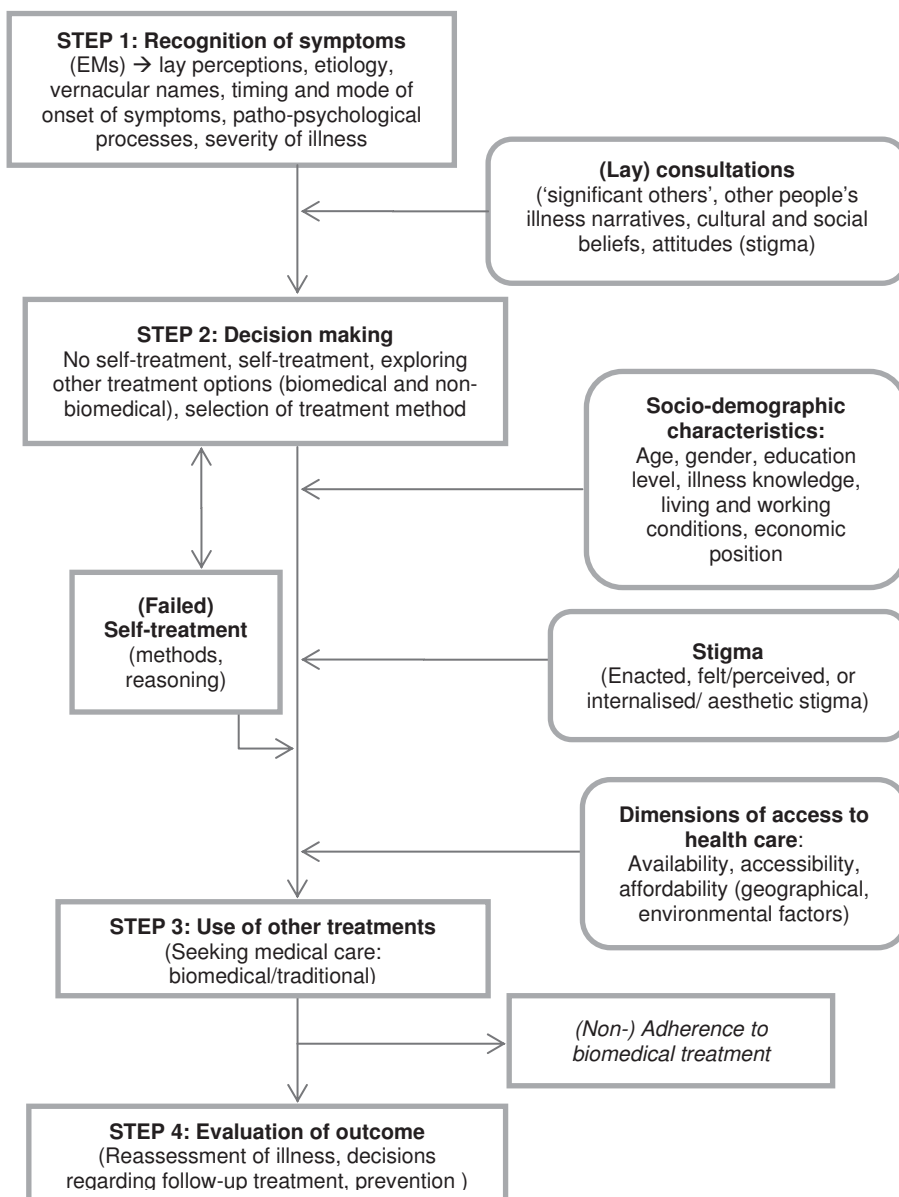
Guided by the pathway concept, my research is partially influenced by Arthur Kleinman's (1980) Explanatory Model (EM) approach for understanding health seeking behaviour within the clinical setting. Kleinman provides the idea that there is a conceptual framework, which he named 'explanatory models', which is held both by patients and health practitioners, according to which the process of illness is patterned, interpreted, and treated (Helman 2001:85). EMs address five aspects of illness: 1) the aetiology or cause of the disease; 2) the timing and mode of onset of symptoms; 3) the patho-physiological processes involved; 4) the natural history and severity of the illness; and 5) the appropriate treatments for the condition. These aspects, according to Kleinman, play an important role in health seeking. They are, amongst other things, also the focus of pathway models, and I viewed them not in isolation but in terms of the ways in which they correlate with each other and how they influence or affect the perceptions, attitudes, behaviours, and actions of CL patients.

In line with the focus of pathway models, I also looked at the role of 'significant others' in the health seeking process, especially from the viewpoint of CL patients. Social networks are often important and very influential in terms of decision making and health seeking (Good 1987). Identifying and understanding the social networks of people suffering from CL illuminated how or why certain choices were made. A social network can best be understood as a socially bounded group in which the relationships of all members to each other can be defined (Trotter 1999:6). In my research, certain groups of people – such as gold diggers, hunters, woodcutters, and those used to living in the forest – had more ethno-medical treatment knowledge of the disease CL than other groups. It was therefore useful to inquire into the social networks of CL patients and to explore the relationships that CL patients had with members of these social networks and the ways in which this influenced decision making. In complementing my research by taking the model of the four As as my point of departure, I particularly looked into the role of the availability, affordability, and accessibility of health care services in the health seeking processes of CL patients.

Below I have sketched out a multidimensional pathway model for health seeking, which I followed when conducting the research in Suriname. The vertical arrows indicate the steps involved in the health seeking process of CL patients. The horizontal arrows indicate the detected socio-cultural, socio-psychological, economic, geographical, and environmental aspects, which contribute to the

contextualisation and in-depth understanding of the health seeking behaviour of CL patients.

Figure 2: A multidimensional pathway model for health seeking by CL patients in Suriname



In the above model, I have used different components from different health seeking models in order to understand the health seeking behaviour of people who had either previously experienced or were currently experiencing CL at the time of my research. The model contains elements from the pathway concept, investigating one aspect at a time in the process of the illness experience. It uses a part of the model of the four As to focus specifically on the many dimensions of health care services, and it also zooms into the larger multi-contextual situation in which health seeking takes place. This multidimensional pathway model represents a somewhat different approach to many current health seeking studies, where the use of models with such diverse components – in the way that I use them – is generally lacking. The model that I propose is broad and enables health researchers to combine health seeking models in such a way that several contexts important to a given situation can be added, or in the reverse situation removed, as needed. This model can be viewed as a 'route map', a guide for collecting data on various aspects present or emerging from the field and which require further in-depth investigation. It can be used in exploratory/descriptive and explanatory studies. It is designed in this case especially for the illness CL; however, because of its flexibility, it can be adjusted for other types of chronic and non-chronic illnesses.

Taking into consideration the overall aim of the larger, multidisciplinary programme of which my research was a part, the benefits of such a multidimensional approach are clear. Changing or influencing the adaptation of behaviour is often the concern of public health organisations and health promotion initiatives. Without in-depth understanding of people's (health seeking) behaviours, as well as insights into wider (socio-economic, geographical) aspects contributing to these behaviours, the possibilities for change or effective interventions are unlikely to be identified.

2.1.4 (Non-) compliance or adherence

Imbedded within the concept of health or treatment seeking is the issue of adherence and compliance, or the opposite, non-adherence and non-compliance. Non-compliance is reported as a major problem in the health care sector, especially for patients with chronic diseases. In the US alone, the financial burden due to non-compliance has been estimated at US\$100 billion each year (Vermeire et al. 2001:331). In Suriname, medical doctors treating patients with CL, who were interviewed for this research, also reported problematic compliance among patients.

Compliance is defined differently in different health studies, but in general means complying with the prescriptions of doctors, using their medicine(s), and following a prescribed course of therapy or medical advice. Non-compliance is the failure to do so (Vermeire et al. 2001:332). The concept of non-compliance is very broad and can be characterised as:

delay in seeking care (population at risk), non-participation in health programmes (screening), breaking of appointments (follow up), failure to follow doctor's instructions...receiving a prescription, but not having it made up at a pharmacy, taking an incorrect dose, taking the medication at wrong times, forgetting one or more doses of the medication, stopping the treatment too soon, either by ceasing to take the medication sooner

than the doctor recommended or failing to obtain a repeat prescription. Furthermore compliance may be intentional or unintentional (Vermeire et al. 2001:332-333).

To many, the term compliance implies negative connotations. It suggests “yielding, complaisance and submission”, and “implies disobedience” and “accepting punishment” (ibid:332). It indicates a “hierarchical relationship where one person obeys another for the good of the individual”, and is a “value-laden term and implies a one-way flow of information from practitioner to client rather than a transaction between the two parties” (Parry 1984:929). These criticisms reflect the authoritative attitudes that medical doctors may have towards patients. Other terms such as adherence (Dunbar 1980) and concordance (Anon 1997) are therefore proposed as an alternative to compliance, to promote the idea that medical treatment should be communicated between doctor and patient with a tone of mutual respect and understanding.

Adherence is often defined as “the extent to which a person’s behaviour coincides with medical advice” (Velligan et al. 2006:724). This term seems to reduce the attribution of greater power to the doctor-patient relationship and gives room to “incorporate broader notions of concordance, cooperation and partnership” (Vermeire et al. 2001:333). In the concept of concordance, the patient is viewed as a decision maker; concordance is a patient’s considered choice. As Vermeire and colleagues (2001:333) state, “This [model of concordance] is a fundamental step away from the traditional compliance model. Compliance signifies the theoretical intention of prescription; concordance signifies the practical and ethical goal of treatment”. Being aware of the conceptual differences between and debate over the terms compliance, adherence, and concordance, I decided in my research to work with the concept of adherence. Important questions in this regard were: To what extent is there non-adherence to biomedical CL treatment? And is there negotiation between doctors and patients about medication treatment? Apart from (non-) adherence, another concept closely related to health seeking, and next to be discussed, is that of health related stigma.

2.1.5 Stigma

Certain beliefs, perceptions, and attitudes that people have about a disease often transform relationships to cause stigma. Starting from Goffman’s (1963) classic definition of stigma as implying a ‘spoiled identity’, authors focusing on health related stigma emphasise that the symptoms and perceived causes of a disease may discredit patients suffering from that particular disease as well as those associated with them (Herek & Capitanio 1999; Jacoby et al. 2005; Van Brakel 2006; Weiss et al. 2000; Weiss & Ramakrishna 2004). Stigmatisation is a process of social disqualification; it creates and maintains social inequity and possibly reinforces other forms of inequity (gender, poverty, ethnicity), in addition to leading to the suffering of pain and dependency due to the disease.

Over the past four decades, the concept of stigma has been increasingly used in health research studies (Balasubramanian et al. 2000; Boonmongkon 1994; Jacoby et al. 2007; Herek & Capitanio 1999; Johansson et al. 1999), leading to a wide variety of definitions and conceptualisations. Rather than being a debated

concept, stigma is currently viewed as one of the key concepts that is (or can be) central to many other debates about coping mechanisms as well as prevention strategies. Focus on health related stigma in particular – due to its contribution to the burden of illness and its negative influence on the effectiveness of case detection and treatment – has grown strikingly in recent years. Many health researchers therefore urge for more investigation into the experience and impact of health related stigma, the relationships between distinct components of stigma and factors resulting in stigma, the development of a generic set of stigma assessment instruments, and identification of effective intervention strategies to reduce stigma (Callard et al. 2009; Van Brakel et al. 2006; Weiss et al. 2006).

In response to the growing public health interest in stigma and the need for a working definition of health related stigma, Weiss and Ramakrishna (2004) proposed a concise yet comprehensive definition as a guide for better public health research, policy, and action. I base my own understanding of health related stigma on their definition:

Stigma is typically a 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. [In health related stigma] [t]his judgment is based on an enduring feature of identity conferred by a health problem or health-related condition, and the judgment is in some essential way medically unwarranted. In addition to its application to persons or a group, the discriminatory social judgment may also be applied to the disease or designated health problem itself with repercussions in social and health policy. Other forms of stigma, which result from adverse social judgments about enduring features of identity apart from health-related conditions (e.g. race, ethnicity, sexual preferences), may also affect health; these are also matters of interest that concern questions of health-related stigma (Weiss & Ramakrishna 2004:13, emphasis added).

In short, health related stigma is thus “typically characterized by social disqualification of individuals and populations who are identified with particular health problems” (ibid:1). It is a prominent dimension of many chronic health problems such as HIV/AIDS, leprosy, tuberculosis, mental ill health, and epilepsy, and can have a severe impact on individuals and their families (Van Brakel 2006:2). In the context of stigma, I worked further with the concepts of enacted, perceived or felt, and internalised stigma (Scambler 1984; Scambler & Hopkins 1986).

Enacted stigma refers to “episodes of discrimination against people [with an illness or chronic disease] solely on the grounds of their social and cultural unacceptability” (Scambler 2004:32) or to “overt acts of discrimination and hostility directed at a person because of his or her perceived stigmatized status” (Steward et al. 2008:1226). *Perceived or felt stigma* has two referents: 1) the shame of being associated with a certain illness; and 2) the fear of encountering enacted stigma (Scambler 2004:32). It may also relate to “expectations about the circumstances in which stigma will be enacted” (Herek et al. 2009:32). It reflects “a person’s internalized social values about his or her condition or difference” and refers to the “subjective awareness of stigma” (Steward et al. 2008:1226). *Internalised stigma*

refers to the “personal acceptance of stigma as part of one’s value system and self-concept” (Herek 2009:32), whereby individuals accept the validity of the stigma. As Albrecht and colleagues (2003:1226) explain:

When stigma is internalized by members of the non-stigmatized majority, the result is prejudice toward the stigmatized. When it is internalized by stigmatized individuals themselves, the result is self-stigma. In the latter case, people’s self-concept is congruent with the stigmatizing responses of others; they accept their discredited status as valid.

As I pointed out in Chapter One, CL is often related to stigma. However, only a few studies have investigated the particular dimensions of stigma in depth (Kassi et al. 2008; Reitingner et al. 2005; Yanik et al. 2004); in these studies, while there is no specific reference to enacted, perceived or felt, and internalised stigma, these dimensions can nevertheless be easily recognised.

Regarding stigma, in my research the first aim was to ascertain whether people in Suriname actually do experience stigma related to CL, and if so, what kind of stigma. Investigations took place from a multi-level perspective. The first level was that of the individual. The focus was on CL patients and other people experiencing CL at the moment of research, and I tried to gain an understanding of their perceptions of their own condition and whether they experienced any of the different dimensions of stigma. The questions I posed here included: How did they experience the illness? In what ways did they experience negative remarks from or the negative attitudes of others? Did the stage of the disease or the number and location of lesions or scars influence the experience of stigma, and if so how?

I focused further on possible causal relationships between stigma and health or treatment seeking. If people suffering from CL actually did experience enacted, perceived or felt, and internalised stigma, how did it then affect health or treatment seeking? Did it stimulate self-treatment or use of traditional treatment, and if so, why and how? What influence did stigma have on treatment seeking in the biomedical field? How was the issue of stigma related to compliance or non-compliance? I also sought to understand, on the one hand, if and how gender – i.e. the socially constructed roles, behaviours, activities, and attributes that are ascribed to men and women within a given society – predisposes people suffering from CL to stigma and the social impact of it on their lives; and how, on the other hand, gender differences may generate and maintain the stigmatisation of people with CL. Research into all of the abovementioned questions and issues is important for understanding the scope, meaning, and experience of enacted, perceived or felt, and internalised stigma related to those suffering from CL.

On a community level, I examined the complex concept of stigma and its many dimensions within the social network of people suffering from CL. I discussed with people’s family members, friends, and community members how CL is perceived, and how people behave towards those who have the disease. Do they feel that people with CL are stigmatised? If so, in what way(s)? Are there collective socio-cultural beliefs and notions about the disease, and is this reflected in overt stigmatisation?

At the third level, I focused on the perceptions of health professionals regarding the issue of stigma. Do they notice CL patients being stigmatised, and if so, by whom and how? In their opinion, does (suspected) stigma influence and complicate professional treatment and how? The various perceptions and experiences regarding CL at all levels are compared and contrasted in the light of their different interests and involvements.

2.1.6 Medical pluralism

Health or treatment seeking happens in all sectors of health care. Medical pluralism refers to the “multiplicity of health systems” (Hardon et al. 2001:27) or the “co-existence of a variety of different medical traditions within a given context” (Lambert in Barnard & Spencer 1998:359). The existence or development of medical pluralism in a society is usually related to the presence of various cultural or ethnic populations who adhere to their own medical tradition, as well as to the influence of foreign medical traditions in a culture (Hardon et al. 2001:27). In my research, medical pluralism is viewed both as a phenomenon that complicates health or treatment seeking, as well as an advantage to people suffering from CL, because in both cases it increases the wide variety of therapeutic options.

In general, debates regarding medical pluralism are linked with issues of domination and the maintenance of medical power, resulting in huge and differing socio-cultural, political, and economic implications. On the global level, it is acknowledged that biomedicine holds a hegemonic position in relation to various other co-existing healing systems, a dominance that is historically rooted in European expansion and colonialism. Even today, despite the growing recognition of traditional medicine, biomedicine still more or less holds the same position (Baer 2004:110). It is viewed as ‘cosmopolitan’, ‘scientific’, or ‘modern’ (Dunn cited in Islam 2005:2; Crandon-Malamud 1991:23), and is supposedly “grounded in natural laws and scientific principles” (Singer & Baer 2007:14). Alternative health systems to biomedicine are regarded as traditional medicine (TM) or complementary and alternative medicine (CAM). According to the WHO (2000b:1), traditional medicine is:

the sum total of the knowledge, skills and practices based on the theories, beliefs, and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in the prevention, diagnosis, improvement or treatment of physical and mental illness.

Traditional health practitioners are those who practice traditional medicine. The terms complementary/alternative/non-conventional medicine are used interchangeably with traditional medicine in some countries. They refer to “a broad set of health care practices that are not part of that country’s own tradition and are not integrated into the dominant health care system” (ibid). Under the grouping of CAM health care systems, the commonly mentioned examples are Ayurvedic medicine, Traditional Chinese medicine, Chiropractic medicine, homeopathic medicine, naturopathic medicine, religious healing systems, and folk medical systems (Baer 2004a:ix; White House Commission 2002:9; Soo Han 2002). Health

researchers nevertheless point to blurred boundaries between the various health systems. There are, for instance, groups of biomedical professionals who are open to alternative healing systems and have integrated them into their own systems due to their appeal to patients. Other medical professionals, however, view folk medical systems, in particular those that combine methods and are offered by lay practitioners, as mere quackery (Hardon 2002:27).

In the context of medical pluralism, I have sought to understand multiple issues. First, I tried to understand how people with CL relate to the two health systems present in Suriname (biomedicine and traditional medicine), and how and why they make use of these systems and the services they offer. What does traditional medicine mean to them and what does biomedicine signify? Second, I investigated the kind of therapies or treatment practices used, and how people perceived the merits of and/or possible health risks involved in these treatments (both biomedical or non-biomedical). An example of the latter is a CL research study on (traditional) treatment practices in small agricultural villages in the Northwest Pichincha Province in Ecuador (Weigel et al. 1994). Health researchers found that aside from biomedical and traditional treatment methods (the latter mostly based on botanical ingredients), people suffering from CL also used chemicals such as homemade rum or trago, wood alcohol, iodine, menthol, menthiolate, and sulphur to treat CL. Acids were also often reported as being used, especially sulphuric acid from car and auto batteries, as well as undiluted gasoline, kerosene, or creosote poured onto open ulcers. Similar findings were reported in a later study in north western Ecuador (Weigel & Armijos 2001). Aside from the use of several bitter/acidic plants, the researchers also found that hot liquids, heavy metals, and cauterisation were used to treat CL. They noted that some of these and other folk remedies have the potential to disrupt parasite pH, membranes, or metabolism, and could therefore be effective as a cure. Given their potential clinical merit, these remedies warrant further investigation. But the researchers also stress that the application of such substances as battery lead, thermometer mercury, and petroleum by-products to open lesions is contraindicated and should be discouraged due to their toxicity and the potential for damage to soft tissue and bone, as well as their contribution to profound scarring (Weigel & Armijos 2001:401).

Third, I sought to understand how traditional and biomedical health practitioners view each other's treatment methods, in particular in their efforts to provide healing for CL. This matter of interest is particularly related to a specific CL treatment method used at the traditional clinic of the Trio Indigenous people in the village of Tepu in Suriname. As the Trio Indigenous people say, this method seems to be successful in the treatment of CL. What views do biomedical health practitioners and traditional healers then have about each other's practices? Do they make any efforts to collaborate?

2.2 The central proposition and working hypothesis

I have tried to provide clear insight into the core concepts of my research, the multidimensional character of my study, and the variety of issues or aspects that are examined. Initially, however, there were two main foci in my research. On the one hand, the focus was on health or treatment seeking by people suffering from CL in

the context of medical pluralism; on the other hand, special attention was given to stigma caused by the disease. A causal relationship was assumed between both issues, but the obscurity surrounding CL related stigma in Suriname made it quite difficult to state a clear and strong proposition. Empirical observations of patients heavily disfigured and mutilated by the disease (large ulcerated body parts, abnormalities in the face, significant scar formation) as well as the increasing attention paid to stigma related to CL at the international level supported the theory that stigma seriously affects the CL illness experience and complicates treatment seeking.

In case of Suriname, however, I hypothesised that people suffering from CL are not heavily stigmatised by the community and that stigma does not play a significant role in the health or treatment seeking process in general. Enacted, perceived or felt, and internalised stigma is confined to limited cases of people who are heavily disfigured by the disease. The hypothesis is therefore that stigma does not inhibit timely biomedical treatment in Suriname, neither does it favour resort to traditional health practitioners. I argue that the factors for (possible) non-adherence to biomedical treatment and use of traditional treatment practices are not related to stigma, but are imbedded in the socio-cultural, professional, economic, geographical, and environmental context in which people live their day-to-day lives.

2.3 Conclusion

Some unexpected theoretical discussions emerged from my study, which I address shortly here and on which I will elaborate more in the chapters to follow. First, regarding the aspect of “knowing and not-knowing in the anthropology of medicine” (Littlewood 2007; Last 1981), my study reveals how not knowing or not being certain about disease causation gives rise to an enormous variety of explanations, food and attitudinal taboos, and treatment methods linked to CL. Everything – causes, illness characteristics, contamination, illness severity, chances for mutilation or amputation, ‘correct’ or effective treatment methods – is surrounded with uncertainty and doubt. How do patients then navigate in such uncertainty to find a cure, and what is their rationality behind such navigations? Rationality is hereby a mouldable concept, in which multiple contexts, illness perceptions, and the concept of associative reasoning through analogies, metaphors, and metonyms are all present. As we will see in Chapter Six, Crandon-Malamud’s (1993) approach to treatment seeking in Bolivia is enlightening in this respect. My research illustrates how treatment seeking is related to more than simply medical reasons: socio-economic conditions, occupational obligations, cultural perceptions, and socio-psychological concerns prevail. Moving on from the theoretical body of my research, in the next chapter I discuss the study’s methodological framework.

Chapter 3 Contexts and methodological matters

Part 1 – Sketching Suriname's contextual profile

My research focused on those living and working in the remote tropical Amazon Rainforest areas of the hinterland of Suriname. The main inhabitants of the hinterland are Indigenous peoples and Maroons. Also targeted within the research was the small number of other social groups that stay in or visit the hinterland for occupational or leisure activities. In part one of this chapter, I sketch the geographical, environmental, socio-demographic, and historic-cultural profile of the country's locations where I conducted research. Part two explains the methodological dimensions of the research.

3.1 Geographical, demographic, and socio-economic profile of Suriname

Suriname is a democratic republic headed by a president and located in the northern part of South America. French Guyana is its neighbouring country to the east, Guyana to the west, the Atlantic ocean lies to the north and Brazil to the south. It comprises a total of 163,820 km², of which 20% is coastal areas and 80% dense tropical rainforest, the so-called hinterland. The country is scarcely populated with only 541,638 inhabitants (Algemeen Bureau voor de Statistiek 2013:20); nevertheless, this small population is very culturally mixed.

The Indigenous people (formerly called Amerindians) were Suriname's first inhabitants. Due to colonisation – first by the British in 1650 and afterwards by the Dutch from 1667 until 1975 – slaves were imported from Africa. Once slavery was abolished in 1863, many contract migrants were brought from China, India, and Indonesia to work on the plantations. The Indigenous peoples of Suriname inhabit mostly the coastal areas and the southern part of the hinterland. The main groups are formed by the Karin'a (or Caribs), Lokonon (or Arowaks), Wayanas, Trios, and Akuryos (Guicherit et al. 2005:12; Heemskerk et al. 2007:28), with several other smaller minority groups in addition. Because of the location of their living areas, the Caribs and Lokonon are also distinguished as the *Benedenlandse Indianen* (highland Indigenous people), while the Wayanas, Trios, and Akuryos are known as the *Bovenlandse Indianen* (lowland Indigenous people) (Van Arkel 2006:12). One of the largest groups in south Suriname are the Trios (Heemskerk et al. 2007:29).

The descendants of African slaves who managed to flee from the colonial plantations into the hinterland are called Maroons. According to De Groot (1974:6), the name Maroon is derived from the Spanish word *cimarrón*, a word first used for cattle that fled into the hills of Hispaniola (Haiti). Later on, it was used for Indigenous peoples who fled from the Spaniards, and since the second part of the sixteenth century for African slaves who successfully fled to the hinterland. Like the Indigenous peoples, the Maroons are culturally diverse, currently comprising six groups, namely the Saramacca, Aucan (or Ndjuka), Paramaca, Matawai, Aluku, and

Kwinti. Those African slaves who stayed at the plantations in the cities were called the (city) Creoles.

Currently, Hindustanis, descendants of British-Indian migrants, are the largest population group in Suriname (27.4%), followed by Maroons (21.7%), Creoles (15.7%), Javanese (13.7%), people of mixed descent (13.4%), and then smaller groups of Indigenous peoples, Chinese, Lebanese, Dutch, and 'other' (7.6%) (Algemeen Bureau voor de Statistiek 2013:42). The majority of Surinamese people live in the coastal areas. Paramaribo is the smallest district of Suriname (measuring 183 km²), but it has the highest population density at 1323.8 inhabitants per km² (Algemeen Bureau voor de Statistiek 2013:24), and is home to about 50% of Suriname's population (ibid).

Suriname's economy is largely based on the mining industry. In 2007, bauxite, oil, and gold accounted for about 98.7% of total foreign exchange earnings (Heemskerk et al. 2007:28). Other sectors contributing to the Gross Domestic Product (GDP) are lumber, plywood production, molasses, rum, agriculture, fisheries, and forestry (ibid). In 2011, the International Monetary Fund (IMF) reported an increase of GDP from 3% in 2009 to 4.5% in 2010 (IMF 2011:3). National income is also gained through bilateral development aid; furthermore, the government is one of the largest employers "accounting for almost 18 percent of formal employment" (Heemskerk et al. 2007:29).

While the Human Development Report 2006 ranked Suriname in 89th place as a Medium Human Development Country (Republic of Suriname & European Union 2008:16), this ranking dropped to 100 in 2013 (United Nations Development Programme 2014:161). With a Gross National Income (GNI) of US\$15,113 per capita in 2014, Suriname citizens are reported to be better off than in other Caribbean countries (ibid). However, this income is not equally divided. More than 50% of the Surinamese population is reported to be living on less than one US dollar per day (Republic of Suriname & European Union 2008:44), and more than 70% below the poverty line (Heemskerk 2009:6). In 2014, the unemployment rate (of those aged 15 and above) was 9.5% (United Nations Development Programme 2014:201). Much employment is reported to be informal and thus "outside of national regulations and unrecorded in national statistics" (Heemskerk et al. 2007:29). Nevertheless, according to the Human Development Report 2014, literacy rates for Suriname are high at 94.7% (of those aged 15 and above) and at-birth life expectancy is 71 years. Suriname has a relatively young population, but causes of death are worrying. According to the Bureau for Public Health (BOG) (Punwasi 2012:12), in 2011 the three main causes of death were cardiovascular and cerebrovascular disorders (25.3%), malignant neoplasms (12.8%), and external causes (traffic accidents and violence) (12.5%). Deaths due to HIV/AIDS decreased from 5.9% in 2005 to 3.5% in 2011 (ibid:44).

On the national level, the Ministry of Health is the governmental health organisation responsible for the availability, accessibility, affordability, and quality of health care services (Ministerie van Volksgezondheid 2006:2). The Central Office of the Ministry of Health, the Inspectorate, and the Bureau for Public Health are the core institutions of the health care system. Global health planning and standard setting, inspection, and monitoring all fall under the responsibility of the Central Office and the Inspectorate. The Bureau for Public health is responsible for research, planning, execution, and monitoring of public health issues and, related to

that, programme development and health education (PAHO 2002:i; Ministerie van Volksgezondheid 2006:8).

In the intramural sphere, the Ministry of Health itself has six hospitals – the *Academisch Ziekenhuis Paramaribo*, the *Diakonessehuis*, the *Lands Hospitaal*, the *Rooms Katholiek Ziekenhuis St. Vincentius*, the *Psychiatric Centrum*, and the *Streekziekenhuis Nickerie* (the regional hospital for the second largest city in Suriname) – and several nursing and care houses to provide health care services, all of which are situated in the coastal area. In the extramural sphere, the Ministry of Health provides government subsidised primary health care for the poor and near-poor through two organisations, namely the Regional Health Services (RGD) and the Medical Mission (PAHO 2002:i). While in the coastal area the RGD is responsible for first line – both preventive and curative – health care, in the hinterland it is the Medical Mission, locally abbreviated as MZ (*Medische Zending*). The Medical Mission is a private, non-profit, primary health care organisation providing free medical health care in the hinterland, and is one of the key partners in the ‘Leishmaniasis in Suriname’ project. At the time of the research, it was running 57 village clinics delivering basic health care services to 63,400 inhabitants (Medical Mission 2011).⁶

Further health care services are provided by: the Youth Dental Care Service for young people between the ages of 0 and 18 years; the Dermatology Service; private general practitioners providing primary health care services in private clinics; medical specialists who provide clinical and polyclinic services through hospitals; several institutions that provide diagnostic services; pharmacies; dental care practitioners; obstetric clinics; psychologists; physiotherapy clinics providing both intramural and extramural services; and several home care institutions (Ministerie van Volksgezondheid 2006:8). Many non-governmental organisations (NGOs) also provide health care services, such as the Lobi Foundation, a family planning institute.

In general, people in Suriname are not legally obliged to have health insurance. However, health insurance is offered by the State Health Insurance Fund (SZF), the Ministry of Social Affairs (MSA), and several private health insurance companies. The MSA offers “safety net programmes to the poor and certifies eligibility to receive subsidized health services. It also functions as a payer to hospitals for this certified poor population”(Van ‘t Klooster 2009:104).

3.2 Field locations and key partners in CL research

Suriname is divided into ten districts, eight in the coastal areas – Commewijne, Coronie, Marowijne, Nickerie, Para, Paramaribo, Saramacca, and Wanica – and two in the hinterland – Brokopondo and Sipaliwini. Paramaribo is the capital city. In Paramaribo (the small red coloured area in Figure 3), the Dermatology Service was the prime research location.

⁶See web reference number 6.

3.2.1 The Dermatology Service in Paramaribo

The Dermatology Service in Suriname, known as the *Dermatologische Dienst* or 'Derma' for short, is an executive part of the Ministry of Public Health, reporting directly to the Director of Public Health. It is responsible for research, prevention, and treatment of skin conditions and sexually transmitted infections (Ministerie van Volksgezondheid 2006:8). The Dermatology service was established almost four decades ago in 1972, after the closing of the last leprosarium, the *Groot Chatillion*.⁷ The Dermatology Service is built on the same location as the former Leprosy Service and serves to combat the stigma attached to the service, but because of its location still holds a somewhat stigmatised character in society (personal communication Dr. Sabajo 2009). The Dermatology Service is one of the main stakeholders in the 'Leishmaniasis in Suriname' research programme. From September 2009 to June 2010, I worked (with some periods of interval) at the Dermatology Service.

3.2.2 Reaching the hinterland

In the hinterland, data was collected at five different villages: Godo-olo, Pelele-Tepu (hereafter referred to as Tepu), Brokopondo Centrum area, Donderskamp, and Benzdorp. These villages were spread over the districts of Sipaliwini and Brokopondo. Brokopondo district (the white coloured area in Figure 3), which comprises a total area of 7364 km² (or 5%) of the total Surinamese land area, has a population density of 2.2 inhabitants per km² (Algemeen Bureau voor de Statistiek 2013:24). Sipaliwini district (the light green area in Figure 3) is the largest of the ten districts in Suriname, covering a total of 130,567 km² or about 80% of the country. It consists of wide areas of tropical rainforest and therefore has the lowest population density of 0.3 inhabitants per km² (ibid). In 2012, both districts together were populated by only 10% of Suriname's total population.

Large parts of the hinterland are only accessible by boat, all terrain vehicles (ATVs), or airplane (the latter as a result of Operation Grasshopper, initiated by the Dutch colonial government in 1959, whereby airstrips were cut open at strategic points, making the hinterland accessible by air) (Heemskerk et al. 2007:37). I reached Godo-olo and Tepu by air from the local airport Zorg en Hoop in Paramaribo. To reach Benzdorp, I first took a flight to the nearest airstrip at Antino, and was then driven for about half an hour by truck along a very bumpy road. Donderskamp was also reachable by airplane, but I travelled instead by car and boat. Brokopondo Centrum area was the closest to the city, a three hour drive by car. For the villages Godo-olo, Brokopondo Centrum area, and Donderskamp, the Medical Mission was the key facilitator.

3.2.2.1 The Medical Mission

The Medical Mission (MZ), as mentioned above in section 3.1, is the most important primary health care organisation responsible for delivering health care services in the Suriname hinterland. It is financially supported by government subsidies and donor funds (Terborg et al. 2004:141). Biomedical health care provision by

⁷See web reference number 7.

missionaries in the hinterland dates back to the second half of the eighteenth century; however, the basic structure of the MZ, as it is known today, was formed in 1946 with the arrival of the medical doctor P.A. de Groot. Upon the request of the national government to the Evangelical church governing board, Dr. de Groot was the first to design a plan for biomedical health care that covered the entire hinterland. In this plan, he also identified the need to train local people as health workers,⁸ and the system of training he developed has functioned up to today. Spread over the entire hinterland, MZ now works through a network of clinics where mostly medically trained local health workers deliver health care services at different levels. The MZ's headquarters is in Paramaribo.

In daily practice, the local health workers are the first contact persons for clients, and are capable of handling a large spectrum of inquiries. Through a vast network of radio communication and the periodic visits of medical doctors, the local health workers are constantly supervised and whenever needed can seek the medical advice of nurses, medical doctors, and specialists based in the city.⁹ At the time of the research, the MZ ran different programmes, such as for reproductive health, traditional healing, immunisation, HIV/AIDS, and malaria, focused on the hinterland population.

Because of their focus on the often difficult to reach hinterland populations and their expertise in working with those communities, the MZ is one of the most important partners of the 'Leishmaniasis in Suriname' programme. As mentioned above, my stay in most of the hinterland villages was facilitated by the MZ; from the MZ office in the city, for instance, contact was made with the health workers of the village clinics, who prepared my stay.

3.2.2.2 Amazon Conservation Team¹⁰

At the village of Tepu, the Amazon Conservation Team (ACT), another partner in the Leishmaniasis research programme, was the key facilitator. This organisation is an independent NGO that has established partnerships with Indigenous peoples in the southern part of Suriname with a focus on the conservation of biodiversity, health, and culture. Their activities began in 1999 under the supervision of Dr. Mark Plotkin.¹¹ ACT is especially engaged in long term partnerships with the Trio people, who live in the hinterland scattered over mountainous forests, lowlands, floodable forests, liana forests, and savannah areas (Heemskerk et al. 2007:47). In 2001, ACT established a traditional health clinic at Tepu, called *kapi*, as part of a shaman apprentice programme that they had initiated with the Trio people to "promote the preservation of traditional medicinal and other knowledge" (ibid:89). ACT has also collaborated with the MZ.¹² In 1999, they signed a Memorandum of Understanding in which they committed themselves to search for possibilities to integrate traditional

⁸See web reference number 8.

⁹See web reference number 9.

¹⁰At the end of writing this dissertation, ACT – in terms of the organizational structure as it was during the fieldwork – had ceased to exist. Future collaboration with the Trio people should therefore be considered using a different format.

¹¹See web reference number 10.

¹²See web reference number 11.

healing into the regular healthcare provision of the MZ. According to the MZ, a more practical and cheaper solution for the cure of certain health problems (e.g. alleged cure of CL by the Trio people, cure of bone fractures by Saramaccan people) was, amongst other matters, the main motivation for this collaboration.¹³

3.2.2.3 Bureau for Public Health

My entry to the village of Benzdorp was organised by the Bureau for Public Health (*Bureau voor Openbare Gezondheidszorg*, BOG). As one of the core institutions of the Ministry of Health, the BOG focuses on preventive health care. In 1927, it was known as the *Dienst ter Bestrijding van Volks- en Besmettelijke Ziekten* (Service to Combat Public and Contagious Diseases) its name was changed in 1954 to the *Bureau voor Openbare Gezondheidszorg*. BOG promotes and protects the general health of the total Surinamese population through health policy development, epidemiological surveillance, health education activities, clinical research, laboratory diagnostics, and public health interventions.¹⁴ It consists of several departments (Environmental Inspection, Epidemiology, Medical Pedagogical Bureau, Food, Communicable Diseases, Non-Communicable Diseases, Family Health, Health Education, and the Central Laboratory), through which public health is monitored and illness prevented.¹⁵ Without doubt, the BOG is crucial for the 'Leishmaniasis in Suriname' programme. In terms of gaining access to Benzdorp (where there is no MZ clinic), BOG – in particular the Department for Communicable Diseases, which also coordinates the malaria project in Suriname – provided logistical support; their network at Benzdorp ensured my safe stay (see 3.3.2) in the village for the anthropological fieldwork.

3.2.3 Overview of all research sites

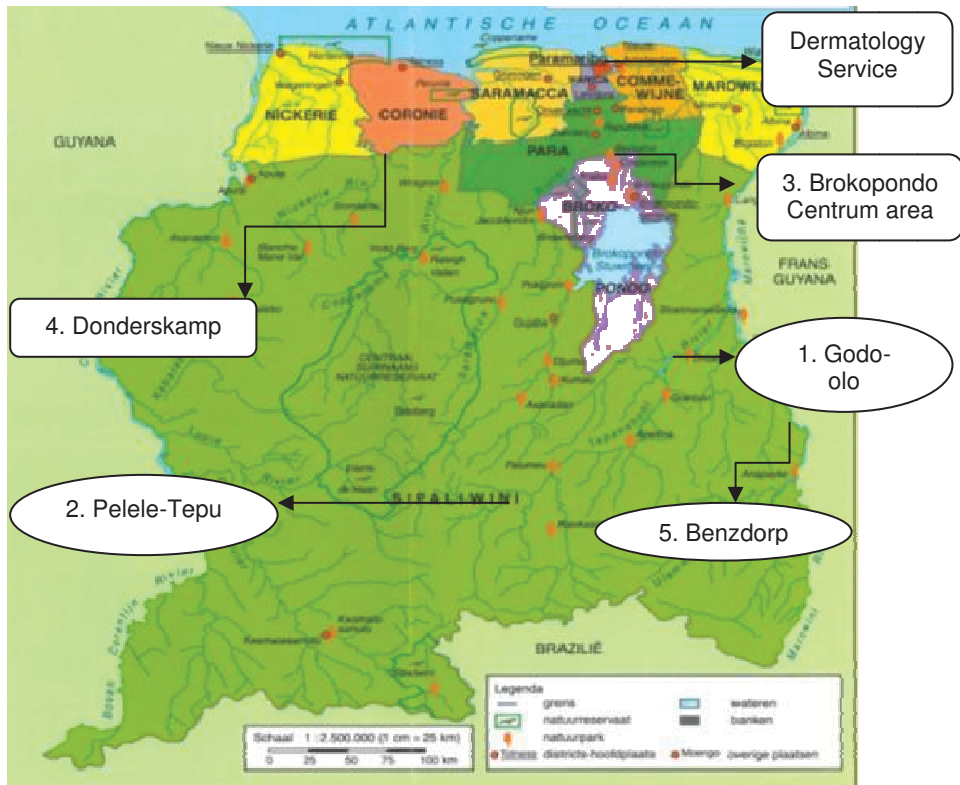
The map below shows Suriname by district and the locations of the research sites. The villages Godo-olo (location one) and Tepu (location two), located far down south, lie along the Tapanahony river. Donderskamp (location four), bordering the coastal zone, is located along the Wayambo river. Benzdorp (location five) is near the Lawa river, close to the border with French Guyana. Brokopondo Centrum area (location three) lies along the left shore of the Suriname river and north of Lake Brokopondo ('Brokopondo Stuwmeer' in the map). Research was conducted in three areas in the Brokopondo Centrum area – Klaaskreek, Brokopondo Centrum, and the close-by villages of Tapuripa, Ballingsula, and Boslanti – and also in Brownsweg (about one to one-and-a-half hours away from Brokopondo Centrum), which includes the villages Wakibasú and Ganze.

¹³See web reference number 12.

¹⁴See web reference number 13.

¹⁵See web reference number 14.

Figure 3: Map of Suriname, by district and CL research site



Source: Hebri B.V. International 2004

3.3 Indigenous peoples and Maroons in the hinterland

According to Heemskerk et al. (2007:36), in the 16th century when Europeans first set foot on land in the Guyanas, the Indigenous people numbered an estimated 60,000 to 70,000 people. However,

Warfare, slavery, and above all Western diseases decimated their populations soon after foreign occupation. Most lowland Indigenous groups eventually made peace with the colonial government and established communities at the river mouths and along the beaches. Highland Indigenous peoples were mostly ignored by the European invaders and had little contact with the coast. They only made occasional trips southward to trade with the Maroons (...) (ibid).

In my research, fieldwork among the Indigenous peoples was concentrated in the Trio village Tepu and the Carib village Donderskamp. Tepu is surrounded by high forest, and because of the possibility of high waters during rainy seasons the village is built on higher ground. Tepu, home to approximately 400 Trio people, is about 45 years old (built around 1966) and consists of an airstrip, a Baptist church, a

primary school, a Medical Mission health clinic, and a traditional health clinic called *kapi* (see Photo 1 below). The *kapi* was established in 2001 as part of the shaman apprentice programme mentioned above; here, young apprentices are taught plant-based medicine by older shamans.

Photo 1: The traditional health clinic *kapi* at Tepu



Source: Collection S. Ramdas, Tepu, district Sipaliwini, 2010

The village of Donderskamp is built on white sand, and is nestled in a small savannah landscape surrounded by the rainforest (see pictures below), though smaller creeks and swampy forest are also part of the ecological habitat. Donderskamp is home to an estimated 300 people. The Carib are the oldest of the Indigenous groups in Suriname and, despite the colonial situation between 1667 and 1975, form an independent group with their own cultural rules and structures. In Suriname, the total Carib population is estimated at 2500 people. Donderskamp consists of one primary school, the medical post of the Medical Mission, a Roman Catholic church, the Full Gospel movement, a governmental administration office, a recreation hall, and a football field.

Photo 2: Youngsters playing football at Donderskamp



Source: Collection S. Ramdas, village Donderskamp, 2010

For fieldwork among the Maroons, I stayed in the village of Godo-olo and at Brokopondo Centrum area, populated respectively by Aucan and Saramacca Maroon populations. These two groups form the two largest groups among all Maroons; an estimated 46% of the total Maroon population (Ramdas 2008:13; Terborg 2001:4). The Aucan Maroons live mostly along the Tapanahony, Marowijne, Lawa, and Cottica rivers (Köbren in Price 1973:321; Guicherit et al. 2005:11; Terborg 2001:3). The photograph below shows a daily scene along the Tapanahony River in Godo-olo village; washing clothes and pots and pans in the morning is part of everyday life.

Photo 3: Villagers of Godo-olo busy with daily activities along the Tapanahony River



Source: Collection S. Ramdas, Godo-olo, district Sipaliwini 2009

Saramacca Maroons mostly still live along the Upper Suriname River, particularly its tributaries Gran Rio and Pikin Rio (Van 't Klooster 2009; Guicherit et al. 2005:11) and in French Guyana (Terborg 2001:3). Due to the construction of the *Afobakkadam*, a hydroelectric dam in 1960, the natural habitat of a large part of Saramaccan territories was flooded. Therefore, in and around Brokopondo Centrum, transmigration villages (see the photo below for an example of a transmigration village) were built by the Surinamese government.

Photo 4: Part of a typical transmigration village near Brokopondo Centrum



Source: S. Ramdas, Brokopondo Centrum area, district Brokopondo, 2010

Growing urbanisation among Maroons has been reported since the 1980s due to the 'internal war' between the Surinamese army (lead by Desi Bouterse) and a guerrilla army (the 'Jungle Commando' lead by the Maroon Ronny Brunswijk) that lasted from 1986 until 1992. The majority of the Maroons who migrated to the city live in poor neighbourhoods in and around Paramaribo under poor economic conditions (Terborg 2001:4).

Despite centuries of living in the hinterland, the Indigenous peoples and the Maroons lack legal title to the land they inhabit (Guicherit 2005:11; Terborg et al. 2006:146). The 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).

On a district level, gold mining – and to a lesser extent sand and shingle mining – is one of the most important economic activities in addition to the lumber sector. The gold business has long been lucrative due to the high prices for gold on the world market; in September 2011, the gold price peaked at US\$61.3 per 1 gram (Proses 2011). Maroon populations and Brazilians in particular work in the gold sector in the hinterland. Ecotourism is one of the region's upcoming economic sectors. Although the hinterland of Suriname is rich in natural resources – gold, minerals, bauxite, hydroelectricity, and wood – this wealth is often not reflected in local people's lives. On the contrary, the majority of the inhabitants live in poverty, with poor access to basic household needs (Guicherit et al. 2005:6) and low or no formal education levels and high early dropout rates from school (Terborg et al. 2006). In many villages, there is only a primary school, thus further education involves high costs to cover the stay in the city. The Medical Mission provides basic medical services and clinics can be found spread over the hinterland, but for further medical investigations, travel to Paramaribo is a must. The increase of HIV/AIDS is one of the major health concerns in the hinterland. Due to the thriving gold sector, increasing uncontrolled commercial sex work, criminality, drug abuse, and violence are also major problems. Most villages lack constant electricity, safe drinking water, and sanitation (Guicherit et al. 2005:6). In many villages, generators are used to generate electricity, mostly from 6:30am until 11:00pm or 12:00pm. Some water projects to ensure safe drinking water have successfully been initiated, such as in Godo-olo. In some parts of the hinterland, telecommunication has only been made possible in the past few years by the telecom provider Digicel.

In spite of the relatively poor situation in the hinterland, life is nevertheless becoming more 'modernised'. In many villages (both Maroon and Indigenous), household items such as CD and DVD players, freezers, and washing machines are bought and utilised. While in the past, houses were made only of wood and palm leaves, now in many villages they are constructed of wood and stone; aluminium roofs are also a common sight and even the use of tiles and (Western style) toilets is increasing. Whenever affordable, building materials are bought in the city and transported via airplane or boat to the hinterland.

3.3.1 Life in the villages: social structures and making ends meet

Maroons and Indigenous peoples live in tribal systems. The communities are led by their own tribal authority, consisting of the head of the village, called the *kabiten* (captain), the assistants of the captain, called *basiyas*, and the village elders. At a

higher level, Maroon groups are led and controlled by paramount chiefs, who have the highest authority. In the villages, political power lies in the hands of the captains, who together with the *basiyas* and elders guard the village's territory, norms and values, and the culture of family and community. The village boards collaborate at the governmental level with the district council, specifically with the government representatives known as *bestuursopzichters* (board supervisors) (Emanuel 2003:10-11; Guicherit 2005:11).

Indigenous peoples are partly nomadic, partly settled, and the various groups are similar in terms of their historical roots, patrilineal structure (Jara 1996:35), and intimacy with the natural habitat in which they used to live. There are, however, differences in terms of language, involvement in income generating activities, and way of life. The Aucan and Saramacca Maroons are similar to other Maroon populations in that they share the same historical background, ecological environment, and similarities regarding several cultural aspects such as kinship systems (matrilineal), but these two groups nevertheless differ socio-culturally and economically because of differences in "language, diet, dress, patterns of marriage, residence or for example migratory wage labor" (Price in Van 't Klooster 2009:52).

In general, the lifestyle of the inhabitants of the hinterland is quite 'traditional'. Gender tasks are clearly divided between men and women. In the Maroon communities, men are mostly engaged in the lumber or gold sector; in the latter as gold diggers as well as owners of gold mining companies. They are also involved in hunting and fishing, laying out plots for agriculture, building houses, boat construction, and making a living with tourism by offering transportation and guide services or processing wood into souvenirs such as paddles, houses, benches, umbrellas, and other artefacts. In search of employment, men also tend to go for shorter or longer periods to other areas in the hinterland or to the city Paramaribo, as well as to the neighbouring countries of Guyana or French Guyana, leaving women and children behind.

Women are viewed as important producers within the village economy and are engaged in planting crops – such as rice, peanuts, cassava, and all kinds of fruits and vegetables – and in the (small scale) trade of agricultural products. Women are also engaged in processing food, preparing and selling food products, knitting, and trading in *pangis* (cotton cloths used mostly as traditional skirts). Assisted by their younger children, women take care of the household, prepare food on gas stoves or wood fires, and are mostly responsible for the care of sick children and the elderly. Women also work as civil servants, teachers, or health workers. In many villages, women have small businesses, such as selling embroidery or fish, or they own small shops where they sell beverages, snacks, and other food products. Together with their partners, some own small shops selling luxury items, phone cards, batteries, flashlights, etc. In villages like Godo-olo, where flights arrive from the city, mostly older children, sometimes accompanied by their mothers, go around the village door to door with wheelbarrows carrying fresh vegetables, other food products, and drinks that arrive by plane. These items sell very fast since they are not available every day in the villages, and women can earn a living this way.

Indigenous communities bear many resemblances to Maroon communities in terms of the gender tasks of men and women, though there are also some differences. Both men and women are very active, though the nature of their daily activities can differ. Walking through the Indigenous villages in the hinterland, one

will often see women engaged in the processing of different kinds of fruits and roots. Mangos and wild cashew, for example, are favourite fruits; bitter cassava is also popular, as it is processed into the local drink *cassiri* and used for big round cassava pancakes. Women often sit in their hammocks weaving cotton or making ornaments from seeds, which are also sometimes combined with feathers and animal teeth. Similar to the Maroons, Indigenous women and children are also busy with planting, harvesting, and transporting products like bitter cassava, maize, watermelons, and vegetables. Women, together with men and children, collect fruits, nuts, seeds, and wood for cooking fires in the forests nearby or further upstream.

Fishing, hunting, training hunting dogs, cutting wood and leaves for house building, and constructing canoes are tasks usually done by men. Unlike in the Maroon communities, Indigenous men are also engaged in weaving household utensils such as sieves, manioc presses, jars, containers, and baskets to carry fruits, roots, and other agricultural products. Indigenous peoples are mostly self-sufficient because of the high cost of boat and air transportation. Indigenous men are, in general, not involved in the gold sector, a substantial difference with the (common) occupational activity of Maroon men. At Tepu, for instance, men mostly earn their living through the sale of wild animals such as snakes, songbirds, parrots, and fish, especially big sweet fish like the popular *anjumara*, which is often in high demand. There is also lively exchange trade with the Maroons (mostly the Ndjuka Maroons who live further down the Tapanahony river), among whom Trio hunting dogs are very popular.

Indigenous villagers also earn some money through tourism: offering guided tours; selling arts and crafts, jewellery made of natural products, and other items to tourists; and by constructing and renting housing for tourists (as in Tepu). At Donderskamp, income generating activities are agriculture (especially the plant Pomtayer for its root, popular in Suriname for making a dish called Pom) and the small scale sale of fish and wild meat to neighbouring villages or in the city. Some villagers find part-time jobs in the lumber sector as well. Money is needed to buy all kinds of household items, food products (rice, salt, sugar, tea, coffee, etc.), soap, lamp oil, electric batteries, bullets for hunting, flashlights, and gasoline for those who have outboard motors.

3.3.2 Brazilians in the hinterland: gold diggers in Benzdorp

Benzdorp is a gold diggers' area located in the eastern part of Suriname, in the district Sipaliwini along the Lawa River (see field site 5 in Figure 3), close to the border with French Guyana. Here, an estimated 1000 gold diggers operate directly or indirectly within the small scale gold mining sector in the forty registered gold mining camps (Narain 2008:10). There are, however, an unknown number of unregistered camps, and some of the villagers of Benzdorp estimate a higher number of people engaged in the gold mining sector: approximately 3000 Brazilians in and around Benzdorp, about 20-30% women, 5% children, and the remainder men. The majority of the population are of reproductive age, with few elderly. In general, the area is mostly populated by Brazilian gold diggers, who moved to Suriname due to harsh government policies against them, both in Brazil and in French Guyana (Heemskerk 2009:16). Here and there, some Maroon men also work in Benzdorp. The Brazilian gold diggers are a highly mobile group, easily moving

back and forth between Suriname and Brazil across borders that are hardly controlled by the Surinamese government.

Benzdorp has often been described in the media as a kind of 'Wild West', with daily violation of laws, frequent fights due to alcohol intake and over women, and where violent crime is part of the everyday scenery. According to one informant, 25-year-old Manuel, it used to be a lot more like this in the past, but since the Ministry of Justice and the police initiated Operation Clean Sweep in 2008, where they tried to organise and 'clean up' the area, much of this violence has vanished. Over the past five to seven years, the Surinamese government has also been engaged in trying to get an overview of and grasp some control over the area. Gold diggers operating in Benzdorp are given the opportunity to register and gain legal status (Cairo 2011); many of those offering services such as renting materials and delivering transportation services, sellers of fuels, owners of bar-restaurants, and shopkeepers have been provided with legal status so far (Zandgrond 2008).

At the time of my research, in the centre of the village of Benzdorp there were about 100 to 150 buildings, all made of wood with aluminium roofs, many of which had been deserted¹⁶. There were only perhaps about thirty to thirty-five quite colourful houses where people actually lived. The roads were made from bauxite, very dusty in the dry season and dangerously slippery in the wet season. The village contained supermarkets, mostly Chinese owned. Four cabarets (clubs where commercial sex workers operate) were active at the time of my research, though they were small, with around two, four, or six women per club. The village also had restaurants, bar-shop-canteens, beauty salons, clothing stores, goldsmiths, mechanic shops, two churches, and drugstores selling Brazilian medicines. Everyone in the village had to take care of their own water supply and everyone owned a motor to generate light. Benzdorp could be reached by telephone; just like in Donderskamp, the provider is the Caribbean telecom operator Digicel. In Photo 5, taken from the air, Benzdorp village can be seen on the right hand side, and on the left side there is an open area for gold digging. Photo 6 captures part of the village in ground view. Many ATVs drive up and down these bauxite roads, and are a common sight in the village.

Photo 5: Part of Benzdorp village, air view



Photo 6: Part of Benzdorp village, ground view



Source: Collection S. Ramdas, village Benzdorp, district Sipaliwini, 2010

¹⁶ The majority of gold diggers rarely stay for a long time in one place. Thus once they have completed a job in an area, they will move to another, abandoning the houses in which they lived.

Everything in Benzdorp is expensive, since everything has to be imported. Gasoline, for example, is brought in via Albina and transported by boat as far as the shores of Beira do Rio in Cabanafo, another small village half an hour away from Benzdorp. The Chinese conduct a lively trade in gasoline. Payment is made in gold at Benzdorp; the price of one gram of gold peaked at about US\$37-38 in 2010. In Cabanafo – viewed by the Surinamese media as a smugglers' village (Zandgrond 2008) – mostly Euros are accepted. The cost for a boat ride from Albina to Benzdorp was, at the time of research, about €1300-1400, and from the river shore inland to Benzdorp transportation cost about 20 grams of gold (approximately US\$750). As an example of the exorbitantly high costs of many imported items, at the time of research a one-and-a-half litre bottle of Coca-Cola cost two grams of gold (approximately US\$75). According to the people with whom I spoke, "everybody stands on his own in this village" and had to take care of his or her situation by his/her own means.

Part 2 – Method matters

3.4 Rapid ethnographic approach

Qualitative research methodologies in medical anthropology primarily utilise 'ethnographic' forms of research. Central in ethnographic studies are listening, observing, learning, and a good sense of 'intuition' regarding the sensitiveness of situations in which one is doing fieldwork. It is important to gather valid, reliable, and 'rich' data, which will enable the researcher to understand the field and "throw light on the issues that are the focus of the research" (Hammersley & Atkinson 1995:1). For this reason, ethnographic fieldwork often requires lengthy stays in the field. Depending on the type of research, budget, and time constraints, however, ethnographic investigations are often split into shorter, intense periods of fieldwork. This research is an example of such a 'rapid ethnography' (Hardon et al. 2001), characterised as it is by relatively short periods in the field – stretched over a period of ten months from September 2009 to November 2010 – and using a variety of qualitative methods to collect data. In the following paragraphs, I discuss how this rapid ethnographic research approach actually unfolded in the field, since methodological transparency creates openness that helps others to 'follow' how the research was conducted. Such transparency also enables readers to "assess the validity and credibility of the presented research findings" (Gerrits 2008:21). I also discuss ethical and emotional issues that emerged in the field. Such reflections draw attention to the dynamics at play during fieldwork and their possible impact on research outcomes (ibid:22), as well as issues that may, to a greater or lesser extent, mould a researcher's own personal and social position in the community he/she is studying.

3.4.1 'Clearance' to conduct research

The empirical inquiries made for this research would not have been possible without the approval of the Surinamese national health and village authorities. Formal

approval to conduct the research at the Dermatology Service was obtained in 2009 from the medical ethical commission – the *Comissie Medisch Wetenschappelijk Onderzoek* (Commission Medical Scientific Research) – of the Ministry of Health. At the Dermatology Service, CL patients were informed thoroughly about the research and asked to participate on a voluntary basis. A formal written consent form was prepared in the national formal language Dutch and the national local language Sranan. Some CL patients signed the forms, but the majority consented verbally.

In the hinterland, the Medical Mission and ACT played an important role in facilitating the process of obtaining formal approval. As custom requires in Suriname, the captains of villages must first be informed and it is they who grant access and give approval for all activities that 'outsiders' want to undertake in their villages. At Godo-olo, in the Brokopondo Centrum area, and at Donderskamp, the health workers in charge of the Medical Mission were the bridge between me and the captains. At Tepu, ACT was the key organisation. Upon arrival, I verbally explained the purpose of my stay to the captains. This procedure in Suriname usually includes handing over a present to the captain. After the explanation, the captains verbally granted me access to their village. Inquiries among the villagers also started only after their verbal consent was obtained.

Unlike the four other villages, Benzdorp did not have a captain or head of the village, and seeking formal approval to conduct research there was therefore not applicable. All people who work there do so at their own risk and responsibility. However, at first contact, the informants were informed thoroughly about the research and interviews were continued only after consent was given.

3.4.2 Research populations and methods

Guided by the research questions, inquiries were carried out among multiple research populations. CL patients seeking biomedical health care at the Dermatology Service formed the core research population. Additional inquiries were conducted among ex-CL patients of the clinics of the Medical Mission, people experiencing CL who were seeking Indigenous health care at the Traditional Health Clinic in Tepu, and other inhabitants (of the selected villages) who believed that they had contracted CL and had cured it by their own means.

3.4.2.1 Data collection at the Dermatology Service

At the Dermatology Service, 205 clinically diagnosed CL patients participated in the research through questionnaires. The questionnaires were structured and contained open ended questions concerning a whole range of aspects regarding perceptions and explanations of the illness, health seeking, self-treatment, stigma, disease contamination, and prevention. Each interview lasted approximately 30 minutes, and in some cases 45 minutes or one hour. The answers were written down on the form, or in some cases first audio-recorded and then transcribed. The interviews were usually conducted in Dutch, but often the language shifted to Sranan or other local languages, depending on the ethnic background of the interviewee and his or her preferred language of communication.

Every day, interviews were carried out with two, or sometimes three or four, CL patients. Most of them expressed happiness that research into CL was being

done. I felt that patients were in general open to me; maybe because I did not hide my identity. I clearly explained to all participants that I was not a doctor but a researcher interested in *their* side of the story. To enhance reliability, I cross-checked some of the information with my colleague Dr. Hu at the Dermatology Service and with information from the patient files.

To conduct the interviews and manage time effectively, flexibility was built into the interview schedule. Usually, interviews with CL patients were conducted after they had consulted the doctor, while they were waiting for their injection. But whenever possible, patients were also interviewed before the consultation. To guard the privacy of the participants, interviews were usually conducted in the room assigned to me by the Dermatology Service. As it turned out, however, patients found it easier to have the interviews in the waiting room. As some said, it was better to have the conversation in the waiting room, because they could keep an eye on the medicine room where patients had to go to receive the injections, which was visible from the waiting room but not from my room. The waiting room was quite spacious; whenever it was less occupied, I talked with patients there, but if it became too busy, the interviews were held in my room. In the photograph below, one can see part of the waiting room and some of the clinic's health personnel having a discussion. At the Dermatology Service, work starts around seven o'clock in the morning, and at around two or three in the afternoon the waiting room is usually empty.

Photo 7: Part of the patients' waiting room, where nurses are sitting and discussing



Source: Collection S. Ramdas, Dermatology Service, Paramaribo 2009

At the Dermatology Service, apart from CL patients, several other groups of people were interviewed: the nurses involved in the treatment of CL patients, medical doctors, and health personnel working in the laboratory. Doctor-patient and nurse-patient interactions were observed during treatment, as well as laboratory personnel working with the biopsies of CL patients. I spent quite some time in the clinic archives searching for patient files, and I studied them to understand patterns of adherence to the biomedical treatment.

During my absence from the Dermatology Service, initially the nurses working in the medicine room assisted me by conducting the questionnaires. Later

on, I was assisted by two sociology students from the Anton de Kom university, Tilborg Shyreeta and Jaya Narain, who were themselves engaged in health related research. With all of these assistants, I discussed the questionnaire, the aims of the research, the issues that required extra attention, and I instructed them on how to conduct the interviews. Each time I returned from the hinterland, we had meetings in which we evaluated how the work was developing. Aside from being a research site, the Dermatology Service also served as a base to which I returned after my fieldwork in the hinterland, where I discussed my preliminary findings and other relevant issues with my colleagues, including further fieldwork planning and the progress of the work.

To complement data collection, I carried out investigations at a national level among the heads or representatives of governmental and non-governmental organisations, based in the city Paramaribo, which carry out hinterland related activities, as well as with health workers in the hinterland. Literature research, secondary analysis of national statistics and other written texts, the study of patient files, and my personal diary were also part of the methodological package.

3.4.2.2 Inquiries in the hinterland

In places where I stayed for a relatively long period of time, such as Godo-olo (three months) and Tepu (one month), I used the ethnographic method of participant observation to build up rapport with the people there. Taking a bath in the river, washing dishes, and doing laundry helped me to get acquainted with the people in my neighbourhood. When I walked from my house to the river and back again, I tried to talk to many of the villagers whom I met, and the fact that I spoke in their language often brought a lot of laughter. Laughter, I felt, lessened the distance between me and the villagers, and encouraged others to talk to me, especially at Tepu where the villagers were less talkative than at Godo-olo.

Helping others to catch fish, or donating the fish I caught to children or other women, helped to establish contact. Going for a fishing trip or helping women with planting plots or harvesting fruits and vegetables, or helping with the processing of food (as seen in the photograph below), also helped to build friendships.

Photo 8: Grating cassava in Tepu during a conversation with a Trio woman



Source: Collection S. Ramdas, Pelele-Tepu, district Sipaliwini 2010

In this way, I felt that I was taken in by the village communities. In all villages, the people understood that I was not a doctor, but “just a researcher interested in CL”. Participating with the local people in their daily activities, and also having conversations with people living in nearby villages, ‘camps’, or gold diggers’ camps, contributed to deepening my understanding of the local context.

I conducted several interviews – from informal conversations to in-depth interviews – with ex-CL patients, both men and women, and key figures such as group community leaders, their assistants, the owners of gold digging companies, traditional health practitioners, and local experts (healers) in curing specific diseases. Among the health workers, individual interviews and focus group discussions were used to find out about their thoughts on CL, prevailing ideas about the disease, traditional treatments known to them, and their opinions on the general attitudes of villagers towards people with CL. Sometimes health workers even remembered some CL patients vividly and shared their stories with me.

At the gold diggers’ centre of Paaston, a four hour boat ride from Godo-olo, I conducted ‘chain interviews’ with gold diggers in groups of two to seven men, as well as with shopkeepers and transporters of goods. These interviews lasted for hours, with some participants leaving and others joining the conversation. On several occasions, I held informal individual and group conversations with gold diggers, teachers, boat makers, and hunters; and some spontaneous discussions with village elders, my surrounding neighbours, and other villagers.

During my fieldwork, I conducted many short inquiries using the technique of ‘free listing’. Using the free listing method, for example, I asked villagers to list all descriptions of the illness CL that are used in the village, or that they had heard of, or to list in order of importance the most feared diseases in the hinterland. A technique that I had not previously thought of before going into the field, but that I used extensively and which produced much data in a short period of time, was that of ‘associative listing’. With people who passed by my house or who just had a few minutes to talk to me, I asked them to list everything that came to their minds if they heard the name Busi Yasi or CL. During interviews, I also used vignettes; hypothetical cases of people with CL were presented to villagers during interviews and they were asked how they would react to the person if he/she were a close family member, and what type of advice would be given to him/her.

In places where I stayed for a relatively short period of time, such as Donderskamp (three weeks), Brokopondo Centrum area (one week), and Benzdorp (two weeks), the method of focus group discussions helped to collect data quickly. However, in these villages I also carried out several individual interviews, short conversations, and group interviews (see photograph 9).

Photo 9: Group conversation with some Saramacca women



Source: Collection S. Ramdas, Brownsveg area, district Brokopondo, 2010

At Benzdorp, different groups of people were interviewed, such as gold diggers, drugstore keepers, commercial sex workers, goldsmiths, mechanics, and the local pastor's wife. My assistant and I also conducted a small survey in the village, with specific questions about (bio)medications for CL. We visited gold mining camps, which lay ten, twenty, and thirty minutes away from the village, by ATV. At the camps, we held interviews with gold diggers and camp owners. We also visited Canabanafo, where restaurant owners, shop owners, drugstore keepers, and some of the local people were interviewed. Almost all of the conversations were held in Portuguese, sometimes mixed with the Sranan language. In the villages of Godo-olo, Tepu, and Donderskamp, I went on plant recognition tours, where local key informants showed me many plants used to cure CL.

3.4.2.3 Key actors in the field and sampling

A challenging issue concerning sampling was the question of whom to talk to in the field sites, as well as how many. In contrast to quantitative studies, where the aim of achieving a probability sample – whereby everyone in the studied population has an equal chance of being selected – is common, my aim, as with most qualitative studies, was that of purposive sampling (Green & Thorogood 2004:102) – whereby the study sample are selected based on their knowledge and the purpose of the study – and to communicate with as many 'information rich' people as possible. At the Dermatology Service, this was not a problem; a survey was held and patients diagnosed with CL were asked to participate over the whole fieldwork period of ten months. The clinics of the Medical Mission were an important entry point in the hinterland, especially in the villages of Godo-olo, Donderskamp, Tepu, and in the Brokopondo Centrum area. During my stay in the villages, I first checked with the health workers about cases of CL. Unfortunately, in most of the villages, there were no people currently experiencing CL. At Tepu there was only one person, whom I was able to observe in his own contextual environment. Together with the health workers, I therefore composed a list of ex-CL patients who had gone through treatment. The traditional health clinic served as a second entry point. Apart from the

list of the Medical Mission, a second list of people who were treated traditionally for a condition diagnosed by the traditional health workers as CL was composed. This list was put together in collaboration with the traditional health workers, after studying their notebooks.

Through the patient list of the Medical Mission clinics and the traditional health clinic of Tepu, CL patients were selected. Through these CL patients, I used the snowball method to get in touch with further people who had experienced the disease. In Godo-olo, I built up very good relationships with some informants (like the captain, some of his assistants, and local healers); all people in key positions in the village. Through them and the village board, I came in touch with other informants who had experienced CL.

At Tepu, school teachers were very helpful in the sampling. Because they spoke Dutch quite well, and since most of them were Trio themselves, I was able to find out more about the Trio people's perception of CL and how they try to cure it. I found out that some of the teachers had even experienced CL themselves. Through these local teachers, I used the snowball method to get in touch with others who were willing to talk about the disease and their knowledge of and attitudes towards it.

In villages news travelled fast. The villagers were curious about the kind of research we were conducting and I felt that most people discussed the topic of CL without any hesitation. At Brokopondo Centrum and Benzdorp, gold diggers who had heard of our investigations into CL even came to us spontaneously to show us the sores on their bodies, which they suspected to be CL. Since there was no official government medical post at Benzdorp, the gold diggers had to find medical help over the border in French Guyana.

At the end of the research, a total of 526 people had been approached through formal and informal, individual and group, conversations, interviews, in-depth interviews, and focus group discussions: the core group of 205 CL patients at the Dermatology Service and 321 people in the hinterland villages. All research sites in the hinterland were selected in close collaboration with all stakeholders in Suriname and based on 2006-2008 epidemiological data from the Medical Mission, the Dermatology Service, and ACT.

3.4.2.4 The research assistants and the role of language

Language(s) played an important role throughout the entire fieldwork. In some research studies, misunderstandings due to language can complicate fieldwork and pollute the data with invalid information. In this regard, my national identity as Surinamese and my knowledge of local languages gave me some benefits as a researcher. In addition, as preparation for the fieldwork, I took several lessons in the Aucan and Trio languages as well as Portuguese. My ability to speak Sranan and Spanish was helpful in this case. For the fieldwork in the hinterland, I worked with bi- or multi-lingual assistants, most of whom were local people, which was very helpful for understanding and interpreting the data.

At Godo-olo, the language spoken is Ndjuka, but people could also speak Sranan and in some cases Dutch. Here I was assisted by Marily, a local twenty-five-year-old Ndjuka woman. I did not need her constant help as a translator, so instead Marily became more like a village guide and a key informant, bringing me in touch

with people who had experienced CL, introducing me to other women in the village, and taking me along on fishing trips or to farming plots. Over the course of time, we became good friends.

In Brokopondo Centrum area, the Saramacca language is dominant, but Ndjuka is spoken in some of the villages, and Sranan and Dutch are also spoken. Here I was assisted by Yvonne, a Maroon woman in her forties. Yvonne was of mixed ethnic descent: her father was a Saramacca Maroon, her mother an Aucan Maroon. Yvonne therefore spoke both the Aucan and Saramaccan languages very well. Yvonne lived in Paramaribo and assisted me in the preparations for my stay in Brokopondo Centrum area. At the field sites, Yvonne helped me with the focus group discussions, interviews, and transcription of the interviews. Since Yvonne knew both Saramacca and Aucan cultures very well, she was a valuable assistant, as well as an informant with whom I could discuss all kinds of aspects emerging from the data. Sometimes we had lengthy and insightful discussions into the night about how certain comments of people should be interpreted, which were then discussed the next day in the sessions with informants.

At Tepu, the Trio language is spoken, but also some Sranan and Dutch. The Trio language was difficult for me, since I did not speak it well, though prior to leaving for Tepu I did take several sessions with a contact person who taught me some of the basics of the language. I managed to conduct my investigations at Tepu through conversations in Sranan, some Dutch, and with the help of two Trio women, Anneke (about 26 years old) and Marian (about 19 years old), who were appointed by the captain as translators. Like Marily, they lived locally. With them I discussed the aims of the research, the research topics, the questions related to these topics, and what I expected from them. Both women were helpful and divided the days of the week among them to assist me. Anneke assisted in translating the questions on the first day, and the next day I checked them with Marian. With both assistants, I was able to learn more of the Trio language and they guided me through the village to all the people on the list. Often they had comments after the interviews; for instance, telling me whether or not they thought that someone was telling the truth.

In Donderskamp, communication in Sranan is common. The Carib language is spoken mostly by the older generation, but Dutch is also spoken. Having conversations with the villagers was therefore not difficult for me and translation was not necessary. I was, however, assisted by Eugenie, a young 25-year-old Carib woman and the mother of three children. She was introduced to me by the local health worker, with the approval of the captain of Donderskamp. Eugenie was more of a guide, leading me through the village as we walked from home to home. Since she lived at Donderskamp, she knew all the people and brought me easily into contact with some of them.

At Benzdorp, Portuguese is spoken, and some Sranan. I worked in Benzdorp with Marlon, a 40-year-old man who was proposed to me by the BOG and who functioned as both my translator and 'bodyguard'. He accompanied me everywhere in Benzdorp, and helped me with the interviews. Marlon did not know Benzdorp, but he was an expert in the sense that he had much work experience in the hinterland; in particular, he had knowledge about the gold sector and the illegal trade of medications in the hinterland. He served as an assistant to me and as someone with whom I could discuss data that emerged in the field.

3.4.3 'Natural groups', anonymity, and confidentiality

In this research, I tried to work with groups in their 'natural' environments as much possible. At Brokopondo Centrum and Benzdorp, for instance, interviews were carried out among naturally formed groups of people; those busy combing and weaving hair, working on motorbikes or other machines, sitting together with children, playing draughts, or drinking beer at or sitting in front of small shops. In Godo-olo, Donderskamp, and Tepu, people at the river shore doing their daily activities, or women and men working in their yards or (public) workplaces making canoes, raking the garden, baking big round cassava pancakes in their (open) kitchens, all formed ideal natural groups with whom to talk. Formal in-depth sessions with the captains or their assistants were held at their homes. Formal sessions with health workers were held at the clinics of the Medical Mission and informal individual interviews at their homes. Formally structured focus group discussions were held in a convenient and suitable location; in Donderskamp, for example, focus group discussions were held in the local public recreation hall. Finally, I often made appointments with informants to come to my home in the village, where we could have (sometimes lengthy) conversations.

In this way, throughout the whole fieldwork period, I, together with my assistants, conducted investigations in the hinterland among 321 people: 66 people at Godo-olo, 37 at Tepu, 58 in the Brokopondo Centrum area, 33 people in Donderskamp, and 127 people in Benzdorp (including a short survey among 46 villagers). Like most researchers, I carried my notebooks, an audio-recorder, and photo camera everywhere in the field. With the informed consent of the informants, I tried to record most interviews and take pictures whenever allowed. For others who did not like their stories to be recorded, I made notes in my notebooks. All information collected during the research was treated as confidential and with sensitivity to the informants. The identities of all CL patients and people living in the researched field sites have been anonymised in this dissertation. However, the names of official village heads or chiefs have not been anonymised.

3.5 Dealing with diversity

One tree, so many leaves, one tree
One river, so many creeks, all are going to one sea
One head, so many thoughts, thoughts among which one good must be...
– Robin Raveles (1973)

These lines by Robin Raveles, one of the most famous poets in Suriname, symbolise well the diversity that exists within this single study about CL. The diversity is visible in the central questions of the research, the thematic and theoretical approaches, and the methods and techniques used, as described in the preceding chapter and sections above. Methodologically, this diversity also posed different challenges, some less difficult to act upon, some quite tricky. In the following, I provide insight into some of the methodological and analytical aspects of this study, and discuss some of the main issues that I had to deal with.

3.5.1 Generalisation, evolving questionnaire, and data analysis

What do I say with my qualitative analysis, and about whom? First of all, this study is mainly about the Surinamese population. However, the (Surinamese) population targeted in my study was diverse: Ndjuka and Saramacca Maroons, Indigenous peoples, Hindustanis, Javanese, and people of mixed ethnic descent. In addition, Brazilians, as a non-Surinamese population, were included in my research. Each of these groups have their own cultural constellations of ideas and health systems, which inform and guide their behaviour. I decided not to focus on one of these groups or communities in detail, as anthropological studies usually do; rather, I intended to gain an overall impression of CL in Suriname.

Instead of using the ethnic or cultural identity of my research population and generalising the results based on those premises, I chose to be guided by the *contextual identity* of the research population. First, to avoid confusion and safeguard validity, it was important to include informants in my study who had been (bio)medically diagnosed with the illness CL. CL patients – i.e. those who had contacted and received therapy from biomedical posts in Suriname, namely the Dermatology Service and the Medical Mission – thus formed the core research population. Through laboratory testing and confirmation of a diagnosis of CL, it was certain that those with whom I spoke in this context were actually talking about CL and not other diseases that look like it. Departing from this biomedical context, I let the data ‘talk’ to me, instead of me ‘talking’ to the data. The environmental context (hinterland) and the occupational and socio-cultural context (gold diggers, wood cutters, hunters, fishermen, campers – i.e. those *working* and *living* in the hinterland, mainly Maroons and Indigenous Peoples – and others visiting the forest for leisure activities) were thus other important characteristics of the identities of my research population.

Overall, therefore, in terms of who my analysis is about, it can be summarised as those affected by the disease CL. Taking respondents’ contextual identity into account, I conducted supporting research in the four selected key field sites in the hinterland. One could argue that these four sites, as selected by the national stakeholders in the ‘Leishmaniasis in Suriname’ project, are just four of the many villages and places where people are confronted with CL. This is indeed true, but they were nevertheless key sites selected on the basis of disease prevalence, accessibility, safety, transportation costs, and other logistical matters. In addition, the exploratory nature of this research allows and even requires selectivity.

I managed to get in-depth information on a variety of issues, some of which I had at first not even thought of. This led to the use of an evolving questionnaire at the Dermatology Service. For example, at first there were no questions in the questionnaire about food taboos. Upon learning that in the villages certain food types are associated with the disease – and therefore forbidden to consume – this resulted in the inclusion of questions concerning food, drinks, and social taboos. In addition, research was steered by certain issues coming up in the interviews at the Dermatology Service, which required further in-depth research in the villages. Participants at the Dermatology Service reported, for example, that some people had advised them not to have sex when they had CL sores. Why this was could not always be answered by the participants; they simply answered that “It’s what they [elders] say”. I tried to investigate this aspect further when I was in the villages. I also cross-checked data often with my colleague at the Dermatology Service. For

example, continuing on the theme of not having sex, some patients said that “the doctor said so”. In meetings with my colleague, I then cross-checked whether this was the case. Cross-checking data with my colleagues, or inquiring into issues at village level, required being sensitive to the anonymity of the respondents, which I always was. In the villages, for example, I never provided information about the participants’ identities and tried to open up discussion about a certain issue by introducing it tactfully, for instance: “I heard that...” or “People said that...” and continuing with questions like “Would you know more about this issue? What do you think about it?” This strategy usually worked, and sometimes led to the application of other techniques such as listing and vignettes (as explained in section 3.4.2.2), or the formation of other research instruments, such as the development of another questionnaire (at Benzdorp, for example).

Despite the huge amount of information gathered, no saturation point was reached in the research. New data kept emerging. Therefore, in this thesis I neither generalise nor state fixed results, but rather state what I found among the research population. I am, however, able to address several aspects that emerged from the data and point to possible relationships that (may) require further investigation.

All information from the questionnaires was translated into English by my multi-lingual research assistants in the Netherlands, and both the original Dutch version and English versions were manually entered into the computer and stored using Microsoft Word. Each questionnaire contained the standard twenty questions, which in the course of the research evolved into 27 questions. After categorising and labelling the answers, all information was thematically entered into Microsoft Excel spreadsheets, which I found very practical and useful for my data analysis. The questionnaire data was then coded and entered into a thematic framework of the software programme Statistical Package for Social Science (SPSS). Thematic content analysis helped me to analyse the data that I collected in the hinterland. Familiarising myself with the content of the interviews by reading them over and over again also helped me to extract and label excerpts of the interviews and group them into major themes. This working method – with the help of the combined pathway concept for health seeking that I proposed in this research – proved a good foundation for structuring and steering data analysis.

3.5.2 Reflections on access: the ‘purity’ of intentions and the role of mediators

In general, the process of acquiring permission to conduct the CL research in Suriname reflected a willingness to collaborate, as well as trust and mutual respect between national health authorities, local NGOs, and the authorities at the villages. However, in one field site – Tepu – gaining access to the village was slightly problematic. As Hammersley and Atkinson (1995:54) point out, “Much can be learned from the problems involved in making contact with people as well as from how they respond to the researcher’s approaches”. Usually, one formal meeting with the head of the village sufficed; but at Tepu, acquiring permission was a two day process in which two formal meetings – the first with the captain only, the second including under-captains and the assistants – were held before I was granted permission to do research in the village. It was a process of observation, negotiation,

and, as it seemed to me, a matter of weighing the pros and cons before permission was given.

The reasons for my delayed access to the village were not explained to me, but emerging issues that I came to know of during my stay included uncertainty about the 'purity' of my research aims – whether or not the research served money making purposes – and 'distrust' in the village about outsiders that was rooted in past negative experiences. Another reason was that the Trio people in this village claimed to have a 'traditional' medicine, an ointment, for curing CL, which they felt entailed opportunities for future (financial) exploitation. Protection of their 'traditional knowledge' was therefore a priority. My audio-recorder and photo camera were, due to this distrust, not always appreciated at Tepu, and I only used them (as described above) after the verbal consent of informants was given. In the process of gaining access in Tepu, ACT functioned as a mediator; as they were trusted by the captain of the village, ACT managed to convey the purity of my intentions as a researcher to the village board. This experience emphasised how important such mediators are in communities, since their negotiations may also influence the success or failure of the fieldwork.

3.5.3 An ethical dilemma: how to deal with reciprocal relationships

After having experienced the hospitality and friendliness of many of the villagers in all of the sites I visited in the hinterland, I was left with some dilemmas. Each village had its own dynamics. In most villages, I felt at ease, both as a researcher and personally. In one village, however, I felt my position as a researcher and as a person was – and still is – more closely watched by the community, especially the board of the village, and that my presence and work was somehow associated with money. I felt as if openness towards this project and the approval for me doing research in that specific community was being traded for what the project would bring for the local people there. Questions like "What will you do with your writings about our village? Will you sell your book, earn money, and will the community benefit from it?" seemed in the back of (some of) the villagers' minds.

I also experienced that the friendliness that some villagers showed to me somehow tied me into forced responsibilities towards them and their families. I often heard questions like "Can you send me a package from the city with cloths?" or "I don't have tea, coffee, salt, sugar, rice. Can you send this to me?" or "My son is in the city, can you send him some money?" I realised that my informants lived very far away from Paramaribo and that much that was easily bought or not even seen as a luxury in the city was very scarce in these communities. When I returned to Paramaribo, I did send some of the families packages with household products. I also met some of the villagers in the city and brought along second hand clothes that I found. I did all this with pleasure, but I also felt burdened by it. In terms of finances, for example, how much could I spend at the cost of the project? And what about after the project? What to do with all of these people who expect me to 'give' back to them because I have worked with them?

On the one hand, I felt the poverty that they experienced, but on the other hand, I was startled by the 'luxury' that I saw. Many villagers wore expensive clothes and watches. They knew what the big city had to offer and were only satisfied when something expensive was given to them. Even the perfumes that they used were

from expensive brands. Many did not have basic household products such as oil or salt, but they owned DVD players and bought many DVDs and other entertainment accessories, which they used when there was electricity. It felt somewhat double-sided to speak of poverty when they were able to afford such expensive items.

Sometimes, remarks such as “Yes, you are a student researcher *now*, but after this you will gain a lot of money” also made me feel very uncomfortable. The assumption was that they were helping me now, but that I would become someone important in the future, someone known. Giving information now therefore meant for them getting finances or other materials in return in the future. I have still not found a way to handle these somewhat ‘forced’ reciprocal relationships that I found myself in during my fieldwork. Maybe understanding the historical and social background of the communities and analyzing this dilemma further might help in dealing with it.

3.6 Conclusion

Suriname owes its rich history to the ethnic diversity of the people living there. The many different groups have all managed to hold on to many elements of their culture: language, clothing, food, religious beliefs, healing systems, and norms and values. At the same time, the co-existence of so many different people in society – which entails mutual respect for one another’s culture, sharing one (national, informal) language, having a collective code of conduct and way of living – has contributed to the formation of one Surinamese identity. Research in such a diversified yet unified cultural arena therefore poses quite some challenges.

Multiple contexts – occupational, environmental, socio-economic, historical – that constitute people’s lives often complicate data analysis because of their (unseen) confluences and (unfelt) interrelatedness, and often also because of their (seemingly) opposing or (clear) contradictory characteristics. In the sections above, I have made some rough sketches of the contextual and methodological framework in which this research was carried out. Within this framework, the empirical findings can be better understood or placed within the contexts from which they emerged. As I believe, research design and research methodology feed outcomes, and outcomes reflect methodology. In the following chapters, the empirical findings will be discussed, starting with illness perceptions and aetiological explanations.

Chapter 4 Not knowing': lay perceptions and explanations of cutaneous leishmaniasis

What illness perceptions and explanations do CL patients and others in the hinterland who have experienced CL have about the disease? What is the disease like, and what is it called? What do CL patients and others know about the disease? This chapter zooms in on the first category of the concept of health seeking, as described in Chapter Two. It presents and discusses research findings on local (lay) knowledge about the disease: vernacular names for the illness, explanatory theories, description of symptoms, knowledge about the progress of the disease, perceptions of the severity and contagiousness of the illness, and beliefs and attitudes related to these explanations.

In discussing these topics, I have taken up the concept within the anthropology of medicine of 'not knowing', as introduced by Murray Last (1981). Last conducted research among the Muslim Hausa population in northern Nigeria, and explored people's knowledge (what they know) and their interest in knowledge (what they care to know) about their own medical culture. Distribution of knowledge in a society is often uneven and knowledge of medicine and medical systems is far more complex than it may seem (Littlewood 2007). Last claimed that Hausa healers lack a clear and systematic idea of their own healing methods. Furthermore, he criticised anthropologists for their persistence in obtaining answers from informants, even when the informants may not have the relevant knowledge; as a result of such persistence, he argued, informants will usually provide an answer, though its accuracy may be called into question.

Last's urge for caution in terms of informants' (lack of) knowledge fits the context of my study, to the extent that the informants with whom I spoke did not have a single clear and certain explanation about the aetiology of CL, but rather provided a wide variety of answers. What is puzzling is why, despite it being a generally well known and relatively common disease in the hinterland, local knowledge systems do not seem to have a common explanatory theory about CL. What does 'not knowing' reveal in my study and what does it reflect? One of Last's conclusions is that "don't knows" or "don't cares" reflect people's disinterest in medicine (Last 1981:11). Rather than disinterest, my study reveals that both knowing and not knowing are rooted in the different contexts of people's daily lives and are a reflection of historical, socio-cultural, occupational, educational, biological, environmental, and public health related conditions.

This chapter presents insights into lay knowledge, perceptions, and experiences of CL, and the wide variety of tentative and fragmented illness explanations that CL patients and others confronted with the illness have about it. Looking first into vernacular names, I analyse what these names reveal about the illness and how they are related to lay diagnosis and treatment practices. Subsequently, I turn to knowledge about the aetiology of the illness, lay diagnosis, and highlight the experience of the disease, perceived illness severity, and notions about the spread of the disease. Beliefs related to CL and the existence of taboos related to food, drinks, and health seeking attitudes are also discussed.

My analytical emphasis is on CL patients seeking treatment at the Dermatology Service in Paramaribo, and ex-CL patients of the Medical Mission in the hinterland, whose illness was confirmed through clinical investigations and laboratory tests. Findings and analysis are also derived from qualitative observations and inquiries in the different parts of the hinterland where the majority of CL patients live and work.

4.1 CL vernacular names

Knowledge of local terms for an illness is important for health professionals because it leads to improved case findings (Liefoghe et al. 1997), provides insight into how illnesses are locally understood, and sheds light on the decisions patients make for certain treatments (Van der Geest & Meulenbroek 1993). The names – and other local terms – differ due to the multiple languages spoken in Suriname. The vernacular names for CL are given in the following languages, based on the language used by the research population:

- Sranan (Sr), i.e. the *lingua franca* or the national common language, which is influenced by several languages such as English, Carib, Dutch, Arawak, and Portuguese (Van 't Klooster et al. 2003:21). This language is spoken and understood in Suriname by most of the various ethnic groups.
- Surinamese Dutch (SD), the official language in Suriname.
- The Maroon languages: Ndjuka or Aucan (Au) and Saramaccan (Sa).
- The Indigenous¹⁷ language: Trio (Tr).
- The Brazilian language: Portuguese (Po).

In Suriname, CL is commonly referred to as *Busi Yasi* in Sranan or as *Bos Yaws* in Surinamese Dutch.¹⁸ The combination of the vernacular terms *Busi/Bos* with *Yasi/Yaws* reveals on the one hand lay knowledge about the environment in which CL is contracted, and on the other is a reference to another disease from a century ago in the hinterland of Suriname. Both terms, *Busi* and *Bos*, mean 'bush', the area where CL is generally contracted. The term *Yasi* refers to the disease Yaws, or framboesia,¹⁹ a tropical infection of the skin, bones, and joints caused by the bacterium *Treponema pertenue* (Jochems & Joostens 2009:325; Peters & Pasvol 2007:329), which, in appearance, shares certain similar characteristics with CL. In the photographs below, visible similarities between both diseases can be noted; this is especially the case for non-biomedical experts.

¹⁷Currently, in Suriname the official substitution for the term 'Amerindian' is 'Indigenous'.

¹⁸In health publications on CL in Suriname (Van der Meide 2008:91; Lai a Fat et al. 2002), medical professionals still tend to write the terms *Busi Yasi* and *Bos Yaws* according to the old spelling of Sranan and Dutch, respectively *Boessi Yassi* and *Boschyaws*.

¹⁹Framboesia or Yaws is currently considered a disease that has either been eradicated or greatly reduced in many parts of the world (Sanchez 2011).

Photo 10: Yaws (eroded papillomas covered in crust) Photo 11: CL lesions covered in crust



Source: Sanchez 2011 (fig. 201-4 C) Source: Collection S. Ramdas, Dermatology Service 2009

Confounding the association between the two diseases, around 1911, P.C. Flu, a medical doctor, treated framboesia in the hinterland of Suriname successfully on a large scale (Snijders 1946:40); in the same period, he also first detected and identified CL (Flu 1911).

Some Saramacca and Ndjuka Maroons call CL *Krabu* (Sr) or *Kaabu* (Au) *Yasi*. Once again, these names refer to Yaws; specifically, to one characteristic of it, which is that Yaws can cause painful hardened ulceration on the soles of the feet, a condition known as 'crab yaws', because patients "walk with a deliberate slow, crustacean gait" (Sanchez 2011).²⁰ Inhabitants of the hinterland likely experienced similar health conditions due to Yaws a century ago and subsequently associate this local knowledge with current experiences of CL.

The Ndjuka Maroons speak of *azo* (Au), which means "a sore that never dies". Zisa, a 50-year-old Ndjuka woman living at Godo-olo, explained:

That [*azo*] is how they [Ndjuka people] call it [CL]. But people of the city call it *Busi Yasi*. Ndjuka people, as we are here [in the village of Godo-olo, in the hinterland], we call it *azo*. That's how we call it. *Azo, a soro sa ne dede* [a sore that never dies]. It's difficult to cure it. (Zisa, Godo-olo, November 2009)

A Ndjuka captain claimed that *azo* is also known in the hinterland as *bussweli* (Au), meaning a bush ulcer. The Trio people of Tepu call it *kaasa*, meaning a dangerous sore, a wound that does not heal fast. According to villagers, it is also called *kaasa piye*, meaning "the one with *kaasa*", and the sore is also referred to as *aikagaime*, a very dangerous pimple. As with the Ndjuka Maroons, these vernacular names speak of a characteristic of the sore. The Carib Indigenous people of Donderskamp indicated that everybody among them knew CL as *Busi Yasi*. As mentioned earlier, according to the Carib people, the Carib language is slowly dying out, and even the oldest people in the village did not recollect how CL was referred to in Carib.

²⁰See web reference number 15.

Cutaneous leishmaniasis is popularly known among the Saramacca Maroons as a *leishmania* or *leishmania*, from the biomedical name leishmaniasis. According to a Saramacca woman, people are used to the way in which medical doctors refer to the disease. But in their own language, Saramacca Maroons call CL *Matu Yasi*. *Matu* (Sa) means bush, linking the illness to the place where it usually occurs. In focus group discussions at *Ballingsula*, a Saramaccan village near Brokopondo Centrum, Saramacca Maroons spoke of another vernacular name: *Tatay yassa* (Sa). According to them, *tatay* (Sa) literally means rope (*Tei* in Sr), though the Saramacca people call the lianas that hang down from trees *tatay*. CL is thus called *tatay yassa* because the Saramacca people believe that certain lianas are the main cause of CL. Some, mostly gold diggers, mentioned the name *dala soro* (Sr) for CL, meaning the 'dollar sore', after the dollar shape that the sores usually take.

In Benzdorp, Brazilians generally know CL as *leisho*, abbreviated from the biomedical name. They also call the illness a *ferida brava* (Po), an 'angry sore/wound'. A *ferida brava* "is something that is violent, it signifies something that is not controllable, it grows and grows and grows" (PW, Benzdorp, 2010). This vernacular name for CL is common in Brazil (Camargo & Langoni 2006:530; Lainson 2010:13). A small scale qualitative research study conducted in the context of this present CL research in Corte de Pedra – an endemic area for CL in Brazil – also showed that, similar to the Brazilian community of Benzdorp, CL is widely known by the Corte de Pedra community as *uma ferida brava* (Machado, Bahia, 2012). It is an aggressive, uncontrollable, hard to cure illness (Nurse X, Health Post Corte de Pedra, 2012). According to some informants at Benzdorp, the vernacular term *ferida brava* is not exclusively used for CL. It is an umbrella concept used for illnesses that – similar to CL – constantly develop (without medical interference), such as cancer or leprosy. A key informant at Benzdorp, a pastor's wife and a biologist by training, explained that "a *ferida brava* concerns often an illness that isn't cured by medical treatments. In the past there were no medical treatments for it, so that's how *leisho* was called. Nowadays it is easily treatable, but people still call it *ferida brava*" (Pali, Benzdorp, 2010).

Depending on how the sore looks, the people at Benzdorp distinguished between *leisho majosu* (Po) or *seco* (Po) and *leisho chorao* (Po). Upon being asked why CL was called *leisho majosu*, informants said that it is simply known to them as such, and there is no specific meaning attached to it. The local name *leisho majosu* may, however, reveal something about the educational level of the people living in Benzdorp. According to the pastor's wife at Benzdorp, *leisho majosu* is derived from the biomedical name leishmaniasis, but "because the people here are mostly uneducated, they don't know how to pronounce it. That's why they say *leisho majosu*" (Pali, Benzdorp, November 2010). The terms *leisho seco*, however, says something about the type of CL experienced. *Seco* means dry or dead, and as most people described, "the one [sore] that has a crust on it from above [seems dry or dead], but inside it's deeper, it lives". *Leisho chorao*, which literally means 'crying leisho', refers to how the sore sometimes appears: leaking wound fluid, the 'wet' type (see following photograph).

Photo 12: A lay diagnosed 'crying leisho'



Source: Collection S. Ramdas, Klaaskreek, April 2010

4.1.1 Interpretation of CL vernacular names

One way to understand the diversity and significance of vernacular names is to look further into their meaning. Using Fainzang's (1986) categories of *dénomination descriptive*, *dénomination causale*, and *dénomination curative* for illness terms, Van der Geest and Meulenbroek (1993:287-288) have shown how illness terms among the Mossi in Burkina Faso describe, explain, or point toward the treatment of an illness. Similarly, I found that some vernacular names for CL also partly *describe* the perceptible features of the illness and *explain* its causes.

The names *leisho seco* and *leisho chorao*, *dala soro*, *azo*, *kaasa*, and *ferida brava* all describe the symptoms, characteristics, and development of the illness, and make reference to its difficult treatment. *Tatay yassa* refers to illness aetiology: liana causes CL.²¹ I found that, in general, vernacular names show the *environmental* context in which CL occurs, and the names reflect lay knowledge about the environmental context: *busi*, *bush*, *bos*, *matu* are all terms for the forest, which is where CL occurs.

Similar to these findings, other international biomedical studies of CL show that geography and environment play an important role in naming practices. For instance, health professionals in Italy reported CL to be known as 'oriental sore' or 'tropical sore', referring to the climate zones or broad geographical areas in which CL occurs (Coradetti 1952:618). Just as in Suriname, where the name *Busi Yasi* reveals the geographic-environmental area where CL occurs, many local names for CL elsewhere refer to the place where the disease is often found, such as *Aleppo button* or *boil* in Syria, *Delhi boil*, *Lahore sore* or *Kandahar sore* in India, *Baghdad*

²¹In Pakistan and Afghanistan, CL is known by the local people as *Kal Dana*, meaning 'the year-long sore' (Kassi et al. 2008:12), which also relates to characteristics of CL.

boil in Iraq, *Jericho's Button* in Jericho, *Bouton de Crete* in Greece, *Ashkhabad sore* in Turkmenistan, *Bouton de Biskra* in Algeria, and *Balkh sore* in Afghanistan (Hepburn 2003:50; Kent 2013:14; UI Bari 2006:24-25; Jacobson 2003:242). Vernacular names also make reference to specific endemic areas and the people who come from there; in Ecuador, for instance, the names *la Colombiana* (the Colombian) and *Marca de Santo Domingo* (Mark of Santo Domingo) refer respectively to people with CL ulcers coming from coastal southern Colombia and the Ecuadorian town of Santo Domingo (Weigel et al. 1994:145).

Some vernacular names refer to *associations with other diseases*, because they are related to illness histories of the past. In naming CL, people make associations with a disease experienced in the forest, in particular Yaws or framboesia. As already mentioned in the previous chapter, the inhabitants of the hinterland have lived in the Amazon rainforest for centuries. While living in the woods, their past experiences with several illnesses, either 'imported' or already existing, and contact with biomedical doctors have undoubtedly contributed to their current naming practices, explanations, and understandings of CL. The increase in biomedical services in the hinterland through the Medical Mission in more recent times (starting around six decades ago), has also left its mark, with local names revealing the *biomedical influence* or *familiarity* with the illness; for instance, Brazilian gold diggers' and Saramacca Maroons' naming of the disease as *leisho*, a *leishmania*, or *leisho majosu*.

4.1.2 Metaphoric language

As this research shows, CL patients use metaphoric language to describe their illness. Both the illness as a whole and its symptoms (the sores) are attributed human features: *azo*, the sore that cannot be 'killed'; *leisho chorao*, the 'crying' sore; and *ferida brava*, an 'angry' wound. Other studies on CL show similar findings. Weigel et al. (1994:145) reported that the most widespread name that villagers in the Northwest Pichincha Province in Ecuador used for CL was *sarna brava* meaning 'angry sore' or *charra brava* meaning 'angry ulcer'.

CL patients in Suriname also metaphorically *perceive* the disease: CL has a bad 'reputation'. Patients call it *moeilijk* (SD), difficult; *takru* (Sr), evil; *hogii* (Au) or *hogri* (Sr), cruel; *wreed* (SD), gruesome; *tangaayesi* (Au), stubborn; *gevaarliki* (Sr), dangerous; *fisti* (Sr) or *morsu* (Sr), filthy; *toff* (Sr), tough; and *diri* (Sr), expensive illness (*siki* (Sr)). CL is viewed as difficult, stubborn, and tough primarily because it takes a long time to cure. It is seen as evil, cruel, gruesome, and uncontrollable because it keeps growing, spreading, and "eating away the flesh". It is dangerous because it poses a severe threat to health, including the loss of a finger, hand, arm, or leg. Almost all CL patients expressed the fear of amputation should the sore not heal. CL is also seen as expensive because of the high (biomedical) treatment costs involved (this is relevant in the city).

An important component of lay diagnosis is precisely the attributing of such characteristics:

... it [the CL sore] leaks fluid, it has round bullet-like things, it stays for a long time on the skin, people get tired of seeking treatments, it just won't die [heal] till you let the doctors treat you. You won't get it healed easily,

you can't kill it, that's how you know it's azo. (Bubba, Godo-olo, October 2009)

Kaasa...is not a normal, usual kind of wound, it is a wound that takes a very long time to heal, and it can become very big, and it is very dangerous. (Apasi, Tepu, February 2010)

It is a very dangerous illness, because it eats up your skin and the sore becomes broader and bigger, it can almost eat away your foot. You know then this is *Busi Yasi*, a gruesome [*wreed* (SD)] disease. (Marley, Donderskamp, May 2010)

Attributing humanised characteristics to the illness, as expressed in the vernacular names and other vernacular descriptions, help lay people to begin to recognise and establish a diagnosis for the disease. Such meanings are also indirectly related to health seeking practices. Diagnosis of the condition as CL means, logically, seeking treatment to cure the condition.

4.1.3 Lay diagnoses and explanations

For CL patients at the Dermatology Service, clinical investigation and laboratory research provided a definitive diagnosis of their condition as CL. Prior to coming to the Dermatology Service, most patients had discussed their condition with people in their living and working environments in the hinterland. Lay diagnosis was, therefore, often made beforehand. In all communities in the hinterland, sores are recognised and diagnosed as CL based on the symptoms and characteristics of the disease: rapid growth, the different types (wet or dry), its causing nodules, thick lifted borders, or deep oval or round shaped wounds, the (occasional) anaesthetic feeling, itching in the initial phase, and its being extremely difficult to heal. According to the CL patients and others in the hinterland, there is more than one type of CL: there is a wet type, a dry type, and one that spreads over the whole body. CL is further known to cause nodules in the body and is notorious for its flesh eating ability. According to the informants, everyone – men, women, and children – can contract it, and although one can contract it anytime and anywhere in the hinterland, there are some periods when CL is seen more often, namely during the rainy season between November and February.

Health workers in the hinterland reported that CL patients usually come to the clinic with the diagnosis already made:

They don't say, "Doctor I don't know what I have". They say "Doctor, can you look at this sore? I think it is *Busi Yasi*". (Nurse Rosie, Medical Mission clinic Brokopondo Centrum, April 2010).

Of the CL patients at the Dermatology Service who claimed to have knowledge about CL (123 CL patients, 60%), all reported coming to the Dermatology Service because the sore would not heal, and it was for that reason, among others, that they knew – or had been told – that it was CL. Another way to diagnose CL, according to villagers in the hinterland, was to use various botanical medicines or other kinds of traditional remedies that are proven to be one hundred percent effective against

normal sores. If the sore does not heal with these medicines, then the diagnosis is CL.

In itself, a correct lay diagnosis contributes to greater patient independence and assertiveness: patients actually *know* what is happening to them, and based upon this knowledge can initiate symptom management and explore therapeutic options that may accelerate the healing process (Etkin 1994:26). Lay diagnosis becomes problematic, however, if therapeutic options are chosen that aggravate symptoms or 'hide' the caused aggravation, or if it delays/obstructs necessary health seeking in the biomedical sector. One health worker reported:

If people know what they have, if they know it [the sore] is *Busi Yasi*, they don't come to the *polikliniek* [outpatient clinic]. They'll come if they don't know what it is. (Nurse Robbie, Medical Mission clinic Klaaskreek, April 2010)

Prolonged lay treatment (based on lay diagnosis) often contributes to late biomedical health seeking; sometimes very late. Another health worker remarked:

People do not register easily at the poli [outpatient clinic] when they have *Busi Yasi*, unless it is in a very advanced stage. They do a lot of self-treatment. (Nurse Herman, Medical Mission clinic Donderskamp, May 2010]

This research shows that 181 of the 205 CL patients (88.3%) sought treatment at the Dermatology Service within one to three months of noticing the sore. Among these, 93 patients (45.4%) sought treatment within one to four weeks, 62 patients (30%) within two months, and 26 patients (12.7%) in the third month.

A group of fourteen patients (6.8%) sought treatment within four to six months, and a small group of five patients (3.4%) within seven months to one year. Two patients sought treatment very late: one after one year and the other after three years. Three patients did not provide information on this topic. The findings show that many patients sought treatment after one month: 109 CL patients (53.2%).

Late treatment seeking at biomedical services as a result of prolonged lay treatment may lead to an increased risk of disability, complications in the biomedical treatment, higher treatment costs, and a prolonged healing process. One 26-year-old Saramacca Maroon gold digger at Klaaskreek, Brokopondo, who had been self-treating his CL sore for about six months, shows his sores in the photograph below.

Photo 13: Lay diagnosed CL sores



Source: Collection S. Ramdas, Klaaskreek, April 2010

4.2 Contagiousness of CL

A group of 76 CL patients (37%) at the Dermatology Service thought that CL is a contagious disease. According to them, if leaking wound fluid from one person's sore comes into contact with another person's body, that person could contract CL. Wound fluid is also viewed as a source of further infection or spreading of sores for a person who initially has only one sore. Many people living in the hinterland have similar ideas. This perception was discussed by two inhabitants of Godo-olo: Wino, a 61-year-old man, and Zennie, a 50-year-old woman. The fragment below represents the way in which many people speak about the illness and the extent to which it is contagious:

W: If you medicate it [the sore], don't touch another part of your body.

You have to wash your hands very well with soap after you're finished.

Z: Yes, because the wound fluid is contagious. If it gets in contact with another place on the body, it will cause another sore to break open.

R: So, it's contagious for yourself, on your own body?

W+Z: Yes! For yourself yes, yes!

R: If you touch your nose after touching a sore, it will get you in the nose as well [all laughing].

(Wino, Zenna, Ramdas, October, 2009, Godo-olo).

To prevent the disease from spreading, villagers are cautious when cleaning the sore, as the fragment of a conversation with an ex-CL patient in the hinterland shows:

I: With what did you always clean it [the CL sore]?

R: Always with boiled water with tree barks in it.

I: And where did you dispose of the things you used to clean the sores with?

R: You clean it with a piece of cloth, nice and soft cloth. And if you're finished cleaning, you dig a hole and throw it in it and bury it. I always worked like that with that of mine.

I: Why did you do so?

R: If I just threw it away, a dog could walk over there, take it and eat it. And it's a thing of yours; it's not good for a dog to eat it. It's you that's spreading things further in that way, you understand? You, who has got the disease, you should always make efforts to be clean and tidy with it. Thus, if it would get you and you and I are sitting here, I'd always advise you to never throw your cloths here and there; you should not work like that.

I: But didn't you wash them and re-use it?

R: No, no, it's only one time I used the cloth and then I threw it away. Because I didn't trust it to re-use it. Because I didn't know how the sore was caused.

I: What did you do with the water that fell off the sore while cleaning it?

R: Thus, when I cleaned it, I always had my own place where to do it, then you dig a hole and put the leg in it and all the water I used to clean it would then fall into the hole. Thus, when you're finished cleaning it, you bury that too. And you bury the cloths there as well.

I: So you were very careful with it?

R: Yes, 100%, it was no joke. I was really, really careful with it, because I was so afraid!
(Jacki, Ramdas, December 2009).

Among those treated at the Dermatology Service, 89 patients (43%) did not believe that CL is contagious. A group of 40 CL patients said that they did not know if it was contagious (20%); among these, four patients doubted it, saying “I don’t know, but I don’t think so”.

4.3 Severity of CL

A striking paradox emerged concerning opinions on the severity of CL. While the vast majority of the CL patients perceived CL as either a very dangerous (176, 86%) or serious (183, 89%) illness, at the same time, nearly half of the CL patients (99, 48%) said that they did not fear it. The main reasons that patients mentioned for considering CL a dangerous and serious disease were:

1. The – often fast – growth of small sores into large and deep ones, transforming it from an innocent to a very aggressive and severe type of illness, with its ‘flesh eating’ character, the unstoppable growth of the sores, and the difficulty in healing it without biomedical treatment. Here is a selection of some of the explanations given:

It’s a very serious illness, a very tough kind of illness, because if you don’t go to the doctor, it can get bigger till I don’t know how big.

It is a dangerous illness because it got so big, while it was so tiny.

Because it is small first, and then it becomes bigger and bigger... it’s like a worm, eating you away.

A very serious illness, because it’s not a sore that you can treat yourself. It is not a sore that you can buy medicine somewhere and treat it yourself.

For sure [CL is dangerous], it eats you up and ... it becomes bigger.

If you don’t kill it, it can become big and eat up your whole skin. It is a fucked up disease!

A very serious illness, what! Do you know how many kinds of bush medicine I applied? ... that thing just doesn’t want to cure.

(CL patients, 2009, 2010, Dermatology Service)

2. The idea that CL sores can progress so far as to necessitate amputation of body parts, or even cause death if the sores reach the intestines or vital organs of the body. Patients expressed such concern, both in terms of what they personally experienced and what they had heard from or seen on others:

I still have it and it is the first time I have it, but I have it already for such a long time. And it is dangerous, because it can make a hole in the hand and then the hand and fingers must get amputated.

Because it can cut your foot and that's dangerous. You can compare it with diabetes. It can give you similar kind of sores that do not heal till your foot has to be amputated.

If you don't do anything to treat it, it becomes dangerous. Somebody said it can damage your organs if you don't do anything against it.

It is a serious illness. My niece – I saw it on her – she said that if the sore looked red, you can find help better. But if it turns grey and the meat falls off it, then they can amputate your arm or leg.

A very serious illness. It rots your feet, then it's really serious, right!

It is very dangerous, because it keeps on eating [the flesh], and somebody almost lost his foot, since it had eaten all the way to the bones.

It can kill you once the worms reach your intestines.

(CL patients, 2009, 2010, Dermatology Service)

3. The idea that CL is generally contagious, but especially on the patient's own body, so that the disease can or does spread quickly to other parts of the body:

If the wound fluid drips somewhere else you can get another sore.

If you don't take care of it, treat it, it can spread everywhere on your body.

It spreads all over and it spreads fast!

It was on my neck, from there it went to my cheek, thus it can spread further and that makes it very dangerous.

(CL patients, 2010, Dermatology Service)

Some patients felt that most importantly, the danger and seriousness of CL lay in the fact that they did not know anything for sure about the disease: about its development, what happens inside the sore, how or when one gets it, or what causes it. Others felt that the mere fact that they were visiting the doctor emphasised the seriousness of the illness: "otherwise I wouldn't be here [at the Dermatology Service]" or "otherwise you don't go to the doctor for it". That it took injections to cure the disease was, according to patients, also an indication of the seriousness of the illness. Some patients felt that CL was serious and dangerous because of its deceptive character: "It's tricky, because it doesn't hurt. And that's the biggest danger. You think it is a normal kind of sore, but it's not" (Radjesh, 2010,

Dermatology Service). Another patient said: “It looks like a *normal* illness, like an ant bite. But it is bad!”

4.3.1 Fear of CL: injections, amputations, and gruesome appearances

One group of 82 CL patients (40%) expressed fear concerning several aspects of the lived experience of the illness. At the time of research (2009-2010), the standard biomedical treatment to cure CL involved a minimum of three intramuscular injections – in the buttocks or in some cases intra-lesional – in a period of one week, with a maximum period of three weeks. Although patients usually need three ampoules to complete the treatment, depending on the severity of the lesions, sometimes even more drugs are required. My data reveal that great fear of the biomedical treatment was generated by insufficient information about the injections, the drug (Pentamidine Isethionate) used for treatment, and the side effects of the medication. In the social context, several dramatic stories about the painful effects of the injections contributed to this fear. Patients said, for example, that an injection causes one to “crawl over the floor”, “vomit”, “faint”, “be unable to walk”, “have the feeling of being electrified”, experience “extreme pain in the buttock for a whole week”, and various other serious side effects. Unlike in other communities where injections are desirable (Birungi 1994; Whyte & Van der Geest 1994), CL injections are unpopular in Suriname.

One of the other frequently mentioned aspects was fear of amputation. The way in which the sores develop and grow on the skin, especially their *rapid* spread and growth, often leads patients to fear amputation. Patients feared in particular the illness’ capacity to devour and rot the flesh, and to cause co-infections and blood poisoning. CL sores were feared by some patients because of their “looks”, particularly their “horrific” image as they develop. Some patients were even afraid that CL could develop further and reach the intestines, thus causing death. A small group of patients claimed, however, that they feared the disease just because they *did not know* exactly what it was; there was no biomedical information ‘out there’ to reassure them that whatever they had, it was not serious or dangerous.

4.3.2 No fear: CL is curable

While many CL patients feared CL (as described above), many others did not (99, 48%). The main reason for this was the perception and experience that the sores will heal. Almost all CL patients (199, 97%) perceived CL as a curable illness. As one patient remarked: “I never heard someone dying from it. I think it is just a disease like influenza. Only, if you neglect it, you can get deep wounds... [But] as long as you take the injection, there is no problem. It’s curable” (Wiso, Dermatology Service, 2010). A few patients, however, felt that they did not fear the illness simply because they did not know anything about it; not knowing was, in these situations, experienced as a blessing.

It was striking that among those CL patients who felt bad and fearful about the disease, these feelings were especially strong during their first visit to the dermatologist and the first treatment sessions. In follow-up conversations, it became clear that as patients continued biomedical treatment, their fear and worry about the disease disappeared upon seeing the results: the CL sores slowly drying up. Those

who experienced difficulties with healing, however, continued to be afraid, cautious, and anxious. Those who healed were “just very happy” that it had gotten better. I found that CL patients and others in the hinterland who had experienced the disease remembered the difficult healing period of the illness, the “horrific” image of CL, its rapid development, and the painful treatment; but then they also reported that once the sores had cured, their worries related to them also vanished.

4.4 ‘Mysterious’ CL: lay illness causation theories

Regarding the issues of naming and severity, CL patients and others in the hinterland were able to respond without hesitation, for the illness is well known to many living and working in or visiting the rainforest. But when asked about the *causes* of the illness, no one – apart from the Brazilian community at Benzdorp – seemed to know exactly how – or better said, how from a biomedical perspective – the disease is caused. CL proved (in this sense) to be a mysterious disease.

In response to the question of whether they knew the aetiology of the disease, 82 CL patients (40%) said that they *did not know* what caused CL and 123 (60%) responded that they *did know*. Though some of the patients seemed rather certain about their information, others were hesitant in their answers. In both cases, they provided multiple disease causation theories. Nichter (2008:42) speaks in this regard of “multiple causality”, namely when “any one of several or a combination of causal factors can be thought to cause illness”. In the table below, an overview is provided of all of the mentioned causes of CL, as categorised by CL patients, and the number of times they were mentioned.

Table 1: Aetiological explanations provided by 124 CL patients (multiple responses possible)

CL patients' explanations for cause of illness	Frequency
Flies and all kinds of insects or 'something from nature'	85
Something of the bush: trees, lianas, leaves, flowers	26
Something supernatural	6
Dirt	5
Allergies and by contamination	5
Sand flies (as heard from the doctor)	5
By other (prior) wounds	1
Some kind of bacteria	1

As the table clearly shows, the majority attributed CL to the sting of a fly or mosquito, or the bite of an insect. The exact type of fly, mosquito, or insect was not known; patients mentioned “a fly”, “some kind of fly”, “mosquitoes”, “an ant”, “a spider”, “an insect”, or “something from nature”. The second most frequently mentioned category of causes was plants and trees. Only a few patients (5) mentioned the sand fly as the cause of CL, and at the same time they reported having heard this from the medical doctor or nurses at the Dermatology Service. In the sections below, the aetiological theories of CL patients are discussed in depth and complemented with information on this topic gathered in the hinterland villages.

4.4.1 Flies and insects

CL patients referred to a variety of flies and insects locally known in villages to cause one to itch after a bite, such as *Sunna* (Au), *Honjo honjo* (Sa), *Maku* (Sa), *Kosombo* (Sa), *Fongo Fongo* (Au), and other types of (unidentified) flies. According to the patients, their CL sores often started where a bite was felt. Two of the frequently mentioned flies were horseflies – the *kawfree* (Sr) cow fly (i.e. *Dichelacera marginata*) and the *Brokoston* (Sr) (i.e. *Lepiselaga crassipes*) – both of which stem from the family *Tabanidae* (Hudson 1987:22). In the hinterland, ex-CL patients (of the Medical Mission) and other villagers especially emphasised the *kupali mofo* (Au), mouth of the tick, or *kupari* (Sr), the tick itself, as one of the main culprits of CL: “It was this tick who bit me and his mouth stuck behind when I pulled it out of my foot, and that gave me *Busi Yasi*” (Marga, Godo-olo, October 2009). Especially listed were ticks on turtles, white lipped peccaries (*pingos*, Sr) (Husson 1973:11), collared peccaries (*pakiras*, Sr) (ibid), deer (*dia*, Sr) (ibid:12), capybaras (*capuwa*, Sr) (ibid:13), South American Tapir or bush-cow (*tapir*, *bofru*, Sr) (ibid:11), bush rabbits, agoutis (*kon koni*, Sr) (ibid:13), dogs, and the black curassow (*powisi*, Sr) (Alonso & Mol 2007:15). Bites from bush spiders, ants, certain types of bees, mites, and other insects were all also suspected of causing CL. CL patients at the Dermatology Service also frequently mentioned mosquitoes as a cause of the illness, as did many villagers and gold diggers in the hinterland.

Despite the fact that biomedical experts in the research team stated that sand flies are too tiny – almost invisible to the human eye – and that their bites are therefore unnoticeable, CL patients and ex-CL patients reported actually *feeling* the bite of some types of fly. Many CL patients and ex-CL patients provided detailed descriptions of the bite, and when and how the sore on their body started. In the excerpt below, an ex-CL patient of the Medical Mission, a 34-year-old Trio woman, describes her illness as being caused by a kind of mosquito; she vividly remembered the event, even after seventeen years:

I: Have you experienced *kaasa* [CL]?

R: Yes, in a Brazilian area.

I: How did it start?

R: I got it, it started itching, it started ...with the bite of a kind of insect, it had bitten me.

I: Do you have any name for it?

R: *Thuleke* [Tr].

I: Is it an insect or a mosquito?

R: Yes, it is like a mosquito, a big one, like a bee. ...there are yellow ones; the big one is a green one.

I: Oh, it is a green one?

R: Yes, there are several colours; yellow with black stripes... Then you also have the green one. And when it stings you, you get it easily, because it's going to itch.

I: And where were you at that time? In the jungle or where?

R: I was in the field, there was only grass. Amidst the cows ... in a field, busy watching cows that were eating grass in the field...

I: How long ago was it?

R: Let's say, I came back here [to Tepu] when I was seventeen years old, then I came back here. ...

I: And what is your age now?

R: Thirty-four.

I: That's really a long time ago, yes. But how did it start? That thing stung you, where?

R: I got it here [showing right underarm], you see, here... It started to itch me, I thought it was just a gnat, but it was not a gnat...

(R, Tepu, March, 2012)

Some CL patients explained that their CL sores resulted from an earlier infection of the skin due to cutaneous myiasis (a parasitic infestation of fly larvae under the skin), which is caused by flies locally referred to as *maskita woron* (Sr) (mosquito that causes worms) or *dia woron* (Sr) (i.e. *dermatobia hominis*) (Peters & Pasvol 2007:352). Many in the hinterland thought the same. An ex-CL patient of the Medical Mission, a 47-year-old gold digger at Godo-olo, remarked: "I think I passed by a leaf when I walked away [from the workplace in the gold field] to take a bath. I think I contracted something *dia woron*-like" (GD, Godo-olo, November, 2009). Another said that "People ... say if you've got *dia woron*, and if the worm is out of the body, you can get a *Busi Yasi* from the sore that's left behind" (Betty, Godo-olo, December 2009). Aside from flies that cause cutaneous myiasis, CL patients mentioned blowflies (*Calliphoridae*) as causing CL. A 34-year-old CL patient, a Hindustani man, suspected that his sore had been caused by the bite of "a dark coloured fly, the ones usually seeking to lay their eggs in meat" (a description that matches that of *Calliphoridae*).

A 40-year-old Ndjuka gold digger thought that annelids, or ringed worms, caused CL, because of the development of the shape of the CL sore. A 25-year-old Saramacca man had another insect-related theory: he explained how certain *anansi-tei* (Sr) (spider webs), especially the "sticky" ones, cause CL sores upon contact with the body. He had heard this from his father, a known local tree expert, and could therefore recognise and avoid those webs: "...you know those spider webs, don't you, the ones that shine in the night? If that thing sticks to your body, it really sticks, and then it starts itching terribly; and it causes *Busi Yasi* too".

In terms of knowledge of the cause of CL, the Brazilian community at Benzdorp seemed to have more (biomedical) knowledge than the Surinamese CL patients and the research population in general. Almost all Brazilian villagers reported that it is 'a mosquito' that causes the illness. According to Brazilian health professionals (Machado, Lagoo, personal communication, Brazil 2012), it is the sand fly that is most likely meant by 'a mosquito'. Brazil is one of the ten countries that together harbour more than 90% of CL worldwide (WHO 2007a; Kassi et al. 2008), and according to Brazilian health workers at Corte de Pedra in south-eastern Brazil, information about CL is provided to all CL patients at health posts. At these health posts, the sand fly is referred to as 'a mosquito'. Because CL is widespread in parts of Brazil, many are affected by it. The *Braziliensis* parasite causes a more aggressive development of CL sores and it is this variant that causes the majority of people to visit health clinics for biomedical treatment. Those visiting the health post learn about the (biomedical) cause and character of the disease and then pass on this information to others. It is therefore understandable why almost all of the Brazilians at Benzdorp provided a single explanatory theory about CL aetiology.

4.4.2 Caused by the forest habitat: lianas, leaves, trees, and flowers

A second major explanatory category of illness aetiology, according to CL patients, has origins in the forested habitat. Rubbing against leaves or trees can reportedly cause CL, and although patients did not know for sure, they assumed that it is due to some kind of bacteria on the leaves or trees. The majority of patients mentioning trees and plants as causes of the disease specifically pointed to lianas in the forest. The lianas were unidentified; some even claimed they were “invisible”. One of the CL patients at the Dermatology Service explained: “If you cut it [the liana], the water [it secretes] will splash on you and will cause CL”. Indeed, the illness aetiological theory of the liana was widely claimed by many of the informants in the hinterland. Some people in the villages viewed lianas as poisonous, and thought that it was this poison that causes CL. During a focus group discussion in the Brokopondo Centrum area, a 40-year-old Saramaccan woodcutter mentioned that the liana was known as a kind of *faja tatai* (Sa), literally translated as ‘fire rope’. He explained that this kind of liana literally burns if it rubs against the skin and that these ‘burns’ develop into CL. Another Saramaccan villager, who participated in the group discussion, agreed: “Yes, the *faja tatai* is a kind of liana, if you cut it by chance, it has a milk pouring out of the cut and if that milk drips on your skin, you have a problem [CL]”. The villagers at Donderskamp stipulated that they did not know for sure what caused CL, but that flies and lianas were possibilities.

Presumably epiphytic bromeliads, existing in the tropical rainforest, are also viewed as causing CL. In the excerpt below, two Saramaccan women (R1 and R2) – both in their thirties and teachers at a primary school in one of the villages – describe how these cause CL:

I: But do people know the disease [CL] there [at Klaaskreek]?

R1: Yes, it occurs a lot. Both men and women, and also children get it. They always say if you go to the bush something will fall on top of you, a kind of milk or something, I don’t know how it exactly looks like.

I: Milk?

R1: Juice, yes, some kind of [liquid], but it drips on your body, and that’s how you get leishmania.

I: But is it of a tree?

R1: From a tree or liana, one of both, I don’t know exactly, or of the pineapple [presumably referring to epiphytic bromeliads]. I’ve heard of it only, never seen it.

R2: It has a pink flower. It’s exactly like a pineapple, only it grows on trees.

I: And if that [its leaves or the flower from its stem] breaks and its milk drips on your arm?

R2: Yes.

R1: Yes and it itches a lot, you’ll get small pimples and from there on [CL develops].

Similarly, Saramaccan and Aucan villagers mentioned that fluids secreted from the barks of certain (unidentified) trees caused CL. As a 53-year-old *basiya* of one of the Maroon villages said:

No one knows what it is, but these are the things people suspect. Maybe if they are cutting something somewhere and something falls on their

skin, they start linking that; maybe it's the thing that fell on my skin that caused the *Busi Yasi*. Because it [the sore] leaks a bit of fluid and when you itch and itch it, it already forms a pimple. And after that one, it starts making other small ones, around the bigger sore, and it grows and all the smaller ones burst open and that's how you start thinking that maybe when I was cutting the bush, the thing I cut, its juice fell on my skin and gave me the pimples.

When I discussed the lay theories of lianas, trees, or leaves as being the cause of CL with biomedical colleagues in the leishmaniasis project, they commented that sand flies, sitting on lianas, tree barks, and leaves probably bit many people when disturbed. Because of their smallness, the flies go unnoticed, but rubbing against the lianas or other plants is noticed, and is therefore associated with CL.

4.4.3 Caused by other wounds: CL sores are evolving sores

At the Dermatology Service, a few CL patients (3) explained that their sore had resulted from previous wounds on the body or due to other skin damage. In the hinterland, however, this explanatory theory found resonance in almost all villages. Apart from flies and lianas, ex-CL patients and others thought that skin damage due to rashes, thorns, wooden splinters, twigs, or by falling onto a stone, as well as cutaneous myiasis (as mentioned earlier), could develop into a CL sore. For them, it was a clear and visible possibility.

At Tepu, the Trio people believed that several sharp grasses and plants with sharp leaves or flowers, such as babun-nefi banun-nefi (Sr) (*Scleria secans*, *Cyperaceae*), pitigilikai (Tr), saura (Tr), oïme (Tr), kongogato (Tr), sokoine (Tr), and other (scientifically) unidentified plants, caused CL. As one traditional health worker said, "You'd notice it, the cut first and then it would turn to *kaasa*" (Traditional health worker, Tepu, 2010). Another villager, a 47-year-old Trio woman, explained that after her husband had scratched his leg badly on a rock, he developed *kaasa* in the same place as the wound. Another Trio woman explained that her 16-year-old son had slid down while playing football, and that exactly at the place where he had his scratch, CL had developed. Wounds due to the bites of snakes, piranhas, or other animals could, according to villagers in Tepu, also lead to CL. At Donderskamp, villagers mentioned red ants as causing sores that could become CL.

The Saramacca and Ndjuka Maroons hold similar explanatory models. Manko, a 20-year-old Maroon gold digger and ex-CL patient, whose job is to handle the water hose in the goldfield, said about the cause: "People say different things [about the cause of CL]. Dirty water and a kind of liana that exists in the bush. I think my skin was ripped by a piece of stone, I went into the water and that's how I got it".

4.4.4 Caused by 'dirt': dirty water, unhygienic bodies, and faeces

Manko, cited above, mentioned another cause of CL, namely dirty water. Five CL patients at the Dermatology Service thought that this was the cause of their sores. The dirty water theory was held mostly by gold diggers, who work in conditions that cause them to sit or work in muddy water in the gold fields (see following photograph).

Photo 14: Gold diggers at work



Source: Collection S. Ramdas, Benzdorp, November 2010

The majority of the researched population in Godo-olo and Brokopondo Centrum explained that the dirty water in the gold pits led, or could lead, to CL. The mercury in the water is often viewed as poisonous; thus, when one has an open wound, this kind of contaminated water is thought to cause a sore to become CL. It is not only the dirty water in the gold fields, however; villagers also mentioned the common black (dirty) looking water (*tjobo watra*, Sr) in small creeks or ponds in the area as being culpable.

The idea also exists among gold diggers, wood cutters, hunters, and others living in the hinterland that unhygienic bodies can also be a cause of CL. A 37-year-old Maroon man, a hunter, explained:

If you are dirty, I mean, if you keep your body dirty, you can get it [CL]. If you go to a dirty place and your skin gets dirty, causing many dirty crusts on your skin, and you scratch those [with your fingernails], thereby scratching your skin open, you can get a sore that turns into *Busi Yasi*...

Another theory that exists, especially among Saramacca Maroons, is that human faeces causes CL. Faeces is dirt, associated with bacteria and unhygienic conditions, and this could lead, according to the informants, to CL. This illness causation theory was also linked to the metaphysical environment, to be discussed in the next sub-section. CL patients at the Dermatology Service did not mention human faeces but rather the secretions of a fly – either its faeces, urine, or both – as causing CL. Strikingly, all three of the patients who mentioned this explanation were Javanese, and were living in the districts closer to the capital city. They were hunters and fishermen who usually visited the forest in groups. According to 48-year-old Sari, although he was personally not sure about the theory, he claimed that many of his hunter colleagues discussed the matter:

I only heard about it, but I think it might be a fly that shit or urinated on me. It can also have crawled in between my clothes and shit and peed on me, and if you wear your clothes you can get the illness as well.

Another CL patient, a 32-year-old Javanese man who went to the forest to hunt with his friends, explained the cause of his sore in a similar way:

My family told me that it is *Busi Yasi*, because I come from a hunting family. Several people got it [CL]. I heard it is a fly that lays eggs on your skin and it hatches and worms come out of it and eat your body. Even if it does not come immediately in contact with your body, the eggs can be laid on your clothing as well.

In the hinterland, the explanation was not related to the urine of a fly but to the urine of other animals, such as snakes, though even one's own urine could cause CL. These explanations, however, just like the faeces theory, were related to the supernatural world (as is discussed below).

4.4.5 Caused by the supernatural world

In this study, the majority of the CL patients and people in the hinterland placed the origin of the disease in the natural world (Helman 2000:91) or explained the illness in naturalistic terms (Foster 1998:143), and related it to their (sometimes constant) presence in their environmental habitat. According to the vast majority, natural conditions cause CL. However, not knowing about the cause or different types of CL, or the development of the illness, provided room for another explanatory theory of illness, this one related to the "supernatural world" (Helman 2000:91) or religious beliefs. As Foster (1998:143) has put it, the illness is explained from a personalistic point of view in which it is caused "due to the active, purposeful intervention of an agent, who may be human (a witch or sorcerer), nonhuman (a ghost, an ancestor, an evil spirit) or supernatural (a deity or other very powerful being)". My research findings show that although a few CL patients (six) reported CL to be caused by supernatural agents, and a further six kept open the possibility that CL could also be caused by "invisible, supernatural matters". Whether more patients actually believed in this theory was difficult to establish. Patients were often doubtful about the cause of CL, and therefore contracting the illness due to "someone or something evil" or because of "sorcery" was viewed as a possible scenario.

The explanatory theory that CL sores could be caused by elements beyond the 'natural' was supported by many in the hinterland, particularly in cases where small sores developed quickly into larger ones, sores broke out in several places on the body, biomedical treatment failed to work instantly, or healing took a long time (more than six months). Cultural and religious beliefs were then turned to more frequently.

As the study shows, some explanations are closely related to the prevailing cultural or religious beliefs. According to Van Binnendijk and Faber (2008:32), Maroons with the 'traditional' religion believe in an upper God – the Gaan Gadu – who delegates tasks to many lower gods (or spirits) who have the power to influence people. There are the spirits of reptiles (*Papa Gadu* or *vodu*), predators and vultures

(*kumanti*), ancestral spirits (*yooka*), and bush spirits (*ampuku* or *apuku*) (ibid). In my inquiries about disease causation, both the *ampuku* or *apuku* and the snake spirit were frequently mentioned, the former more than the latter. *Ampukus* are believed to have their homes in trees and termite nests, called *akatomassi* or *akantamassi* (Binnendijk & Faber 2008:33). A 40-year-old gold digger, an Ndjuka man at Godo-olo, mentioned the *ampukus* and believed them to cause CL:

Sometimes though you see them [*ampukus*], there are a lot here in the bush. If you cross their path or they yours, they can obstruct your path in many ways. They don't do good things, in general, but there are also ones that do good. For example, if you're lost in the woods, they'll bring you closer to your village or closer to people. Some people believe they are real human beings, real Amerindians, the descendants of the fled Amerindians [during slavery], but they are so fast, you can't see them. And it is said that these *ampukus* can blow thorns at you from their flutes, and wherever the thorns stick in you, you'll develop BY [*Busi Yas*].

Ex-CL patients, those working deep in the jungle (gold diggers, wood cutters), and other forest inhabitants often believed that fluids dripping from *akantamasie* caused CL.

According to Van Binnendijk and Faber (ibid), the most important of the reptile spirits is the spirit of the head snake, the boa constrictor or *daguwe* (Sr). Maroons believe that if it is tortured or killed, it can take revenge by making the person ill. A 30-year-old gold digger at Godo-olo said:

If you, for example, go to your plot and you cross over the snake *daguwe*, *Papa Gadu*, then you'll become ill and you'll get the sores as well. It can make you very ill. There are some things that you can contract just like that.

Van Binnendijk and Faber (ibid:33) found that in case of violation of certain laws, for example entering the living areas of spirits without respect, or harming or destroying the living space or house of the spirits, these spirits can manifest themselves through revenge, harassing the offender. In this manner, spirits can cause ill health. The explanatory theory that shitting in certain areas – for instance, shitting or urinating close to certain trees that function as homes for certain bush spirits – can cause CL is understandable against this background. Many informants remarked that it is wise to keep to the rules of the bush, especially to ask permission from the spirits or gods – even if one does not know them – before defecating or urinating in the bush. When staying in or leaving the jungle, people should also always leave the area clean.

Especially among CL patients and ex-CL patients who believed that they had 'enemies' in their social environment, i.e. persons who were envious and jealous of their success, either colleagues at work or people in the neighbourhood, CL is said to come from *wisi*: negative magic intended to cause harm (Wooding 1984). A 41-year-old Saramacca Maroon man who had developed a big sore on one of his feet explained that his CL was probably caused by others: "I think someone

did something [evil] to me” (Eman, September, 2009, Dermatology Service). This man had been walking around with the sore for about one year.

4.4.6 Caused by ‘allergies’, contamination, or sexual intercourse

A small group of CL patients, especially Brazilians, thought that CL could be caused by certain food allergies. For instance, one Brazilian gold digger said that CL “could also be caused by shrimps, if you eat them. The sore is a reaction to it” (Rodi, Dermatology Service, 2009). Some Brazilian gold diggers believed that CL sores could develop as a reaction to eating wild meat.

Some CL patients believed that contamination through contact with an animal that had CL sores could also cause CL. One CL patient, a 56-year-old Creole man, thought his sore was caused by contact with a tiger he had killed while hunting. “I carried the animal around my neck, and now you see, I have these sores here. It is the contact with this tiger, I am sure, that caused the *Busi Yas*” (Resa, December, 2009, Dermatology Service). At Tepu, some villagers thought that eating the infected meat of animals with CL sores on their body could cause CL.

Sexual intercourse as a possible cause of CL was primarily brought up by villagers at Tepu. One of the villagers, a 35-year-old man, explained:

If you relate [have sex] to a lot of people, Javanese, Creole, and other folks, then you will get *kaasa* [CL]. I have heard it from the elderly, you can't have sex with different kinds of people. Because that causes *kaasa*. You can have *kaasa* by having sex, but it is in fact not a sexually transmitted disease. *Kaasa* is not a disease you get through sex with other women ... But the vaginal fluids can give you *kaasa* and you can get it so too. It is a kind of a sexually transmitted disease that you can get on your skin, on arms and legs and also on your face, but not on the genitals, although that might be possible. I heard this from my ancestors and I believe in it a bit. I think it is important what elder people say about *kaasa*.

But while some believed in this causation theory, others disagreed. Another villager, a 45-year-old woman, argued: “It is not true you get *kaasa* by having sex with others... you can get *kaasa* from a *kanamittige* [tick] and the *thuleeke* [mosquito]” (Angie, March, 2010, Tepu). The idea that sexual intercourse can cause CL may be associated with illness experiences of the past. With the arrival of Dutch colonisers in the 17th century in Suriname, indigenous populations suffered significant mortality due to the introduction of infectious diseases that they had no prior experience with and therefore little or no resistance to (Praag 1977:43). This legacy is felt even today, when upon the appearance or arrival of an outsider in (some of) the hinterland villages – as I experienced during fieldwork – the Indigenous peoples and the Maroons are careful in their approach. The theory that sexual intercourse (i.e. bodily contact) with other people (‘outsiders’) may cause illness is therefore understandable.

4.4.7 A note on bias

Having provided an insight into the variety of illness explanations for CL among the participants in my research, I take into consideration that some bias may have occurred in the responses of the CL patients at the Dermatology Service in Paramaribo. When people come to a biomedical health facility, they come with the expectation that biomedical professionals have their own 'scientific' explanatory models concerning illnesses. An often heard remark was that it was not the patients but the doctors who were competent to answer such questions about causation. "That is why I have come for medical help", patients would remark. The following excerpt of an interview with the mother of a 13-year-old CL patient exemplifies how many patients 'really' thought. At first, the 32-year-old mother said that she did not know how the sore had been caused, and had heard from the doctor that it was caused by a sand fly. Later in the conversation, however, she revealed another idea about the sore's origin:

The doctors say it is *Busi Yasi*, but I don't think so. We were busy building a sand field in the yard and filling it up with yellow sand. I think the heap of sand, which my boy was also working on, must have had some kind of dirt that caused the sore. Surely it must have had some kind of insect in it and that bit the boy and that's how he got the sore. I don't believe the doctor at all that it is *Busi Yasi*, because I have shown it to my colleagues who are hunters, experienced people of the bush ... and one of them said that's not how a *Busi Yasi* sore comes... It may also be that my boy stepped over some [bad, invisible] thing and had gotten the sore on his feet. But let's see what the [biomedical] treatment does to him.

According to this woman, in addition to something 'natural', something 'supernatural' could have caused the sore. When talking about the aetiology of CL, another 42-year-old CL patient, a Saramaccan Maroon man, similarly revealed a variety of explanations. First he explained that "If you rub against certain leaves, then it starts itching and if you scratch it, it becomes a wound" (Maju, September, 2009, Dermatology Service). But later in the conversation, he revealed his 'real' thoughts about the cause of illness, saying that he believed that his sore was probably caused by someone doing something supernatural with him. Despite possible bias – which I tried to counter through interview techniques and skills (as mentioned in sub-section 3.5.1) – the quantity and variety of explanations provided by informants in this study is nevertheless dazzling and puzzling.

4.4.8 Not one explanation

Why the dazzling variety of illness explanations? The simple answer is that people do not know exactly how CL is caused. But why the absence of *one single* illness explanation for CL? Going back to the introduction of this chapter, I mentioned that, in contrast to what Last argues, I believe that 'not knowing' in my study does not reflect disinterest or nonchalance towards medical culture or the cause of illness. Rather, it reflects certain aspects that are part of the different contexts that shape people's illness perceptions, explanations, and experiences, and in which those experiencing CL live their day-to-day lives.

The first reason for the absence of one single illness explanation is related to the biological context of the illness, namely its unnoticed beginning. As mentioned in section 4.4.1, biomedical experts in the CL research team stated that the bite of a sand fly evades human perception. This biological perspective is, however, diametrically opposed to the emic experience of CL patients, some of whom provided exact and very detailed descriptions of when and how the sore on the body started (see section 4.4.1). The accounts of the CL patients are examples of how illness is interpreted when the biological cause is not known (see section 4.4). Lack of a visible and noticeable start is one of the reasons for the absence of a single illness cause.

Second, 'not knowing' is rooted in the neglected position in which people in the hinterland have been living for centuries (see previous chapters). Lack of higher education in general (see Chapter Three) and lack of CL health education by public health authorities are two important constraints fuelling the inhabitants' neglected position. Up till now, CL itself was a neglected disease and nationwide CL health information and education campaigns by public health authorities have never been initiated. Therefore, the lack of CL information and education campaigns, in particular for those living and working in or visiting the rainforests, is one of the most important reasons for the absence of one single explanation for the cause of the illness. Related to the lack of CL health information, the environmental and socio-cultural contexts also contribute. The forested environment where most of the CL patients in this study lived, worked, or visited, the co-existence of many insects, flies, plants, rocks, and other natural surroundings, as well as existing cultural beliefs (see section 4.4.5), all contribute to the lack of a single explanation for the cause of CL.

Finally, 'not knowing' reflects the general attitude of hinterland inhabitants about CL as a less prioritised disease compared to other diseases or health conditions such as malaria, HIV/AIDS, snake bites, and stingray stings. CL, as my study shows, is viewed as a curable disease; to some, CL is not even viewed as an illness, merely a sore that should be healed. Furthermore, the occupational context²² in which many in the hinterland are engaged and their (often) poor economic position keep people fully occupied; there is no time to reflect on the aetiology of the illness, and rather its aggressiveness and rapid development make finding a cure a higher priority. Because of these perceptions and attitudes about CL, (lay) investigations into a (single) cause of the illness was not prioritised; and this in turn contributes to the absence of a single illness explanation.

As my study shows, the multiple contexts in which people live, work, and operate, including their personal experiences with the illness, are the cause for the absence of one single explanatory theory, and the presence of a dazzling variety of illness explanations. These explanatory theories are speculations and uncertainties, yet are nevertheless logical and understandable.

4.5 Conclusion

My investigation into (lay) illness perceptions, explanations, and knowledge of CL reveal that CL patients and others confronted with the illness in the hinterland *know*

²²See Appendix 3 for the socio-economic, occupational, and demographic profile of all CL patients.

much about the illness, yet simultaneously *don't know* much about its aetiology. CL is known by various local names reflecting the environmental context in which the disease occurs, its assumed aetiology, biological appearance, the characteristics and symptoms of the sores, associations with and similarities to other diseases of the forest, and biomedical familiarity with CL. Naming and framing illness in such a way has a clear function. It helps lay people to (partly) recognise and establish a diagnosis of the disease.

Inquiries into lay knowledge of the disease shows that it partly overlaps and partly differs from biomedical knowledge. Through experience, by observation, and through visits to biomedical health clinics, certain biomedical aspects concerning CL are known to some people. Nevertheless, the majority of those experiencing CL perceive and explain the illness through the other contexts in which they live their everyday lives. CL patients and inhabitants in the hinterland could recognise a CL sore and many *knew* how to diagnose one, based on their lived experience of the illness, its symptoms, characteristics, and appearance, the difficult healing process, and the inefficacy of 'traditional' medicines to cure the sore. Lay diagnosis is not without risks, however, because of the often prolonged lay treatments that contribute to late biomedical health seeking.

My research further shows that those who suffer from CL sores experience their development and aggressive behaviour intensely. They reported 'periodic' suffering and agony, but depending on the type of treatment chosen from the start of the illness the duration of this period of suffering varied greatly from person to person. Though many thought that CL is contagious, surprisingly it was not for this reason that CL was most feared; rather, the biomedical treatment and the risk of amputation were the more fearful aspects for CL patients. Some fear CL simply because of their own personal or social experiences and observations that CL is hard to cure; others do not.

Concerning the aetiology of CL, I have discussed the large variety of explanations (multiple causality) and have shown how different contexts – biological, educational, public health related, environmental, socio-cultural, socio-personal, occupational – feed and shape perceptions and explanations. Lay understandings of illness and aetiological explanations are topics of interest in many health studies, because they provide in-depth information about the ways in which an illness is understood and explained by those suffering from it, and reveal the complex processes of health seeking. Such studies also provide valuable insights for health policy makers, to help them understand the quantity and complexity of (structural) barriers in the fight against illness. Public health authorities should be aware of such barriers and take them into consideration when designing treatment and illness prevention programmes.

In this chapter, I have elucidated the first aspects of the health seeking behaviour of CL patients, according to the multidimensional pathway model of health seeking as proposed in section 2.1.3. In the next chapter, I continue with the second step of CL patients in their search for health or treatment seeking.

Chapter 5 Seeking therapy: self-treatment, local healers, and the abundance of medicines

While the previous chapter reported on lay perceptions of and aetiological explanations for CL, revealing how CL patients and others in the hinterland view the illness, this chapter attends to the actual steps that the CL patients in this study undertook to get cured. Health or treatment seeking is a vastly studied topic in medical anthropological research (e.g. Glick 1967; Janzen 1978; Kleinman 1980; Young 1981; Matthews 1982; Etkin & Tan 1994; Whyte et al. 2002). Such studies have shown that health seeking can be a very complicated process, and one that differs in various aspects cross-culturally. Such complexity was already observed in the previous chapter: while CL patients perceive CL as a “horrible”, “cruel”, and “stubborn” disease, the vast majority sought treatment at the Dermatology Service only between one and three months after they first noticed the sore, and some even later, from four months to three years. The question now posed asks what actions CL patients undertook in the period prior to visiting the Dermatology Service.

Based on the ethnographic material, this chapter is the first in a series of three (including Chapters Six and Seven), that present the health seeking patterns of CL patients and describe how, upon noticing the sore(s), they began their quest for a cure. These three chapters illuminate and analyse the health seeking trajectory of CL patients, starting with self-treatment and ending with treatment seeking at the Dermatology Service.

In this chapter, the focus is on self-treatment. A wide variety of medicines used in self-treatment are listed and other dietary restrictions and ‘cultural rules’ to stimulate cure of the illness are described. Though few CL patients in this study reported having turned to professional traditional healers for advice on treatment, local healers in the hinterland do often play an important role in treatment seeking. Attention is therefore also paid to local healers and their knowledge of CL and its treatment.

As the data shows, in the quest for a cure, the advice given by those in the sufferer’s social environment plays an important role. Patients’ self-treatment involved a dazzling variety of treatments and medicines – from bush medicines and biomedicines to harmful non-biomedical chemicals – which were used either alone, often successively, or in combination. Patients and others in the hinterland also reported dietary restrictions and keeping to certain ‘cultural rules’ to support the cure of the illness. Patients sought the ‘right’ medicine in their determination to cure their sore. Few CL patients at the Dermatology Service reported having sought treatment from local healers, but inquiries in the hinterland revealed that local healers are often consulted for treatment.

In Chapter Six, the variety of medicines used by CL patients is further analysed and the impact of multiple contexts on self-treatment is discussed. In Chapter Seven, patients’ decision to turn to the Dermatology Service to seek treatment is illuminated. Chapters Five, Six, and Seven thus describe the quest of CL patients to cure their sores and reveal intricate treatment seeking strategies that range from self-treatment and seeking treatment from local healers, to treatment seeking at the Dermatology Service.

5.1 Health seeking patterns

In case of illness, self-treatment – the usual starting point in the therapeutic trajectory – is in fact the most common form of all therapy. Van der Geest and Hardon (1990:199) estimate that, depending on the definition applied, 50 to 90 percent of all therapeutic interventions can be labelled as 'self-treatment'. Self-treatment happens because, as Etkin (1994:26) states, "people are not passive recipients of medicine", but rather often "initiate symptom management prior to consulting an "official" healer or dispenser, and ... continue doing so with or without the healer's approval (or knowledge)". According to Kleinman (1980:51), self-treatment happens primarily in the popular sector:

The customary view is that professionals organize health care for lay people. But typically lay people activate their health care by deciding when and whom to consult, whether or not to comply, when to switch between alternative treatments, whether care is effective, and whether they are satisfied with its quality. In this sense, the popular sector functions as the chief source and most immediate determinant of health care.

The popular sector is the lay, non-professional area of illness recognition and treatment by patients (ibid:59). In line with Kleinman, Van der Geest and Hardon (1990:199) emphasise that, especially in developing countries, self-treatment is extremely widespread due to poor economic and infrastructural conditions, as well as differing cultural cognitive contexts. With CL in Suriname, the majority of the CL patients indeed attempted self-treatment prior to consulting a medical doctor.

5.1.1 Majority of CL patients attempt self-medication

Of the 205 CL patients that I interviewed at the Dermatology Service, 161 (79%)²³ said that they had attempted to self-medicate before coming to the Dermatology Service: 19 females (12%) and 142 males (88%). The rest, a relatively small group of 44 (21%), reported that they had not self-medicated, and had only kept their sores clean with alcohol (100% 'rubbing alcohol' often used by biomedical health professionals to clean the skin), water and soap, or baby oil. For the numbers and percentages of the health seeking patterns of the 205 CL patients at the Dermatology Service by sex, see Table 2.

²³In an earlier article (Ramdas 2012), a total number of 155 CL patients were noted as having self-medicated. Further interpretation of the data, however, showed the actual total number to be 161 CL patients.

Table 2: Number and percentage of health seeking patterns of the 205 CL patients at the Dermatology Service by sex

	Males	Percentage of total (%)	Females	Percentage of total (%)	Total (M+F)	Total combined percentage (%)
Total number of CL patients	183	89	22	11	205	100
CL patients that attempted self-medication	142	69	19	10	161	79
CL patients that did not attempt self-medication	41	20	3	1	44	21

Because of their socio-demographic and occupational characteristics (see Appendix 4, Table 14), the overwhelming majority of the CL patients who attempted self-treatment were men. In the small group of 22 women, 19 had tried self-medication. Among the 161 patients who self-treated, Maroons were the largest cultural group (54%), followed by Hindustanis (15.5%) and Javanese (11%). The majority of these patients (80%) were of working age, between 20 and 49 years, and visited the hinterland for occupational, recreational, or familial reasons. The women were mostly living in the hinterland and working on their plots (31.6%) or were visiting family (21%).

Among the few young patients below 19 years of age (20 CL patients in total, see Appendix 4, Table 13), those who self-medicated (or whose family treated them) were three girls aged four, 13, and 19 years, who were either living in the hinterland or visiting the hinterland on school vacation to see their families. The young men who attempted to self-medicate were mostly between 17 and 19 years and were working part-time in the lumber, construction, or gold sector. The rest were students visiting the hinterland to see family or to play sports (especially football).

5.1.2 ‘Advisors’ for self-medication

Studies show that in treatment seeking, often more than one person (i.e. more than simply the sick individual him- or herself) is involved in the process of choosing a medicine (e.g. Young 1981; Mullen et al. 1987; Kleinman 1980; Janzen 1978). Janzen (1978) referred to this therapeutic network as the ‘lay therapy management group’, and showed in detail how kin groups in Zaire influenced treatment seeking. The composition of such a lay therapy management group varies cross-culturally, “e.g., the individual patient, the nuclear family, mother and grandmother, paternal kin, or extended family” (Sussman 2008:41).

In this study, a lay therapy management group was also detected. During interviews, CL patients were asked who had advised them on the medicines used in self-treatment. A large group of 52 CL patients (32.3%) answered that the treatment choice was their “own idea”, what they had learned from childhood, or that they had been raised with that (cultural) knowledge. A group of 42 CL patients (26%) said that they had been advised by a family member, especially by their mother, nephew, or

aunt, while a smaller number had been advised by their uncle, grandfather, brother, father, or a *bigisma* (Sr) (older person) in the family. Another group of 27 patients (16.8%) had heard about the medicines from their friends (8.7%) or from colleagues (8.1%). A group of 24 patients (15%) reported that others, such as “people around”, acquaintances who recognised the sore, neighbourhood elderly, old men, and friends who had also contracted CL and been cured of it had told them what to use to cure their sore(s). Eight patients – generally living in the city and from different cultural backgrounds – reported that “people [inhabitants] of the hinterland”, “a *Ndjuka*”, or “an Amerindian” (*Ingi*, Sr) had advised them on the medicines. Three patients claimed that they had been advised by local healers.

The findings show that the lay therapy management group or lay network of health advisors emerging in this study go beyond kinship (Janzen 1978) and are more complex in terms of composition, where not only significant others (close family members, friends, colleagues) but also ‘strangers’ are consulted. Whoever was consulted, however, it was clear that patients had confidence in these ‘advisors’ and the knowledge they apparently had about medicines to cure CL.

Because it was not asked during the inquiries whether the ‘advisors’ also helped with the treatment, it was not possible to determine the level of involvement of others in ‘self-treatment’. Therefore, self-treatment in this study is viewed as all actions that patients undertook to cure their sore outside of the professional biomedical circuit. Furthermore, though it was not possible to determine the level of involvement of traditional healers²⁴ (*traditionele genezers*, SD) in the treatment process, inquiries in the hinterland revealed that they were also consulted in cases of CL. In part 5.3, local healers in the context of CL treatment seeking are further discussed.

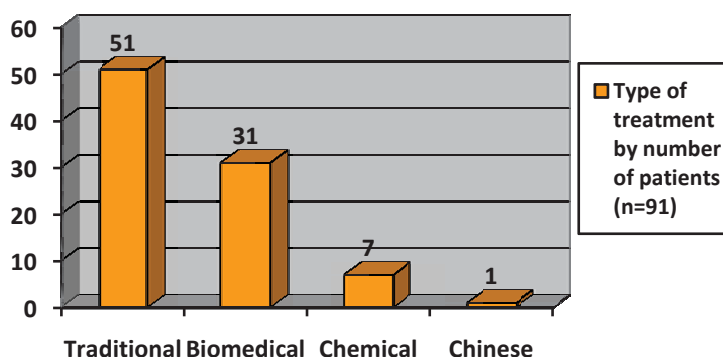
5.2 Different types of treatments used in self-medication

CL patients at the Dermatology Service were asked what they had actually used to cure their sores prior to visiting the Dermatology Service. They reported a variety of medicines that I have categorised into different types of treatment: 1) *busi dresi* (Sr) (i.e. bush medicines or so-called traditional medicines); 2) biomedicine; 3) non-biomedical chemical substances; and 4) Chinese medicine.

Within the group of 161 CL patients who attempted self-treatment, 91 (56%) used only one type of treatment. Among these, 51 patients (57%) used traditional or bush medicine, 31 (34%) used biomedicine, seven (8%) used non-biomedical chemicals, and one (1%) used Chinese medicine (see figure 4).

²⁴The term ‘traditional’ medicine has been criticised in medical anthropological literature as being a “misleading, embarrassing and naïve term” (Van der Geest 1995:360), erroneously suggesting (amongst other things) that the biomedical tradition is not a ‘tradition’ (ibid; WalDRAM 2000:604). In this study, the term is still used; however, this is not as an expression of “ethnocentric ignorance”, but rather to avoid confusion, since the non-biomedical tradition discussed in this study is generally known in Surinamese society as ‘traditional’ medicine or ‘bush medicine’, both by Surinamese lay people and biomedical health professionals. ‘Bush medicine’ is generally used as a more ‘neutral’ term, but at times the term ‘traditional medicine’ is also used. From here on, the inverted commas, except when needed, will be omitted when speaking of ‘traditional medicine’.

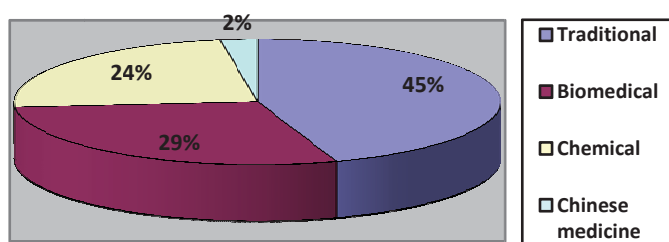
Figure 4: Overview of single treatment types used by 91CL patients, by treatment type



The remaining 70 CL patients (43%) combined different types of treatment. The majority of this group, 60 patients (85.7%), combined two types of treatment, while the rest (10 patients, 14.3%) combined three types of treatment.

Bush medicine tops the list, either used alone or in combination with other treatment types. Among the group of 161 CL patients,²⁵ 90 used this treatment type, followed by 58 patients who used biomedicines, 48 who used potentially harmful chemicals, and a small group of five patients who used Chinese medicine (see figure below). As Chinese medicine was used by so few, this group is of negligible importance in terms of the medicines used by CL patients.

Figure 5: Usage of treatment type by 161 CL patients in percentages (multiple answers possible)



5.2.1 Self-treatment with *busi dresi* (bush medicine)

In Suriname, local so-called 'traditional' treatments in the hinterland are popularly referred to either as *busi dresi* (Sr), i.e. 'bush medicine', or *oso dresi* (Sr), i.e. 'home

²⁵Patients reported more than one treatment type.

remedy' (medicines made at home). According to some informants, *busi dresi* products are so named because they are made in the bush in the hinterland (*busi* = bush in Sranan). The term *oso dresi* is used more by people who live in urban areas rather than in the hinterland; furthermore, *oso dresi* may not necessarily consist of botanical materials.

Busi dresi treatments generally consist solely of botanical or herbal products from trees and plants or plant materials. This botanical type of *busi dresi* is prepared in several ways with various parts of plants (the leaves, barks, roots). As 67-year-old captain Henki – who is also a local expert – described:

If you have to wash them [leaves], you wash them, if you have to drink them, you drink them; but you have to sieve them [mashed leaves] hygienically, put it [the decoction] neatly so it stays clean, so that you don't drink something that your stomach cannot take. Also, we clean them [the leaves] with stones Sometimes we burn them, till ashes, then we sieve them in a fine sieve, then you need a lot of things for [to make] the medicine, you burn all and mix all till it becomes one, and then you keep it [the sieved ashes] in something you want. If you want it, you put it on the sore, or if you want it you drink it. If it's two times a day or three times a day, you drink it. That's *busi dresi*. ...You have medicine for the belly, you have medicine for the bowels, you have medicine if your belly hurts, we have medicine for what you call liver illness. All those kinds of medicine we have in the interior. (Henki, Godo-olo, September 2009)

Apart from using leaves or parts of plants, a defining component of *busi dresi* is that it is handmade with one or a combination of ingredients:

With *busi dresi*, the thing is that you have to *make* a medicine. You have to *make busi dresi*. You'll take other things, maybe a mix, until it *becomes* a medicine. Thus, it is not a doctor's medicine. A doctor's medicine is a completely different thing. You have a certain wound, [for example] we call it *sneki siki* [Sr], then we use *pemba* [Sr, a type of earth], soap, and eggs, then you call that *busi dresi*. Thus *busi dresi* doesn't only mean plants and leaves, it means it is not a Western medicine [a doctor's way]. (Local healer HW, Paaston, December 2009)

Bush medicines can thus also be made with a mixture of botanical and other natural materials or substances (earth, mud, clay), or mixed with (small) insects, the body parts of different kinds of animals, animal secretions (such as skin fluids, animal droppings), or with other household products (cooking oil, salt, soap).

As the local healer indicated above, for the hinterland population, the term *busi dresi* covers all types of medicines or treatment methods that fall outside of the domain of the biomedical sector, and are contrasted with *datra dresi* (Sr), i.e. a doctor's (biomedical) medicine. *Busi dresi* remedies are often made with the use of ancestral knowledge. This knowledge is orally passed on from generation to generation, the recipe only known to the healer, the person who made the medicine, or the family or community to which the formula belongs. Informants also said that people do not easily share their secret prescriptions with outsiders but choose to keep it within the family. One informant shared:

For example, my arm was so badly broken above my wrist. I went to a village, everyone knew that there they [local healers] could heal something like that very well; in the whole area, he [a person living in that village] was the best [healer]. He is dead now, but only passed on his knowledge to someone he wanted, someone in his family. Each family has their own secrets, [but] they are not going to pass that on [to] just anyone... (Rob, Godo-olo, December 2009)

Knowledge of the medicinal qualities of plants and plant extracts is guarded among people living in the hinterland. People believe in the medicinal knowledge of others: "Sometimes you see that a Ndjuka [Maroon] seeks help from a Saramacca [Maroon]. It's possible that the Saramaccan has a more effective medicine" (Ben, Brokopondo, October 2010). Exchange of medicinal knowledge among Maroon and Indigenous groups in the hinterland does occur, but not often. Roger, a 43-year-old *basiya*, explained:

...show me your recipe and I will give you mine. You see. If you walk somewhere and a very dry hard stub [of a plant] stings you, I know the cure for it. You can ask me for it. I will say: okay, I'll show you the stub medicine, only if you show me the medicine to cure a cut by a knife. You see. In this way, people in the woods exchange what they know about those things [medicines]. (Roger, Godo-olo, December 2009)

In the hinterland, people also experiment with botanical products (or other non-botanical products) to produce 'new' bush medicine. When someone finds something new that is seen to cure an illness or wound, it becomes a *busi dresi*. The one who discovers this medicine is the owner of it, and is free to share or not to share his medicine with others; he can ask money for it, or pass on the knowledge for free. Though not experts, these persons 'know' certain medicines that help with certain ailments. In this study, many patients came to know of CL medicines through such people, who can be anyone: a relative, friend, acquaintance, or stranger (see section 5.1.2). Others experimented themselves with different types of medicine to treat their CL sore.

As mentioned, bush medicine or traditional treatment tops the list of treatment types used by the majority of CL patients, both alone or in combination with other treatment types. Within this treatment type, I found a variety of compositions:

- 1) Botanical bush medicines, consisting of (only) medicinal plants, botanical extracts and oils, other processed botanical products, and unspecified bush medicines.
- 2) Bush medicines in which botanical and other types of materials are combined.
- 3) Ritual healing through herbal baths and prayers.

5.2.1.1 Botanical treatments

Botanical medications that are part of traditional medicine are most frequently used. Following is a list of all plants and botanical products reported by CL patients who used them as medicine against their CL sore. I neither collected nor determined the reported plants; I used several botanical resources and literature, but most extensively Van Andel and Ruyschaerts (2011) on medicinal and ritual plants in Suriname. This is a comprehensive documentation of a large variety of Surinamese plants, locally known and used for medicinal and ritualistic purposes, in particular in the hinterland. I compared the reported local plant names and descriptions provided by the CL patients and other informants with the documented plants, photos and drawings, plant descriptions, and information in the ethno-botanical literature, and in this way identified the plants²⁶ used by CL patients. My own (common) botanical knowledge, plus botanical trips to the forest in the different villages for plant recognition, also contributed to the identification process. In the table below, the botanical names and brief²⁷ description of the plant type are provided, as well as the part(s) and method(s) used by CL patients.

Table 3: List of plants reported by CL patients

Local plant name reported by CL patient(s)	Scientific name and short description of plant	Part used and method of use
Aloe vera (SD), Sempre wisi (Sr)	<i>Aloe vera</i> (L.) Burm.f. (Xanthorrhoeaceae) Perennial herb, height up to 1m (Van Andel & Ruyschaert 2011:92). (See Picture 1).	<u>Leaves</u> Mash leaves and smear onto sore.
Báibái lopu (Sa), Popokai nangra (Sr)	<i>Uncaria guianensis</i> (Aubl.) J.F.Gmel. (Rubiaceae). Liana; bold stalk, climbing with woody, sharp hooks (ibid:426). (See Picture 2).	<u>Liana</u> Burn and spread ash over sore.
Banana (Sr), bana (Sr)	<i>Musa x paradisiaca</i> L. (Musaceae). Tree-like herb, height up to 4m (ibid:345). (See Picture 3).	<u>Leaves</u> Burn the leaf, mash it fine, and apply ash to sore. <u>Brown skin/bark</u> (dried) Cook dry bark till a paste and use as a plaster on sore. <u>Green skin</u> Place green skin on sore.
Bitakama (Sr)	Unidentified	<u>Leaves</u> Mash leaves and place on sore.
Bitá ksaba (Sr), bittere cassava (SD)	<i>Manihot esculenta</i> Crantz. (Euphorbiaceae). Shrub, height 2-5m (ibid:207).	<u>Roots</u> Mash or grate the root, apply paste to sore and bandage it.

²⁶ All scientific names were checked and updated using Kew's online Plant List: a working list of known plant species, developed, disseminated, and widely accessible as a direct result of the Global Strategy for Plant Conservation, adopted in 2002. See web reference number 16.

²⁷ See referenced literature for more elaborate information on the plants listed. See Appendix 8 for photographs and drawings of the plants.

	(See Picture 5).	
Bontete (Sr)	Unidentified	<u>Leaves</u> Burn, mash till powder, spread on sore.
Brokobaka (Sr)	<i>Mikania micrantha</i> Kunth. (Asteraceae). Climbing herb, stalk slightly hairy (ibid:105) (See Picture 8).	<u>Leaves</u> Boil leaves in water, dab sore with hot water.
(Uma) Busipapaya (Sr)	<i>Cecropia peltata</i> Linnaeus. (Cecropiaceae). Tree, height up to 15m (ibid:152). (See Picture 9).	<u>Top of branches</u> Milk appears after cutting or breaking the top of branches; this is dripped onto sore.
Dedu (Sr)	Unidentified	<u>Bark</u> Boil bark in water and wash sore with it. Scrape off part of the bark and stick it to sore.
Diatitei (Sr), Fayatatai (Sa), Schuurpapier (SD)	<i>Davilla kunthii</i> A. St.-Hil. (Dilleniaceae). Liana (ibid:191). (See Picture 10).	<u>Liana</u> Cut and grate liana, sun dry for two weeks, sieve and apply powder to sore. Burn the (dry) liana, mash till powder, and apply ash to sore.
Donke (Sr)	<i>Dieffenbachia seguine</i> (Jacq.) Schott. (Araceae). Terrestrial herb, growth up to 1m (ibid:62). (See Picture 11).	<u>Leaves</u> Mash leaves and apply to sore. Boil leaves in water and wash sore with it.
Ghedu (Sr)	Unidentified	<u>Bark</u> Boil bark in water, wash sore with it.
Jáfi (Sr)	<i>Jacaranda copaia</i> (Aubl.) D. Don (Bignoniaceae). Tree, height up to 3m (ibid:121) (See Picture 12).	<u>Bark</u> Boil bark in water, wash sore with it.
Kaapà (Sa)	<i>Carapa guianensis</i> Aubl. (Meliaceae). Tree, height up to 35m (ibid:334). (See Picture 13).	<u>Bark</u> Boil bark in water, wash sore with it.
Kalebas (SD)	<i>Crescentia cujete</i> L. (Bignoniaceae). Shrub-like tree, height 6-10m (ibid:118). (See Picture 15).	<u>Leaves</u> Crush leaves, finely mash, apply to sore.
Knoflook (D) (Garlic)	<i>Allium sativum</i> L. ²⁸ (Amaryllidaceae). Perennial plant. ²⁹	<u>Bulb</u> Mash garlic cloves fine and apply to sore.
Kwassibita (Sr)	<i>Quassia amara</i> L. (Simarubaceae). Shrub or small tree, height up to 3m (Van Andel & Ruyschaert 2011:442). (See Picture 18).	<u>Leaves and bark</u> Boil all in water, dab sore with it.
Kasyu (Sr)	<i>Anacardium occidentale</i> L. (Anacardiaceae).	<u>Bark</u>

²⁸See web reference number 17.

²⁹See web reference number 18.

(Cashew)	Small tree with knotty branches, height up to 8m (ibid:31). (See Picture 16).	Boil bark in water and dab sore with it. Smear juice of cashew bark on sore and bandage it. Mash bark, apply to sore, and bandage.
Kototiki (Sr), Pipa tiki (Sr)	<i>Mabea piriri</i> Aubl. (Euphorbiaceae). ³⁰ (See Picture 19).	<u>Leaves</u> Mash leaves, apply to sore, and bandage.
Lemmetje (SD) (Lemon)	<i>Citrus aurantifolia</i> (Christm. & Panzer) Swingle (Rutaceae). Tree, height up to 5m (ibid:429). (See Picture 19).	<u>Fruit</u> Squeeze juice, drip onto sore. Rub lemon onto sore to clean it.
Loksi (Sr)	<i>Hymenaea courbaril</i> L. (Fabaceae). Tree, height up to 45m (ibid: 233). (See Picture 20).	<u>Bark</u> Burn bark, crush to powder, apply to sore.
(Uma) Luisawiwiri (Sr), Bhangraiya (Sarn.), Tótobiá (Sr)	<i>Eclipta prostrata</i> L. (Asteraceae). Erect herb, height between 20-50cm (ibid:101). (See Picture 21).	<u>Leaves</u> Squeeze juice out of leaves and drip onto sore. Crush leaves and place on sore.
Mopé (Sr)	<i>Spondias mombin</i> L. (Anacardiaceae). Tree, height up to 25m (ibid:35). (See Picture 23).	<u>Bark</u> Boil bark in water and wash sore with it. Scrape bark, apply to sore, and wet with alcohol.
Niem (Sr)	<i>Azadirachta indica</i> A. Juss (Meliciaceae). Tree, height up to 20m (ibid:332). (See Picture 25).	<u>Leaves</u> Boil in hot water and dab sore with it. Crush leaves and drip the juice onto sore.
Nikasa (Sr)	Unidentified	<u>Bark</u> Boil bark in water, dab sore with hot water.
Noni, didibri- apra (Sr)	<i>Morinda citrifolia</i> L. Rubiaceae. Shrub, height up to 6m (ibid:418). (See Picture 26).	<u>Fruit</u> Mash ripe fruit and apply paste onto sore. <u>Leaves</u> Heat the leaf and cover sore with it like a bandage.
Okro (Sr), oker (D)	<i>Hibiscus esculentus</i> L. (Malvaceae). Annual herb, height up to 2m (ibid: 301). (See Picture 27).	<u>Leaves and branches</u> Dry them, burn them, mash finely and apply the ash to sore.
(Uma) Parabita (Sr), Mananga (Au)	<i>Solanum leucocarpon</i> Steud. (Solanaceae). Small tree, height up to 7m (ibid:456).	<u>Leaves</u> Squeeze juice out of leaves and drip onto sore.

³⁰See web reference number 19.

	(See Picture 29).	Boil leaves in water, bathe with warm water.
Pinja wiri (Sr), Pikin pindya (Sa)	<i>Vismia guianensis</i> (Aubl.) Choisy (Hypericaceae). Small tree, height up to 9m (ibid: 268). (See Picture 30).	<u>Leaves</u> Boil water with leaves and dab sore with it. Also to be used: fry young top of the branch in a hot pan, mash till powder and apply to sore. Will kill the worm in the sore, if present.
Redi katun (Sr)	<i>Gossypium barbadense</i> L. (Malvaceae). Shrub, height up to 3m (ibid:306). (See Picture 31).	<u>Leaves</u> Boil leaves in water and wash sore with it.
Slabrikiwiri (Sr), Sakoor (Sarn)	<i>Senna alata</i> (L.) Roxb. (Fabaceae). Shrub, height up to 4m (ibid:250). (See Picture 32).	<u>Leaves</u> Boil leaves and flowers in water and wash sore with hot water. <u>Flower</u> Mash flower and leaves and drip the water/juice onto sore. <u>Bark</u> Scrape the bark of the plant and apply to sore.
Tassi (Sa)	<i>Geonoma baculifera</i> (Poit.) Kunth (Arecaceae) ³¹ (Heemskerk et al. 2007:53). (See Picture 34).	<u>Leaves</u> Burn leaves, mash fine, and apply ashes to sore.
Tayablad (Sr)	<i>Colocasia esculenta</i> (L.) Schott. (Araceae). Herb, height up to 2m, without stalk (Van Andel & Ruyschaert 2011:60). (See Picture 35).	<u>Leaves</u> Heat leaves on fire and apply them (hot) to sore. Burn leaves, mash fine, and apply ashes to sore.
Waki (Sr), Abonkini waki (Sa)	<i>Inga alba</i> (Sw.) Willd. (Fabaceae) (Van 't Klooster et al. 2003:297). Big tree, height up to 40m (Van Andel & Ruyschaert 2011:236). (See Picture 36).	<u>Bark</u> Boil bark in water, wash sore with it. Scrape the inner bark of the tree and apply to sore.
Wonderblad (SD)	<i>Bryophyllum pinnatum</i> (Lam.) Kurz (Crassulaceae). Straight standing herb, height up to 1.5m (ibid:178). (See Picture 37).	<u>Leaves</u> Heat a leaf on the fire and cover sore with it.
Yorkapesi (Sr)	<i>Senna occidentalis</i> (L.) Link. (Fabaceae). Shrubby herb, height 1-2m (ibid:252). (See Picture 38).	<u>Leaves</u> Heat leaves on fire and stick them (hot) onto sore.
Zoete patat (SD), or switi patata (titei) (Sr)	<i>Ipomoea batatas</i> L. (Convolvulaceae). Herbal climbing plant (ibid:173). (See Picture 39).	<u>Tendrils</u> Rub the sore with the tendrils. <u>Root</u> Mash root and apply to sore for 24 hours.

³¹ See web reference number 20.

Some CL patients (26), without providing further details, reported having used bitter leaves and tree barks, and ‘just’ or ‘only’ bush medicine. Similar to the methods listed above, sores were treated with (hot) herbal baths, the paste of fresh leaves, the powder of burned leaves, herbal baths with boiled bark, and the juice of bark dripped onto the sore. Other patients used unspecified ‘bush medicine’ in combination with biomedicine or non-biomedical chemicals.

A small group of 19 CL patients also used other botanical substances and oils in the treatment of their sores. Coconut oil, *hoepeolie* (SD), and *krapa* (Sr) oil were the most popular. Known popularly as *Palm*, a rum of 90% alcohol produced by the local Paramaribo company ‘Suriname Alcoholic Beverages N.V.’ was often used to clean or ‘burn’ CL sores. Table 4 shows the botanical substances and oils that CL patients (also) used.

Table 4: List of botanical substances and oils reported by CL patients

Botanical substances and oils (and number of CL patients ³² using them)	Substance abstracted from	Local plant name	Scientific name and short description of plant	Method of use
Aloe vera gel (1)	Gel from leaves	Aloe vera (SD)	<i>Aloe vera</i> (L.) Burm.f. (Asphodelaceae) (see Table 3).	Smeared onto sore.
Bredebon tarra (1)	Milk from tree bark	Bredebon (Sr)	<i>Artocarpus altilis</i> (Parkinson ex F.A. Zorn) Fosberg (Moraceae). Tree, height up to 35m (Van Andel & Ruysschaert 2011:338). (See Picture 7, Appendix 8).	Milk smeared onto sore to seal it.
Coconut oil (8)	Coconut meat (fruit)	Kokosnoot (SD), Kronto (Sr)	<i>Cocos nucifera</i> (L.) (Araceae). Solitary palm, often a bit oblique, height up to 20m (ibid:80). (See Picture 17, Appendix 8).	Smeared onto sore.
Hoepelolie (SD), opo-oli (Sr), Óleo de Copaieba (Po) (3)	Tree bark – after making a small cut in the bark, the resinous oil can be collected the next day (Van Andel & Ruysschaert 2011:223)	Opro-udu (Sr), Hoepelhout (SD), Copaieba ³³ (Po)	<i>Copaifera guyanensis</i> Desf. Big tree, height up to 50m (ibid). (See Picture 28, Appendix 8).	Smeared onto sore.

³²Patients used more than one product, often in combination with other treatment types.

³³See web reference number 21.

Krapa olie (SD) (2)	Krapa seeds	Krapa (Sr)	<i>Carapa guianensis</i> Aubl. (Meliaceae) (see Table 3)	Smeared onto sore.
Palm (SD) (alcoholic beverage, rum, 90% alcohol) (3)	Sugarcane	Suikerriet (SD)	<i>Saccharum officinarum</i> L. (Poaceae). Perennial, clump forming grass, height up to 6m (ibid:401). (See Picture 33, Appendix 8).	Alcohol poured onto sore.
Tea tree oil (1)	Tree bark	Not a local plant. Origin: Australia. Local name: Ti-tree	<i>Melaleuca Alternifolia</i> . Small tree or shrub with needle-like leaves, height up to 7m. ³⁴	Dripped onto sore.

Aside from extracted botanical substances and oils, four CL patients used other processed botanical products. The first is *kwaka* (Sr), made out of *Bita ksaba* (Sr) *Manihotesculenta* Crantz. (Euphorbiaceae). To make *kwaka*, *bita ksaba* is grated, the juice is squeezed out of the pulp, and the dry pulp is fried on big plates above a wood fire. The end product is *kwaka*, which is consumed as a substitute for rice. *Kwaka* can be kept in buckets for more than six months. In the treatment of CL, water is added to the *kwaka* so that it becomes a soft and sticky paste, which is rubbed onto the sore. According to people in the hinterland, “it keeps the sore dry” because of its ability to absorb the wound fluid. The second method is charcoal, obtained from burning wood. This is often used by inhabitants of the hinterland; Maroons, for instance, use mashed charcoal to treat the umbilical cord of newborns (Ramdas 2008:55). One CL patient used mashed charcoal for his sore. The third is tobacco, which, according to villagers in the hinterland, is a well known medicine against both CL sores and other cut wounds. To treat CL, slightly moistened tobacco is stuck onto the sore. The fourth are tea leaves: one patient made tea water and dabbed the sore with it.

5.2.1.2 ‘Hot’ treatments

From the information provided by the CL patients, it becomes clear that aside from ‘dry’ or ‘soothing’ treatments, treatments with heat are often employed to cure CL, either through the dripping of hot liquids onto sores or the pressing of hot objects to the sore. Several types of leaves and barks are boiled in water, and the liquid, which should be as hot as possible or as hot as one can tolerate, is dabbed onto the sore. Leaves are also heated on a fire and placed on top of the sore. Using bush medicine or home remedies in this way is generally quite common among the Surinamese population, and among inhabitants of the hinterland in particular.

At Godo-olo and in the Brokopoondo area, gold diggers reported the use of hot copper. Rob, a 41-year-old gold digger, mentioned: “I know that gold diggers also use hot copper. Copper, just make it warm, hot, and place it on the sore. Sometimes it helps, sometimes not”. Several gold diggers at Paaston and Godo-olo reported the practice of pressing hot objects onto CL sores, as well as the use of hot coconut oil. Kwami, a 43-year-old owner of a gold digging company, described:

³⁴See web reference number 22.

Another one [treatment] is coconut oil; first make a sable or machete red hot on [a wood] fire, then heat up the oil on the sable, and then stick it to the sore. Others let the hot oil drop into the sore. If the sore is big, it lies deeper and if they drip the hot oil in it, then you feel it [burning], and when you feel it, it's on the good, fresh meat. So you know that's good. (Kwami, Godo-olo, October 2009)

Papi, a 34-year-old Maroon gold digger, described the method of dripping hot coconut oil onto a sore:

You can treat BY [CL] with coconut oil only...what works is a clean knife or machete, heat up the oil and make the oil flow from the hot knife or machete into the sore. This will burn the bacteria away. It burns, it's really hot, but within three to four days the sore will be healed. I have seen this when I was in the Matawai river area, someone did it for someone else and I have seen it. There is no other medicine that can kill the sore, because the sore makes seeds. (Papi, Paaston, December 2009)

One CL patient at the Dermatology Service heated camphor until it melted and then dripped the hot liquid onto the sore. At Tepu, a 47-year-old woman reported using the hot liquids secreted from burning wood, often seen when a wood fire is made, to treat CL sores:

Just drip the hot, brown, sizzling hot juice of the wood on the sore...tsss [sound of the hot liquid falling onto the sore], and see how it cures the sore. The meat will turn white and heal. (Ira, Tepu, March 2010)

Dripping hot liquids onto the CL sore is also common in Benzdorp, especially hot cooking oil:

First you build some wall around the *leisho* borders with toothpaste and then you pour hot cooking oil. The toothpaste prevents the oil from getting out of the wound, it fries the wound and everything living in it. It really hurts, but I still used it because I had nothing else to use. (Rogero, Benzdorp, November 2010)

Burning sores with gunpowder is also practised. A 24-year-old Brazilian gold digger explained:

I know also of people who put gunpowder on the sores. Some just place it on top of it and cover it, others they insert it in the wound and put it on fire... They burn the gunpowder on the sore. (Ribero, Benzdorp, November 2010).

At Tepu, a 60-year-old villager reported that heated wooden termite nests – *nukke* (Tr) – is an effective medicine against CL sores: “Just mash a piece of the nest, heat on [a] wood fire and spread it – warm – over the sore”. The practice of using hot charcoal is also used in Tepu. Ex-CL patients at Tepu mentioned tipping hot

charcoal onto the sore. According to a 68-year-old villager who treated his own CL sores, heat works:

The sores itched me and then I took wood fire, a piece of wood with hot coals on the end, and I kept that close to the sore; I heated the sore. It stopped itching and I did it every day, every day, every day, and many times throughout the whole day. I've tried bush medicines, but they didn't help me. Like cashew bark, it didn't help. But the wood fire did. I even burned the sore a bit. It helped. (Aro, Tepu, March 2010)

5.2.1.3 Home remedies or bush medicine made with two or more ingredients

CL patients used bush medicines or home remedies that were made with two or more ingredients. Table 5 provides a list of the mentioned medicines, as well as a short description of the botanical ingredients, plus the methods for use.

Table 5: List of home remedies or bush medicines (and number of patients) and the methods for use

Home remedy or bush medicine ingredients (and number of CL patients using them ³⁵)	Description (brief) of botanical ingredients: local and botanical plant name (if applicable)	Method for use
Tobacco with alcohol (2)	Processed tobacco leaves	Alcohol used to clean and burn sore. Tobacco is moistened with alcohol and stuck onto sore.
Olive oil mixed with biomedical ointment (1)	-	Smearred onto sore.
Garlic and camphor (1)	Knoflook (SD) (Garlic) <i>Allium sativum</i> L. ³⁶ (Allium).	Not specified.
Okra leaves and something else (1)	Okro (Sr), oker (SD) <i>Hibiscus esculentus</i> L. (Malvaceae) (Van Andel & Ruysschaert 2011:301).	Dried, burned, mashed, mixed; ash applied to sore.
Garlic and salt (1)	Knoflook (SD) (See Table 3)	Mashed and mixed, and stuck onto sore.
Seed of the <i>awara</i> (Sr) fruit mixed with horseshit (1)	Awara (Sr) <i>Astrocaryum aculeatum</i> G. Mey. Solitary palm, height up to 20m. Awara tree and leaves are covered with needle-like thorns (Van Andel & Ruysschaert 2011:74).	Awara seed burned, pulverised, and left to cool, then mixed with horseshit and applied to sore.
Lemon, coconut oil, and battery lead (1)	Lemmetje (SD) (Lemon) <i>Citrus aurantifolia</i> (Christm. & Panzer) Swingle (Rutaceae) (ibid:429).	Sore cleaned with lemon, smearred with coconut oil, and sealed off with sore-sized lead layer.
Lemon and copper powder	Lemmetje (SD) (see Table 3)	Sore cleaned with lemon and

³⁵Patients used more than one home remedy, or used these medicines in combination with other treatment types.

³⁶See web reference number 23.

(1)		sprinkled with copper powder.
Pepper, mixed with salt and lemon juice (1)	Peper (SD), Pepre (Sr) <i>Capsicum annuum</i> L. (Solanaceae). Straight, shrubby plant, height up to 1.5m. Lemmetje (SD) (see Table 3)	Paste applied to sore.
Bones of crab, mixed with pepper, salt, and tobacco (1)	Peper (SD) (see above)	Mixture applied to sore and covered with a bandage.
Turtle skin (2)	-	Skin is burned, mashed, and the ashes applied to sore.
Tobacco, with ash, mixed with shilling oil (1)	Tabaka (see above)	Mixture applied to sore and covered with a bandage.
Leaves (burned), mixed with salt and coconut oil (1)	Kokosnoot (SD) (see Table 3)	Paste applied to sore.
Bitter cassava mixed with salt (1)	Bitasaba (Sr) (see Table 3)	Paste applied to sore.
Powder of salt meat bones (1)	-	Salt meat bones burned on fire and the ash applied to sore.
Pomtaya (Sr) mixed with salt (1)	Pomtaya (Sr), Pomtajer (SD), Taya (Sr) <i>Xanthosoma sagittifolium</i> (L.) Schott (Araceae) (Van 't Klooster et al. 2003:288), a herbaceous perennial, has a main underground stem from which swollen secondary shoots sprout (underground). From the main stem also several large leaves sprout. ³⁷	Grated to the root, mixed with salt, and applied to sore.
Ash of bones of salt meat mixed with gunpowder and lemon (1)	Lemmetje (SD) (see above)	Salt meat bones roasted, pulverised, and mixed with gunpowder and lemon. Paste applied to sore.
Cigarette ash (2)	-	Cigarette ash applied to sore.
Pure salt (1)	-	Applied to sore.
Vinegar (1)	-	To clean sore.
Sawdust of a bitter tree mixed with cooking oil (1)	Unidentified bitter tree	Applied to sore.
Lemon, mixed with salt and vinegar (1)	Lemmetje (SD) (see above)	Sore dabbed with vinegar, then cleaned with lemon juice mixed with salt.
Lemon mixed with <i>bom tobacco</i> , battery lead (1)		Mixture of lemon juice and tobacco applied to sore, then sore is 'bandaged' with battery lead.
BM: Mixture of Kwasibita, Niem, Bitter cassave, Neku and other ingredients (1)	<i>Kwasibita</i> , <i>Niem</i> , <i>bitter cassave</i> , <i>Neku</i> (see Table 3)	Not specified.
Leaves mixed with garlic (1)		Leaves mashed together and applied to sore.
Udu Jongo or Jongo udu	Udu Jongo (Sr) Unidentified	Bark crushed, mixed with baby

³⁷ See web reference number 24.

(Sr) mixed with baby oil (1)	oil, and applied to sore.
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5.2.1.4 Use of animal skin, bones, fluids, and faeces in bush medicine

As noted in Table 5, medicines made out of animal skin or bones are also used in the treatment of CL. In the hinterland, turtle skin is a well known medicine. Turtle skin is especially popular among Saramacca Maroons and the Brazilian population in Benzdorp. At Tepu, the skin fluid of the blue poison dart frog (*Dendrobatus azureus*) or *okopipi* (Tr) (Heemskerk et al. 2007) is used. This frog secretes a poisonous liquid through the skin. To cure CL, the frog is held in the hand and its back rubbed against the sore. According to a traditional healer, “it burns terribly, but it cures the sore” (Shaman, Tepu, March 2010). Among the 205 CL patients, one mentioned use of animal (horse) faeces as an ingredient in the medicine for his sore.

5.2.1.5 Ritual healing

Two CL patients (both males) mentioned ritual healing. One had gone to a traditional healer who treated him with prayers against *hogri ai* (Sr) or ‘evil eye’. The other took ritual baths. As described in Chapter Four, the majority of those confronted with CL ascribe the disease to something in nature, so treatment is therefore sought in the ‘natural world’ (Helman 2000:92). However, according to inhabitants of the hinterland, depending on the severity of the illness, the spread of the sores (if sores occur all over the body), and the period of illness (if it takes a long time to cure the sores), people with CL may also seek ritual healing. One CL patient explained that he went to the traditional healer for prayers, “just to make sure that one is protected from all sides”.

5.2.2 Self-treatment with biomedicines

As to biomedicine use in CL self-treatment, 58 CL patients reported having self-medicated with biomedicine. A slight majority (53.4%) of this sub-group used only biomedicine (one or more types), though the rest (46.6%) used biomedicine (one or more types) in combination with other treatment types. The medicines that patients used comprised six groups:

- Ointments: Betadine ointment, Zinc Oxide ointment (ZOK-zalf), Zinc-Ichtyol ointment, Whitefield ointment, Miconazole ointment, Betamethason ointment, Penicillin (eye) ointment, ‘just’ sore ointments or ‘antibiotic’ ointment.
- Pills/capsules and tablets: Amoxicillin (antibiotic) capsules, “antibiotic” tablets, Paracetamol tablets.
- Powders: Dermatol powder dutimon (yellow biomedical powder against cuts and bruises).
- Biomedical solutions: Betadine iodine, rubbing alcohol, salt water, other unidentified “biomedical purple liquid”.
- Muscle pain relievers: Radian B muscle rub, Polar-Ice analgesic gel.
- Other topical creams or products: Nixoderm, Vicks, warm compress.

The most commonly used biomedicines were ointments, used by fifty-one patients (88%); of the ointments, the majority (28 patients, 55%) used Betadine ointment – some to clean sores, others applied to and left on the sores.

Pills and tablets were the second most commonly used treatment, used by 37 patients (64%); of these, patients mostly used amoxicillin capsules (22 patients). Twelve patients spread the powder inside the capsule over the sore, followed by the swallowing of further amoxicillin capsules – either only a few or as a treatment (*kuur*, SD). Biomedical liquids were the third most commonly used remedy, by 22 CL patients (38%). In particular, rubbing alcohol was used to clean sores (18 patients); Nixoderm and Vicks were the least used (by 6 patients, 10%). One patient used a warm compress and another used muscle pain relievers.

It is possible that the number of CL patients using biomedicines in self-treatment may be lower or higher than registered here, because self-treatment was sometimes carried out in combination with professional health care. Some patients mentioned that prior to coming to the Dermatology Service, they had visited their family physician, or another doctor in the city or in a clinic in the hinterland. Some medicines were prescribed by these doctors and used by the patients before they finally visited the Dermatology Service. It was unclear, however, which medicines were bought from a legal pharmacy as prescribed by a doctor, and which were bought illegitimately.

Inquiries revealed that different medicines are sold, often illegally, in many of the local small shops in the hinterland, especially in the gold digging areas. In Photo 16, a shopkeeper in the hinterland ‘promoted’ some of the many medicines he sold. In Photo 15, amoxicillin is displayed in the lower right hand corner of the showcase.

Photo 15: A small shop at a centre for gold diggers



Photo 16: Promotion of available medicines



Collection: Ramdas, S., 2009, Paaston, District Sipaliwini

5.2.2.1 Self-injection practices among Brazilian CL patients

Health workers at the Dermatology Service also reported self-injecting practices among CL patients, specifically among the Brazilian population. According to one of the nurses at the Dermatology Service:

Oh, the Brazilians they inject each other. The *Ndjukas* [Maroons] are more concerned and prefer to go to the medical post in their village, but Brazilians? They are not afraid. If you die, you die. They don't worry about that. (Nurse Ana, Dermatology Service, January 2010)

Investigations in the Brazilian gold diggers' village of Benzdorp confirmed this practice. What follows is part of an interview with a key informant, a 45-year-old Brazilian woman, who owns a small 'pharmacy' in Benzdorp. She claimed to be a nurse. Having lived in Benzdorp for eight years, she (R) described how self-injection to treat CL works among the Brazilian population.

I: In the eight years you've been here, how many people would you estimate you saw?

R: Well, a lot!

I: An estimation?

R: About 200 people I think.

I: And if they come to you with a *leisho* [CL sore], what do they ask mostly?

R: They always ask me for advice: "What can we do? What can we use to treat it?" They all come to search for a treatment.

I: If they show you the sore, do you know it's a *leisho*?

R: They have diagnosed it themselves, they know it very well!

I: But do *you* recognise it?

R: Only if it's in a quite developed stage, only then I can know if it's a *leisho*, but otherwise not. But you know what the tricky thing about it is? It doesn't hurt, it only grows bigger.

I: Do they express their worries to you? What are their worries?

R: If the people come, they have a *leisho* or *leishos* on their body and the most important thing they worry about is whether it's going to heal or not. They worry about how to cure it.

I: What do you advise in most cases?

R: I advise them to go to Maripasula [in French Guiana territory, close to the Surinamese border in mid-east, where there is a hospital], but they don't really want to go there because they lose a lot of time, money, and it's a hassle.

I: If they don't want to go to Maripasula, what do you advise them then?

R: I tell them to buy the medicine, whether in Paramaribo or at the French side and then inject it.

I: Do you also inject?

R: No, no, I'm licensed for it, I've worked ten years in a hospital as a nurse, but I can't prove it. That's why I'm afraid to do it here. I have no documents to prove anything, so I don't want to take the risk. Plus, I can't work legally; it's illegal here. That's why people inject it amongst each other and for each other. Here you have many *garimpeiros* [gold diggers] with a lot of experience and they know very well how to do the injections.

I: Does it cause any complications if people inject it for each other just like that?

R: There are people who have been doing it for a long time, but no one can confirm if it's the way it should be done. They just do it, they inject each other, some of them get infections, but often it's good. No problem. The thing is that the environment here is not sanitised, it's not hygienic, but still they inject however they want.

I: Do people ask money to do the injections?

R: No, nobody asks money for it. You know, all *garimpeiros* work for a boss, and the boss often says, "Go buy the medicine and bring it, I'll inject it". Because he [the boss] is experienced or he saw it elsewhere and he doesn't want to lose his worker or have the work delayed.

I: But you sell medication as well?

R: Well, only the basics. I can't go and buy the medicines because I'm not authorised. You should have all kinds of official documents to buy medicines in large quantities from the city. But I don't have that, so I have to look my ways.

I: And what are your ways?

R: I'd rather not talk about that.

I: Ok, did you see things going bad with people who got injected here in the moments after the injection?

R: No, no, no. As I said, the people here are very experienced about how to use the medication, what the side-effects are or might be, and what they should do if things went wrong. I've never experienced such cases. I know that before injecting, the person injecting asks the 'patient' about heart problems or other health problems the person might have. That's already what they know about each other. And then they play doctor for each other, but I've never met cases where it went wrong. You have to know, the people here are very experienced, they know a lot in between the rules. It's all street knowledge, but it works.

(Mary, Ramdas (I), Benzdorp, November 2010)

As the excerpt above shows, self-injection with the biomedical drug Pentamidine Isethionate (or Pentacarinate) – used generally by medical doctors in Suriname to treat CL³⁸ – is a common practice among the Brazilian population, who, due to their occupation, are particularly vulnerable to CL. A 40-year-old owner of another 'pharmacy' at Benzdorp explained:

Well, you know, [it is] mostly because they [*garimpeiros*] don't have the money to go there [Paramaribo, Dermatology Service] for help. And another very important thing is that they think about the time it takes for the sore to heal. As long as it doesn't really heal they can't work, so if they have the money for it [the medicine], they rather go and buy the medication, bring it here [Benzdorp], and inject it here, and get cured here. So they can continue doing their work.

Often colleagues, friends, or a local injectionist are asked to administer the injection. A 24-year-old Brazilian gold digger reported that the injectionist "is a man from here,

³⁸Pharmacies in Suriname sell two types of Pentamidine Isethionate (more information is provided in section 5.2.2.2).

he worked as a nurse in Brazil, but is now here at Benzdorp... he can do it very well". Because of their experiences with mucocutaneous leishmaniasis in their native country (which affects the mucous membranes, especially the nose, mouth, and throat), the Brazilians approached in this research were fearful of CL. As one gold digger who suspected he had a CL lesion on his ear expressed:

I'm afraid it's that [CL], because if it's *leisho*, it will eat away all. I've seen others with big sores around, it doesn't look nice at all, it's not a good thing. I had hoped it's not a *leisho*, but I'm almost sure it is.

According to a 24-year-old Brazilian gold digger, some people are afraid of an injection because of the pain:

People are afraid of the injection, because the fluid is very thick, and if it's injected, the muscles cramp if you don't know how to inject, and then it hurts a lot...

According to most people approached in Benzdorp, due to the risky business that the Brazilian gold diggers are engaged in, they do not fear the injections. Asked whether he was afraid of the Pentamidine³⁹ injections, a 39-year-old *garimpeiro* (who had lived for five years in Benzdorp) replied, "No, I'm not. We are from the *garimpo* [gold digging site], and if you seek gold you're not afraid of anything". However, even though the injections were not feared, they were nevertheless experienced as a nuisance

5.2.2.2 *Illegal trade in biomedical drugs for treatment of CL*

Officially, biomedical drugs to treat CL are only available in Suriname via a medical doctor's prescription. The *Bedrijf Geneesmiddelen Voorziening in Suriname* (Drug Supply Company Suriname, BGVS), established in 1983, is a government owned company and is "the principal importer and distributor of pharmaceuticals, as well as other health related goods ... in Suriname".⁴⁰ The BGVS primarily imports the biomedical drug Pentamidine Isethionate (PI) or Pentacarinat (that has the same generic concentration as PI, but is produced under a different brand name) needed for the treatment of CL. Both Pentamidine and Pentacarinat are expensive, though Pentamidine, which is produced by Interpharm (Brussels, Belgium), is cheaper (about US\$30 per ampoule) than Pentacarinat (about US\$100 per ampoule), which is produced in the Netherlands.⁴¹ The BGVS distributes the medicine to all pharmacies in Suriname; some pharmacies, however, do import the drugs themselves (Hu, personal communication, 2013). With a doctor's prescription, CL patients can buy the biomedical drug at a pharmacy.

Some of the Brazilian CL patients at the Dermatology Service reported being able to buy Pentamidine or Pentacarinat without a doctor's prescription. Although I lack factual evidence, according to these patients the biomedical drug

⁴⁰See web reference number 25.

⁴¹Estimated prices 2013.

used in the treatment of CL is available in a particular pharmacy located in the heart of Tourtonne, a neighbourhood close to the centre of Paramaribo. The majority of Brazilians living and working in Suriname – primarily in the gold and commercial sex sector – reside in this neighbourhood. Many Brazilian shops, supermarkets, restaurants, motels, money exchange businesses, enterprises buying gold, and other Brazilian undertakings can be found there. Rodrigo, a 23-year-old Brazilian CL patient, mentioned the particular pharmacy and reported that “many medications from Brazil and French Guyana are available. It is more expensive, but you can get the medicine, so you don’t have to stay in the city” (Rodrigo, Tourtonne, September 2010). According to Rodrigo, it is also possible to receive injections at the pharmacy. “I took the second injection at the pharmacy, no problem. You can ask for it. Many Brazilians come and buy the medicine there. No problem, really”.

People with CL at Benzdorp, either self-diagnosed or diagnosed by a medical professional, reported buying their medicines from shops and pharmacies trading in both legal and illegal medicine. These shops are located: 1) at the ‘French side’ or ‘Maripasula’ (in French Guiana along the eastern border of Suriname, where the nearest hospital to Benzdorp is located); 2) in Paramaribo; 3) in St. Laurent, a town in neighbouring French Guiana; or 4) in Benzdorp itself. According to informants, there is a lively illegal trade in and around Benzdorp in both biomedical drugs – Pentamidine and Pentacarinate – for treatment of CL. A 50-year-old man at Cabanafo, a town close to Benzdorp, revealed: “Yes, there are persons who sell the injections. They buy it in the city and they sell it here”. Others at Benzdorp reported: “There is someone here who sells ampoules, and I bought it here, and she [the person selling the medicine] also injected it in the butt” or “People usually go to the doctor as soon as they suspect CL, and buy the medicines at Maripasula or Paramaribo, and get it injected here at Benz”. The 32-year-old wife of a pastor at Benzdorp, a biologist by academic training, commented:

In the five years I have been living here, I’ve seen that from the people with *leisho*, almost 95% seek medical treatment. They buy the medicine, either here in Benz or in the city. They search for medical help, because they know otherwise cure is not certain. From my experience, I believe 40% buys the medicine, 50% goes to the doctor, and 10% apply a lot of other remedies to the sore which they believe helps.

According to some informants, whether diagnosed by a medical doctor or self-diagnosed, a patients’ language plays an important role in his/her self-injecting practices. Mary, the pharmacist, explained:

The *garimpeiros* living in French Guyana and Suriname [Benzdorp] don’t go to the city because they don’t understand the language. They are very much afraid that doctors do not understand their problem or the kind of illness they have and prescribe different medicines, the wrong medicines. They are not able to communicate with the doctors and explain what they have, and that’s why they’re afraid of the wrong medication. That’s why they don’t go to the doctor. They know that *leisho* is killed by the medicine named Pentacarinate or Pentamidine, they buy it and stay within their own system, they have their own

language, that's why they do it for each other, they inject amongst each other.

As it turns out, in terms of treating CL with injections, Brazilian CL patients differed significantly from the Surinamese population. Language, and the existence of one's 'own network' in which everybody knows how to 'find his way', contribute to self-injecting practices. Others do go to Paramaribo; not to visit the Dermatology Service, but rather to a few specific medical doctors who have a large Brazilian clientele. As one female Brazilian CL patient revealed:

He [a particular doctor in Paramaribo] speaks Portuguese, and all Brazilians and Dominican people are his patients. It's better and nicer to talk in your own language, no? They also say he's good, so...

Widespread self-use of injections in developing countries is a matter of concern for biomedical health professionals, because such injections may lack medical justification, are unhygienically administered, or are unsafe in relation to blood borne pathogens (Whyte & Van der Geest 1994:137; Simonsen et al. 1999:789). One of the medical doctors at the Dermatology Service commented:

...if well done [injection], there is no need for concern. But we can't control that, and such a situation can lead to many different kinds of complications. (Medical doctor, Dermatology Service, September 2010)

The fragment below of an interview with a Brazilian gold digger, who said he had been diagnosed with CL at a biomedical health facility, illustrates the concern of the doctor above. It also shows how Brazilian gold diggers use injections based on the perceived effect of the medicine on the sore, rather than in terms of adhering to a medical protocol.

The basic knowledge is three [there are three injections needed for treatment of CL]. But first they [CL patients] use one, and if it heals, they don't use any more. It all depends on the organisms, people's health condition. Some use three, some four or five injections. If one doesn't help, they try a second or even a third shot. (Gold digger, Benzdorp, October, 2010)

Self-injection practises may also complicate (bio)medical treatment, because those who do not visit the Dermatology Service or any other biomedical health clinic, but do buy drugs for treatment of CL based on their own knowledge, hold a differing 'adherence scheme'.

During a conversation, two Brazilian gold diggers, Robinho (R) and Carlos (C), aged 20 and 30 years respectively, explained how they treated themselves with biomedical drugs. Robinho had been diagnosed with CL the year before and Carlos had a few sores on his left ear at the time of research. Here is a fragment of our conversation:

I: When did you get your sore?

R: I got it one year ago. It really became big. The injections really hurt me, I got them in my butt. I think it's a mosquito that causes *leisho* [CL]. My sore healed with Pentacarinat. I bought it in Paramaribo.

C: I got the first one six months ago, on my hip. That one is healed but I have some now on my ears. The first one really grew big, it hurt me a lot. I got it in Benzdorp. It's caused by a mosquito, I've read it in a book. I used Pentacarinat for it.

I: Who injected it for you?

R: We injected for each other. I did it for him, he did it for me.

I: You're friends?

R: Yes, friends, colleagues.

I: How do you know how to inject?

C: We *garimpeiros* teach each other about how to do it, we learn from each other.

I: So how did you do it?

R: Thus clean the area with alcohol, then inject fifteen minutes slowly, it hurts, so you should lie down a bit and that's it.

I: Did you eat anything before getting the injection?

R: No

C: Me neither.

I: When did you get the injection?

R: In the morning, I did have breakfast [but not because of the injection].

C: I took it in the afternoon. I had eaten already.

I: Are you afraid of the injection?

R: We're not afraid of the injections. We're only afraid of the sore, it shouldn't become bigger.

I: What do you use to clean the sores?

R: We wash it with water, that only. Mine cured within one day. I got two injections.

I: How many days after the first injection did you take the second?

R: After 6 days.

C: I took a first injection only, and that's now 2 months ago.

I: Why that long time?

C: It's my own attitude [nonchalance], it was cured, but then I didn't make efforts to get the second injection, that's why it didn't cure. But I will do my best one of these days.

(Robinho, Carlos, Ramdas, Benzdorp, November 2010)

The problematic character of self-administering injections for self-diagnosed CL is clear. Both Robinho and Carlo followed their own adherence schemes – very different from the biomedical regime – and had no information regarding the intake of food before receiving the injection (neglect of this can result in serious complications, see Chapter Eight).

To conclude, self-injecting practices specifically related to the treatment of CL were primarily found among Brazilian gold diggers in Benzdorp. Inquiries among gold diggers at Paaston and in the Brokopondo Centrum area confirmed this finding. A 43-year-old Maroon owner of a gold digging company at Paaston remarked: "We generally don't do injections here [at Paaston, among the Maroon gold diggers]. It is a dangerous thing. It can happen occasionally that a boss decides to inject [CL biomedical drug] for his workers, but it doesn't happen often." (Kontu, Paaston, December 2009).

5.2.3 Self-treatment with Chinese medicines

Chinese medicines, as already reported, were used by a small number of five CL patients as additional treatment. Of these five, three patients used Shilling oil, dripping it onto the sores. The other two smeared Chinese Vicks onto their sores. Both medicines are popular in Suriname and almost every household keeps them in their medical kit as a remedy against small aches and pains.

5.2.4 Self-treatment with potentially harmful chemicals⁴²

Within the group of 161 CL patients who attempted self-treatment, 48 (30%) used potentially harmful chemical products. Seven (14.6%) of these 48 CL patients had used only one chemical product; the remainder (85.4%) had used more than one, sometimes in combination with herbal medicine, home remedies, and/or biomedicine. The non-biomedical chemicals that CL patients used comprised of six groups:

- 1) Personal hygiene, skincare, or beauty products, such as Dettol soap, other soap types, skin cream, Vaseline, pomade, and make-up remover.
- 2) Household products, such as candle wax, Dettol disinfectant, pine oil, and bleach.
- 3) Household insecticides and repellents, such as Baygon sprays, mosquito repellents, and moth balls.
- 4) Chemical products used in cars, clocks, flashlights, guns, and fuels, such as methylated spirit, lead, battery acid, small batteries, gunpowder, mixed and pure gasoline.
- 5) Herbicides, such as Gramoxone.
- 6) Veterinary insecticides, in particular Smeerex, known more generally in Suriname as *bom* (spray), or *dagubom* (dog spray).

Five patients (10%) used one or a combination of the personal hygiene products. The remaining 43 (90%) used 'harsher' chemical products, as presented in the following table.

Table 6: Overview of 'harsh' chemical products used by 43 CL patients

Chemical product	Number of patients	Percentage (%)
Smeerex	23	53.5
Lead	5	11.7
Battery acid	4	9.3
Household insecticide or mosquito repellent	3	6.9
Household disinfectant (pine oil) and vinegar	3	6.9
Gasoline	2	4.7
Bleach or chlorine	2	4.7
Herbicide Gramoxone	1	2.3
Total number of CL patients	43	100

⁴²Treatment with potentially harmful chemicals has been extensively discussed in Ramdas (2012).

Similar findings in Ecuador

The findings of this research regarding the use of different types of medicines to treat CL correspond to some of the few studies conducted globally on 'traditional' practices and treatment of CL. From 1989 to 1991, Weigel and colleagues (1994) conducted a large-scale qualitative study in 26 agricultural villages in Ecuador. They noted the use of "indigenous plants, chemicals, acids, antibiotics, heat-treatments or petroleum by-products" (Weigel et al. 1994:142); use of chemicals such as sulphur, battery acid, gasoline, kerosene, or creosote were also noted. Also in Ecuador, Weigel and Armijos (2001) found that in addition to different plant preparations (traditional medicine), people also used veterinary products, hot liquids, heavy metals, and cauterisation.

5.2.5 Dietary restrictions and keeping 'cultural rules' as part of self-treatment

It was only after inquiries in the hinterland villages that questions concerning dietary restrictions and 'cultural rules' when one is infected with CL were added to the questionnaire administered at the Dermatology Service. These hinterland inquiries revealed that dietary restrictions and maintaining certain 'cultural rules' were often simultaneously practiced as part of treatment to stimulate the healing of CL sores.

5.2.5.1 Cultural beliefs: food, drink, sex, and pregnancy related taboos

At Tepu, villagers believed that avoiding certain food prevented aggravation of the illness and stimulated the healing of CL sores. "You have to fast [abstain from food] during your illness", many remarked. Those who had experienced CL in the village mentioned avoiding consumption of the following foods during their illness:

- Fish such as *anjumara* (*Hoplias aimara*) (Heemskerk et al. 2007:60), *piranha* (*Pygocentrus nattereri*), *maroko* (Tr) (unidentified), *warawara* (*Hypostomus ventromaculatus*⁴³), *slaapia* (Tr?) (unidentified).
- Meat of animals such as *babun* (Sr) or howler monkey (*Alouatta seniculus*) (ibid:194), deer (*Cervidae* spp.) (ibid:212), *pingo* (Sr) or white-lipped peccary (*Dicotyles pecari*) (ibid), *pakira* (Sr) or collared peccary (*Tayassu tajacu*) (ibid).
- Birds, such as *kamikami* (Sr) or grey-winged trumpeter (*Psophia crepitans*⁴⁴) and mawi (Tr) or *anamu* (Sr) (*Crypturellus cinereus*) (ibid:197).

Villagers said that only small fish should be eaten, though according to one traditional healer, one should consume neither fish nor meat. Pepper, salt, and cold or 'sweet' drinks made from processed fruit – such as cashew (*Anacardium occidentale*, Van Andel & Ruysschaert 2011:31), *sakura* (Tr), and *kurura* (Tr) – are to be avoided as well. Processed food products of the *Manihot esculenta*, namely soft cassava bread and *kasripo* (Sr), and the (uncooked) yellow juice of the bitter

⁴³See web reference number 26.

⁴⁴See web reference number 27.

cassava, are warned against; consuming dry cassava bread, however, was not seen as a problem. Walking in the hot sun was advised against, as well as bathing in the river.

Similar to the Trio people, Carib people at Donderskamp emphasised that pepper and *kasripo* should be avoided, as well as *peprewatra* (Sr) (watery pepper soup) – since it also contains *kasripo* – and *kasiri* (Tr). Unlike at Tepu, the villagers in Donderskamp did not mention dietary restrictions concerning the eating of wild meat or fish. Only one person, a *basiya* (assistant of the captain), said that those with CL sores could eat all fish, but preferably roasted:

You can eat all kinds of fish. All fish. But in most cases, if you suffer from sores like that, the advice is given to eat only roasted things [laughing]. Especially in cases where people do not know any medicine for it. (Alka, Donderskamp, May 2010)

In Benzdorp, the Brazilians (ex-CL patients and others) reported avoiding consumption of home raised chickens, pork, and wild animals; also listed were scaled fish, shrimps, pepper, and eggs. Drinking “sour things like lemon” should also be avoided. In addition, at Corte de Pedra, Brazil, CL patients reported that – aside from the foods listed by Brazilian gold diggers at Benzdorp – consumption of all kinds of creeping, wet, juicy, or slimy plants or vegetables should be avoided. At Brokopondo, villagers also mentioned dietary restrictions, namely not eating wild meat and pepper. But, as they remarked, they do not always believe in these restrictions. A 30-year-old ex-CL patient, a gold digger at Brownsweg, said, “Well, I don’t know of others, but I ate everything. All kinds of meat. I cannot have food without meat” (Jo, Brownsweg, October 2010).

Often reported was the belief that if infected with CL, one should abstain from sex. Having sex, especially while taking traditional treatment, is viewed as dangerous because it could lead to aggravation of the sore. I found that this belief existed in every village I visited in the hinterland. Having sex would “worsen the sore”, the sore would “hurt a lot more”, “would not heal”, and “would take a long time to cure”.

Another widely shared belief was that a CL sore worsened if a pregnant woman looked at it. Pregnant women “should not look at the sore” and “should not treat the sore”. While on treatment, those with CL were thus generally advised not to allow pregnant women to see the sore. At Tepu, some believed that if a person is infected with CL, even taking food or drinks from a pregnant woman is risky. In other villages, pregnant women are not allowed to treat sores. During a group conversation with four Saramacca Maroon women at Kadju, Brownsweg, one remarked, “People experienced it; if a pregnant woman treats the sore, it will not heal” (Lina, Kadju, Brokopondo, October 2010). Avoiding contact with pregnant women is not seen as a way to prevent CL, but as a way to prevent aggravating the illness and to stimulate cure.

5.2.5.2 “Beliefs do not affect CL cure”

Not only did ideas about CL differ enormously, but they were not always believed. At Tepu, the head of the village remarked that many of the beliefs were “not true”. It

was, according to him, not a problem if pregnant women approached those with CL with food or drinks. Furthermore, those with CL could eat everything, drink everything, have sex, and do everything; nothing interfered with the treatment of CL:

If you have *kaasa* [CL], you can eat everything, it doesn't matter what, nothing will happen. You can work and walk everywhere freely in the village. It is also not true that you get *kaasa* if you have sex with other ethnic groups. *Kaasa* is not contagious. (Captain, Tepu, February 2010)

Some other villagers (ex-CL patients) also mentioned that they rejected such ideas; for example, that dietary restrictions hindered treatment. In Donderskamp, there were villagers who also did not believe in such ideas. The following excerpt of an in-depth interview between myself and a traditional healer (S) about dietary restrictions shows that certain ideas were completely rejected:

I: Ok, the *Bus' Yasi* has no *trefu* (Sr) [allergy, or things one should not eat or do when infected with an illness]?

S: No.

I: You can eat, drink everything?

S: Yes, drink [everything]...

I: So when someone has *Bus' Yasi*, you can eat everything? Pepper, *peprewatra*, *kasripo*?

S: Yes, yes, that doesn't have any effect.

(S., traditional healer, Donderskamp, May 2010)

A *basiya* explained that certain beliefs were perhaps strong in the past, but that now much of what the elders said was lost or not held to.

In the villages in and around Brokopondo Centrum, several villagers were surprised about questions concerning beliefs surrounding CL. When questioned about whether they had heard about specific beliefs related to having CL, several answered, "No, I don't know" or "No, never heard of anything". One villager remarked, "You know, people hear it from others, the one tells it to the other and people believe in it. But they cannot explain why they cannot eat or do certain things".

Many in Benzdorp said that they knew there are supposedly "many things" they should not do or eat, but they refused to believe in it. A 34-year-old Brazilian gold digger who had had CL several years previously said: "They told a lot of stuff, but I ate ... and drank all kinds of things" (Mario, Benzdorp, November 2010). Another ex-CL patient, a 24-year-old Brazilian gold digger, remarked: "they say I can't eat chicken, but I don't believe it; I eat everything" (Roberto, Benzdorp, November 2010).

In all visited communities in the hinterland and among the CL patients of the Dermatology Service, alcohol was almost always listed as a beverage not to be consumed when one is infected with CL; in particular, if one is undergoing biomedical treatment. According to the informants, this is "because the doctor said so". Sometimes, however, certain cultural beliefs were labelled as 'medical advice'. In Benzdorp, but also in the Ndjuka and Saramacca Maroon villages, gold diggers who claimed to have experienced CL reported that medical doctors had advised them "not to have sex" and "not to eat pepper". Upon being questioned about this

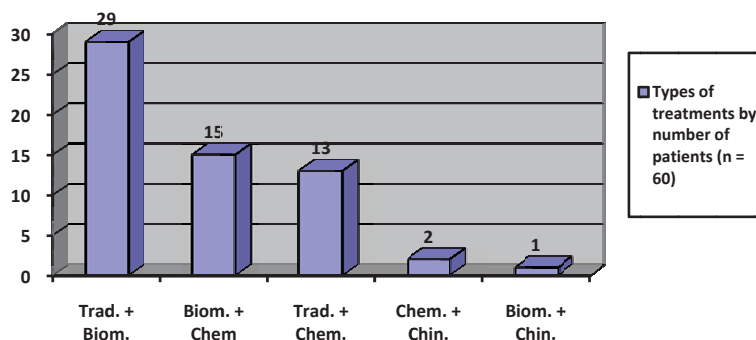
issue at the Dermatology Service, medical doctors explained that in general, nothing is advised against. “In fact, protocol wise there is nothing that CL patients should not drink or consume, there are no restrictions” (Hu, personal communication, Dermatology Service, November 2010). Only in some cases is alcohol warned against when CL patients receive biomedical treatment. Pentavalent antimonials (a group of compounds used for the treatment of leishmaniasis), for instance, can cause a mild to moderate increase in liver enzymes (see also Oliveira et al. 2010:87), and therefore intake of alcohol by some patients is advised against during medical treatment. Other practices, such as having sex or eating pepper, were considered medically irrelevant: “They already have these ideas when they come to the clinic” (Hu, personal communication, 2012).

At the Dermatology Service, of the 72 CL patients who were asked specific questions about beliefs concerning diet, 42 (58%) responded that they “eat everything”. The remainder (42%) responded that they did not consume alcohol and pepper. A few CL patients also added that they did not eat garlic or fatty foods. When specifically asked about abstinence from sex and caution when encountering pregnant women, most of the CL patients laughed; a few responded that they abstained from intercourse, and several superficially explained that such ideas existed in the hinterland, so they had heard. The majority at the clinic, however, did not discuss these matters further.

5.2.6 Quest for the ‘right’ medicine

My study shows that among CL patients practicing self-treatment, almost half combined two or more types of treatments. The majority of these, 60 patients (84.5%), combined two types of treatment. The remaining ten patients (15.5%) combined three types of treatment. In the chart below, an overview is provided of some combinations.

Figure 6: Overview of two treatment types used by 60 CL patients, by combination



From this subgroup of 60 CL patients, 29 (48%) combined bush medicine and biomedicine treatments, followed by 15 patients (25%) who used biomedicine and non-biomedical chemicals, and 13 patients (22%) who used bush medicine and non-biomedical chemicals. Only a few patients made combinations with Chinese

medicine: two (3%) combined non-biomedical chemicals with Chinese medicine and one (2%) used both biomedicine and Chinese medicine. Within the subgroup of ten CL patients who combined three types of treatment, 9 (90%) combined bush medicine, biomedical, and chemical treatment, while one patient (9%) used the combination of biomedicine, chemicals, and Chinese medicine.

In practice, this means the use of many medicines (sometimes more than six) by a single patient. Many of the health workers at the Dermatology Service and at the Medical Mission clinics in the hinterland with whom I discussed the medicines used by CL patients were stunned by the number and variety of medicines used. While most of them knew of the fact that patients used “many things”, for some it was “just unbelievable” and inconceivable *why* patients would want to use *so many* things. Even CL patients who did not self-medicate or who self-medicated with only one medicine were dazzled by the number of CL treatments they heard about from others around them. One CL patient said that he had heard of so many things to use for the CL sore that he thought he would be better off just going to the doctor. Another patient said that “all these people are just crazy. They tell you to do this and do that and in the end, nothing works”. The excerpts below illustrate how two CL patients searched for the ‘right’ medicine in their quest to cure their CL sores. Ro is a 24-year-old Creole man working as a cook and welder in the hinterland:

I used several bush medicines, such as garlic and salt, I mixed it and put it on the sore. I used that for one week. I cleaned my sores with alcohol, and so now and then I used Whitefield ointment when it itched. I did so for about one and a half months. I was in the hinterland, but then I came back to the city, I met my dad and he showed me another home remedy. He told me to burn the *awara* seed, mash it fine, and mix it with horse faeces. Then you let everything cool off and apply it to the sore. It burned, but I did that for about one week. It didn't help. I then went to a man who helps people with all kind of illnesses, a kind of traditional healer. He applied his own medicine, and I had to come back the next day with two pots and a bottle. He gave me bitter [leaves] to cook and drink. He also gave me some other kind of leaf to boil it in water and dab the sore with it. He said my blood was sweet, that's why I needed bitter. I paid him SRD 150 for it, he treated me for one week, but I don't see any value for what I paid. It didn't help me. (Dermatology Service, March 2010)

The second patient is Podo, a 23-year-old Maroon man, a gold digger who also worked as a hinterland tour guide in his spare time:

I cleaned it [the sore] with lemon, and you have to make real red powder out of copper and spread it on the sore; it burns terribly ... one must have guts to do it! I also used lead. The battery pole, take that, make it flat with a hammer or so, then melt it and pour it in the form of the sore. Then you clean the sore with lemon, smear some coconut oil on the sore, and stick the lead on it, tie it off [bandage it]. Then each day you have to take it [the bandage] away and wash the lead with alcohol and repeat everything. I also used *tassi* leaves... I burned it, squeezed it fine, and put it on the sore. I also used battery acid of small batteries.

Yes, and after that, also pepper mixed with salt and lemon and put that on the sore. (Dermatology Service, January 2010)

In the sequences of treatments (see Etkin, Ross & Muazzamu 1990; Matthews 1982; Young & Garro 1982), CL patients used different products, different types of products, sometimes in a particular order and sometimes haphazardly.

5.2.6.1 *Medicine should “love your body”*

The quest for the ‘right’ medicine shows how patients speculated about the outcome of the medicines. The reasoning behind this is the belief that the effectiveness of a medicine depends on how one’s body ‘receives’ the treatment. A Ndjuka Maroon villager, a 43-year-old *basiya* and ex-CL patient, said:

There is always an explanation why something did not work. Not that it [the medicine] is not a good medicine, it may not be good for you. ... and this is not only the case with *busi dresi*. It’s with all medicine. ... Sometimes it [medicine] helps, sometimes not, because everyone is built differently, everyone’s body differs. The *busi dresi* did not work on me, though they worked well on others. (Otto, Godo-olo, December 2009)

A local expert of traditional medicines remarked:

The danger [of using many medicines] lies also in the fact that some remedies are more effective on one person than another. People say *a lobi i skin* [Sr, it loves your body], meaning a medicine can ‘love’ your body, heal you. If it doesn’t work, it doesn’t mean the medicine is not good. It could mean that it doesn’t work on your body. (Rob, Godo-olo, October 2010)

This belief that medicine should “love the body” (*lobi a skin*) (Sr) resembles the Philippine concept of *hiyang*, the Indonesian concept of *cocok*, and the Sri Lankan concept of *behet ahavana*, as discussed by Whyte and colleagues (2002:33). In the Philippines, *hiyang* is a concept “traditionally used in relation to food, company, and medicines. If a drug has no effect, then people tend to conclude that the drug is “not *hiyang*” (not suitable) for that particular patient” (Hardon 1992, cited in Henry 2001:22). In Java, Indonesia, people use the concept of *cocok* to indicate the compatibility between a patient and a healing therapy; only if the patient ‘clicks’ with the chosen treatment will he or she find cure (Sciortino 1987:118). Similarly, in Sri Lanka, *behet ahavana* (medicine answering) is used, when “a type of medicine is suitable for one’s body and interacts in a healthy way” (Nichter & Nordstrom 1989:382). As the above examples show, in these cultures as well as in Surinamese Maroon culture, the body’s relationship to the medicine is central. The medicine may be fine, but its effectiveness depends on the acceptance by the body of each individual person. The body in this regard is considered a mass with its own will.

Henry (2001:22), in her work on contraceptive practices in Quirino, the Philippines, describes how patients found that the effect of a drug on their body changed over time: while in the beginning the medicine may not seem to work (was

not *hiyang*), later it would (was *hiyang*). For CL patients in Suriname, a medicine may be good, but if it is found not to work on a person's body, it is not used by that person anymore (unlike in Quirino) and is explained by the fact that his or her body 'does not love' the medicine. The same medicine may, however, work perfectly well for someone else.

Another form of reasoning behind the use of so many different remedies and medicines is the conviction that an effective medicine does exist, but that the patient has yet to discover it. One has to "keep searching for the right medicine". In Donderskamp, 58-year-old Baba explained:

The sore does not heal very fast. You have to keep medicating it until you find the *right* medicine. That's what it's all about. Finding the right medicine. Because we, [Amer-] Indians here, we know a lot of bush medicines. When in the past there were no doctors, we had to find ways to treat ourselves. And we know them [the medicines] or have people who know the *koni* [the wisdom, trick]. It is the same with *Busi Yasi*, you try out a lot of medicines, there will definitely be one that will cure it.

This reasoning provides a rational motive for the use of many medicines. It also contributes to the relatively late registration of CL patients at biomedical health facilities. While observing the efficacy of a particular medicine, time passes quickly: the first medicine is applied, for example, for one week, when the sore is still small. After one week, if this medication has failed, another medicine is tried. After another week, or maybe two, a third medicine is used, and observed again. If 'lucky', one's sore will heal. But when nothing helps, biomedical treatment (through injections) is an option of last resort. Patients are often determined to cure their CL sores, and thus the quest for the 'right' medicine and, therefore, the use of many medicines is part of this determination.

5.3 Local healers

As mentioned in section 5.1.2, the quest for a cure for CL also leads some CL patients to local healers, who generally play an important role in health seeking. Though very few CL patients actually visited local healers to find a cure for their sore, inquiries in the hinterland revealed that traditional healers and other local health experts knew much about the illness and purported to have ways to cure it.

In this study, I spoke with a small number of traditional healers: one at Godo-olo, one (the Shaman) at Tepu, and one at Donderskamp. I had conversations with the captains of the villages, and some of the *basiyas* who knew much about traditional healing and bush medicines. I also spoke with a few local health experts who claimed to have – and were viewed by villagers as having – the expertise and knowledge to cure CL, as well as other specific illnesses and health conditions such as snake bites or wounds caused by sting rays (two men at Godo-olo, one man at Donderskamp, and two men at Brokopondo Centrum). These experts, including the traditional healers, captains, and *basiyas*, were all men between the ages of 45 and

70 years.⁴⁵ At Tepu, aside from the Shaman, I also had conversations with two male traditional health workers who worked under the supervision of the Shaman.

The traditional healers and all the other local health experts said that they recognised CL very well, mentioning characteristics as described in Chapter Four (section 4.1.3). They also perceived CL as a very 'difficult' disease (as explained in Chapter Four), very hard to cure. Just as the captain of Donderskamp remarked, "the illness can become dangerous if it is not cured in an early phase, because it [the sore] can eat away your leg [if the sore is on the leg]". Because of its ability to devour flesh and to spread over the body, CL can, according to the healers, become a serious illness.

However, in spite of the fact that the healers perceived CL as a 'tough' disease, according to them, it is still not an illness that is life threatening or to be worried too much about, in contrast to other diseases such as malaria. In this regard, H, one of the local health experts, said:

People are not too much worried about the illness, no, no. ... With malaria, they were very concerned. But *Busi Yasi* is not an illness they worry too much about, it is not like they're nervous of contracting it, or that they're afraid or anything, no. It's possible you can contract it, it's possible you don't. But with malaria it was different, it was a huge problem.

Especially if the sore is healed in an early stage, it is not perceived as something serious. The captain of Donderskamp, who said that he had also contracted CL before, remarked: "For me this illness is something 'normal', it is not grave ... I did not feel ill, everything was normal ... my sore was healed very quick, because I had acted quickly". He reported that initially he used a biomedical ointment, but when that failed, he used a bush medicine advised by an old lady in the village, the latter of which turned out to be very effective.

The healers further reported that CL does not occur often, or only during certain periods such the rainy season. They all mentioned that both men and women could contract CL and that, similar to the findings in Chapter Four, it is a disease from nature. The exact cause was not known to them, but they had similar aetiological explanations to CL patients, as has been extensively described in Chapter Four.

Listing a variety of medicines to cure the sores, the healers said that they had often helped people with CL, including villagers or people from outside such as Brazilians, Hindustanis, or people with other cultural backgrounds working in the woods. As the 60-year-old traditional healer at Godo-olo said:

Yes, if they [people] get *Busi Yasi*, you have to treat it; if they come [for help], then you show them how they should treat it ... but it doesn't get cured fast! It's stubborn, it doesn't die [heal] quick. You get tired of medicating it; it takes a long time before it heals. So you use a lot of medicine for it.

⁴⁵Because some of the healers in the hinterland said that they did not know when they were born, their ages are estimations.

At the traditional health clinic *kapi* in Tepu (see Chapter Three), people with CL were treated with what they claimed to be a highly effective (Indigenous) medicine *Sipuinuime*. *Sipuinuime* is a dark coloured ointment (see picture below), made partially of the fluids of a liana together with other ingredients. It is a *busi dresi* of the Trio people, produced with their Indigenous knowledge. To protect this medicinal knowledge from being misused by the ‘outside world’, the local healers at Tepu keep the ingredients and method of preparation secret; this is only known to the Shaman and his apprentices. In terms of efficacy, the ointment is considered by the Trio traditional healers to be highly effective against CL. Though treatment may take weeks or months, according to both the health workers and the Shaman, the CL sore definitely heals. Patients seeking health care at the *kapi* have to register at the clinic, after which a health worker diagnoses their illness and discusses the treatment scheme. All patients diagnosed with *kaasa* (CL) are treated daily with the *Sipuinuime* ointment; the treatment period varies from several days up to weeks or months until the sore is completely healed.

Photo 17: Trio traditional medicine against CL: *Sipuinuime*



Source: Collection Ramdas S., 2010, Tepu

Information obtained from patient registers and inquiries among health workers at the *kapi* show that aside from *Sipuinuime*, other (Indigenous) ointments are also used to cure CL, such as *Pejowewe* (Tr), *Retu* (Tr), and *Ankarani* (Tr). These ointments are made in a similar way to *Sipuinuime*, and are also based on Indigenous knowledge. According to a health worker, all the ointments had juices extracted from lianas as their main ingredient. One of the health workers explained the use of the different medicines (used also in combination when needed) as follows: “Sometimes one [medicine] does not work, but the other does. We look at how the healing process of the sore goes”.

The use of all medicines for each type of illness was noted in patient registers at the *kapi*; with the other traditional healers interviewed in this study, no written reports were kept about their patients and the medicines they used. Nevertheless, all healers knew the medicines by heart. They used different types of plants, tree juices, leaves, barks, and other plant parts for most of the medicines. In the table below, the botanical names and a brief⁴⁶ description of the type of plant, as

⁴⁶See referenced literature for more information on the plants listed. See Appendix 8 for photographs and drawings of the listed plants.

mentioned by the healers, are provided, as well as the part(s) and method(s) used.⁴⁷ Similar to in Table 3, I neither collected nor determined the listed plants, but mainly used botanical resources and literature (see section 5.2.1.1).

Table 7: List of plants mentioned by traditional healers and other local health experts

Local plant name reported by healers	Scientific name and short description of plant	Part used and method of use
Apokoño	Unidentified	No details.
Banana, bana (Sr), bak-banaan (SD)	<i>Musa</i> sp., <i>Musa x paradisiacal</i> (Musaceae) Tree-like herb, height up to 4m (Van Andel & Ruyschaerts 2011:345). (See Picture 3).	<u>Bark</u> Dry it, mash it into powder, apply to sore.
Bisangula (Au)	<i>Maprounea guianensis</i> Aubl. (Euphorbiaceae) Shrub or tree, height up to 25m (ibid:209). (See Picture 4).	<u>Leaves</u> Boil leaves in water, wash the sore with it. Mash leaves, usually mixed with salt, and place on top of sore.
Bitatiki (Au)	<i>Banara Guianensis</i> Aubl. (Salicaceae) Shrub or small tree, height up to 10m (ibid:435). (See Picture 6).	<u>Stalk</u> Cut pieces of stalk, burn to ash, mix with tobacco, and apply to sore.
Diatitei (Sr), Fayatatai (Sa)	<i>Davilla kunthii</i> A. St.-Hil. (Dilleniaceae) A liana (ibid:191). (See Picture 10).	<u>Liana</u> No details.
Kakanoto (Au)	<i>Jatropha curcas</i> L. (Euphorbiaceae) Shrub-like plant, height 1-4m (ibid:205). (See Picture 14).	<u>Leaves</u> Dry leaves, mash to powder, apply to sore. <u>Bark</u> Scratch the skin, squeeze juice of pulp onto sore.
Kasyu (Sr) (Cashew)	<i>Anacardium occidentale</i> L. (Anacardiaceae) Small tree with knotty branches, height up to 8m (ibid:31). (See Picture 16).	<u>Bark</u> Boil bark in water and dab sore with it.
Kokosnoot (SD), Kronto (Sr)	<i>Cocos nucifera</i> (L.) (Araceae). Solitary palm, often a bit oblique, height up to 20m (ibid:80). (See Picture 17).	<u>Coconut oil obtained from dry fruit pulp</u> Heat oil on a sable and drip hot liquid onto sore.
Kaapà (Sa), kalapa (Au)	<i>Carapa guianensis</i> Aubl. (Meliaceae) Tree, height up to 35m (ibid:334). (See Picture 13).	<u>Bark</u> Boil bark in water and dab sore with it
Manja (Sr), manyan (Au)	<i>Mangifera indica</i> L. (Anacardiaceae) Big tree, height up to 40m (ibid:33).	<u>Bark</u> Boil bark in water and dab sore with it.

⁴⁷There were some healers who provided only the names of the plants, without further specifying how to use them for treatment of CL; others did not provide plant names, but mentioned the parts that were used. The listed plants may also be the main ingredient, but be only *part* of the medicine eventually used on the sore.

	(See Picture 22).	
Ngobaya (Au), gujave (Sr)	Myrtaceae, <i>Psidium guajava</i> L. Small tree (ibid:357). (See Picture 24).	<u>Leaves</u> Dry leaves on top of wood fire, mash to a powder, sprinkle onto sore.
Opu maka (Au)	<i>Uncaria guianensis</i> (Aubl.) J.F. Gmel. (Rubiaceae) A liana. Stalk, 4-sided, bold, climbing with woody, sharp thorns (ibid:426). (See Picture 2).	<u>Bark</u> Scratch the bark, place in the sun to dry, mash to a powder, apply to sore.
Tupuru (Car.)	Unidentified Also known as black potato because of its dark purple colour. (See Picture 40).	<u>Fruit</u> Grate the fruit, place pulp on the sore.

At Godo-olo, the traditional healer also mentioned other types of treatment, for example: applying ground chalk onto the sore and then 'burning' the sore by dripping hot cooking oil on top of it; and using a mixture of tobacco and water, where the tobacco (usually bought in the city) is mixed with water, after which the water is first sniffed and then blown out of the nose. According to the traditional healer at Godo-olo, this treatment is especially advised if the patient suffers from CL in the nose. In the photographs below, the mixture is seen in a plastic bottle, and the healer is demonstrating how to use it.

Photos 18 (a, b, c): Mixture of tobacco with water, and a traditional healer demonstrating how to use it



Collection: Ramdas, S., 2009, Plata Kampu, (area Godo-olo), District Sipaliwini

At Tepu, the captain told of another treatment (also mentioned by villagers, see section 5.2.1.2) to treat CL: tipping hot charcoal onto the sore daily would make it shrink and ultimately heal completely.

It was striking that many of the plants and methods listed and used by the local healers are reflected in the plants and methods used by CL patients. As inquiries revealed, local healers themselves do treat CL patients, but often it suffices for them to simply tell patients which plant should be used and how. Patients can then treat themselves at home, or ask a family member for help.

The data also shows (see section 5.1.2) that CL patients did not shy away from approaching people to find effective medicines. There appears to be a thin line between self-treatment and being treated by local healers. Due to the low impact of the illness on mobility (patients are able to walk, and are physically strong enough to

undertake activities) and the visibility of the sores (often on arms and legs), patients themselves can relatively easily medicate their own sore(s). These considerations, and the fact that CL is not experienced as a life threatening illness (unlike illnesses caused by snake bites or stingray stings), probably also contribute to the low incidence of treatment seeking at traditional healers, as the data shows (see section 5.1.2).

In general, all of the local healers whom I spoke to in this study thought that CL could be very well cured with the medicines they advised, but they also advised people with CL, in cases where their medicines were not effective, to go to a medical doctor. Captain Henki commented:

I'd say, use the doctor's medicine, see how it works. If it doesn't help, then come to me, I'll start helping you. But I won't mix them. Or if you use *busi dresi*, if it doesn't help, then go to the doctor immediately. Because in the past we didn't have doctors here, so use the *busi dresi*; if it doesn't help, then go to the [capital] city to find help. If it helps, it's fine. If it doesn't help, go to find [a] doctor's help. It's better. For example, if a woman comes here, I tell her to go to the doctor. When the doctor can't help her, she comes back to me and then I'll do all that's possible to help her. And if you don't find a cure, then I can't help anymore. (Captain Henki, Godo-olo, October 2009)

At the time of the research, with the exception of one person at Tepu,⁴⁸ no patients with (biomedically diagnosed⁴⁹) CL were observed using the medicines advised by traditional healers.

5.3.1 Acknowledgement of biomedicine by traditional healers and other local health experts

In general, traditional healers are often able to cure illnesses and are therefore respected in their communities. Although they enjoy status and are the medical authorities in their communities, they acknowledge and respect the knowledge and capability of medical doctors in general. They have trust in the biomedical system. As one of the captains remarked:

Because why I have trust in the doctors; the doctor knows more and in depth what's inside the body than we of the *busi kondre* [forest community]. We never learned to go and do research about illness, how it's caused inside your body. Based on what the ill person tells you, what he feels, you can have an idea of what it could be, for example that it is something with your liver, according to what you tell about how you feel. Sometimes we also say "go to the doctor"; and if he does an examination tell him it's liver illness that's bothering you. Then they'll help you and then you come back again to me. So, go and let yourself [be] examined first, to be sure. Maybe you feel something in your belly,

⁴⁸More about this patient is provided in Chapter Six.

⁴⁹It was necessary to have a biomedical diagnosis, because otherwise it would have been impossible to determine whether the sore that the patient was treated for was actually CL.

but maybe it can be your bowels, ... maybe your liver, all those kinds of things. I won't be able to know exactly. (Henki, Godo-olo, October 2009)

For the traditional healers and other local health experts, medical pluralism is a given. Both biomedical treatment (i.e. going to the medical doctor) and traditional treatment are common. Treatments in both systems are used and advised; the type of treatment depending on the type of illness. Some traditional healers stipulated that they *know* certain conditions: they can recognise symptoms very well and in these cases they do not hesitate to use their traditional treatments. With unrecognised diseases, however, the help of medical doctors is appreciated.

Honestly, it's two ways for me. If, for example, a snake bites, I won't go to the doctor, because there are experts here who could cure me. If my arm breaks or leg breaks, I won't go to the doctor. Here I'll find cure. If my body hurts for nothing, I won't look for a medicine here, I'd always want to make an echo [ultrasound] for it, because I don't know what it is. Thus in fact, I'm neutral. They say "In life one never should be neutral, but choose sides". But I'm neutral. It's how the illness is which shows me where to find a cure: at the doctor or somewhere else. Or if I try to find a cure and it doesn't help here, then I'll go to the doctor. (Basiya Ottie, Godo-olo, December 2009)

Perhaps to avoid conflict, especially when a biomedical clinic and a traditional clinic are located side by side – as is the case at Tepu – traditional healers choose to focus on the illness rather than the treatment type. The Shaman at Tepu commented:

I have no problems with traditional or doctors' medicine. You [the patient] must see where you can get cured. That is important. Sometimes we can't help, then you go to the doctor; sometimes they can't help and we can. (Shaman, Tepu, March, 2010)

In general, as my research shows, there was open recognition on the part of traditional healers towards the capabilities of biomedical health professionals, while they nevertheless maintained their authority. When needed, traditional healers reported that they did not hesitate to advise their clients to visit a biomedical doctor. The biomedical health system is viewed as complementary, serving either as an addition to their own treatments of a certain health condition, or possibly addressing different aspects of the same health condition. It is also viewed as "coexistent" (Csordas in Helle & Lázár 2006:x), serving as the better or most appropriate treatment, depending on the type of illness.

5.4 Conclusion

This chapter revealed a complex array of self-treatment possibilities and practices. It provided insight into how the majority of CL patients, prior to visiting the Dermatology Service, acted upon their disease. CL patients were out on a quest to cure their sore that translated into a wide variety of treatments, (partly) advised by their social environment. From dietary restrictions and other 'cultural rules' that

reportedly contribute to a speedier cure for CL, to the use of (painful) bush medicines, non-biomedical chemicals, and – potentially dangerous – self-injecting practices (especially among Brazilian gold diggers), a variety of intricate patterns of CL health seeking behaviour emerges.

The fact that the majority of CL patients turned to so many different treatments is remarkable; indeed, no saturation point was reached at the end of the research regarding the number and type of medicines used to treat CL. Furthermore, a contradiction can be observed in terms of the treatment seeking of CL patients. Despite viewing CL as a dangerous illness that is hard to cure, many CL patients used some very ‘peculiar’ and ‘puzzling’ kinds of medicines. Some biomedical health workers considered the use of such medicines as “crazy” or examples of “quackery” (Health workers, personal communication, 2010). The important question, however, is *why* CL patients use particular kinds of medicines? Is there anything ‘special’ about these medicines? What effect do they have on the sores, according to CL patients, and what do the medicines have in common? Moving a step further, these questions are addressed in the following chapter.

The findings within this chapter have particular practical implications, and may be of importance for public health authorities, who should be aware of the multitude of medicines used in self-treatment for CL. Self-treatment contributes to relatively late treatment seeking at biomedical facilities (as already mentioned in the previous chapter), and could hamper detection of new cases of CL. Inaccuracy in the statistics concerning CL prevalence and incidence in Suriname could also be an outcome of treatment seeking outside of the biomedical sector. The issue of self-treatment with a variety of medicines should therefore be placed on the agenda of public health authorities, and communication structures between health professionals and inhabitants of the hinterland should be put in place to aid discussion of the quest to cure and the variety of medicines used. In this discussion, other aspects, which are illuminated in the following chapter, should also be incorporated.

Chapter 6 ‘Suitable’ medicines: a closer look at self-treatment

Different substances and materials are used as medicine because of their perceived potential to cure. Medicines are “substances with the power to transform bodies”, “potent symbols and tokens of hope for people in distress”, or “things...supposed to do something, to change the body in a discernible way” (Whyte et al. 2002:8). In the previous chapter, a large variety of medicines were presented – products and substances ranging from botanical to biomedical and even non-biomedical (household and industrial) chemicals – which are used by CL patients in their quest for a cure.

Focusing on self-treatment, this chapter zooms deeper into two ‘why’ questions related to the variety of medicines used in self-treatment. The first asks *why* these types of medicines are used. What is so ‘special’ about these medicines that they are found ‘suitable’ to cure a ‘harsh’ illness like CL? The study shows that regardless of the type of medicine used – botanical, biomedical, or chemical – patients seek medicines with certain qualities. It is remarkable how, despite their variety, the different medicines have specific characteristics in common.

Second, the impact that multiple contexts have on self-treatment is illuminated. Biomedical treatment in the hinterland is free, yet despite this, patients self-medicate. The question arises therefore of *why* there is a felt need to self-medicate when free medical treatment is available. Van der Geest (1987:295) wrote on self-medication:

It is sometimes hard to explain the obvious... People hardly decide to practise self-medication any more than they decide to eat or sleep. Self-medication is a self-evident first reaction to the experience of feeling unwell; it is a non-decision...however, in countries where health facilities are difficult to reach, self-medication can be an explicit decision following deliberation about the costs and benefits of taking such a step. This refers to self-treatment as a second step, self-treatment of an illness which people suspect may lie beyond their competence, but which they nevertheless venture to treat because better alternatives...are lacking.

Van der Geest points to the lack of better alternatives as a reason for people to self-medicate. My research shows other additional reasons: multiple contexts – historical, socio-cultural, personal, socio-economic, occupational, geographical, infrastructural, environmental, and health policy related – which lead to self-treatment in Suriname.

6.1 A closer look at medicines used in self-treatment

All of the reported and identified plants used in self-treatment for CL are medicinal plants, known to inhabitants of the hinterland in particular, and to the wider Surinamese population in general, because they are used to treat and/or prevent a great variety of illnesses, as well as to stimulate general health. They are also used

for ritual purposes. In terms of usage for skin conditions, they are popular for the treatment of many skin infections, irritations, cut wounds, blisters, pimples, skin fungus, boils, itchiness, mosquito bites, and many others (Van Andel & Ruyschaert 2011). Below, these plants are listed and briefly described.

6.1.1 Plants used in bush medicine

Table 8 below provides a list of the plants used by CL patients to cure their sore(s), and includes the specific plant characteristics, as documented in the ethno-botanical literature, with brief descriptions of their medicinal usage specifically on the skin.⁵⁰

Table 8: List of reported plants by CL patients and some plant characteristics and medicinal uses on the skin in Suriname

Local and scientific plant name	Specific plant characteristics and (brief) description of medicinal use on the skin in Suriname
Aloe vera (SD) <i>Aloe vera</i> (L.) Burm.f. (Asphodelaceae) (Van Andel & Ruyschaert 2011:92).	The leaves contain two kinds of juices with distinct medicinal qualities. A yellow-green liquid appearing on the leaf when cut superficially contains aloin, an irritating substance. The transparent juice inside the meaty leaf is cooling. The plant contains antimicrobial characteristics (Robson et al. 1982, in Van Andel & Ruyschaert 2011:92). The whole leaf, as well as only the transparent juice inside the leaf, is used against many skin infections and irritations.
Báibái lopu (Sa) <i>Uncaria guianensis</i> (Aubl.) J.F.Gmel. (Rubiaceae) (Van Andel & Ruyschaert 2011:427).	The plant contains a lot of tannic acid (Ostendorf, in Van Andel & Ruyschaert 2011:427). Processed leaves are used on wounds for quicker healing, and fresh leaves in combination with salt and coconut oil are used as a disinfectant on cut wounds.
Banana (Sr), bana (Sr) <i>Musa x paradisiaca</i> L. (Musaceae) (Van Andel & Ruyschaert 2011:345).	All parts of the banana plant are widely used against many illnesses and health conditions. The medicinal use of this popular plant is attributed to the high amount of tannic acid in the bark, leaves, and juices of the banana tree. The strong astringent juice of banana bark is dripped onto cut wounds, while scraped trunk tissue is applied to a wound and covered with a fresh leaf. Unripe banana fruit is rasped and applied to cut wounds to stop bleeding. Juice of the trunk – which turns brown and gelatinous after a while – is applied to hard-to-cure old wounds, skin fungus, blisters, and boils (ibid:346-347).
Bitakama (Sr) Unidentified	Unidentified. According to one informant, a very bitter plant.
Bitá ksaba (Sr), bittere cassava (SD) <i>Manihot esculenta</i> Crantz. (Euphorbiaceae) (ibid:207).	The roots are very poisonous and contain cyanide, which is the basis for the medicinal use of this plant. The poisonous juice is applied to burn wounds. Together with other botanical products, the roots are also used on poorly healing wounds, abscesses, fungal infections, and sores (ibid:208).
Bontete (Sr) Unidentified	No details.
Brokobaka (Sr) <i>Mikania micrantha</i> Kunth. (Asteraceae) (ibid:105)	The tendrils are boiled in water and used against skin irritations, itchiness, pimples, spots on the back, measles, and smallpox. Finely mashed leaves are rubbed against scabs (ibid:106).
Bredebon (Sr)	The bark and leaves contain a sticky white milk. According to

⁵⁰See referred literature for elaborate descriptions of the plants and their medicinal use.

<i>Artocarpus altilis</i> (Parkinson ex F.A. Zorn) Fosberg (Moraceae).	informants, the milk is used for sealing off the CL sore: "If the sore is sealed off, the bacteria in it will die".
(Uma) Busipapaya (Sr) <i>Cecropia peltata</i> L. (Cecropiaceae) (ibid:152).	The white marrow of the trunk is scraped out with a knife and smeared onto cut wounds against inflammation. Leaves, processed and fresh, are also used for other health purposes (ibid:153).
Daguwiri (Sr) Unidentified. (According to patient, not to be confused with Dagublad (Sr) <i>Ipomoea aquatic</i> Forsk. (Convolvulaceae) (ibid:172).	No details. According to one CL patient, the roots help to flatten the swollen borders of a sore.
Dedu (Sr) Unidentified.	No details.
Diatitei (Sr), Fayatatái (Sa) <i>Davilla kunthii</i> A. St.-Hil. (Dilleniaceae) (ibid:191).	Leaves can cause severe skin irritation and are very rough. They are used in herbal baths for several health conditions and rituals (ibid). According to CL patients, the leaves are very rough, and burn a lot when they scratch the skin.
Donke (Sr) <i>Dieffenbachia seguine</i> (Jacq.) Schott. (Araceae) (ibid:62).	The leaves and stalks contain needle-like calcium oxalate crystals that can cause very painful skin irritation. Despite its toxicity, after processing the plant is used for medicinal purposes, such as for burn wounds and itchy skin (ibid). According to CL patients, the plant has a very strong smell and a very powerful juice.
Ghedu (Sr) Unidentified.	No details.
Opro-udu (Sr), Hoepelhout (SD), Copaieba ⁵¹ (Po) <i>Copaifera guyanensis</i> Desf.	This oil is used for many health purposes. It is smeared onto insect bites, pimples, cut wounds, gonorrhoea, and haemorrhoids. The oil is very bitter due to the presence of sesquiterpenes (Brockhoff et al. 2007:6236) and diterpenes, and has a disinfecting, sedative, and anti-inflammatory effect (Cascon & Gilbert, in Van Andel & Ruyschaert 2011:223).
Jáífi (Sr) Yasi man bon (Au, Pa) <i>Jacaranda copaia</i> (Aubl.) D. Don (Bignoniaceae) (Andel & Ruyschaert 2011:121).	The pulp of the unripe fruits is sour, the seeds are bitter. The leaves are strong smelling, and when mashed to a pulp are sometimes combined with soap and applied as a compress to CL sores (ibid). Also known as <i>Yasi man bon</i> ('the tree for <i>Yasi</i> [CL]', Au, Pa), because of its specific use for CL (ibid).
Kaapà (Sa) <i>Carapa guianensis</i> Aubl. (Meliaceae) (ibid:334).	The red-brown bark contains a brown, bitter juice with which the popular <i>krapa</i> oil is produced. This bitter, sharp smelling oil is used for several medicinal purposes, such as a lotion for the skin, to disinfect wounds or insect bites, against eczema, itchiness, measles, smallpox, or as prevention against skin parasites, sand flies, grass lice, mosquitoes, and ticks. The medicinal use of the oil or <i>Carapa</i> species is attributed to the presence of limonoids ('andirobins') and triterpenes (ibid:334-335).

⁵¹ See web reference number 28.

Kalebas (SD) <i>Crescentia cujete</i> L. (Bignoniaceae) (ibid:118).	The pulp of the fruit is smeared onto wounds, eczema, skin fungus, tropical sores, and scabs. Leaves are mashed and the juice is dripped onto wounds and sores; this burns a lot, but cures the condition. The fruit is poisonous; it contains cyanide. Leaves have antimicrobial qualities (Verpoorte et al. 1982, in Van Anandel & Ruysschaert 2011:119).
Knoflook (D) (Garlic) <i>Allium sativum</i> L. ⁵² (Allium).	According to CL patients, garlic has a burning effect on the skin.
Kokosnoot (SD), Kronto (Sr) <i>Cocos nucifera</i> (L.) (Araceae).	Coconut oil is a very popular product used in the kitchen and as a medicinal product. Coconut oil alone, or in combination with numerous different (mashed) local plants, is used to prevent and cure illnesses, and to stimulate health. Coconut oil is used on dry skin, burns, painful limbs, or other body parts, and as a massage oil for babies and pregnant women (ibid:80-81). The benefits of coconut oil are ascribed to the presence of lauric acid, capric acid, and caprylic acid, and to its antimicrobial, antioxidant, antifungal, antibacterial, and soothing properties. ⁵³
Kwassibita (Sr) <i>Quassia amara</i> L. (Simarubaceae) (Van Anandel & Ruysschaert 2011:442).	The bitterness of the leaves and bark kills bacteria. <i>Quassia amara</i> contains the extremely bitter substance quasine (ibid).
Kasyu (Sr) (Cashew) <i>Anacardium occidentale</i> L. (Anacardiaceae) (ibid:31).	The high amount of tannic acid in the leaves and bark is used against diarrhoea, infections, and skin sores (ibid:32). According to patients, the bark has a strong astringent juice. Villagers in the hinterland also mentioned that the fruit seeds contain a very corrosive liquid; if it drips onto your finger, it will eat away the skin.
Kototiki (Sr) Unidentified	No details.
Lemmetje (SD) (Lemon) <i>Citrus aurantifolia</i> (Christm. & Panzer) Swingle (Rutaceae) (ibid:429).	The sour juice contains much vitamin C and is used on the skin against insect bites, bruises, swellings, and stingray stings (ibid). According to patients, the juice is very sour, strong, and cuts all dirt.
Loksi (Sr) Hymeneae courbaril L. (Fabaceae) (ibid:233).	The bark contains much tannic acid, and all kinds of diterpenes and antimicrobial substances, and is also used for medicinal purposes (ibid:234).
(Uma) Luisawiwiri (Sr), Bhangraiya (Sarn), Tótóbiá (Sr) <i>Eclipta prostrata</i> L. (Asteraceae) (ibid:101).	The plant is used for many medicinal purposes. Juices extracted by squeezing the finely mashed or stamped leaves are extremely burning; the juice, which has a very bitter and sharp taste, is used on wounds, sores, and open fractures (ibid:102).
Mopé (Sr) <i>Spondias mombin</i> L. (Anacardiaceae) (ibid:35).	The presence of tannic acid in the bark, with its antimicrobial characteristics, makes it good to use as a medicinal plant (Olugburiyo et al., in Van Anandel & Ruysschaert 2011:35). The bark has a very strong and bitter flavour.
Niem (Sr)	Different parts of the plants have medicinal characteristics or are

⁵²See web reference number 29.

⁵³See web reference number 30.

<i>Azadirachta indica</i> A. Juss (Meliciaceae) (Van Andel & Ruysschaert 2011:332).	effective for treatment of many skin conditions, bacteria, malaria parasites, and insects (ibid:333). According to CL patients, the leaves contain bitter juice.
Nikasa (Sr) Unidentified	No details.
Noni, didibri-apra (Sr) <i>Morinda citrifolia</i> L. Rubiaceae (ibid:418).	Fruits have a very strong, bad smell and taste extremely bitter. Both the fruit and leaves are popular for their healing qualities against many illnesses, such as skin diseases, diabetes, burn wounds, and swollen limbs (ibid).
Okro (Sr), oker (SD) <i>Hibiscus esculentus</i> L. (Malvaceae) (ibid:301).	This plant is popular for its fruits, which can be eaten as a vegetable. Also used for the improvement of many health conditions (ibid:302). According to CL patients, the leaves and branches have many thorny hairs, which are irritating to the skin.
(Uma) Parabita (Sr), Mananga (Au) <i>Solanum leucocarpum</i> Steud. (Solanaceae) (ibid:456).	The leaves of this plant are strong smelling and extreme bitter, but are often used for medicinal purposes (ibid:457). CL patients report that the plant has very bitter leaves.
Peper (SD), Pepre (Sr) <i>Capsicum annuum</i> L. (Solanaceae).	The pepper plant is well known for its spicy fruit: peppers. In Suriname, there are many cultivars; <i>alata pepre</i> (Sr) is mostly used for medicinal purposes. Red peppers contain capsaicin, an alkaloid that stimulates the receptors on the tongue sensitive to heat and pain, which causes a burning sensation. The whole plant or some fruits are documented as being used in herbal baths (ibid:448). In the studied literature, use of red pepper on broken skin is not reported.
Pinja wiri (Sr), Pikin pindy (Sa) <i>Vismia guianensis</i> (Aubl.) Choisy (Hypericaceae) (ibid:268).	The bark contains orange latex used as a drawing ointment on abscesses and sores. Boiled leaves are also used as a compress on sores and other infections (ibid:269). CL patients reported that the plant has very bitter leaves.
Pomtaya (Sr), Pomtajer (SD) <i>Xanthosoma sagittifolium</i> (L.) Schott (Araceae).	The corm (skin and flesh), stem, and leaves contain oxalates. The corms should not be eaten raw because they taste acrid and can cause sharp irritation and a burning sensation. "The acidity is caused by needle-like oxalate crystals (raphides) that can penetrate soft skin" (Lumu & Katongole 2011:n.n.).
Redi katun (Sr) <i>Gossypium barbadense</i> L. (Malvaceae) (Andel & Ruysschaert 2011:306).	This plant is used for a variety of illnesses and health conditions. Fine stamped leaves are heated, mixed with oils or water, and applied to wounds, abscesses, warts, and bruises (ibid:307).
Slabrikiwiri (Sr), Sakoor (Sarn) <i>Senna alata</i> (L.) Roxb. (Fabaceae) (ibid:250).	This plant is widely used in countries all over the globe for a variety of ailments. The leaves contain anthraquinones (sennosides and senna glycosides). A herbal bath with the leaves is used against several skin conditions such as eczema, itchiness, pimples, and skin fungi (ibid:251- 252).
Tassi (Sa) <i>Geonoma baculifera</i> (Heemskerk et al. 2007:53).	Tassi leaves are popular in the hinterland. They are usually used as material for roofs. The sharp edged leaves are also used for medicinal purposes. Dry leaves are burned to ash and used in the treatment of raw wounds, such as on the umbilical cords of newborns (ibid:47). According to a CL patient, the leaves have sharp borders.

Tayablad (Sr) <i>Colocasia esculenta</i> (L.) Schott. (Araceae) (Van Anandel & Ruyschaert 2011:60).	All parts of the plant contain calcium oxalate crystals that can cause skin irritation and itching (ibid:61).
Waki (Sr), Abonkini waki (Sa) <i>Inga alba</i> (Sw.) Wildl. (Mimosaceae) (Van 't Klooster et al. 2003:297) (ibid:236).	The bark of the <i>Inga alba</i> is a popular medicine. The bark has some antimicrobial effects (Verpoorte & Dihal 1987, in Van Anandel & Ruyschaert 2011:236-237). The moist inner part of the trunk is scraped and applied to sores to stop bleeding. The bark is also used for sores and abscesses (Van Anandel & Ruyschaert 2011:236) .
Wonderblad (SD) <i>Bryophyllum pinnatum</i> (Lam.) Oken (Crassulaceae) (ibid:178).	The juice of the meaty leaves are warmed up and dripped onto infected wounds or sores, and onto the scalp against dandruff. Heated leaves are put on painful muscles, bruises, or other injuries (ibid:179).
Yorkapesi (Sr) <i>Senna occidentalis</i> (L.) Link. (Fabaceae) (ibid:252).	This plant is a well known medicinal plant. The leaves spread a strong unpleasant scent. A compress of the leaves is placed on skin infections caused by annelids (Rolander 2008, in Van Anandel & Ruyschaert 2011:252).
Zoete patat (SD), or Swit'patata (titei) (Sr) <i>Ipomoea batatas</i> L. (Convolvulaceae) (Van Anandel & Ruyschaert 2011:173).	<p>The turnips of this plant are consumed to prevent illness and stimulate good health. Tendrils are also used in some ritual and post-natal baths (ibid:173-174).</p> <p>CL patients reported that the tendrils can cause severe skin irritation if rubbed against skin.</p>

Investigation shows that most of these plants contain very strong liquids, secretions, or juices that are extremely corrosive, sharp, bitter, spicy, astringent, and in some cases even poisonous. Certain plants also have a strong smell. A small number of plants or plant extracts were, by contrast, cooling. They were usually used by patients on the sore more as supportive treatment: to keep the sore cool, to "flatten the borders of the sore", to fight symptoms, and to stimulate healing. They were not "strong enough" to cure the sore, but rather facilitated cure.

6.1.2 'Biting' and 'burning' home remedies, and other non-botanical natural medicines

The mixture of different ingredients with botanical substances to make medicines with a 'biting' or 'burning' effect on the sore was striking. People in the hinterland reported similar types of home remedies, with the majority being aggressive and painful. According to ex-CL patients, sores should be cleaned properly and not merely superficially, because any remaining "rotten flesh" can hamper quick healing. According to a villager in Godo-olo, lemon should be "really squeezed into the sore, so you polish the sore and clean it from the debris". Salt, vinegar, and lemon burn terribly, but "it cuts away all the dirt". Only when CL sores are properly cleaned can the next medicine work. Pepper causes extreme burning sensations on the skin, yet it is commonly used as a remedy for CL. The skin fluid of the Blue Poison Dart Frog (as reported in the previous chapter) contains a poisonous liquid, causing a burning

sensation when rubbed onto the sore. Burning, according to informants, is also caused by the powder of turtle skin and the powder of salted meat bones when applied to the sore. The patient using horse faeces with other ingredients also reported that the medicine burned a lot when he used it on open skin.

According to CL researchers in Ecuador (Weigel & Armijos 2001:398), many of the CL treatments cited in their study (see previous chapter) were also described by the research population as being 'hot' or 'strong' due to intense burning, stinging, or pain.

6.1.3 Soft and strong biomedicines

Looking at the types of biomedicines used by CL patients in Suriname for self-treatment, two types were broadly distinguished: 'softer', soothing, and cooling types of medicines (ointments, topical creams, powders, or other products), and 'stronger', more aggressive, and burning types of medicines (such as the powder of amoxicillin pills, muscle pain relievers, and biomedical solutions). Here again, similar to the bush medicines, there is the contrast between 'strong' and 'soft'.

6.1.4 Hot and cold Chinese medicine

The two Chinese medicines used by patients in this research also cause initial burning followed by cooling sensations. A closer look at the ingredients of shilling oil shows that these effects are caused by the active ingredients: camphor, menthol, methyl salicylate, and other ingredients such as mineral oil, eucalyptus oil, and lavender oil. Similar ingredients are contained in Vicks, the other product used, which includes camphor and turpentine oil.⁵⁴ Striking are the manufacturers' warnings for both shilling oil and Vicks⁵⁵: "For external use only, do not use on wounds or damaged skin other than as directed as such use may be dangerous".⁵⁶

6.1.5 Corrosive chemical substances⁵⁷

By far the most frequently used chemical was a Brazilian product called Smeerex (see photograph below). Smeerex is a larvacide promoted for veterinary treatment and control of tissue infestation by fly larva on the open or infected wounds of animals, such as dogs, cows, and goats. It is made of chemical ingredients, such as chlorfenvinphos and dichlorvos, which are discredited for human medical use, even banned or restricted in several countries (Agency for Toxic Substances and Disease Registry 1997; Raeburn 2006). These substances are reported to have harmful effects on the nervous system, plus concerns exist over acute and chronic toxicity (Raeburn 2006:26).

⁵⁴See web reference number 31.

⁵⁵See web reference number 32.

⁵⁶See web reference number 33.

⁵⁷For more elaborate information, see Ramdas (2012).

Photo 19: A CL sore sprayed with Smeerex Photo 20: A can of Smeerex on a shoe rack



Source: Collection, Ramdas. S., Brokopondo Source: Collection, Ramdas. S., Benzdorp

Many of the other chemical substances that CL patients use are also noted to be hazardous, poisonous, and even lethal when inhaled or swallowed (Addo & Poon-King 1986).

Gramoxone is a toxic liquid herbicide; skin contact with it may result in “irritation, blistering and potentially full thickness burns” (Health Assessment and Environmental Safety Department of Syngenta & the Medical Toxicology Unit 2008:5). Other chemical companies and community health institutes (Department of Community Health 2004; Camden Electronics LTD 2006:1) warn against skin contact with bleach, chlorine, and battery acid because they can cause severe burns, blistering, or other permanent skin damage.

CL patients also used lead and gasoline. Several studies emphasise the negative health effects of lead exposure, including lead poisoning (Markowitz & Rosner 2000; Bellinger & Bellinger 2006). Gasoline causes irritation or burning of the skin upon direct contact.

To ‘kill’ their sore, some CL patients used chemical products made for killing or preventing flying and crawling insects. The WHO (1999:19-20) stresses the necessity to “avoid inhalation of [insecticide] spray mist or direct contact with skin and eyes”. One CL patient, however, sprayed the insecticide Baygon directly onto his sore. Another patient crushed mothballs – containing pesticides – into a powder and applied it to the sore.

6.2 Reasoning behind ‘suitable’ medications and treatment practices in self-medication

CL patients often use plants that contain strong, corrosive, biting, and poisonous juices/liquids. The ethno-botanical literature and personal experiences of CL patients and other informants gives the impression that this group of plants or plant extracts can be harmful, especially to the skin, since they can cause severe skin irritations, itching, and burning. Yet these plants or plant extracts are used as active treatment. In fact, the attributed – potentially harmful – qualities of the plants as strong, corrosive, penetrative, biting, burning, and poisonous are common characteristics of the majority of the CL medicines. Despite this potential harm, the research shows

that these CL medicines were deliberately chosen as treatment. Why do CL patients use such harmful types of medicines? Why this variety and these characteristics? The answer to these questions lies first of all in patients' perceptions of the illness, and the associative reasoning of CL patients in treatment seeking.

6.2.1 Associative reasoning

Aetiological ideas and analogies in associative logic (Matthews 1982) are often used in health seeking to find appropriate treatment. Such heuristics in treatment seeking are widely reported in medical anthropological studies (e.g. Evans-Pritchard 1937; Turner 1967; Matthews 1982; Nichter & Nichter 1996; Nichter & Vuckovic 1994; Van der Geest & Meulenbroek 1993; Van der Geest & Whyte 1989). Associative mental connections between one thing and another become the basis upon which people use or experiment with certain medicines, or on the contrary avoid them.

As described in Chapter Four, CL is commonly referred to in Sranan as *Busi Yasi* or in Surinamese Dutch as *Bos Yaws*. Both terms, *busi* and *bos*, mean 'bush' or 'forest'. The exact biomedical cause of CL is often unknown by patients, but the terms suggest that CL is "something caused by nature", a belief confirmed by most CL patients who cited many natural causes of the disease (see Chapter Four). Locating the cause of CL in nature, patients employ treatments believed to counter-attack the natural agents causing the illness. Pista, a 21-year-old Maroon man, used the extremely toxic herbicide Gramoxone to cure his sore. His decision to use this poisonous chemical came from his association between the origin of the sore as "something from nature" and Gramoxone as a "killer of nature". Other patients used mothballs and the insecticide Baygon because, again, associations were made between killing the 'bacteria', 'worms', and 'insects' of the sore by using a product designed to kill these things.

In the same vein, botanical treatments are used that are strong, strong smelling, corrosive, biting, burning, and poisonous. These medicines are used to 'kill' whatever is in the sore, eating away the skin and flesh. Home remedies were also described as 'biting' and 'burning' away the sore. To kill the sore, CL patients even dripped hot liquids onto the sore, since "everything dies if fried in hot oil"; as treatment, this will 'fry' all the organisms that eat the flesh. Sores are 'burned' because obviously fire or heat kills everything in nature. Certain botanical juices or chemicals are used to suffocate whatever is living in the sore: "If they [whatever organism is living in the sore] cannot breathe, they'll have to die" (Nally, Dermatology Service, October 2009). Therefore, the extremely sticky milk of the *Bredebon* tree or nail polish are used to "seal off" the sore. When CL sores are associated with dirt in the domestic sphere, products are used because of their disinfecting power, such as lemon, salt, rum, rubbing alcohol, pine oil, methylated spirits, Dettol, or bleach. Despite the excruciating pain, patients tried these harsh medicines to treat their sores.

In analogical thinking, treatments for certain (unknown) illnesses are chosen because of resemblances or similarities with *known* conditions (Mathews 1982). In this study, turtle skin, for example, was used because of its resemblance to the round or oval shaped sores. A local expert in healing CL at Brokopondo Centrum, a 52-year-old Saramaccan hunter, said about the use of turtle skin:

When you look at the turtle skin [holding the carcass of a turtle in his hand], you will see the form of the *Busi Yasi* [showing with his finger the 'house' of the turtle, as can be seen in the photograph below]. You see, it is also round shaped. That's why you take that part of the skin and use that to make the medicine. It will definitely kill the sore.

Photo 21: A local healer showing the part of the turtle skin used as medicine against CL



Source: Collection Ramdas S., 2010, Brokopondo Centrum, District Brokopondo

Turtle skin is thus used metaphorically: sores are treated with shapes that look like the sore. The homeopathic principle of “like cures like” (see Frazer 1957, cf. Van der Geest & Meulenbroek 1993) seems applicable here. Other medicinal items are also symbolically used: lead is melted and moulded into an oval or round shape, similar to the sore. Bandaging it to the sore is believed to offer a cure.

Allopathic associations were also made: some patients compared CL sores with sores on animals, so treatments successful for animals were used to treat human sores. Patients using Smeerex said that seeing the spray work on animals made them try the product on themselves. One patient explained, “I thought it [the CL sore] would heal. Because if that thing [Smeerex] could cure a cow, it could probably also cure me” (Patient, January, 2010: Dermatology Service). Both homeopathic and allopathic principles of cure and their relationship with associative reasoning is further elaborated in the following sections.

6.2.2 Why ‘harsh’ and ‘painful’ medicines?

As described above, the similarity between many medications and treatment practices are their harshness and often ‘cruel’ and painful effects. The botanical treatments used are strong, strong smelling, corrosive, biting, burning, and poisonous. Home remedies have a biting and burning effect on the skin; most are aggressive and very painful. Similar practices include the pressing of hot objects to CL sores, the dripping of hot liquids onto the sore, and fires (with gunpowder) that are lit on the sore. Biomedicines that are equally strong, biting, and burning are also used. The same goes for harsh chemical substances, which are made of powerful corrosive materials, have strong penetrating odours, and occasionally are very poisonous.

Why do CL patients use these harsh medicines to cure their sores? The answer to this question lies in the distinct ways of reasoning related to the perceptions that CL patients have of the illness, their beliefs in the curing capabilities of certain substances, and several specific environmental, geographical, and socio-cultural conditions that ‘invite’ the use of harsh medicines.

6.2.2.1 *Cruel disease, cruel medicine*⁵⁸

Perceptions of CL are tied to the symptoms and the process of the disease; and CL has a bad reputation. In Chapter Four, I discussed how CL is perceived. Patients call it a “difficult”, “evil”, “horrible”, “stubborn”, “dangerous”, “filthy”, and “expensive” illness. CL is believed to be difficult and stubborn primarily because it takes a long time to cure. It is seen as cruel and uncontrollable because it keeps on growing, spreading, “eating away the meat”. One patient commented: “If it wants, it can spread all over your body, you’ll feel the nodules, then you see a sore breaking open at that point. It’s just horrifying” (Sico, Dermatology Service, February 2010). It is viewed as dangerous because it threatens the integrity of the body, and many fear losing a finger, hand, arm, or leg. Indeed, almost all patients expressed the fear of amputation in case the sores would not heal. To counter-attack the sore, curative methods and medications are chosen that are equally harsh, horrible, and cruel. An older Maroon woman in one of the hinterland villages explained:

We, Ndjuka people, have a saying: *hogii siki, abi hogii desi* [cruel diseases need cruel cures]. That’s what old people say. If you have some terrible disease, you have to treat it with equally terrible medicine. You hear the boys [gold diggers] use all kinds of things, sometimes very dangerous things, but *Busi Yasi* is the kind of disease that asks for it. Oh no... it is a horrible disease! (Mammi, Godo-olo, October 2009)

The belief that “cruel diseases need cruel cures” plays a major role in the decision by CL patients to use harsh, painful, and potentially harmful medicines. Studies examining the meaning of medication (e.g. Turner 1967; Van der Geest & Whyte 1989; Etkin 1994; Nichter & Nichter 1996b) point at metaphoric and metonymic associations between non-medical phenomena and the qualities of medicinal materials. Van der Geest and Meulenbroek (1993), in a study in Burkina Faso, point to the importance of such associations in naming and explaining illnesses and applying medicine; natural phenomena or domestic tools are linked to symptoms of illness because of similarity (metaphor) or contingency (metonym).

In this study, both of the adages ‘like produces like’ (allopathy) and ‘like counteracts like’ (homeopathy) (cf. Van der Geest & Meulenbroek 1993:286) seem applicable. First, the homeopathic principle: the appearance and aggressive development of CL sores stimulates use of harsh chemical products that work equally aggressively on the skin. Aggressiveness, both of the condition and the cure, is the metaphorical link that inspires the choice of medication: strong corrosive materials, strong penetrating odours, bitter plants, biting fluids, and chemicals with

⁵⁸This section draws on Ramdas (2012).

the ability to kill anything such as bacteria, insects, and other dirt. One CL patient commented:

That's why we use these kinds of products. You should try to kill the sore, if not with herbs, then with other things like battery acid. Those things are powerful, heavy. It will burn through everything and kill the sore. (Kajo, January, 2010: Dermatology Service)

The same reasons why non-biomedical chemicals are advised against – the capacity to burn the skin – become reasons for using them. The same characteristics that lead one normally to avoid certain leaves, trees, or animals – because they are corrosive, itchy, poisonous – indicate their applicability (Ramdas 2012:6-7).

Interestingly, the converse (allopathic principle) was also found, as patients would avoid contact with sharp and aggressive objects, ingredients, and beings. Earlier, I reported a variety of fish and animals that are not eaten by Trio Indigenous people when suffering from a CL sore. The piranha fish, for instance, is not consumed because of the aggressive behaviour of the fish. Similar to how the piranha aggressively devours everything with its sharp teeth, eating the piranha is believed to aggravate the fast and aggressive development of a CL sore. All kinds of animals with sharp teeth (such as the howler monkey), or sharp nails or horns are, for similar reasons, not eaten: because of their ability to devour food with their sharp teeth or scratch the soil with sharp claws for food, they are believed to aggravate the sore(s). Linking this aggressive behaviour metaphorically to CL, people judge that eating such fish and game will not only worsen the sore, but cause more pain.

Aggressive and burning ingredients, such as pepper, are also avoided in food (see section 5.2.5). Pepper can be used on the open sore, but one should not eat it. Because of the fiery sensation when eaten, pepper is believed to aggravate the sore by causing painful prickling and burning sensations within the sore. Among the Brazilian gold diggers (specifically), though the application of hot fluids directly onto the sore is practiced as a cure, eating *comida hermosa* (Po), i.e. 'hot' foods, is avoided. Chicken (mostly home raised), eggs, pork, and pepper are all also avoided because of their ability to 'heat' the blood and worsen the sore.

This belief was also found to be common among the community at Corte de Pedra, Brazil. Villagers in Corte de Pedra explained that a chicken scratches the soil and eats whatever it finds, including all kinds of bacteria, worms, and dirt. By eating the chicken, a person will make the wound worse because the chicken is 'polluted'. Similarly, a pig sniffs in dirt, eats "all kinds of things, dirty things", and "his body is also dirty". Eating pork therefore worsens the sore. All kinds of creeping plants and vegetables are also not eaten because of the fear that sores will spread over the body in a similar way as the plants spread over the ground. All kinds of slimy or juicy vegetables are also not consumed when one has CL, because the sore, similar to the vegetables, will secrete more wound fluid. The abovementioned adage 'like produces like' seems applicable here.

In a similar way as I described in section 5.2.5.1, the villagers at Tepu and Donderskamp believe that neither *kasripo* nor *peprewatra* (Sr, watery pepper soup) should be eaten, since both contain *kasripo* and fluid. *Kasripo* has a yellowish watery consistency, like pus (see Photo 22), and linking this metaphorically to CL

(see Photo 23 below), villagers believe that eating *kasripo* will cause the sore to secrete more fluids and pus.

Photo 22: Raw *kasripo* in a bowl



Photo 23: Pus and slime on a CL sore



Collection: Ramdas, S., 2010, Donderskamp

Collection: Ramdas, S., 2010, Dermatology Service

During a group conversation at Donderskamp, three men – 52-year old John (J), a hunter, 32-year old Ron (R), a planter, and 30-year-old Wesly (W), a hunter – explained this to me (I):

R: ...thus, the elderly say that if you've got an injury, or any kind of sore, you don't eat *kasripo*. That thing [*kasripo*] doesn't mix with it [the condition]. Not at all. Thus it is something that as long as you have a cut, you can't eat that thing. Otherwise it'll get worse.

I: But how come? What is the relationship between CL and the *kasripo*?

W: Yes...thus the *kasripo* itself looks like the puss that comes out of the body. And that combines in your body and makes it [the sore] worse. ...

R: And that's correct. We've experienced it. As long as the person keeps on eating *kasripo*, tomorrow morning you'll see more puss and it hurts more. Sometimes you can't even sleep, you can say it is because you've broken the rule.

J: It's like it's breathing, the sore [opens and closes his fingers to demonstrate something breathing]. And if you eat that [*kasripo*], then you'll feel at night as if it [the sore] wants to talk to you. It's very dangerous.

(John, Ron, and Glenn, Donderskamp, May 2010)

Salt is used on the open sore as treatment, but is reported not to be eaten when one suffers from CL (see Chapter Five, section 5.2.5.1). When salt is added to vegetables, it extracts juices. In the same way, salt is believed to cause the sore to secrete more fluid, and should therefore not be consumed. Cassava bread, soaked in water or other liquids (soups), is also reported by the Trio people as not to be eaten when one is suffering from CL because, once soaked, the swollen bread looks similar to the swollen borders of a CL sore. So, by analogy, eating such bread is believed to worsen the sore.

To prevent the blood from 'sweetening', some fruit juices and drinks are advised against. "Sweetness is weakness", a 58-year-old villager in Tepu said. "When the blood is sweet, the sore will not heal". Indeed, another common belief is

that weakness should be avoided, because weakness negatively influences cure. The belief in avoiding pregnant women (see Chapter Five, section 5.1.5.2) is linked to this, since some people believe that pregnancy is a weak condition. An old man at Brokopondo said:

A woman with a belly [pregnancy] is a kind of a weakness. One can say she is ill. Her body is not normal, it doesn't work the way it used to. When a woman is in such a state, she can make the sore go bad, because she is not strong, but weak. So, don't let a pregnant woman look at your sore, it will not heal. (Man, Brokopondo, 2010)

It is also believed that the skin of pregnant women is very sensitive, especially on the belly; there it stretches more and so is vulnerable to cuts and sores. The skin of those with CL will therefore also become more sensitive, similar to the skin of the pregnant woman, if she looks at the sore. Other people believe that in the same way as the belly of a pregnant woman, the CL sore will also grow bigger. For these reasons, pregnant women should be avoided.

To the question of why a CL patient should not have sex, one of the explanations heard in the villages was that weakness of the body is caused by the loss of semen: "When one has sex, the body must work hard, and all the strength is concentrated in the deed [ejaculation]. So, your body does not have the chance to work on your sore, and when the semen gets out, you lose strength". During an interview with four Saramacca Maroon men, one man said: "Yes, it is true what they [the elderly] say. Why they say so is because you use the power from within if you sleep with a woman. That power you need to heal" (Mika, Brownsveg, October 2010).

An even more generally shared belief is that sex 'spoils' traditional medicine. A traditional healer explained:

Some people make traditional medicine by adding a spiritual power to it. Then you have to obey some rules. One of the rules, a very strong rule, is that you cannot meet [have sex] with your partner, otherwise the medicine will be spoiled; it won't work and you won't heal.

During the same conversation, however, another man, an ex-CL patient, remarked that abstinence from sex is sometimes a difficult task: "I had kept to the rule for a long time, but then the sore took a very long time to heal, so I couldn't keep up anymore [all laughing]. But in fact, you have to keep the rule, because you have to heal" (Dudu, Godo-olo).

6.2.2.2 *Natural pharmacy, 'witnessed efficacy', hostile environmental, and occupational pitfalls*

In terms of specifically harsh and painful *botanical* treatments and home remedies, another aspect contributing to the choice for them is the environmental context. The majority of CL patients' physical presence in the forest environment, plus the long distances between the hinterland and the capital city, 'invite' use of the 'natural pharmacy'. Especially for sores, one may be easily inclined to pick leaves and use

them, or to cut a liana and apply its juice. The natural environment, then, becomes a 'first aid' pharmacy.

Photos 24 (a, b, c): Medicinal plants found easily in the natural environment



Source: Collection Ramdas S., 2010, Brokopondo Centrum, Tepu, Donderskamp

In the group of the photos above, informants show three different plants for the treatment of CL. In the first photo (22), a 48-year-old Saramacca Maroon hunter, also a healer of CL, shows how the internal part of the bark of a plant that is easily found in the woods is scratched to make an ingredient for a CL medicine. According to the healer, the scrapings of this plant cause an extreme burning sensations when placed on a sore. In the second photo (23), the 36-year-old son of a Trio healer cut the bark of a liana during a botanical tour at Tepu to show the red fluid (juices) flowing out, which are used to treat CL sores. According to him, the biting juice cures the sores. In the third photo (24), a 53-year-old key informant, a local expert in traditional medicine at Donderskamp, shows me another plant that grows wild "everywhere in the forest" during a botanical tour, which is used for the treatment of CL. The veins of the plant feel extremely rough, and are covered with very small thorn-like hairs. According to the informant, if the vein scrapes on the skin it burns terribly.

Furthermore, because of centuries of experience with (harsh) medicines and the witnessed efficacy of treatments, self-treatment with traditional remedies is considered first by many. A local expert in traditional medicine explained:

You have certain medicines; if a machete cuts you, for example, you clean the wound, apply the medicine, and tie [bandage] the wound; if you don't watch out, the medicine will even grow in the skin [so good and strong it is]. And if it comes out, pap! [Claps his hands.] It's finished, your wound is healed! That's how STRONG *busi dresi* is. (Henki, Godolo, 2009)

The choice of such harsh treatments, according to a key informant, is linked with several factors:

First, it's the certainty you have for healing, the effectiveness. The certainty is a big factor in the choice of method, the certainty to heal. And, second, the duration of the healing process, for example, within a week, or a month... Further, you'll also observe the person who gives

you the advice; does the person have experience with it? How many people did he cure with it? You'll consider all that. Also, you'll use a certain method depending on the position in which you are: do you have time or are you busy working, all those kinds of things. (Kwansa, Godo-olo, 2009)

A combination of these conditions also shapes CL patients' choice for harsh self-medication. An informant, the son of a traditional healer at Godo-olo, stipulated that people often get insights into medicinal use through experimenting and accumulative reasoning. He explained: "One can think: 'I had such a disease, it's healed with this leaf and another disease with that leaf, and if you mix them you'll have a better medicine'. That's how they come up with ideas" (Kwaba, Godo-olo, December 2009).

Related specifically to the use of harmful chemicals, the occupational context in particular creates the conditions in which CL patients can easily resort to readily available chemicals. My research shows that the majority of the CL patients who used chemicals were working in the gold and lumber sectors. To undertake gold mining or wood processing activities, heavy equipment, machines, and all kinds of industrial supplies are required. Workers are therefore constantly surrounded by chemicals such as gasoline, kerosene, battery acid, and lead, as can be seen in the picture below.

Photo 25: Freely available chemicals in a gold diggers' camp



Source: Collection Ramdas S., 2010, Boslanti, district Brokopondo

Most of the CL patients working as gold diggers or in the lumber sector used battery acid or lead to cure their sores. One patient, a truck driver transporting gasoline to the woods, used pure gasoline on his sore. By being surrounded by chemical products and working daily in a chemical environment, the health hazards of certain substances become normalised and so minimised; and, as some patients explained, certain chemicals become first aid medicine.

Whether living, working, or engaging in leisure activities in the hinterland, it means staying in the woods for sometimes undefined periods, lasting weeks or months. Precisely because it is not easy to travel back to the capital, one must be

prepared for all kinds of mishaps, especially those concerning health. Surrounded by the woods, one can easily be attacked by bees, snakes, mosquitoes, and other insects or animals. Household chemical products, such as insecticides, are thus often taken along, as well as chemical items such as batteries for flashlights, which are important for moving about in the dark woods. There are plenty of small shops in the villages and gold fields for those working in the hinterland, which are well stocked with various household insecticides and other necessities. The geographical distance between the hinterland and the capital, and the 'hostile' natural environment, also stimulate use of the common 'medical kit', which contains certain insecticides, especially Smeerex. Though not meant for human use, many are convinced of their healing qualities for humans, and use them as first line treatment.

6.2.2.3 Risk taking and masculinity

Gendered ideologies of masculinity may also play a role in the decision to use harsh medicines. The vast majority of the CL patients using harsh medicines, especially harsh chemicals, were men. Socio-behavioural studies on gender differences in risk taking show that men are more likely than women to take risks and become involved in dangerous activities (Hirschberger et al. 2002; Wagner 2001). Risk taking is seen as a characteristic of masculinity, as is physical strength, toughness, and courage (Krienert 2003). The men in this study correspond to this masculine image, considering the heavy, difficult, and dangerous work in which the majority are engaged in the hinterland. Workers in the goldfields, for instance, deep in the jungle, are used to risk taking. As a Maroon gold digger explained:

Gold digging is hard work, it means taking a lot of risk to leave your wife and children in the village for quite some time and you don't know what can happen to you in the woods. A snake can bite, bees can attack, or someone can kill you for a bit of gold; everything can happen. We take risks, a lot of risks, just to earn a bit of money. (Carlo, Godo-olo, December, 2009)

Among the study population, having 'courage' is linked inherently to being a man; in addition, the majority of the CL patients remarked that it takes a lot of courage to use certain painful medicines.

6.3 The impact of multiple contexts on self-treatment

The act of self-treatment itself can be better understood if other contexts are also taken into account. In the following, these contexts and their relationship with patterns of health seeking are brought into focus. The discussion, both above and here, shows that, on the one hand, individuals are active agents when it comes to self-medicating their sores, and that, on the other hand, there are a variety of contexts that contribute to the way in which patients initially seek a cure through self-treatment.

6.3.1 Historical roots, and self-treatment as a tangible cultural heritage

In Chapter One, I described and discussed how this research is focused primarily on people living and working in the hinterland of Suriname, since they are the ones most often confronted with CL. This is also reflected in Tables 13, 14 and 15.

Indigenous peoples were the first inhabitants of Suriname, while the majority of Maroons live in the hinterland as a result of colonial domination. For the Indigenous communities in the pre-colonial periods, their *own* traditional treatment was the *only* treatment they knew. Specifically for the Trios, this was still the case up to the 1960s (Heemskerk et al. 2007:3), after which biomedical health care and missionary education by Baptist missionaries were introduced. For the Maroons, knowledge of traditional treatment that they have kept from their African ancestors (currently almost 400 years back) was for a long time their only way of surviving in the Amazon rainforest. Living in the forested habitat, remote from the capital city, and for centuries quite isolated without any biomedical health facilities, inhabitants of the hinterland learned to use their natural habitat to treat illnesses.⁵⁹ After all, the natural environment (as I explained in the section above) provides a constant supply of free and easily available medicines. Still today, ancestral knowledge, traditions, and beliefs in that wisdom are prominently present. That knowledge – and the natural habitat – are, in case of illness, still used first.

For Indigenous communities, self-treatment has been a tradition since the beginnings of their existence. For the Maroon communities, it has been a tradition since they were forced to live in the Amazon rainforest. Many inhabitants are proud of the knowledge they inherited from their ancestors: it is part of their identity, a tangible form of cultural heritage. Still today, medicines (or the making of medicines) – in particular, bush medicine (which is used by a majority of CL patients) – are remembered and orally passed on. Self-treatment therefore means respect for, and belief in, ancestral knowledge. A 48-year-old Saramacca Maroon, an ex-CL patient, was moved during an in-depth interview about why he had tried self-treatment:

It [*busi dresi*] means a lot to me. Because my ancestors lived with it, with those things they could survive. And that's why it means a lot to me. I really deeply believe in them. (Ottie, Brokopoondo, April 2010)

Another man, a Ndjuka, the 37-year-old son of a traditional healer, remarked:

It [knowledge of bush medicines] is mostly what your ancestors, your parents have left for you; when there were slaves and you had to take care of yourself. You had to survive, that's how you get *konis* [expertise and knowledge to cure a certain disease]. (Roka, Paaston, November 2009)

One of the captains in Godo-olo, to whom I asked the question of why people in most cases try to treat themselves, said:

Well, let's say, we [inhabitants of the hinterland] have the knowledge of it, the tradition. Let's say, you've learned something [how to make a

⁵⁹Biomedical health care only started to be provided on a large scale from the mid-twentieth century. See web reference number 34.

medicine] from your ancestors; if you have that knowledge, you will use it for yourself. Then you help yourself with it, you don't need to look for other people to help you. Because it is you yourself that has the knowledge. If my brother, for example, gets ill, [and] I know a medicine, then I'll treat him, heal him. Or I help him as far as I can, till someone else can help him [further]. (Captain Henkie, Godo-olo, September 2009)

As the excerpts above show, many in the hinterland respect what they have learned from their ancestors, because ancestral knowledge has led to centuries of survival (cf. Crandon-Malamud 1991).

6.3.2 Self-treatment as an instrument for gaining power and status

In self-treatment, knowledge of the 'right' medicine(s) is obtained from family tradition, from others who are considered knowledgeable in treating CL (whether a traditional healer or a common person), from a person's own experiments with different medicines, or from modification of recipes received from others. The patient him-/herself, however, can also 'make' the medicine and apply it to his/her sores. Once the medicine has proven effective, the patient owns something valuable: a medicine that cures CL.

A key informant at Godo-olo explained that the formula of many traditional medicines is not readily shared, but often kept secret. If a person is able to provide the right medicine to someone else, he/she gains something over the other, something powerful; he/she *becomes* someone important, someone who *has* something on which the other is dependent:

An *Ingi* [Indigenous person] will cure you, but he won't teach you *how* he cures. And they [Ndjuka and Indigenous communities] don't mix. Concerning *Bus' Yasi*, they [Indigenous communities] have a very simple method of curing it [CL]. The Ndjuka also have their own healing methods, but they do not often reveal it. Sometimes they have very good medicines, but they do not show it to the other; the 'how' is not explained, is not passed on. If you know some medicine, it gives status, people get respect for you, and honour you. (Habo, Godo-olo, 2009)

Self-treatment is therefore an attractive way of curing oneself when one can show off one's knowledge and thus become powerful. Especially in remote areas, knowledge about self-treatment is scarce, and so, where needed, it becomes a kind of 'commodity'.

6.3.3 Belief in efficacy and in 'experimental' medicine

When the knowledge of a cure is effective, it provides independence from others, and can be used as first aid before further treatment is pursued, if necessary. A 33-year-old farmer at Donderskamp remarked during a group conversation that "People treat themselves because they believe in their medicines; they have much experience with it" (Robbie, Donderskamp, May 2010). Many years of 'trying out'

medicines, using them and seeing positive results, makes self-treatment a preferred option.

Aside from treatments with bush medicine, belief in the efficacy of other types of medicine also matters. A 49-year-old Maroon woman said: “I had it [CL] before, thus I knew what to do with it... I used antibiotics for it [opened the capsule and spread the powder onto the sore], and a *bita bita* plant. When it didn't heal, my mother advised me to go to the doctor” (Anita, Dermatology Service, September 2009).

6.3.4 Medicinal knowledge ‘travelling’ in networks

Positive stories about the efficacy of all kinds of medicines spread among the hinterland populations, including workers. Hindustani men, for example, working among or with Maroons, learn from their colleagues of medicines that ‘work’. Maroon, Hindustani, Creole, Javanese, and men of mixed descent are often colleagues, have friendships with each other, or know the others through a friend or acquaintance. Therefore there is often exchange of information, especially when one is visiting or working in the hinterland, for it is a hostile environment where if one falls ill, it is often difficult to reach medical professionals in time. Knowledge about medicines for all kinds of illnesses, animal bites, etc. is therefore often appreciated and, as this research shows, eagerly applied in self-medication.

6.3.5 Fear of injections

Paradoxically, fear of biomedical treatment (as described in Chapter Four, section 4.3.1) is another (socio-psychological) aspect that contributes to the use of a variety of (often) painful and potentially harmful medicines. Indeed, many patients tried to cure their sores “in whatever way possible” to avoid biomedical treatment. Insufficient information about the injections and the drug (Pentamidine Isethionate) used for medical treatment, the side-effects of the medication, and frightening stories about the painful effects of the injections create a fear of the treatment and encourage self-medication.

6.3.6 Geographical distance, occupational and financial concerns

Sometimes health facilities are difficult to reach, thus contributing to self-treatment. In Suriname, the distances between the capital city and the interior, and between villages and working places in the hinterland (goldfields, wood exploitation areas), are usually great, requiring travel of several hours or even days, depending on the destination and transport method used (car, boat, all terrain vehicles, airplane), and are furthermore expensive. For these reasons as well, CL patients are inclined to first attempt to treat themselves at their home or work location.

The majority of CL patients in this study who attempted self-medication (as mentioned previously) were working in the hinterland. When there, it is often difficult to leave the job for any period of time. Gold digging, for example, requires some six to eight men to work on one pit, and it takes about four to six weeks to finish the job. Because each worker has his own task that he is expected to complete, finding a replacement in the remote goldfields is difficult. Leaving the place also means

receiving no payment, regardless of the amount of work one has already done. Additionally, most of those working in the hinterland have no other source of income.

With an average salary of only US\$200-300 per month, sometimes far less, CL patients said there is usually “just enough” to cover their monthly expenses. Everything in the hinterland is expensive. At the time of research, for example, one egg cost US\$0.15 in the city Paramaribo, but cost three times that in the hinterland. Daily life activities require use of gasoline and diesel in large quantities to operate gold digging machines, generators, chain saws, and boats. Loans are often taken out to buy machinery. Moreover, many activities, such as fishing, transportation of goods and agricultural products, and even visiting agricultural areas, require travel by boat. Depending on the needs and activities one is involved in on a daily basis, monthly expenses may (and often do) exceed US\$200-300. Having a CL sore then becomes a financial burden, especially if biomedical treatment must be sought in the city.

Photo 26: Gold digging activities

Photo 27: Gold digger with specific task of washing away soil



Source: Collection Ramdas S., 2010, Benzdorp

As explained in Chapter Two, medical treatment in the hinterland is provided free of charge by the Medical Mission. Health clinics, however, often lack the necessary drugs and waiting periods can be long before medicines finally arrive. CL patients therefore often need to go to Paramaribo for further treatment. In addition to the high expenses of biomedical treatment, further costs include travel and living expenses in the capital, which may easily exceed a worker's monthly salary.⁶⁰ Another gold digger, a CL patient at the Dermatology Service, explained that due to his financial debts, he could not afford biomedical treatment. It is therefore understandable that many are tempted to use the free or cheaper medicines to hand.

⁶⁰CL patients enrolled in the clinical study PELESU were treated free of charge.

6.4 View of biomedical authorities: Self-treatment is “understandable”

Aware of the problem of lack of medicines, and having experienced the day-to-day life of people in the hinterland communities, the head of the Medical Mission, Doctor Van Eer, said that it is understandable that people often cannot easily afford the high costs related to travel, stay, and medication in the capital city. Medical doctors at the Dermatology Service share similar views: “It often is a problematic situation for patients, yes. That’s why we agree for some of them to take medicines [Pentamidine] along for further treatment [at the Medical Mission clinics] in the hinterland” (Doctor Hu, personal communication, 2010). As Van Eer continued, there is recognition within the biomedical community of certain traditional healing treatments in specific areas, and respect for certain traditional healers, such as bonesetters among the Maroon populations. He remarked: “I have experience with bonesetters in the interior. If people have fractures, I’d say go to them. They are really good. I don’t know what they do, but they are good” (Van Eer, personal communication, 2010). Therefore, if healing of CL sores can be achieved by traditional treatments, it is seen as a good option:

Pentamidine has to be put on the list. Patients have to pay transport and stay in the city if they come for CL treatment. All becomes expensive... we do not actively refer patients to the traditional clinic, because that is not allowed by the medical inspector, the Director of Public Health, but we do inform them about treatment choices. And they can decide which choice to make. I don’t know what the Shaman does, but I do know what the ampoules do. We tell them, you can go to the city, but also choose to go to the Shaman first, and they have to decide themselves. People do come to the Medical Mission and they are respected for their choices. You can provide the information to go to the Shaman – who can heal the sores maybe in one week – or go to the city. (Van Eer, personal communication, March 2010)

Van Eer above is referring to Trio traditional health professionals who use, amongst other medicines, the Trio traditional medicine *Sipuinuime* (Tr) (see Chapter Five, section 5.3).

At the time of research, traditional health workers of the *kapi* were treating a young Trio man named Ronny with *Sipuinuime* for a sore that he had on his tibia (as seen in Picture 28 below), diagnosed as CL by the traditional healers. During Ronny’s traditional treatment, a medical doctor of the Medical Mission, on one of his periodic visits to the area, arrived at the Medical Mission clinic at Tepu. Every time medical doctors visit remote Medical Mission clinics, patients – informed beforehand – line up at the clinic for consultations. Ronny also went to the medical doctor to show him his wound. I was allowed to observe the consultation. As the medical doctor expressed, he thought that the sore was possibly CL, but because of the ointment covering it he could not come to a sound diagnosis. He did not prescribe anything, and remarked: “I do not want to interfere with that process [of traditional treatment]. People have their own choices whether they want to visit the Medical Mission or the traditional health clinic. It is their own responsibility”. To the patient he

said that if the ointment did not work, he should notify the Medical Mission health worker. The health worker would then inform him and Pentamidine would be sent to Tepu for treatment of the sore.⁶¹

Photo 28: Patient Ronny with a traditionally diagnosed CL sore treated with *Sipuinuime*



Source: Collection Ramdas, S., 2010, Tepu

At the end of my stay at Tepu (which was one month in total), Ronny's sore had not yet healed; but each time I met Ronny, he told me that there was slow progress in his condition and that the sore seemed to be drying up. If this medicine eventually worked, it would save Ronny, like many other CL patients in the hinterland, a lot of money and time.

6.4.1 'Dubious' medicine as cause for concern among biomedical health professionals

When considering toxicity and side-effects, treatment of CL with biomedical drugs is in itself not without 'harm'. The available drugs for CL are reported to be toxic, expensive, and difficult to administer. In addition, they cause side-effects such as nausea, vomiting, abdominal pain, diarrhoea, skin rashes, and headache (Frézard et al. 2009:2318). The difference between these drugs used in the treatment of CL and the non-biomedical (household and industrial) chemicals used by CL patients is that the former have been tested in randomly-controlled trials and found to be efficacious (Van der Meide et al. 2009), while the latter have not. According to the CL patients in this research, the chemicals – and other traditional medicines – have reportedly been 'tried and tested' by family and friends, and have the reputation of being effective. These claims of efficacy, however, lack evidence that the sores being treated were actually caused by CL.

Because of the lack of (biomedical) evidence on the efficacy of traditional botanical medicines, or of remedies using industrial and household chemicals (or

⁶¹When a Medical Mission clinic lacks Pentamidine, the headquarters of the Medical Mission in Paramaribo is informed and the drug is sent to the clinic. Often, however, when Pentamidine is scarce in the city, it takes a long time before the medicines finally arrive. Since the price of the medicine is often very high, it becomes difficult for the Medical Mission to buy the drug from pharmacies and keep it in stock.

mixtures of these and other substances), their potential to cause harm to human health, as well as a lack of knowledge of the consequences of such medicine use in the long term, public health professionals warn against their use (Weigel & Armijos 2001:401), as well as against self-injecting practices, which are viewed as particularly 'risky' (Whyte et al. 2002:115). In Godo-olo, Captain Henki remarked on the use of chemicals by gold diggers:

... a thing like battery acid, you can't use that at all, because it's heavy toxic, right? Battery acid is used by men to experiment... Battery acid is to drive a car with, it's not meant for medicine. No, never. (Henki, Godo-olo, 2009)

Certain health workers thought that many of the medicines used in self-treatment were "crazy" and "idiotic"; for instance, the use of animal faeces in a medicine, or the use of household or industrial chemicals. All are 'dubious' kinds of medicine. Indeed, as Hardon and colleagues (2001:35) suggest, "Policy-makers and health workers have often been puzzled by people's seemingly 'irrational' decisions in their search for therapy".

In Suriname, different kinds of home remedies are available in several local shops or so-called 'cultural' (*kulturu*, Sr) shops; they are also sold in local markets in and around Paramaribo. *Busi dresi* and treatments are also provided by community specialists but, as Slikkerveer (2006, in Van 't Klooster 2009:63) points out, similar to home remedies, "plant descriptions and information on their pharmacology, usage, dose, toxicity and side effects together with indications, contra-indications and potential drug interactions are often lacking". One can easily find such supposed remedies in plastic or glass bottles in street shops or along the roadside, without any product information at all.

Adding to the concerns of biomedical health professionals, traditional medicine is neither institutionalised nor integrated into the biomedical sector in Suriname. A WHO evaluation report (2005:84) on the status of traditional medicine (TM) or complementary and alternative medicine (CAM) (see also Chapter Two) in Suriname shows that:

In the Republic of Suriname, no national policy, laws, regulations, national program or national office on TM/CAM exists, nor are they in the process of being developed. There is no expert committee and there are no national research institutes on TM/CAM or herbal medicines.

Herbal medicines are not regulated in Suriname and consequently have no regulatory status, nor can claims be legally made about them. Neither a national pharmacopeia nor national monographs exist, and no information is available on other materials used in their place.

No information is available on manufacturing regulatory requirements or any control mechanisms to ensure compliance. Safety regulations are limited to reference to scientific research on similar products; no information is available on a control mechanism for this requirement. No registration system exists for herbal medicines, nor are they included on a national essential drug list. No post-marketing surveillance system for

herbal medicines exists, nor is one being planned. In Suriname, there are no restrictions on the sale of herbal medicines.

6.4.2 'Dubious advisors' of medicines as cause for concern: Doctor Peão

Certain 'advisors' of potentially 'dangerous' or 'dubious' medicines in CL self-treatment contribute to the concern of biomedical health professionals, as became evident in the Brazilian gold diggers' village of Benzdorp. There, during my inquiries, I came across the name Doctor Peão. In the excerpt below, a few *garimpeiros* (Brazilian gold diggers) (R, R1, R2) explain about potentially harmful medicines and the identity of Doctor Peão in a group conversation that I (I) had with them:

I: Are there other ways [than biomedical] of curing *leisho*, for example, with oils, battery acid, etcetera?

R: Those things that you put on it are only to make the sore worse. It will only grow, it won't get small. You hear those things from Doctor Peão.

I: What did you say?

R: Doctor Peão [all gold diggers laughing in the background].

I: Doctor Peão? Who is that?

R: Doctor Peão is –

R1: Whoever, anybody –

R: Doctor Peão is another colleague. A person who gives all kinds of advice, gives information about remedies, he uses battery acid, uses hot oil, [he says] use this or that, it will only get worse. Doctor Peão knows nothing! He only knows his work [as a *garimpeiro*, i.e. he is just a worker]. Everybody can be Doctor Peão. I can be Doctor Peão, he can be Doctor Peão [pointing at a colleague], he can be Doctor Peão [pointing at another colleague]. Everyone can be Doctor Peão!

I: But what kind of other medications does Doctor Peão advise?
[Everyone laughing]

R: Oh, there are so many remedies or things Doctor Peão knows that can be good.

I: Like what...?

R: About *leisho*? He can make something not to cure it, but to make the sore smaller, like a medicine of the jungle... Doctor Peão makes it and uses it for you. It's not to cure the wound, but it won't grow anymore. It doesn't get worse but it also doesn't heal.

R2: I also used hot oil ... Dr Peão says it's good, but it's not, it doesn't cure. [All laughing]

R: Doctor Peão 'knows' a lot of medicines...

(R, R1, R2, Ramdas, Benzdorp, November 2010)

Photo 29: Shaking hands with a 'Doctor Peão'



Source: Collection S. Ramdas, 2010, Benzdorp

Acting as Doctor Peão (see photograph above), Brazilian gold diggers at Benzdorp provided an extensive list of medicines used in the treatment of CL. According to them, all the medicines mentioned were, more or less, effective against CL. Medical advice by people such as Doctor Peão – or better said 'worry doctors' – are a matter of concern for biomedical doctors.

6.5 Conclusion

Most CL patients who engage in self-treatment use powerful medicines, consisting of corrosive, sharp, bitter, spicy, astringent, and even poisonous components to cure their sore. These 'strong' medicines have a certain 'harshness' in common with the perception of CL among patients, namely the 'cruelty' of the illness. I examined the paradoxical questions (emerging in both the previous and this current chapter) of *why* self-treatment and *why* these types of medicines for such a 'dangerous', 'difficult', and 'hard to cure' illness. I demonstrate that these preferences are better understood if the type of medicines, the reasoning behind their use, and the multiple contexts in which CL patients find themselves in their daily lives are analysed. With this ethnography, insights into the dimensions of (self-) treatment seeking by CL patients are provided, which biomedical health professionals need to know in order to act with care and in an informed way. Different dimensions require different approaches.

First, in terms of botanical treatments, the large inventory of Surinamese bush medicines (local 'traditional' treatments), especially those based on botanical products, may have the potential to affect the leishmania parasite (Akendengue et al. 1999; Fournet et al. 1994) and thus cure CL sores. Positive developments that support a growing recognition of the potential efficacy of bush medicines for CL, but also for different illnesses, are that over the years – as listed by Van Anel and Ruyschaert (2011:8)⁶² – several documentations have reported the healing

⁶²The first documentations came, according to Van Anel and Ruyschaert (2011:8), from Stahel (1942), Geijskes (1954), and Ostendorf (1962), followed by May (1982), Titjari (1985), Heyde (1987), Slagveer (1990), Plotkin (1986), Tjong Ayong (1989), and Raghoenandan (1994).

qualities of plants known in Surinamese society. In the past decade, moreover, several studies have been undertaken to understand Maroon and Indigenous traditional healing, including their religious use of plants.⁶³ The installation of a chair in pharmacology of herbal medicine at Anton de Kom University in Suriname, plus ongoing scientific research into herbal medicine, may be seen, as Van 't Klooster (2009:64) has reported, as factors strengthening the position of 'traditional' (botanical) medicine in Suriname.

In some parts of the hinterland, as well as in Paramaribo, there are 'clinics' providing (ethno-) botanical healing. Some of these are completely focused on the preservation and promotion of traditional medicine, such as the traditional health clinics at Tepu and Kwamalasamutu, each helped by the local community organisation ACT (see Chapter Three, section 3.2.2.2). In these clinics, herbal medicine is made according to indigenous recipes that are known only by the respective local populations and based on centuries of experience (Traditional healer, *kapi*, personal communication 2010). Another Paramaribo clinic is Odany-Jewa, which claims to be an ethno-pharmaceutical company. It promotes 100% herbal remedies combining traditional knowledge with modern biomedical techniques.⁶⁴ Aside from these clinics and academic interests, there are local organisations and regional movements with platforms for promoting herbal medicine, such as the Caribbean Association of Researchers and Herbal Practitioners (CARAPA) (Van 't Klooster 2009:61-62), which contribute to the growing recognition of local culture in general, and local 'traditional' medical systems in particular, in Suriname.

Clinical investigations are nevertheless needed to further study Surinamese bush medicines and their potential in the treatment of CL. Collaboration is pivotal between local healers and biomedical health professionals for the identification and production of safe and painless (herbal) medicines to treat CL. In fact, during the time of the research, a project by ACT in collaboration with Trio traditional healers to conduct a clinical trial on the effects of the Trio medicine *Sipuinuime* on CL was already in preparation. The objective of the project, entitled "Pre-study of the efficacy of Sipuinuime: a local indigenous treatment for CL in Suriname", was:

...to provide the baseline data for future study that should deliver evidence-based proof that Sipuinuime deliver[s] both clinical healing of CL lesions and parasitological clearance. The outcome of this pre-study is essential to validate the incorporation of traditional treatment into the conventional health care and hence achieve recognition (Uiterloo 2012:13).

Early in 2012, the project proposal was submitted to the *Commissie Medisch Wetenschappelijk Onderzoek* (CMWO), the commission for medical scientific research. After an initial review, ACT was requested to re-submit the proposal after some modifications (Uiterloo, email communication 2012). At the time of writing this

⁶³See Terborg (2001), Heemskerk et al. (2007), Hoffmann (2009), Van 't Klooster (2009), Ramdas (2008), Ruysschaert (2009), Van Andel et al. (2008), Van Andel & Ruysschaert (2011).

⁶⁴Despite several efforts that I made during the time of the research, it was not possible to make contact with the head of this clinic for an interview. Information has therefore been retrieved from the clinic's website. See web reference number 35.

dissertation, the project is still on the agenda of ACT, but has not yet been re-submitted to the CMWO. If this ointment proves to be an effective medicine against CL, it could entail a revolutionary development in the treatment of CL on both a national and international level. Having a 'simple' ointment that can cure CL would be beneficial, both financially for all stakeholders, and in particular physically for CL patients.

Second, 'hot' (local) treatment methods, especially the method of treating CL sores with hot charcoal (as reported at Tepu), require more clinical observation and investigation. Heat therapy, though in a different form, is also used by biomedical health professionals. Prasad and colleagues (2011) used radio-frequency heat therapy to treat the CL sores of a 34-year-old man infected with HIV. They reported complete healing of the lesions within 12 weeks. Similar results were obtained from another male patient. Both patients remained CL free a year after treatment. Based on these observations, as a first line treatment for CL in HIV positive patients, Prasad and colleagues recommend radio-frequency induced heat therapy. Aside from being highly effective and non-toxic – unlike systemic pentavalent antimonials – the researchers also found that heat therapy did not cause (or caused only minimal) damage to underlying healthy tissue, and furthermore the patients adhered better to the treatment (Prasad et al. 2011:610).

Third, the extent to which resistance against first line biomedical treatment is related to the use of other types of medicines remains unknown. Clinical investigation into the efficacy of the listed (bush and other types of) medicines (such as harsh chemicals), and their interaction with the biomedical drug Pentamidine – used by dermatologists to treat CL patients in Suriname – should be conducted.

Fourth, other cognitive, infrastructural, and financial barriers to seeking timely biomedical treatment for CL are problematic issues that should be addressed on a macro level by the responsible policy makers. Infrastructural barriers, for instance – mainly to be addressed by the Ministry of Public Works – can only be lifted if adequate roads are built from the capital to the hinterland areas, and affordable public transport is made available to hinterland populations. Financial barriers are difficult to overcome in a short period of time and require the collaboration of different ministries on different levels to create sufficient jobs and to stimulate other income generating activities for hinterland populations. Furthermore, the socio-psychological aspect of the fear of injections, that leads to the use of many (potentially harmful) medicines in self-treatment, is another issue requiring the attention of the Ministry of Health. Lack of evidence for the efficacy of medicines in the real life contexts of patients is also an issue. Therefore, for policy to be most effective, more in-depth quantitative and qualitative research should be conducted.

Public health authorities, those primarily concerned with the conditions of health seeking, should initiate open and non-judgemental dialogue and discussion between health professionals, CL patients, and communities in the hinterland about the biomedical treatment process, the benefits and side-effects of the treatment, and the health hazards of self-treatment with non-biomedical chemicals and other potentially harmful treatment methods. Harmful self-treatment practices would, in this way, be discouraged and early case registration stimulated, which could render self-treatment with harmful medicines unnecessary.

Chapter 7 **Biomedical treatment seeking and (non-) adherence**

The previous chapters illuminated the diversity and magnitude of self-treatment practices; some of which are extremely painful, toxic, and harmful to human health. Despite experiencing excruciating pain and the awareness that the efficacy of traditional medicines, home remedies, and other treatment practices is dubious, 161 CL patients continued to self-treat their sores. Patients mentioned that some products helped only against the smell of the sore but not against its growth, or that upon using certain medicines, though it seemed that the sores had dried up, they were dry only on the surface while inside they remained moist. A few patients mentioned that self-treatment helped to flatten the borders of the sore. But all had disappointing experiences that eventually led them to seek treatment at biomedical health facilities.

Considering the fact that it was only after the failure of self-treatment efforts that most CL patients sought treatment at biomedical services, CL proves to be a 'challenging' illness, especially from a public health perspective. Had it not been for the failure of patients' self-treatment, these cases of CL infections would have stayed unreported; while early detection and treatment are, according to the WHO, the most important measures to control CL.⁶⁵ On both a global level and in Suriname (Bern et al. 2008; Van der Meide et al. 2008), underreporting of CL cases is a problem, as is non-adherence to biomedical treatment (López et al. 2012).

Because the majority of CL patients in this study tried self-treatment, this study shows that there is relatively late biomedical treatment seeking. As was extensively discussed in the previous chapter, multiple aspects contribute to this practice and complicate biomedical treatment seeking. One of the aspects to emerge in this study is avoidance of the regular biomedical treatment due to fear of injections (see Chapters Four and Six). However, once patients do seek biomedical treatment, the data shows that injections are – surprisingly – preferred by a group of CL patients. The reasoning behind this preference – which is, unfortunately, sometimes based on incorrect information about the functioning of the biomedical drug – is discussed in this chapter.

In contrast to the 161 patients who tried self-treatment, 44 patients sought early (or only) biomedical treatment. This chapter focuses on this group of patients in order to understand their health seeking actions, since early biomedical treatment seeking is what public health authorities in Suriname aim to achieve. Questions explored in this regard are: Why did this group seek biomedical attention instead of attempting self-treatment? What insights can be gained from the various contexts (socio-personal, cultural, geographical) that encourage early (or only) biomedical treatment seeking?

Aside from the problem of relatively late biomedical treatment seeking, this study also shows that 81 CL patients (39.5%) did not adhere to the biomedical treatment. Adherence to (biomedical) treatment is one of the main concerns of the Ministry of Health in Suriname (Ministerie van Volksgezondheid 2011:60) and is

⁶⁵See web reference number 36.

crucial for both biomedical health professionals and CL patients. For patients, adherence is considered necessary for their own physical, mental, and social health and well-being; for medical doctors, it is necessary for the evaluation of drug efficacy and detection of possible drug resistance against first line treatments. This evaluation is important for the development of follow-up clinical and pharmaceutical studies about effective therapies and safe medicines (González et al. 2009:33). Non-adherence to biomedical treatment can also add to the financial burden of public health authorities (Vermeire et al. 2001) and possibly cause unwanted scenarios for public health. Dermatologist Hu, working at the Dermatology Service in Suriname, pointed out:

An important complication, apart from the fact that lesions grow bigger and do not heal, [is that] parasites can become less sensitive for the biomedical drug Pentamidine. This can create another major problem for Surinamese CL patients, since currently there are no other medicines in Suriname to treat CL. (Hu, personal communication, 2013)

Patient adherence to biomedical treatment is therefore a key aspect in the fight against CL.

As pointed out in Chapter Five, this chapter is the last of three chapters (Five, Six and Seven) that present the health seeking actions undertaken by CL patients. The chapters describe how, upon noticing the sore(s), CL patients go on a quest to cure them: ranging from self-treatment, the involvement of traditional health professionals, to finding a cure at the Dermatology Service. Due to time constraints, budget limitations, and the spread of the fieldwork (in Paramaribo and the hinterland), the 205 CL patients at the Dermatology Service were not followed throughout their whole treatment seeking trajectory. Whether cure was achieved after they received the biomedical treatment has thus not been investigated in this study. However, based on conversations with medical professionals working at the Dermatology Service, it can be assumed that, upon receiving the full biomedical treatment, the majority of the CL patients found a complete cure.

7.1 Treatment seeking at the Dermatology Service

During the time in which the 205 CL patients visited the Dermatology Service for the first time, the majority (88.3%) had been walking around with their sore(s) for at least one to three months (see Chapter Four). The remainder had had their sore(s) for a longer period, exceeding four to six months, and in some cases even longer, up to three years. In this period, most patients had gone through the process of discussing the illness with significant others, establishing a (lay) diagnosis, and self-medicating the illness with rather painful (and potentially harmful) varieties of medicines; some had also searched for help from local healers. Upon the failure of these treatments, patients finally went for biomedical treatment.

At the Dermatology Service, patients first have to register at the counter, after which a patient card is made. After registration, they are referred to the laboratory for a blood test, and then to the dermatologist. To support the clinical diagnosis of CL, the parasites are visualised by a Giemsa stain of either skin smears or a biopsy. While Giemsa stains are examined at the laboratory of the Dermatology

Service, skin biopsies are sent to the pathologist for evaluation. When patients arrive at the clinic early in the morning (which most do), and skin smears are sent for testing at the laboratory, patients can choose to wait for the result. If positive, they can see the doctor again, receive a prescription, go to a pharmacy and buy the medicine,⁶⁶ and return to the Dermatology Service for their first injection. Thus, depending on their time of arrival at the Dermatology Service and the type of testing for CL, patients can either wait for approximately one hour for the results and continue consultation and treatment the same day, or go home and return the next or another day for the result and further treatment.

Chapter Four (sections 4.2 and 4.3) revealed that the majority of patients experienced CL as a serious and dangerous disease. Hopes for a cure through biomedical treatment were high: 97% believed that CL is curable, and that the “doctor’s medicine” would be effective. In the course of one week, patients receive three injections of Pentamidine (each time four milligrams per bodyweight); if necessary, patients receive more than three injections. Although CL patients at the Dermatology Service were not followed through the whole biomedical trajectory, follow-up conversations showed that before receiving the first injection, patients were more anxious and worried, but as the treatment progressed, their anxiety diminished. It was striking that most patients, from the beginning of their illness, resented CL injections. Once they accepted that having injections was the last possibility for a cure, however, many thought that treatment through injections was the best option.

7.2 CL patients preferring the ‘un-preferred’: the power of injections

Injections for all kinds of illnesses are noted to be very popular in developing countries (Whyte & Van der Geest 1994; Reeler 2000). They are found to be widely administered in different parts of Asia, Africa, and Latin America. Injections are also found to be overused by informal health care providers (ibid:137). This, however, is not the case among Surinamese people, particularly not in relation to CL treatment. The research shows that seeking biomedical treatment through injection is a last resort for most CL patients, hence the relatively prolonged period of self-treatment. Answers to the hypothetical question⁶⁷ of what patients would choose in case other options like biomedical ointments, tablets, and powder, or herbal or traditional medicine (bush medicine or home remedies) were also available at the clinic for

⁶⁶My fieldwork started in September 2009. From that moment until December, patients had to buy the medicines themselves. However, CL patients enrolled in the clinical PELESU study were, from January 2010 onwards, treated free of charge and received the medicine at the Dermatology Service. The PELESU study is a clinical, parasitological, and pharmaco-economic evaluation of a 3-day versus 7-day Pentamidine Isethionate regimen for CL treatment in Suriname.

⁶⁷This question is another example of the evolving character of the research, as it was only inserted into the questionnaire conducted at the Dermatology Service at a later stage. A part of the answers to this question was derived from the material after analysis of the interviews, and part of it was answered by the CL patients themselves. Of 205 CL patients, 63 patients answered the question; the answers of 65 patients were derived after analysis of the interviews; and for 87 patients, the answer was not completed on the form. For a total of 118 patients, answers could be noted; for this question, multiple answers were possible.

treatment of CL also partially support this finding. Of 118 CL patients, 21 (18%) preferred “everything except an injection”. A small group of four patients (3%) would choose tablets. Others would choose bush medicines (8%), ointment or powder (9%), and home remedies or herbal medicine (9%). Below are a few examples of how CL patients reasoned their choice. Ramhal, a 40-year-old manager at a car company, would choose:

Ointment. If the doctor would say, ointment is good and it’s approved by medical care, I’d use the ointment on advice of the doctor.

Forty-one-year-old Adimba, a gold digger, commented:

[I would prefer] tablets; [it] is [the] easiest [treatment]. Ointment and powder you’d have to apply [the] whole day. Bush medicines can have side-effects. No injections, I’m afraid.

Kasan, a 32-year-old electrician, responded:

I am not afraid of injections, but injections do not work well on me. I have pain and high fever, the doctor injected exactly inside the wound. Something else, like an ointment, would be better.

Rudi, a 28-year-old well worker, preferred:

Bush medicine. I could also take the tablets because it cures from inside and the sore has to cure from inside. If you apply powder and ointment, it will release a lot of fluid; I noticed it myself. The injection is terrible, I hate the injection.

7.2.1 Injections are powerful, “going straight in the blood”

Despite the overall fear or preferred avoidance of injections, 52 (44%) of the 118 CL patients would nevertheless favour injections. As in Uganda (Birungi, in Whyte et al. 2002:109), injections are viewed as powerful, entering directly into the blood (see photograph below). Many answered in a similar way to 33-year old Lesly:

[I’d prefer] injections, because it goes straight in my blood, because the insect also goes in my blood and eats me away. It [an injection] will kill it.

Because many CL patients know of the illness as a condition where one can get multiple sores, it is thought of as an illness that “walks in the veins”, that is “in the blood”. Injections are therefore, as Whyte and colleagues also point out (2002:109), “seen as a more direct treatment”. Min, a 65-year-old patient, commented that “Ointment would be good, but the injections are better. They get injected in the body, and work more directly”.

Photo 30: A CL patient receiving an injection at the Dermatology Service



Collection: Ramdas, S., 2010, Dermatology Service, Paramaribo

Another patient, 53-year-old Kromo, explained:

I'd rather have ointment, I'm very nervous for the injections. But my friends say that the injection is better. If you use a leaf or home remedies, it will heal the sore from above, but the sore walks through your veins in your blood. After a year or so you can get it again. But with the medicine injected in your blood you prevent everything. So I would, in the end, still take the injections.

Conversations in the villages supported the view that injections are a “direct” and effective treatment. A 41-year-old Maroon gold digger at Paaston explained: “If the bacteria are in your blood, bush medicine is not able to heal it, because bush medicine cannot go into your blood. It only cures from above. So, after three months the healed sore can break open again, that's why they [gold diggers with CL] go to the doctor”.

7.2.2 Injections “act fast”

Other reasons why injections are preferred are that the effects on the CL sore of the injected medicines are visible, and because injections are experienced as “fast acting”. Eyewitnesses to the healing of CL sores on others, as well as rapid changes in their own CL sore(s), contributed to this preference. Jabi, a 30-year-old gold digger, chose injections because, as he said: “I noticed changes immediately after the first one [injection]”. Ro, a 30-year-old security guard, would choose injections because, he thought, the other medicines would take a long time, whereas “injections are fast”. Another patient, 45-year-old Sewram, explained his choice for injections: “I saw how my colleague got well; that's why I've come too, regardless of the time it will take the treatment [with injections]”. Roy, a 33-year-old construction worker, said: “Injection is a direct treatment. Others told me that they noticed the sore started to get well three days after getting the injection”. Denki, a 24-year-old patient, jobless at the moment of research, replied: “I would go for injections, everybody that has *Bus Yasi* [CL] takes it; I'd take it too, it gives me certainty”.

7.2.3 Injections because of trust in medical doctors and biomedical science

Another reason for preferring injections is that CL patients trust medical doctors and biomedical science. “I trust the doctor more than others”, Freddy, a 50-year-old technical worker said. Autan, a 31-year old gold digger, remarked: “The doctor will not advise to take an injection that does not help”. Acceptance of biomedical supremacy is further reflected in the words of 30-year-old Mahi, a construction worker: “I would choose for injections, because they are tested in the laboratory; it [an injection] gives more certainty”.

7.2.4 Injections because of shorter adherence timeframe

The perspective regarding the shorter timeframe in which CL injections are administered at the Dermatology Service also influenced patients’ choice of medicine. From September 2009 to June 2010, the regular treatment for most patients was administered within a timeframe of one to three weeks. When the clinical research study PELESU, conducted by Dr. Hu, became operational from January 2010, 19 patients⁶⁸ received fewer injections in a shorter timeframe: two injections in one week (day one and day three). Some of the patients enrolled in this study therefore replied that they would choose injections, since one could receive fewer injections in a much shorter time period. As the 22-year-old gold digger Ricky explained, his choice was for: “Injections, you can take them in one week, so I’d take the injections”. A shorter timeframe would obviously reduce the costs of staying in the city, and thus ensure the possibility of resuming work sooner.

7.2.5 Injections because “it prevents CL”

A final – though incorrect – reason why patients chose injections was because they are thought to be preventive (see next chapter). CL injections are viewed as a kind of vaccine. Baso, a 24-year-old gold digger, said that he preferred an injection “because you won’t easily get *Bus’ Yasi* then”. The 21-year-old salesman Rafa said: “Then you’re sure it [injection] helps, it works direct, all bacteria die. And you’re sure you won’t get the illness again”.

The idea that injections are preventive is thus also behind why certain CL patients eventually sought medical treatment at the Dermatology Service. After applying several other medicines, Drew, a 32-year-old Maroon gold digger, finally came to the Dermatology Service because he thought that the injections would prevent future infections with CL: “I came for the injection because I want the medicine in my blood. That way I won’t get it [CL]”.

⁶⁸All CL patients could participate in the anthropological study, regardless of their participation in the PELESU study. A total of 46 patients (included in the total of 205 CL patients) thus also participated in the PELESU study. Nineteen patients from this group received the shorter treatment of two injections in one week.

7.3 A closer look at those seeking (only) biomedical treatment

Among the 205 CL patients, 44 (21%) said that they sought only biomedical treatment. The majority of this group – 26 patients (59%) – sought treatment at the Dermatology Service in an earlier phase of the illness – within one month after first noticing the sore – while 14 (32%) visited the Dermatology Service between one and four months after noticing the sore. The reason for this delay was the fact that they had first visited family physicians, other physicians, or a Medical Mission clinic and were then referred to the Dermatology Service.⁶⁹

As previously mentioned, early case detection and treatment are, according to the WHO, the most important measures for controlling the illness. This calls for a closer look at the group of 44 CL patients who *did* seek biomedical attention early after detection of their sores. In the table below, some socio-demographic characteristics of the 44 CL patients seeking only biomedical treatment are presented.

Table 9: Socio-demographic characteristics of CL patients who sought only biomedical treatment (n=44)

Characteristics	Number of patients	Percentage (%)
<i>Sex</i>		
Male	41	93
Female	3	7
<i>Age (in years)</i>		
≤ 19	3	7
20-29	16	36
30-39	16	36
≥ 40	9	21
<i>Cultural background</i>		
Maroon	20	46
Hindustani	6	14
Creole	4	9
Javanese	3	7
Mix	5	12
Brazilian	4	9
Indigenous	1	3
<i>Educational level</i>		
No formal education	7	16
Primary	10	22
Secondary	26	59
Tertiary	1	3
<i>Living area</i>		
Capital city and nearby districts	38	86
Hinterland	6	14

The primary question explored here is why this group of patients sought biomedical attention as a first resort, rather than attempting self-medication.

⁶⁹The timeframe between noticing the sore for the first time and eventual treatment seeking at the Dermatology Service are only estimations according to the memory of the CL patients. These patients could have visited the Dermatology Service at an earlier or later time.

7.3.1 Age, less experience, and ‘knowledge’ of illness

First, it is possible that the lower age of these 44 patients, and related to that, their little or no experience in general with bush medicine treatments for CL, may be associated with the fact that they sought only biomedical treatment. Among the 44 patients who sought only biomedical treatment, 19 (43%) were younger than 30 years. In addition, 24 55% claimed to know nothing of the illness. For almost all of the CL patients in this group (43, 98%), it was the first time they had contracted the disease; they knew nothing of the biomedical facts about aetiology, though almost all had heard about the illness in their social environment. Many patients reported that they had seen CL on other people, and concluded that, based on their observations, seeking biomedical attention best fit the disease. They preferred not to self-medicate, therefore, but to seek biomedical attention as soon as possible.

7.3.2 Fear of CL, more ‘certainty’ with biomedical treatment, and higher education

Another reason why only biomedical treatment was sought by this group may be related to the fear that CL patients had of the illness. The data shows that 18 (41%) of these 44 CL patients expressed fear of the disease; it spreads rapidly on the body and is considered to be a contagious, hard to cure, and dangerous illness because of the risk of amputation. While fear of CL fuelled those who self-medicated to keep on searching for the ‘right’ medicine, in the group that sought biomedical treatment, it possibly stimulated the seeking of biomedical care. The remaining group said that they did not fear the illness, though they knew (or had heard) that the illness is very difficult to cure. They also knew (or had heard) that CL is definitely a biomedically curable illness, hence biomedical treatment was considered by them to be the best solution to the problem.

It is also possible that a higher education level may have contributed to these patients seeking treatment at the Dermatology Service. Among those who sought only biomedical treatment, the majority – 26 patients, 59% – had received secondary education. The combination of having received secondary education with a lack of belief in traditional methods and a belief in biomedical healing may have further contributed to the seeking of only biomedical treatment.

7.3.3 Living area and cultural background

Other aspects that possibly stimulated treatment seeking at the Dermatology Service may be related to the cultural background of the 44 CL patients, including their primary living area, and the lesser infrastructural distance and time spent at the Dermatology Service. Among this group, 22 patients (51%) were a mixed city population consisting of Hindustanis, Creoles, Javanese, those with mixed cultural backgrounds, Brazilians, and Dominicans. This city population may possibly be less aware of – or lack belief in – alternative treatments, in contrast to the hinterland community. Hindustanis, for example, often lack knowledge of traditional medications known to the Maroon or Indigenous communities; Brazilians (as noted in Chapters Four and Six) are more familiar with the illness and its biomedical treatment. These groups are thus more likely to seek only biomedical attention.

Paradoxically, hinterland populations consisting predominantly of Maroons and Indigenous peoples, who were the largest group (57.2%) among those who self-medicated, simultaneously formed a large cultural group within the research population that sought only biomedical treatment (49%). Maroons and Indigenous people most often recognise the disease, and precisely *because* they know how difficult it is to heal, some choose to seek biomedical attention as soon as possible.

Regarding patients' main place of residence, 38 (86%) of the 44 patients who sought only biomedical treatment lived mainly in the capital city or in nearby districts. Having a main residence in the capital city or its surrounding districts may have stimulated treatment seeking at the Dermatology Service, because shorter infrastructural distance significantly reduces travel time, expenses, and the time spent on biomedical treatment seeking.

7.4 Biomedical treatment at the Dermatology Service and (non-) adherence

After clinical diagnosis of all 205 patients was confirmed, each was informed of the biomedical treatment method to cure CL. From September to December 2009, treatment involved a minimum of three intramuscular injections (in the buttocks or in some cases intra-lesionally) over the course of seven days. In practice, however, treatment often exceeded one week, when patients did not or could not show up on the agreed date for the second or third injection; or, in particular instances, if more than three injections were required to cure the sore(s). From January 2010 on, after the start of the PELESU study, patients who participated in the clinical trial received (at random) either the same treatment as prior to January 2010, or treatment within a shorter timeframe: two injections only, on days one and three. Whether enrolled in the PELESU study or not, or receiving the longer or shorter treatment, patient commitment to the treatment was required.

7.4.1 Adherence to biomedical treatment

In this research, adherence of the CL patients to the biomedical treatment meant that the patients received a minimum of three intramuscular injections within the timeframe of seven days, up to a maximum of three weeks. When patients received fewer than three injections, or received the second or third injection after the three week timeframe, this was considered non-adherence to the biomedical treatment. For the 19 patients that were enrolled in the two-day treatment timeframe of the PELESU study, this was different. For this group, patients were considered adherent if they had received two intramuscular injections within the timeframe of one week. Receiving only one injection within the week was considered non-adherence for this group.

Data shows that of the 205 CL patients at the Dermatology Service, 139 (67.8%) adhered to the treatment: they received at least three injections within three weeks, or a maximum of two injections in one week. In the following, the focus will be more on the 'problematic' group of patients, i.e. those who did not adhere to the biomedical treatment.

7.4.2 Non-adherence to biomedical treatment

Sixty-six patients (32.2%) did not adhere to the treatment; most of them were male (85%). Of the total group of 66, 37 patients (56.1%) received two injections, and 29 (43.9%) only one. Concerning the problem of non-adherence, the dermatologist Hu remarked:

Almost 33% of CL patients not adhering to biomedical treatment is a lot. As a doctor, I really feel bad if so many patients do not adhere to the treatment. You do your best, as a doctor, to cure patients and you expect positive results. With certain chronic diseases, you can't achieve cure, but you treat the patient and prevent aggravation or complications [of the condition]. But in the case of CL, where you can achieve complete cure, 33% [of the patients not adhering to treatment] is a lot... (Hu, personal communication, 2013)

Though from the 66 non-adherent patients only two could be contacted, follow-up conversations with these two, plus inquiries at the Dermatology Service and in the selected villages, and information collected from CL patients during their first or second visit to the Dermatology Service, suggest several aspects that plausibly contribute to non-adherence.

7.4.2.1 Financial worries and occupational duties

Almost half (47%) of those patients who visited the Dermatology Service and failed to adhere to biomedical treatment could not afford the entire treatment. The majority (61.1%) were Maroons, mostly men (37 men, four women), who were struggling to meet their financial needs. Most of the men were working in the gold, lumber, and casual construction sector, or as petty farmers. Three of the females were children (one four years old, and two thirteen years of age), all from poor families. The fourth was a 28-year-old woman working as a casual farmer and thus also in a financially weak position.

Excerpts of interviews with CL patients show how their difficult financial position is burdened when they must incur the expenses associated with long geographical distances between the hinterland and the city, the high costs of transportation, housing in the capital, and the costs of biomedical treatment:

Yes, money is the problem. I did not have money to come earlier [to the Dermatology Service]. I made a lot of effort to come here. Very much. A boat is SRD40 [about US\$14],⁷⁰ then SRD60 [about US\$21] for transport to the city [Paramaribo]. It's very heavy financially. For now, I stay at my sister's place. (Sammy, Dermatology Service, January 2010)

Yes, I had to struggle so much to buy the medicine for the injection. (Joan, Dermatology Service, May 2010)

Yes, I was working in the hinterland, I had to stop that to come to the city, but I need to work. (Joko, Dermatology Service, June 2010)

⁷⁰At the time of research, the exchange rate was SRD2.8 to US\$1.

Yes [I made a lot of effort], I came from *tapsé* [upstream/hinterland], paid about SR250 [about U\$89] for the boat ride, and after that SRD360 [about U\$129] for the airplane and SRD30 [about U\$11] for a taxi. I have very little money left and medicines are so expensive. (Rudi, Dermatology Service, April 2010)

Among the non-adherent women, one was a Dominican and five were Brazilian. Because they usually stayed just a few days in the city, they took this one-time opportunity to visit the Dermatology Service. They were mostly sex workers. A 32-year-old Brazilian sex worker remarked:

I don't have time to come back; I must go to work in the hinterland. I will leave tomorrow, but I am taking medicine for two more injections. (Lucina, Dermatology Service, September 2009).

Men working in the hinterland also take such one-time opportunities. Like 36-year old Rodrigo, a machine operator, explained: "I was working in the woods, I did not have time for it [visit to the doctor]... now that I am in the city I decided to come" (Rodrigo, Dermatology Service, September 2009). This way of thinking shows the pragmatic approach that CL patients apply with regard to biomedical treatment seeking: going to the Dermatology Service should 'fit' into their plans, especially if their health condition is not that bad (e.g. they have only one sore, or only a small sore, as discussed in section 7.4.2.3). The reasoning is that one must make ends meet, and if during a one-time visit to the city everything that one needs to do in the city can be done, money is saved. Among the non-adherent men, there were three who were either jobless or did not have permanent jobs.

7.4.2.2 Fear of biomedical treatment: painful injections and severe side-effects

Earlier in this study, the fear of biomedical treatment emerged as a psychological factor contributing to self-treatment and late health seeking at biomedical health clinics. Associated with the lack of information about the biomedical drug and its side-effects, there is fear of injections, of the side-effects, and of the supposed side-effects that others have reported. Therefore, beyond occupational or financial problems, sixteen of the non-adherent patients (24.2%) said that they "really feared" the injections, and this was most strong before receiving their first injection:

The injection, I find that scary... (Kira, Dermatology Service, January 2010)

I have difficulty with the injection, it is too strong, I almost can't take it, I want to vomit. (Henk, Dermatology Service, May 2010)

... everything, the pain, the sore... and then...the injection. I don't want to even think about it...oh, boy! (John, Dermatology Service, February 2010)

Afraid of the effects of the injection, I get fever for three days and I feel pain. (Ricky, Dermatology Service, June 2010)

As noted previously, several frightening stories about the side-effects of CL injections exist, and those experiencing CL often “know” of others or “have seen” others who experienced serious side-effects. The power of such stories evidently has an adverse effect on biomedical health seeking and adherence to biomedical treatment.

If serious side-effects occur for a person after injection with Pentamidine, news about their experience travels fast. Nurse Ana, who has injected hundreds of CL patients over the years, shared her experiences about cases that went “wrong”, in particular why they went wrong, and how that contributed to non-adherence:

Calamities occur when people do not eat! The first case: I had a male patient, his blood sugar level completely dropped; he fell down, urinated in his pants, his tongue totally blue. I never saw him back. Second case: a boy, he had lied that he already had eaten, I inject him. He stands up, starts walking and in the corridor he collapses; he defecated and urinated in his trousers, had a weak pulse and finally was hospitalised. A third case: a man says he has eaten already, gets his injection, and vomits over the whole floor. It turns out he had eaten three hours ago. I also never saw him back. (Nurse Ana, Dermatology Service, January 2010)

Such severe lived experiences of the side-effects provide reasons for CL patients not to complete the treatment. Here is what Christa, a 32-year-old Brazilian woman and CL patient who did not adhere to the treatment at the Dermatology Service, said when she was asked about her absence for further treatment:

I: Well, what happened to you after the last time I saw you [at the Dermatology Service]?

C: Oh, I took the injections, but I almost died and I left for Santo Domingo.

I: Tell me what happened.

C: After the injections at Derma [Dermatology Service], my butt, where I had the injections, was infected, totally red, almost my whole butt was totally red, a big area! Where the injections had been given, it had gotten a pimple, infected. ...

I: Why didn't you go back to Derma?

C: The medicines used at Derma are too strong, I almost died. I'll never go back because Derma is not good, [besides] they never analyse your blood and you never know for sure what it [the illness] is.

Another 38-year-old male CL patient remarked:

I'd have everything except injections, because I have horrible experiences with it. With the first injection, my underwear and pants were totally wet with blood.

One CL patient received only one injection at the Dermatology Service, because he reported that he had already received two injections in the hinterland prior to coming to the clinic. Other patients reported the reverse: they received only one or two

injections and then took the rest of the medicine with them for continued treatment in the hinterland. In section 7.5, treatment negotiation between medical doctors and CL patients is further discussed.

7.4.2.3 Number, place, and size of lesions related to non-adherence

Another aspect that may influence non-adherence to the treatment is the number and size of the sores on the body. After studying the patient forms, it could be noted that the majority – 40 patients (60.6%) – of the 66 patients who did not adhere to treatment had only one lesion on the body. Nine patients had two lesions, and another nine had three lesions. Only one patient had more than four sores. For seven patients, the number of sores was not noted on the form. It is possible that having only one rather than multiple sores could prove to be less worrying for CL patients. Related to this, inquiries at the Dermatological Service revealed that 33 patients (47%), almost half of the group of 66 patients, said that they were “not afraid” of the illness. As one patient remarked: “I’m not afraid of the sore, but I’m afraid of the injection”. Thirteen patients did not perceive the illness as dangerous.

Aside from the number of sores, the placement of the lesion on the body may also have contributed to non-adherence. From the patient forms, it was noted that among the 66 non-adherent patients, only six had lesions on their ear, nose, head, face, or neck; the vast majority, 55 patients (83.3%), had lesions on their arms, legs, or on other parts of the body (trunk). It may therefore be possible that patients have fewer difficulties with sores located on places that can be hidden. By wearing appropriate clothing, CL patients can hide lesions and postpone continuation of treatment. Chapter Nine, which deals with stigma, will discuss these aspects in more detail.

In addition, the size of CL sores may play a role for patients in terms of adhering or not adhering to biomedical treatment. Though CL sores were not measured in this study, pictures taken from CL patients in both groups (adherent and non-adherent) show the differences. Photograph 31 shows the CL sore of a non-adherent patient, while Photograph 32 shows the CL sore of a patient who adhered to the treatment. Both had one lesion on their body, but as can be seen, the size significantly differed.

Photo 31: A patient with a sore not adhering to treatment Photo 32: A patient who adhered to treatment



Collection: Ramdas, S., 2009/2010, Dermatology Service, Paramaribo

Again, although none of the sores of the 205 CL patients were measured in this study and no further visual information was gathered on the respective size of the sores of patients in both the adherent and non-adherent groups, the above images illustrate that patients with a larger lesion may possibly be more likely to adhere to treatment than those with smaller ones.

The different aspects, such as number, location, and size of lesions on patients' bodies, in combination with patients' weak economic position and occupational duties, and the long distances they must travel to visit the Dermatology Service, may all have influenced non-adherence, and thus require further investigation.

7.4.2.4 Lack of information about the quality of biomedicine and doubt about medical expertise

In the case of Brazilian CL patients, their lack of information about the biomedicines and doubts about whether the medical doctors at the Dermatology Service could determine the correct diagnosis and treatment were also associated with non-adherence. In a follow-up conversation with the Brazilian Rodrigo, one of the two CL patients who could be contacted after they stopped visiting the Dermatology Service, it became clear that he had feared to receive the wrong medication for his illness and lacked information about the medicine. On his file, the following was noted:

Concerning adherence, he did not make any appointments with the doctor. Received his first injection at the Dermatology Service, the second at a [unknown] pharmacy...On the question why he had not come to the Dermatology Service again for treatment, he complained that after four days, there was no visible change of his wound, that it "stayed the same", it "didn't cure" and it hurt him... His friend told him that the medication was not good. He, according to the friend, had to receive 'Pentamidine' and not 'Pentacarinat'. The doctor had prescribed Pentacarinat. He explained that that is probably why the medicine did not have any effect on this sore. Therefore, he decided not to continue with the Dermatology Service, but to buy the other [good] medicine. (Patient file CL014, collection Ramdas, September 2010)

Non-adherence among the Brazilian population, as my findings show, has a different connotation: it is most likely related to the supposed or actual effect of the medicine. Brazilian CL patients apparently do adhere to biomedical treatment, but the number of injections they take depends on how dry the sore gets after an injection, rather than on the biomedical protocol for treating CL.

7.5 Treatment 'negotiation' and the effect on adherence

This study further shows that patients have the possibility to negotiate treatment. As reported earlier, CL patients can take the medicines needed for injections to the hinterland, where they can continue treatment. This practice points to a certain collaboration and understanding between medical doctors and CL patients that affects adherence to the biomedical treatment in a positive way. Medical doctors are willing to prescribe medication for patients to take to the hinterland, on condition that

patients go to a medical post there – clinics of the Medical Mission – to finish the treatment. Nurse Ana:

It happens that patients bring the medicine with them [to the hinterland] when they leave [Paramaribo]. Sometimes I write down the message on a piece of paper for the health worker in charge at the medical post in the hinterland and when the patient goes to the clinic he has to give it to the health worker. (Nurse Ana, Dermatology Service, January 2010).

Whenever medication is prescribed for further treatment in the hinterland, notes are made on the patient's file. Nurse Ana again:

On the card [patient file] we can also track how much the patient has taken with him to the hinterland. It really is difficult sometimes for them to stay [in Paramaribo]. Better that the patient takes medicine and gets healed, instead of not receiving any medication at all. (Nurse Ana, Dermatology Service, January 2010).

CL patients speak of how convenient it is to have the possibility of taking the medication with them.⁷¹ Ande, a 35-year-old machine operator working in the hinterland, remarked:

I'd rather have the medicine injected here [Dermatology Service], but I don't have time. I must work. That's why I think it is very good that I can get medicine with me [to the hinterland]. I will take [drugs for] three injections with me; I still have to get them at the pharmacy. And I am definitely going to the poly [polyclinic] to get myself injected, because it is very risky. (Ande, Dermatology Service, September 2009)

Negotiation about treatment is based on trust. As nurse Ana remarked: "You don't know for sure if they go to the clinic to get treated further, but I think most of the patients do" (Nurse Ana, Dermatology Service, January 2010). Holding patients responsible for their own actions, biomedical professionals trust in patients' word that they will continue the biomedical treatment at a medical post in the hinterland.

The practice of taking medicine for injections to the hinterland is not without risks. Aside from self-injecting practices (as discussed in Chapter Five), Karin, another nurse, reported: "Most of the time, [when] the blood sugar level of patients drops...you can get calamities" (Nurse Karin, Dermatology Service, October 2009). It is therefore important for patients to be well informed about food intake prior to receiving injections.

According to the nurses at the Dermatology Service, patients are fully informed about the risks and side-effects of the injections. Having been made aware of these risks, some CL patients stay in the capital city to receive the injections, but most of the time they go back to the hinterland. The assumption is that CL patients do go to the medical posts of the Medical Mission for continued treatment; indeed,

⁷¹ Pentamidine Isethionate can be kept outside the refrigerator at a maximum temperature of 30 degrees Celsius. Only after preparation (and non-use) should it be kept in the refrigerator for 24 hours at a temperature of between 2 and 8 degrees Celsius.

sometimes patients – in case of treatment failure – are referred back to the Dermatology Service by health workers at the Medical Mission. Inquiries at the Dermatology Service thus revealed that, according to the nurses, most patients do adhere to the medical treatment as prescribed.

The possibility of taking away the medicine for treatment completion in the hinterland could change the understanding of non-adherence used in this research. Patients who received only one injection at the Dermatology Service but who took the rest of the medicine back to the hinterland did probably adhere to the biomedical treatment, and furthermore this possibility may have even encouraged adherence. However, this practice falls outside of the scope and control of the biomedical doctors at the Dermatology Service and it is therefore difficult to establish whether these patients were adherent or not. Medical health professionals should, however, be aware of these dynamics, and structural possibilities to follow patients' adherence behaviour in the hinterland should be put into place.

7.6 Conclusion

In this chapter, treatment seeking at the Dermatology Service was studied in a wider context. A striking finding was that although injections in general, and CL injections in particular, are unpopular in Suriname, a group of 52 CL patients (out of 118) still chose injections as their preferred treatment. People attributed powerful effects to injections and regarded them as a pragmatic choice, provided that they were administered fewer times and within a short timeframe (less than one week). Unfortunately, in some cases CL injections were also viewed as preventive medicine, and biomedical treatment was sought by some because of this (incorrect) assumption.

While most CL patients visited the Dermatology Service only after first attempting self-treatment, 44 patients sought only biomedical treatment. Health seeking among this group was contextualised, and again the research shows how multiple – socio-personal, geographical, educational, cultural, socio-psychological – aspects speak to the dynamics of treatment seeking. All of these aspects should, however, be investigated further in future research to establish their influence on (non-) adherent behaviour.

Paradoxically, some of the aspects that contributed to *self-treatment* among some patients were reasons for others to seek only *biomedical treatment*. While the previous chapter showed that having prior experience with CL was a reason for attempting self-treatment, here having experience with the illness became a reason for seeking only biomedical attention as soon as possible. Because the illness is known among certain cultural groups in the hinterland for its 'harshness' and 'cruelty', Maroons in particular decided not to wait and instead to immediately seek biomedical help. Similarly, the fear of the spread of the illness (i.e. further sores developing on other parts of the body) that led to successive self-treatment attempts among some became the motivation for others to seek only biomedical treatment.

While 139 CL patients (67.8%) out of the total of 205 did adhere to the biomedical treatment at the Dermatology Service, adherence was a problem for 66 patients (32.2%). Lack of money, work obligations, fear of injections, and side-effects all evidently contributed to this problem. The insights gained and outlined in

this chapter and the previous ones confirm the challenges that public health authorities face in their fight against CL. Clearly, a confluence of multiple aspects leads to the problem of relatively late biomedical treatment seeking as well as non-adherence to biomedical treatment. At the same time, the findings suggest frameworks within which public health authorities can target their CL education, prevention, and control programmes.

Chapter 8 Cutaneous leishmaniasis and stigma in Suriname

Stigma is a broad and complex concept. Stemming from Greek, historically the term was used to refer to a “point or a mark” and “most widely used to designate tattooing, whether decorative, religious, or to indicate ownership” (Bennett 1992:30). According to Bennett (1992) – who wrote about the history of stigma and how it became associated with mental illness in ancient Greece – the term in Greek usage could point to a brand mark on slaves, but seems to lack the negative connotations that are automatically attached to the term in present times. Indeed, “the more negative connotation of the term appears in Latin, where the Greek word is taken over, and metaphorically denotes a mark of shame or degradation” (ibid). The social concept of stigma, in its current state, is hard to define; and, as Link and Phelan (2001:365) point out, different disciplines – anthropology, sociology, psychology, political science, social geography, medicine – have a different emphasis in their definitions of stigma.

Without doubt, Goffman’s (1963) classic work on stigma has contributed much to the elaboration, categorisation, and discussion of the concept in past decades. By defining stigma as a “spoiled identity”, Goffman shows how stigma is attached to the social identity of an individual when he or she is found to possess attributes that mark him/her person as deviant; the individual thus has or develops a “spoiled identity” and consequently is treated differently. *Who you are* is thus overshadowed by *what you have*: an illness, a disability, a health problem (Estroff 1993:256; cf. Kwansa 2013:10). Stigma exists on the basis of the social meaning to which it refers (Reis 1996:243). In contemporary society, it is viewed as “a negative construct, a mark of shame that communicates to others the fact that a person is not able to fulfil social and cultural role expectations” (Green 2009:15). According to Link and Phelan (2001:367), stigma happens when “elements of labelling, 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, characterised by exclusion, rejection, blame, or devaluation that results from experience or reasonable anticipation of an adverse social judgment about a person or group” (Weiss & Ramakrishna 2004:13). This brief discussion of definitions of stigma clearly shows that despite differences, the cross-cutting emphasis is a negative one.⁷²

This chapter focuses on CL related stigma in Suriname. It presents and discusses different types of stigma and the extent to which they occur among CL patients. Furthermore, CL stigmatisation in Suriname – or lack thereof – is contextualised and compared to CL stigmatisation in other countries.

⁷²See amongst others Jones et al. (1984), Scambler (2004:32), Steward et al. (2008:1226), Herek et al. (2009), Jacoby et al. (2005), Albrecht et al. (2003:1226).

8.1 Types of stigma: enacted, perceived, internalised

In this study, the type of stigma targeted is health related: the attachment of social or public stigma to a health condition. Health related stigma refers to the negative attitudes and actions that a community, society, or the general public have or are thought to have against people with certain health conditions. Adverse social judgements (experienced or anticipated) about a person or a group exist due to a “health problem or a health-related condition” (Weiss & Ramakrishna 2004:13), whereby experienced or anticipated negativity may be even worse and disrupt people’s lives more than the actual health problem itself or its symptoms (Scambler 2011:4).

The way this negativity is expressed, however, may be completely different in different situations and contexts. To combat health related stigma in its variety, and on the basis of three decades of theorising stigma, social scientists and other health professionals working in national and international health organisations have proposed a categorisation of the concept into three main types: 1) experienced or enacted stigma; 2) felt or perceived stigma; and 3) anticipated or internalised stigma, and self-stigma (International Federation of Anti-leprosy Associations & Netherlands Leprosy Relief 2011:6-9).

8.1.1 Experienced or enacted stigma

Experienced or enacted stigma is evident where patients are confronted with overt acts of discrimination, name calling, seclusion, or any kind of hostility, abuse, maltreatment, or negative attitudes due to their illness (Scambler 2004; Jacoby 1984; Bharat et al. 2001:16; Das 2001; Van Brakel 2003; Kwansa 2013). Enacted stigma can lead to other types of stigma and form a barrier to health seeking. Hyland (1993), for example, found that people with leprosy in Nepal encountered severe acts of overt stigmatisation that resulted in perceived stigma, which in turn delayed access to health care services and led to poor adherence to biomedical treatment, thus increasing the risk of disability.

8.1.2 Felt or perceived stigma

Felt or perceived stigma occurs when individuals fear encountering overt or enacted stigma, or when they experience the shame of being associated with a certain illness (Scambler 2004:32). This shame or expectation of overt acts of stigma (such as discrimination) “prevent people from talking about their experiences and stop them seeking help” (Scambler 1998; c.f. Gray 2002:72). Felt or perceived stigma may exist even when enacted or experienced stigma is absent, and as ‘hidden distress’ may possibly “disrupt people’s lives even more than enacted stigma” (Scambler 1998; cf. Van Brakel 2003:194).

8.1.3 Anticipated and internalised stigma

Felt or perceived stigma can be further distinguished by anticipated stigma and internalised stigma. When the social or public stigma attached to an illness is internalised, or accepted by those to whom the stigmatisation is targeted, it is

referred to as internalised stigma (Herek 2009:32). “In this sense, internalization refers to a process in which a person with a stigmatized condition accepts perceived exclusionary views of society and self-stigmatizes himself or herself” (Weiss 2008:e237). With anticipated stigma, individuals thus expect prejudice, stereotyping, and discrimination to occur (Earnshaw et al. 2013:270). Anticipated or internalised negativity often leads to self-stigmatisation. Internalised stigma may not be easily evident, but can cause as much as or even more (psychological) suffering than enacted or anticipated stigma.

8.1.4 Self-stigma

When a person self-stigmatises, their perceptions, feelings, and talk about themselves will be negative. It can be overt, felt, anticipated, or internalised stigma that causes people with a certain illness or health condition to “turn against themselves” (Corrigan & Watson 2002:17). In the process of self-stigma, when individuals face overt stigma, such as negative stereotypes, they “often agree with these stereotypes and apply them to themselves, resulting in low self-esteem” (ibid). Self-stigma comprises negative attitudes and low self-esteem in such a way that individuals (with certain health conditions or illnesses) who “explicitly self-stigmatise” may say that “I have this illness [whatever the condition may be], people with this illness are worthless; therefore, I am worthless too” (Rüsch et al. 2010:150; Kwansa 2013). Having a low quality of life is often a result when people self-stigmatise (Link et al. 1997; Ritsher & Phelan 2004; Rüsch et al. 2005, 2006).

8.1.5 The dimensional stigma model of Jones and colleagues (1984)

Another analytical model to approach people's experiences with health related stigma is the dimensional model of Jones and colleagues (1984). Based on evaluation of many social scientific studies, Jones and colleagues distinguish six dimensions of stigma that influence the role of a ‘mark’ in interpersonal interactions. The word ‘mark’, as they define it, covers a wide “range of condition indicators that may give rise to the stigmatization process” (Jones et al. 1984:8). In this current study, the term ‘mark’ implies CL and its symptoms (the sores). The dimensions, including the set of investigative questions into these dimensions, are:

- 1) Concealability. Is the condition hidden or obvious? To what extent is its visibility controllable?
- 2) Course. What pattern of change over time is usually shown by the condition? What is its ultimate outcome?
- 3) Disruptiveness. Does it block or hamper interaction and communication?
- 4) Aesthetic qualities. To what extent does the mark make the possessor repellent, ugly, or upsetting?
- 5) Origin. Under what circumstances did the condition originate? Was anyone responsible for it and what was he or she trying to do?
- 6) Peril. What kind of danger is posed by the mark and how imminent and serious is it? (ibid:24)

These six dimensions may vary across different conditions and may be especially relevant for different aspects of the stigmatising process. In this study, they are also used as a tool to assess CL stigmatisation, and the results are presented and discussed. Because CL affects the skin, of particular relevance to this CL research is the aesthetic dimension, to the extent that one can speak of a particular type of stigma: aesthetic stigma.

8.1.6 Aesthetic stigma

Whenever people are stigmatised, in particular due to aesthetic deformities, health studies report 'aesthetic' or 'unaesthetic' stigma (Desjeux 2004:10; Banuls et al. 2007:10). With aesthetic stigma, stigmatisation (enacted, perceived, or internalised) is caused by visible 'marks' on the body or visible physical deformities. Deutsch and Nussbaum (2000:1-3) speak of "defects" such as "having one of the senses impaired – blindness, deafness, or the inability to speak – as well as physical anomalies like being lame or possessing a humpback... or pockmarked faces ravaged by smallpox". An example of aesthetic (appearance related) stigma is provided by Weiss (1998), who found that in Israel, newborn infants with facial defects were hidden or abandoned by their parents because they were impaired in appearance. Drawing on his work experiences in a psychiatric clinic in the United States, Kleinman (1988) described how facial disfigurement led to severe constraints in the life of one of his patients.

Cutaneous leishmaniasis is – as already described in Chapter Two – also viewed as a health condition that causes unaesthetic (Desjeux 2004:10), aesthetic (Banuls et al. 2007:10), social, and psychological stigma (Kassi et al. 2008:1; Reitingner et al. 2005; Yanik et al. 2004; Weiss 2008). This disease is clinically considered "one of the most serious skin diseases in developing countries" (Gonzalez et al. 2008:1) due to the extensive ulceration and scar formation. Because of the prominent disfiguring elements of CL, health researchers and the WHO (2008:5) have increasingly highlighted the severity of CL related stigma. It is unclear, however, the extent to which CL stigma is enacted, felt, or internalised, how CL stigma varies across cultures, and which dimensions are at stake. The question that therefore arises in the context of this study is: to what extent and in what way are people with CL stigmatised in Suriname?

8.2 CL related stigma in this study: an exploration

In this study, an attempt has been made to contribute to insights into negative experiences related to CL in Suriname. The exploration is aimed at establishing the extent to which, and in what ways, stigma is actually attached to CL in Suriname, if at all; and if it is, what are the dynamics involved. I have focused on the abovementioned types of stigma – experienced or enacted stigma; felt or perceived stigma; internalised, anticipated, or self-stigma; and aesthetic stigma – to understand what CL patients in Suriname experience during the course of their illness. In particular, questions were asked to CL patients at the Dermatology Service about how they experienced other people's behaviour or attitude towards them, and how they themselves felt about their condition. Inquiries were also carried out at the community level in the different hinterland villages about the attitudes of

people towards those infected with CL. As I have described above, in the analysis different dimensions of stigma have been taken into consideration. In particular, I looked at the possible relationship between experiences of CL and the extent to which CL sores can be concealed, the course of the condition, the location, size, and number of lesions, the effect of CL sores on personal aesthetics, the extent to which social interaction is disrupted by the illness, and the perceived etiological origin and risk of the illness. The last two dimensions – the origin and risk of the illness – have already been discussed in Chapter Four, though in this chapter they are reviewed specifically in relation to stigma.

8.3 Inquiries into CL patients' negative experiences

When inquiries began, the term 'stigma' was not mentioned. Consequently, the terms enacted, perceived, or self-stigma were also not mentioned during interviews. Instead, open questions were asked and the answers were analysed to identify complexes of feelings and behaviours indicative of enacted, felt, or internalised stigma. The main question was an open one, inviting CL patients and others in the villages to talk about their experiences, followed by other questions to gain more information. In the box below are a few examples of questions⁷³ asked during the research.

To CL patients:

How do those in your social environment (family, neighbours, friends, colleagues, co-students etc.) react when they see the sores? How are you treated by others? (As usual, differently, nicely or not? In what ways?) What do they say? How do they behave with you, can you tell a bit about what you experienced?

How do you yourself feel about having these sores on your body? Are there certain things you do or avoid because of these sores?

To others (villagers):

Can you tell a bit about how people in this community react to those with CL sores? How, according to you, are people with CL treated in this community?

How do you view someone with a CL sore? How do you treat that person? Will you talk to the person, sit with him, eat with him (etc.)?

Analysis was carried out afterwards into the different related experiences. Sometimes, patients and others in the villages mentioned the term 'discrimination' when talking about their experiences. Aside from following up on this particular term, inquiries were also further elaborated to other forms of stigmatisation apart from discrimination, though again without reference to the stigma categories. Apart from open questions, whenever necessary scenarios that sketched out the different types of stigma were described to the CL patients and other informants, and then it was discussed whether they had encountered similar situations or if they could recognise them in their everyday life or social environment.

⁷³See Appendix 2 on research instruments for the more elaborate topic and question list.

8.4 Others' reactions to CL patients and their illness: enacted stigma

The data from this study shows that from the 205 CL patients, a group of 125 patients (61%) mentioned no experience of any negativity due to their illness. Many patients even reacted with surprise to the questions concerning stigma, or alternatively they either laughed or had little to say. A group of 66 CL patients⁷⁴ (32.2%) reported varied experiences that could be categorised as enacted, perceived or felt, or internalised stigma, either separately or in combination. A small group of 14 CL patients (6.8%) had no comment on the topic of stigma.⁷⁵

Among the 66 CL patients who reported having had negative experiences or feelings indicative of stigmatisation, 47 reported that they did not experience any *overt* acts of hostility or negative reactions in their environment. When these 47 are combined with the 125 CL patients who reported having experienced no negativity, my research shows that the majority of the 205 CL patients – 172 CL patients (83.9%) – did not experience any such overt actions or attitudes related to their illness that could be categorised as enacted stigma.

These findings suggests that in Suriname, people with CL encounter relatively little discrimination or other enacted negative attitudes solely based on the presence of CL sores on their bodies. The majority reported that they were mostly treated as “normal”, “like usual”, or “not differently” by those in their social environment. “People just advise to go to the doctor”, 36 CL patients (17.6%) remarked.

Relatively low enacted stigma can be related to the first dimension of ‘concealability’ of the mark (Jones et al. 1984:45). Jones and colleagues point out that most likely, when stigma is attached to an illness, or is anticipated or internalised, stigmatised individuals try to conceal their mark. Findings from this study indicate that many CL patients did cover their sores, but most (161 CL patients, 79%) did so because they tried to self-treat the sores by applying different kinds of medicines that required bandages (and thus not because of stigma). Patients also mentioned that it was mostly for hygienic purposes that the CL sores were covered. The data further reveals that 151 CL patients (73.7%) had sores on the upper and lower extremities and the rest of the body (trunk), thus in areas that are (or can be) easily concealed by clothing. Among those who reported having experienced any kind of stigma (66 CL patients), however, sores were most likely concealed because of anticipated or overt stigma. Nevertheless, among these patients, the majority (56 CL patients, 84.8%) had sores on their upper and lower extremities and the trunk, places that can easily be covered with clothing, giving patients control over the visibility of their sores.

Concerning the dimension of ‘aesthetic qualities’, Jones and colleagues state that aesthetics – while being a continuous topic of discussion among scholars

⁷⁴These patients reported varied experiences that could be categorised as enacted, perceived or felt, or internalised stigma. A patient could thus have experienced only one type of stigma or several.

⁷⁵It is possible that these 14 informants who made no comment did not understand the question(s) well enough to adequately respond, or that the research assistants somehow ‘overlooked’ them or were unable to ask the questions because of possible interruptions of the interviews (e.g. if patients had to leave the clinic and had no time to continue with the interview).

because of its differing determinants and nature – is an “important dimension of marks” (ibid:49). People marked with certain conditions, and therefore viewed by most observers as aesthetically unappealing, evoke “a response of rejection, revulsion, and disgust” (ibid:50) from others or by and about themselves. Because of these reactions, these people may feel strongly stigmatised or stigmatise themselves. CL is often related to aesthetic stigma. The findings of this study show that the ‘gruesome’ look of the sores co-contributed to overtly negative reactions (enacted stigma) towards and caused anticipated stigma among 66 CL patients (see sections 8.5 and 8.6). However, inquiries also suggest that despite the ‘gruesome’ nature of the sores, social interaction between many CL patients and others continued in a similar way as prior to their contracting the illness. This is reflected in the relatively large group of CL patients (125, 61%) that claimed not to have experienced *any* type of negativity.

8.4.1 ‘Normal’ treatment by social environment

CL patients had a clear explanation as to why people reacted “normally” to their illness: many people recognise the disease and “they know it is not contagious”. This finding can be related to what Jones and colleagues (1984) point out about the dimensions of ‘origin’ and ‘peril’: differences in the way that marks originate and the potential dangers posed by those whose diseases are believed to be contagious “can greatly affect how others view and treat the afflicted individual”, as well as how the individual him- or herself feels and behaves (Jones et al. 1984:56, 65). According to Jones and colleagues, the greater an afflicted person’s role in producing the mark, the more he or she will be stigmatised; alternatively, if a marked individual is not held responsible for the condition, stigmatisation will most likely not occur.

Among the research population, the exact origin of CL was not known. Nevertheless, most patients claimed to have experienced the disease before or seen it on others. There is thus a certain kind of ‘familiarity’ attached to CL. Furthermore, most CL patients stated that it is an illness that exists in the hinterland, and they believe that the cause (origin) of the illness lies in nature (see Chapter Four). In addition, study findings show that most CL patients believe CL to be a non-contagious illness; those CL patients who explained the ‘normal’ attitudes of others towards them attributed these attitudes in part to the lack of fear of contagion.

A few interview excerpts from CL patients at the Dermatology Service serve as examples of the absence of enacted stigma in the case of CL. Thirty-four-year-old Mariana, for instance, a Brazilian woman who had multiple CL sores on her calf, arm, and armpit, said:

[People said] nothing [bad], they [colleagues, other villagers] looked at it and gave advice. Nobody minds it [the CL sore], because you’re in the woods and there are dangers everywhere, and people know it’s a non-contagious disease.

A 32-year-old Javanese hunter, a hobbyist, with disseminated small sores on the back of his neck, replied:

[People treat me] normally; it looks as if it [the illness] is not there, it does not exist. Because they [family, colleagues] are used to seeing me with scratches and pimples; for example, if I play football, I often have scratches etcetera. The father of my wife was also a hunter, so she already experienced this [illness], I think so. Most hunters get it. My kid – she's six years old – does ask what it [the sore] is, and how it comes, but that's just curiosity.

Twenty-eight-year-old Lesly, a Saramacca Maroon woodcutter with one sore on his back, explained: "In the family we know you can get it if you go to the hinterland, so it's not strange". Another CL patient, 34-year-old Ruud, a Creole, working as a wood transporter in the hinterland, had two sores, one on his calf and the other on his thigh. He remarked:

I'm treated as usual, nobody keeps distance. Most of the people I mix with know about it [the illness]. They all advised me to rush to the doctor.

A 46-year-old Hindustani painter described how he freely moved around with his illness and how his family members reacted:

I walk around in short pants. I live with my mother and brother; they both know the illness because my uncle had it. They just treat me as usual. I don't care about them, whatever they would say, but people don't say anything.

This 'normal' or 'as usual' attitude of the community, family members, friends, and colleagues reflects the general experience that people have with CL: it is a well known, non-contagious, and curable disease (see Chapter Four). Clearly, the CL patients in this study were generally not viewed as a 'danger' to others, and therefore they most likely experienced little enacted stigma.

8.4.2 No 'taboos' in talking about CL

Regarding the dimension of 'disruptiveness', according to Jones and colleagues (1984:46), "the more visible, dangerous, and aesthetically displeasing the mark, the more destructive of smooth interpersonal interactions it will be". Hence, stigmatisation will be experienced or anticipated. Findings from this study show that despite the 'gruesome' appearance of CL sores, CL patients were not at all hesitant in discussing their condition with others; on the contrary, those in their social environment (family members, neighbours, friends, colleagues, and others) were often consulted without reservations for a (lay) diagnosis and advice on treatment (see Chapters Four and Five). There is no taboo in talking about the illness. In general, inquiries in the selected hinterland villages revealed a similar attitude.

According to many villagers, CL is not an illness for which people who have it should be avoided, isolated, or discriminated. It is known as a sore that is curable with the right medication. As the captain of Tepu explained:

When you have *kaasa*, it does not matter, you can eat and drink with everyone, it's normal... the *kaasa* does not hurt that much, it keeps eating the meat, it sheds water, it is dangerous, but you won't die of it... so you can walk around everywhere freely, do whatever you feel; there is no problem.

The absence of enacted stigma at Tepu, as explained by the captain, is reflected in the photograph below. Here, a few family members are lying or sitting in hammocks in a hut. Among them, in the middle, is a 19-year-old CL patient with a sore on his tibia. Despite his illness, his family is present around him in close proximity. It was later observed that after he stood up from the hammock, other children went to sit in the hammock without any reservations or fear of contamination.

Photo 33: CL patient sitting in a hammock in close proximity with family members



Source: Collection S. Ramdas, Tepu, 2010

A similar way of thinking about people with CL is present at Donderskamp. There, a 59-year old man, a hunter, said:

There is no one who will reject you or refuse you because you have *Busi Yasi*... 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 the village of Godo-olo, 38-year-old Kadju, a well educated villager, experienced gold digger, and owner of a gold digging company, reported:

Well, in terms of discrimination, there is not really discrimination against people with *Busi Yasi* ... of course if the person has a big *Busi Yasi* [sore] on his body, on his hand, he's not going to cook, naturally. But it's not an illness that's contagious. Thus they [gold diggers] usually say nothing. Sometimes they say: "Hey, you have to be tidy with the disease, you hear", "You have to clean the sore, you have to medicate it", "Hey, don't throw your clothes here", or "Don't put your things here,

put them tidy somewhere". These kinds of things you do hear but it's not that they discriminate. Sometimes you have those untidy, dirty guys, then you'll hear those things. But if you're someone who is hygienic, a tidy neat person, and you have *Busi Yasi*, you won't hear those things.

A 32-year-old Brazilian gold digger at Benzdorp explained:

If you don't want to treat it [a CL sore], it's your problem. But people don't say bad things to you. They tell you to treat it, but that's all. I would eat or drink if someone with *leisho* [CL] gave me something to eat or drink. It's not a serious disease like HIV.

In the photograph below, the Brazilian man in white shorts had two CL sores on his right ear. Despite this, his friend is sitting close next to him.

Photo 34: Sitting together despite CL



Source: Collection S. Ramdas, Benzdorp, November 2010

Social interactions were thus not negatively influenced by the illness; having CL did not seem to block or hamper interaction and communication between CL patients and others in the family and community. This is most likely related to what Jones and colleagues (1984:36) state about the dimension of the 'course' of the illness; namely that if a condition: "1) be progressively crippling and deforming, 2) be nonfatal and chronic, running an unusually long course, and 3) appear[s] to be incurable", stigmatisation occurs (or increases).

It is a biomedical fact that CL sores became bigger over time and can spread over the body. All CL patients at the Dermatology Service experienced that their condition became more severe over time, which ultimately led them to seek

biomedical attention. CL is not, however, a kind of condition or illness – at least for the majority of CL patients in Suriname – that meets the three criteria mentioned above. CL may cause facial disfigurements, though the incidence of this is significantly less in Suriname than in other countries (see section 8.9.4 below) (Hu et al. 2012). CL is also a curable illness; almost all CL patients (97%) at the Dermatology Service believed this to be the case, and as the excerpts above illustrate, this was also well known in the hinterland. These findings provide some insights into why many CL patients did not experience enacted stigma.

8.4.3 Receiving support and compassion

In addition, CL patients reported receiving supportive comments from those in their social environment, and experienced a caring and supportive attitude from their family members. Humpy, a 62-year-old retired teacher, described his family's reaction to his condition:

No one reacts badly. It's no problem [to have CL]; to the contrary, they [family] did not want me to go to the hinterland for a while. They're very caring.

Souzanne, a 48-year-old Maroon housewife and cassava planter, said:

Caring, my family is caring. My sister brought me here [to the Dermatological Service]. They [family, neighbourhood] are all normal to me and to this disease, because they know what it is.

Patients were indeed often helped with the cleaning and medication of sores, mostly by those closest to them such as partners or other close family members. The wife of John, a 42-year-old patient, who accompanied him to the Dermatology Service, explained that she had no problems cleaning the sore for her husband, though she was “shocked after seeing the big sores on his foot”. She added: “He just went to work, he didn't care about it, and that made it worse of course”, pointing to her husband's nonchalance about the disease. Erno, a 46-year-old fisherman, told me: “Everybody behaves normal with me, my friends tell me to go to the doctor. My aunty helps me clean the sore”. Patients also remarked that they received compassion, like 36-year-old Rabin, working in the goldfields: “People around me feel bad for me, and they don't like the disease, but they don't keep me at [a] distance”.

8.4.4 Families are concerned or worried

Some CL patients reported that instead of negative attitudes, family members expressed concern and tended to be worried about the patient's condition. Carlo, a 65-year-old electrician, described how he shared his condition with people and how his family members behaved towards him:

I have talked with many people about it [CL], there is no difficulty in talking about it, everybody is open about it. My family keep worrying, they don't want me driving to the clinic all by myself. My wife behaves

also normally to me. She tells [reminds] me to go get the injections. She cleans my sores with alcohol. My children are worried about me, they tell me not to go to the woods anymore.

A 25-year-old Hindustani truck driver thought that during his illness he was treated exactly as he was beforehand. Only his mother was worried. Smiling, he added: “She asked me why it was necessary to go hunting”.

As previously mentioned, patients reported that the people around them (family members, friends, colleagues) tend to diagnose the illness and discuss symptoms and the development of the sores. They also give advice on self-medication, on what to do and what not to do, on medicines that are known by them to treat the sore(s), and how to obtain them and use them. As the 47-year-old Creole market vendor, Carlos, explained: “I’m not being treated differently. Everyone is normal, some tell me to go to the doctor, others tell me to use *busi dresi* [bush medicine]”. As described in Chapter Four, part 4.2.1, the illness is analysed by those close to the patient, therapeutic options are discussed, and advice is given. Often, when advised to use one of the many home remedies or traditional treatments, CL patients follow up on this advice; sometimes, they choose instead to visit the doctor (see Chapter Five).

8.5 Cases of overt, anticipated, and/or internalised stigma due to CL

This study reveals that the majority of the 205 CL patients visiting the Dermatology Service did not experience differential (negative) treatment from those in their social environment during their illness. However, about one third, a group of 66 patients, reported having experienced negative responses due to their illness. Some of these patients reported only one type of negativity (e.g. overt reactions), others reported more (e.g. both anticipated and internalised negativity). A total of 30 patients reported experiencing enacted stigma: strong, overt reactions of others towards them upon seeing the sores. They reported that others – family members, colleagues, or others in general – kept a distance from them, avoided coming close to them, or openly showed disgust by shrieking, backing off, or making (negative) facial expressions. Ryan, a 27-year-old boatman, said: “No one likes it [CL], such things [sores] are disgusting. It awakens a kind of fear”.

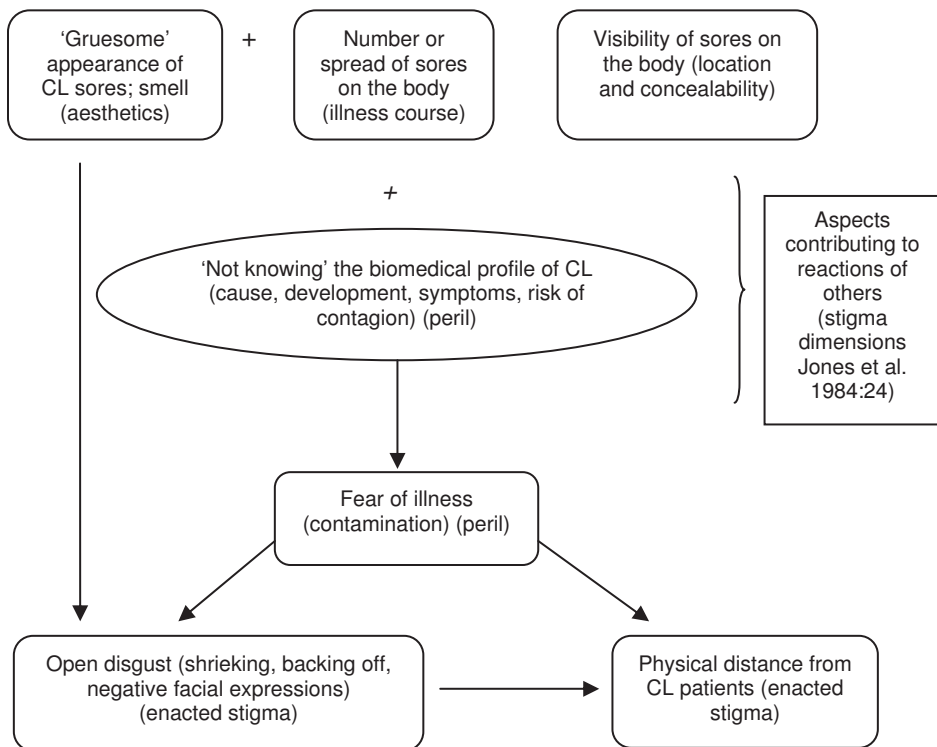
Another group of 32 CL patients (48.5%) reported experiencing anticipated stigma: they avoided certain matters or kept a distance from others because of their illness. They mentioned that they noticed how others avoided them, hesitated before sitting next to them (e.g. on public transportation), “even if nothing was said”. Some of the patients also reported experiencing internalised stigma: they mentioned how they created and maintained physical distance from others because of such reactions, or in anticipation of them. As they remarked, they felt that people only pretended to ‘act normal’, but that in reality they were disgusted by the sore. Some patients felt bad because of the negative overt reactions of others to their sores. A few avoided certain public places in anticipation of negative remarks or aesthetic stigma. As Alberto, a 43-year-old hunter, said: “I don’t go for walks, I don’t go to restaurants, [because] everybody is different, they think it [the sores] are disgusting”. Two patients, both men, one with multiple sores on his neck and ear, and the other

with one sore on his back, explained that they were treated “normally” or “no differently” by others, but they nevertheless “kept their distance”.

8.6 Contextualising (enacted, anticipated, and internalised) aesthetic stigma

In the paragraphs above, the negative experiences that 66 CL patients in this study encountered are described. These negative experiences, in particular the strong, overt reactions of those in their social environment towards CL patients and their sores, are related to a multitude of interrelated aspects: the visual image of the sore(s), which fuels the perceived danger of the illness (i.e. fear of contamination); the number of sores; their visibility on the body; (potentially) the smell of the sores; all combined with a lack of (biomedical) knowledge about the illness (see Chapter Four). This interrelatedness is reflected in the schema below.

Figure 7: Aspects causing strong, overt reactions of others, as experienced by 30 CL patients



8.6.1 Nasty disease, nasty looks: aesthetic stigma

According to Jones and colleagues (1984:49), “aesthetics refer to what is beautiful or pleasing to the senses”. In the case of aesthetic stigma, disfigurements, marks, or wounds on the skin can, depending on their looks, “dramatically affect how attractive

someone is to others” (ibid), or to him- or herself. The more aesthetically disturbing the condition, the more stigmatisation or self-stigmatisation occurs.

Among those who experienced negativity, the visual image of CL sores played an important role. The way the CL sores look was found to be quite ‘disturbing’, evoking fear of the illness (both among CL patients and others in their social environment); in particular, fear of contamination (perceived danger of the illness, or the dimension ‘peril’). Apart from the sores’ nasty looks, the visibility of the symptoms of the illness, especially when sores spread further or when grow in size, and the discharge of bodily fluids, the presence of puss, rawness of the sore, or dry skin crusts around the sore (see pictures below), contribute to (enacted and anticipated) aesthetic stigma.

Photo 35: CL lesions on a patient's neck

Photo 36: CL sore on a patient's arm



Source: Collection S. Ramdas, Dermatology Service, Paramaribo, 2009/2010

Effy, a 34-year-old Javanese man, said for instance that “People gave me nasty looks and that was embarrassing, they kept asking me what it [the sore] is. They said: “Hmm... [in a disgusted tone] What’s that?”” Effy described here an encounter with enacted stigma, as did Ramon, another patient, a 23-year-old student, who reported: “In the beginning, my friends were normal with me, but now the sore stinks a bit, so ... they keep their distance”.

Of the 66 CL patients who reported having experienced negative responses related to CL, the majority – 38 patients (57.6%) – expressed feeling bad about their looks. The ‘gruesome’ visual image of the sores contributed to the negative feelings that CL patients had about their looks. While other illnesses (e.g. malaria) are practically ‘invisible’, the ‘natural dirty’ look of a CL sore itself evokes feelings of disgust and shame in affected individuals, leading to perceived, anticipated, and internalised aesthetic stigma.

Wiels, a 34-year-old CL patient, remarked: “I am really ashamed of it [the CL sore]. It is [looks] very dirty, you can’t give anyone something to eat, his appetite will vanish”. The feelings of being unattractive, and shyness due to having an “ugly sore” that sometimes even smells, is recognised by people in the hinterland. “Yes, it is a horrible illness”, many remarked when we discussed the aesthetics of the sore itself. It was understandable, they said, that people with CL feel bad because of the secretions of the sore, or if the sore becomes bigger and looks gruesome. After all, CL is considered a very nasty illness (see Chapter Four).

Danny, a 52-year-old construction worker, who had a sore on his underarm, remarked: "We [his family] are always very careful with our skin. It was a shock, it [the sore] grew out to such a calibre". Some patients were "disgusted" by their sores. Thirty-year-old Dwight told: "...when I take the bandage off my sores, my family can't look at it, because it looks so dirty...I was disgusted as well". Arno, a 27-year-old gold digger, told me:

My wife doesn't want to see the wound while I'm cleaning it, she turns away. When it's covered she doesn't mind it. Even I am disgusted by it, since I am someone who feels shy very quick, I'm a very sensitive person.

Other patients reported feeling "shy" or "ashamed" because of their sores. These feelings were also experienced if the sores became bigger, or if there were multiple sores. A 25-year-old villager in the Brokopondo Centrum area, an ex CL patient, remarked: "Yes, you are worried about a sore that is so big on your skin, it looks so horrible". Veldi, a CL patient with multiple sores on his forehead, the back of his arm, leg, and calf, expressed:

... the ones on my forehead I can't cover, I wished I could, because I'm ashamed of it. If people see it, what will they think of me? That I have some kind of incurable disease.

Another patient, a 22-year-old gold digger, said that he covered his nose with a handkerchief so that no one would see his sore: "It's disturbing to see it. I'm embarrassed by it, that's why [I use] a handkerchief". Some ex-CL patients in the hinterland villages also remarked that having a sore on their body, especially when it had an odour, made them feel shy. Ron, a 18-year-old CL patient, said that "people just had common reactions. I wasn't treated differently. But, I am not going amidst them, because they might find me dirty".

These illustrative accounts confirm that among those who experienced (enacted, perceived, and anticipated) aesthetic stigma, the look of the sores (the aesthetic dimension) played an important role in terms of (negatively) affecting the socio-emotional being of CL patients.

8.6.2 Spread, location, and visibility of sores

Aside from aesthetics, the course of the illness, the visibility of the sores (location and concealability) are clear dimensions fuelling the overt negative reactions of those in the social environment of CL patients. With regard to the 'course' dimension, strikingly, of the 66 CL patients who reported negative experiences because of CL, 23 patients (35%) had two or more CL sores on their body. The condition of these CL patients was thus (relatively) severe, and as Jones and colleagues (1984) point out, the more a condition aggravates and is visible, the more stigmatisation happens.

Some of the patients were very seriously affected by the illness, with disseminated forms of CL, such as in the case of Sandjay, a 39-year-old woodcutter.

He had many small, pimple-like sores spread all over his body; in this case, his colleagues urged him to stop working:

...my body itched. My uncle said you have to wear trousers. Because he was afraid, I think. But it wasn't that bad. My nephews came and saw it became worse, it smelled, the sores. They were like a pimple and they broke open, water was running out of it. My colleagues say it's contagious, I don't work anymore, because they didn't want me to.

In conjunction with the number of lesions, in some cases the size, location, and visibility of the sores – such as on hard to cover places like the face, ears, and hands – contributed to the experience of negative reactions (enacted stigma). Of the 66 CL patients who reported negative experiences, 10 patients (15.2%) had sores in the facial area (cheek, nose, ear, forehead) and neck. All of these patients had multiple sores; in the facial area but also on other body parts (arms, legs, trunk). The majority of the 66 patients (84.8%) had sores on the rest of the body (upper and lower extremities and the trunk). In fact, the majority of the 205 CL patients at the Dermatology Service – 151 CL patients (73.7%), including the 66 CL patients who experienced aesthetic stigma – had the sores on their legs, arms, and on the trunk; places which could be easily covered or hidden by general clothing (trousers or long sleeves). Although fewer CL patients had sores on the face or neck, in such cases it can be considered to be more grave in terms of aesthetic stigma. Synnott (1990:407) states: “Physical beauty...is inseparable from the face. The face is ... a pre-eminent symbol of the self, it is the mirror not only of the personality but also of the soul, as it is often of the emotions”. Physical beauty is “highly valued, and [a] powerful attribute, of the self” (Synnott 2006:163). Having facial disfigurements can therefore cause enormous distress and self-stigma, because of the importance of the face in social interaction (Synnott 1993).

8.6.3 Fear of contamination and of ‘not knowing’

The dimensions of ‘peril’ and ‘origin’ of the illness may have a great influence on the stigmatisation process (Jones et al. 1984:57-79). This study confirms this among those who experienced (enacted and anticipated) aesthetic stigma. Fear of contamination with CL in general, or for some, fear of contracting CL for a second time, can cause people to take distance from a person with CL. Persie, a 36-year-old gold digger, told me: “A nephew of mine stayed away from me; he had gotten it [CL] once and didn't want to catch it again. Other people were okay [with me]”. Marcio, a 23-year-old gold digger, reported that “people around me don't touch me; the fluid can be contagious”. Kaka, a 32-year-old guard, said that his mother and sister wanted him to keep a distance at home, saying that they could get contaminated if the wound fluid came into contact with their skin.

As elaborately described and discussed in Chapter Four, many patients and others in the hinterland do not know the biomedical characteristics of the illness. This ‘not knowing’ therefore fuels contamination theories and holds in place fear of CL, contributing to the strong reactions (enacted stigma) of those in the social environment of some patients. When it is believed that CL is contagious, or when the cause of the illness is not known, enacted stigma is reported. As many villagers

in the hinterland remarked, people are a lot more fearful and careful when they do not know the aetiology of the illness, and whether or not it is contagious. Taking distance is therefore seen as appropriate and necessary.

Another dimension influencing negative reactions and stigma is the notion of responsibility for the illness. As Jones and colleagues (1984:57) point out:

Many researchers and theoreticians concerned with stigma hold that the afflicted person's role in producing the mark is an important influence in the stigmatizing process. There is also general agreement that a marked individual is treated better when he or she is judged not to be responsible for the condition.

Among the group of CL patients who reported encountering no negativity, however, inquiries show that these patients were not held responsible for their illness; CL was believed to be caused by something of nature.

8.7 'Temporary' stigma

The study shows that enacted or self-stigma seem only to be experienced by CL patients during the course of the illness, i.e. while they actually have sores on their body. Ex-CL patients in the villages remarked that getting the sore cured was the worry. Upon cure of the sore, they no longer encountered others distancing themselves or their disgusted faces. The negativity seemed to vanish, as a 61-year-old man, an ex-CL patient and villager at Tepu, described:

When I had *kaasa*, I only wore trousers, because the sore was ugly. But the small mark that I have now on my body is okay; to the contrary, it has become a mark that I can show people where I got the *kaasa*.

CL patients consider marks that are left after the cure of CL lesions as less important; the most important issue for them is to get their sores healed.

8.7.1 Marks do not matter

Having healthy skin is highly valued in all societies; it forms an integral part of body image (Scheper-Hughes & Lock 1998:356), shaping one's 'being'. An ex-CL patient, a 48-year-old Maroon man, provided this striking description when he was asked the question of how he felt about his skin:

Me? I always look for fighting the thing [CL], because I see it [the skin/body] as a very important thing. Because it's your skin that makes you *be* a person. The skin makes it for you to be. If you don't have a skin, you're nothing. If your skin doesn't hold you together, you're wasted.

Indeed, having smooth, unblemished skin usually matters to people. Despite the value of such skin, surprisingly, for the majority of CL patients, the marks left behind after cure of the sores did not seem to be of major concern. In response to the question of what patients' biggest worry regarding CL was, only two patients (0.9%)

of the 205 replied that they were worried about the scars. This striking finding may be related to the fact that most of the CL patients were men, living and working in a harsh natural environment where, due to the nature of their work, scratches, cuts, and bruises are common and part of everyday life. In addition, being the head of the household and earning money to provide a living and take care of the family are viewed as more important than 'some scars' left from the sores.

Concerning the women, most were also used to working and living in an environment where cuts and scratches are often part of daily life. Furthermore, a hard working woman is highly valued, especially in the hinterland where clearing plots, planting, harvesting, and transportation of fruits and vegetables is the task of women (see Chapter Two). As the hinterland people said, having a female partner with some marks left on the skin due to CL sores is viewed only as a minor nuisance and nothing more. Wonna, a 30-year-old Maroon woman who lived at Godo-olo, experienced big CL sores on both her legs for more than a year. But her husband was caring and supported her, as she explained:

At home everything was normal. I cooked, he ate. If I didn't feel well, he cooked. I told him to sleep separately if he wanted, but he didn't want. He told me he won't get contaminated, that he loved me and that he would sleep together with me on one bed.

Wonna suffered a lot from the CL, but did not feel that she was treated differently:

I suffered a lot with those sores. It really hurt me, I couldn't do anything, sometimes it hurt me so much, sometimes it didn't at all. But nobody said anything to me, it was a normal thing; they [the people in the village], to the contrary, pitied me all the time. I was always an energetic person, but at times, and especially later, I couldn't do anything.

Her sores were cured after she received biomedical treatment at the Dermatology Service. In response to the question of whether she was worried that her husband would abandon her for another woman, she laughed:

I of course find those things annoying on my legs; even my husband says that those marks are making my leg ugly, but I can't do anything about it anymore... I am not afraid at all that my husband will leave me for those marks; that's not an issue at all. The marks are not important.

In the photograph below, the mark of the CL sores on Wonna's legs are clearly visible. She claimed that nobody in the village or elsewhere had ever discriminated against her or called her names because of the sores: "Everybody loves me, nobody says anything about them".

Photo 37: CL marks on Wonna's legs, six years after she contracted the illness



Source: Collection Ramdas, S., Godo-olo, October 2009

It was observed in the village that Wonna was a well respected member of the community and was not treated in any way differently. Neighbours did not avoid her, and Wonna was actively involved in all kinds of social activities – cutting plots open, fishing, dancing – together with other women of the village. She did not seem to be occupied with covering her marks (as can be seen in the picture above), and wore the *pangi* (Sr) – traditional clothing, a piece of cotton cloth – in the usual style: wrapped around the hips or the whole body down to the knees or the calf, leaving the shoulders bare. In the picture above, Wonna wore a *pangi* to her knees, and in the next picture, another Maroon woman can be seen wearing the *pangi* covering her body (the trunk), with bare shoulders and bare lower limbs. In such clothing, marks on the shoulders and the upper and lower extremities are thus clearly visible.

Photo 38: Maroon woman wearing the pangi (traditional clothing)



Source: Collection Ramdas, S., Brokopondo Centrum, April 2010.

8.7.2 Other worries that mattered

The study further shows that of the 205 CL patients, a group of 62 (30%) reported having “no worries” about the disease. Patients said that they knew a cure existed for their illness, thus there was nothing to worry about. Hendrik, a 43-year-old Maroon woodcutter, said:

No, no, no, I have no concerns. My brother told me to come here [Dermatology Service]. He had a lot bigger sores and he got nine injections. I am not afraid at all for this illness, a lot of people showed me. This illness exists a lot. As soon as you go to the woods, you can get it. And everybody who showed me got healed.

The fact that patients believed that the illness is curable contributed to them not worrying about their condition.

A group of 25 patients (12%) worried mostly about their work, loss of income, and the costly treatment. As Blaka, a 40-year-old Maroon gold digger commented: “I am worried that I can’t work anymore, because if I work, water will enter my boots and then the sore will get worse. The sore must get healed”. Blaka also had a large family with eleven children to take care of. He could not afford a loss of income, and with a job like gold digging, income is not always guaranteed. Shaam, a 32-year-old Hindustani man who worked as a furniture maker, who had sores on his hand and on the back of his head, shared: “I’m worried, because I have to take care of my mother, brother and sister. I’m the only one who provides income, and now I can’t work”.

A group of 14 patients (6.8%) worried about disabilities and amputations. Sam, a 37-year-old gold digger, said: “It should heal, because I heard that if the sores get bigger, your legs can be chopped off. And if you lose your leg, you won’t be able to work”. Another CL patient, a 28-year-old security officer, remarked: “Yes, I’m worried. Maybe only my bones will be left over and my arm will get cut off. Who can guarantee me that this won’t happen? Because something is eating me up”. The remainder of the patients (104, 50.7%) were mostly worried about a variety of aspects related to the course of the illness, the (lengthy) period of treatment, and its efficacy. Some often heard comments were: “I’m worried because I don’t know how long it will take to get cured”, “I’m worried because it takes a long time to cure. Can’t it go faster?”, or “I’m worried that the sore will grow larger and larger”.

All 39 patients who had worries thought that CL is a very serious illness, and were more worried about its rapid spread over their bodies than about the scars that the sores would leave behind. Mostly they felt frustrated that it took a long time to be cured. Three patients had to cease their work because of the rapid spread of the sores and the lack of results with self-treatment. They had to leave their work in the hinterland in order to find a cure; as they said, their most important concern was to get well soon and continue with their jobs.

8.8 ‘Absence’ of enacted stigma related to CL

My findings suggest that the majority of CL patients in my study (83.9%) – and thus perhaps the majority of CL patients in Suriname – did not bear enacted social

stigma, and were not blamed or rejected, as is reported in other countries (Kassi 2008; IRIN 2008). The majority of people with CL sores keep their 'personal identity' intact; their identity is not 'tainted' or 'spoilt' (Goffman 1963), and they hardly *become* their illness (Estroff 1993; cf. Kwansa 2013). As far as I have been able to observe, people with CL are not isolated or hidden. Medical doctors and health workers working in the hinterland and at the Dermatology Service also perceive CL as a low stigmatised illness. As a medical doctor commented: "We don't think there is a lot of stigma related to *Busi Yasi* here in Suriname" (Personal communication, Dr. Van Eer, 2009).

Those in a CL patient's social environment stay in touch with the person in a similar way during the illness as before the illness; rejection or social exclusion (Weiss & Ramakrishna 2004) because of the illness does not seem to occur. There is, furthermore, hardly any 'hidden distress' (Scambler 1998) related to CL; there is hardly any taboo in talking about sores or showing them to others, such as close family members, friends, or colleagues. Having CL sores thus does not seem to block or hamper interaction and communication (Jones et al. 1984:24) with those in the social environment. To the contrary, the majority of patients showed their sore(s) openly to others, in the hope of receiving advice for an effective medication in order to avoid biomedical treatment (see Chapters Five and Six).

8.9 Why the relative absence of CL stigma in Suriname?

In sharp contrast to earlier studies on CL related stigma (Kassi et al. 2008; Reitingger et al. 2005), and the international concern for the severity of CL related stigma (WHO 2008, 2007; Modabber 2006; Gonzáles 2013), data from this study shows that most CL patients (61%) did not experience any negativity at all related to their illness, and that during their illness, they experienced 'normal', 'as usual', or 'no different' treatment from those in their social environment. The data also shows that although some patients spoke about the negative reactions of others, these reactions were mostly related to a combination of the dimensions of aesthetics, course, concealability, origin, and peril (Jones et al. 1984). In particular, not knowing the cause of the illness and fear of contagion was mostly shared by the patients themselves, which led to them taking precautions when coming into contact with others or even withdrawing from certain situations or encounters. It was only at this level of analysis that some aspects of anticipated and internalised stigma were found.

In a 2012 press release on cutaneous leishmaniasis, the WHO stated that in the WHO Mediterranean Region (comprising of 23 countries in the Middle East, North Africa, and South West Asia), the disease is highly prevalent, and "despite not being fatal, it causes immense stigma affecting the social and economic well-being of affected people and communities".⁷⁶ In contrast to this assessment, the relative absence of CL stigma in Suriname is striking. Throughout this chapter, as well as Chapter Four, I have provided several insights into why this is the case in Suriname. In the following section, I (briefly) list the already discussed aspects, and add some others that show why, compared to some other countries in the world (such as

⁷⁶See web reference number 37.

Pakistan, Afghanistan, Peru, and countries in the Mediterranean Region), CL patients in Suriname experience less stigma.

8.9.1 CL is a curable, non-chronic, and 'low priority' illness

The first aspect is related to CL's status as a curable illness. CL was perceived as a curable illness by the majority of CL patients (97%) in the study, unlike some other (highly stigmatised) illnesses like HIV/AIDS and some mental illnesses. In most cases, it is just about finding the 'right' treatment. Many people have lay knowledge about CL (60% of all CL patients in the study claimed so), and know or have heard of a variety of treatments to cure it. CL can be categorised as an *I have* illness, and not as an *I am* illness (Estroff 1993:253); patients always say "I have *Busi Yasi*" and not "I am *Busi Yasi*". The illness does not overtake the patients' personality or identity; it is something that affects them from the outside, and most importantly it has a cure. Biomedical treatment is viewed as *the* treatment that makes CL a definitively curable illness.

Added to this, CL it is considered a non-lethal illness, unlike, for example, illnesses such as Malaria (which may be curable, but very quickly can become deadly) or HIV/AIDS (which still has no cure and is lethal without medication). It is, therefore, viewed as a 'low priority' illness. As a CL patient at the Dermatology Service remarked: "*Busi Yasi* [CL] is not really an illness, it is just a sore. That's it and nothing more". Abazid and colleagues (2012), who investigated the knowledge, attitudes, and practices among 70 CL patients in Aleppo, Syria, highlight the work of other researchers (Siage 1964; Peters 1988) investigating CL in Syria who found similar attitudes. They report that:

Siage, working in Damascus in the early 1960's, mentioned that the villagers tended to ignore the lesions because they are indolent, and "the scars are usually not feared" ... Peters, in his 1988 paper on CL in the Arabian Peninsula, mentions that this disease "was simply accepted as part of life...". (Abazid et al. 2012:8)

According to Abazid and colleagues, these research studies, plus their own research, suggest that CL patients are either not stigmatised or experience only low levels of stigmatisation in Syria. Indications of CL as a low or unstigmatised illness are also provided by another (clinical) study conducted by Llanos-Cuentas and colleagues (1984), performed in Tres Bracos, Bahia, Brazil among 182 CL patients. According to the researchers, "it was understandable" that most patients' refused "to have a further biopsy after healing", because "cutaneous leishmaniasis does not carry the stigma of leprosy" (ibid:175). These statements give the impression that also in this region, CL is not viewed as a particularly disturbing illness.⁷⁷

⁷⁷Since this study was a clinical study and the aspect of stigma was not the focus, results may have been different if investigative questions had been asked about CL stigma. Nevertheless, their observation is striking.

8.9.2 CL is a non-contagious, openly talked about illness

CL is generally considered a non-contagious illness. As reported in Chapter Four, of the 205 CL patients, 89 (43%) did not believe CL to be contagious, and 40 patients (20%) did not know if it was. Because of this, CL is a low stigmatised disease. Unlike other illnesses, there is also hardly any taboo in discussing CL, because the biggest concern is to find a treatment that works (see Chapters Five and Six). It could be argued that because there is no taboo, there is therefore no stigma; but no stigma and therefore no taboo could also be the case in Suriname.

The data also shows that the dimension of peril (fear of contagion) plays an important role, especially among patients who experience enacted and internalised stigma. Earlier studies on CL conducted in Aleppo, Syria (Abazid et al. 2012) and Kabul, Afghanistan (Reithinger et al. 2005) support the link between (beliefs about illness) contagion and (low or high) CL stigma. Abazid and colleagues (2012), as mentioned in the section above, found that most of the 70 CL patients in Aleppo did not think CL is contagious. The researchers also stated that although their questionnaire “did not address issues of stigma and did not contain specific questions about marginalization”, they felt that “most probably, if any significant social exclusion/isolation existed, it would have been mentioned one way or another” (ibid:13). On the other hand, in Kabul, Afghanistan, “because erroneous beliefs exist that the disease can be transmitted by person-to-person physical contact... affected people are excluded from communal life” (Reithinger et al. 2005:635).

8.9.3 CL is caused by nature

Although in general CL is well known to many people working and living in the hinterland in Suriname, no one seemed to know the (biomedical) aetiology of the illness, as I have extensively described in Chapter Four. However, the data shows that the majority of CL patients (and others in the hinterland) thought that CL is caused by “something of nature” (most likely a fly or different types of insects); the illness is not believed to be transmitted from human to human, as in other countries of the world such as Afghanistan (WHO 2002:246). CL in Suriname is contracted “if one visits the woods”.

This lay perception of the aetiology of the illness (related to the ‘peril’ dimension of Jones et al. 1984) is yet another aspect that probably contributes to the absence of social stigma, since it is not a human being but nature which is ‘blamed’ for the illness. This means that there is no moral dimension attached to having CL; having the illness does not mean that one is a ‘morally bad’ person. Likewise, Abazid and colleagues (2012), who noted having come across no “social exclusion/isolation” among CL patients in Aleppo, Syria, found that most of their patients linked the origin of the illness to insect bites.

The link between knowing the aetiology of the illness and lower CL stigma is strengthened by studies conducted in Kabul, Afghanistan, where Reithinger and colleagues (2005) reported on the negative social impact of CL on patients’ lives. They found severe stigmatisation of CL patients because CL was thought to be caused by touch, “from person-to-person” (ibid:635). Out of their 66 focus group participants, concerning the origin of CL only “29 (44%) knew that it was transmitted by mosquitoes” (ibid).

8.9.4 CL is less destructive due to differences in parasite species

A possibly crucial aspect contributing to relatively low CL stigma in Suriname in general, and to low aesthetic stigma in particular, both during and after CL illness, may be related to regional differences in parasite species that lead to different symptomatic profiles, and therefore to a less destructive form of CL in Suriname than in other parts of the world.

While in some parts of the world, facial disfigurement due to CL sores on the cheeks, nose, lips, and forehead is more common and/or extremely severe due to harsher types of cutaneous leishmaniasis as well as mucocutaneous leishmaniasis (WHO 2002, 2007; Diniz et al. 2011; Reithinger et al. 2010; Khan & Muneeb 2005; Afghan et al. 2011), in Suriname this is hardly the case. The main causative agent for CL in Suriname is the parasite *Leishmania (Viannia) guyanensis*, which leads to a generally less extensive and destructive form of CL (Hu et al. 2012). The aesthetic dimension that contributes to low or high stigmatisation is thus an important one. Aesthetically, CL sores caused by *Leishmania (Viannia) guyanensis* have a less devastating effect than lesions caused by mucocutaneous leishmaniasis, whereby facial disfigurement can be very devastating.

Van der Meide and colleagues (2008:857) reported on a rare case of *Leishmania (Leishmania) amazonensis* infection in Suriname. According to the researchers, this type of parasite causes standard CL as well as two very serious manifestations of CL: disseminated cutaneous leishmaniasis (DCL) and anergic diffuse cutaneous leishmaniasis (ADCL). As the researchers also point out, however, *L.(L.) amazonensis* infections are rare in humans, and only a few patients have been identified with the condition in neighbouring French Guiana (ibid:859). Hu and colleagues (2012) only recently identified the parasite causing mucocutaneous leishmaniasis, *Leishmania (Viannia) brasiliensis*, in one Surinamese patient. This type of parasite has a different symptomatic profile, leading to severe and extensive destruction of the mouth, nose, and throat.

Up to now, heavy facial disfigurement due to mucocutaneous leishmaniasis, or severely corroded skin due to extensive spreading of sores over the body (leading to total bodily disfigurement) due to CL, and other manifestations of CL, are rare in Suriname, or confined to a few cases only (Van der meide et al. 2008; Hu et al. 2012).

8.9.5 Because location and visibility of the sores on the body matters

Related to the parasitological differences – and therefore varying symptomatic differences – the location of the sores on patients' bodies may also play a major role in the relative absence of CL stigma. In this research, from the total group of 205 CL patients, 151 had sores on their upper and lower extremities and trunk (73.7%), while only 39 patients (19%) experienced sores in their facial area and head (i.e. cheeks, nose, chin, forehead, back of the head, neck, ears).

Disfigurements in the face – the body part that is the most viewed by others, that holds a person's identity and personality, and is the place of emotional expression (Synnott 1993) – can seriously contribute to experienced stigma (Kassi et al. 2008; Reithinger et al. 2003, 2005). The point here, however, is that compared to those who had sores on easily coverable body parts (arms, legs, trunk), those

with CL sores that were more visible made up a much smaller group (almost four times smaller), which in turn led to fewer reports of CL stigma. This is in sharp contrast to findings from CL research in Kabul, Afghanistan, where Reithinger and colleagues (2003:727) noted that “most lesions occur on the face, often leading to severe stigmatisation in affected persons”. Afghan and colleagues (2011:2) further reported that in Pakistan, “lesions are...increasingly seen in various unusual forms, for example, as fissures on lips, with lupoid features on face and/or psoriasiform plaques on the nose”.

Related to the location and visibility of the sores is the aspect of covering sores. Because most of the CL patients in this study had sores on their upper and lower extremities and the trunk, at the Dermatology Service it was observed that sores were ‘automatically’ covered by clothing. In this way, patients could easily conceal their condition, which again makes the relative absence of CL stigma in Suriname understandable. Furthermore, because of its “dirty looks”, some patients covered their sores with plasters, like the patient in the photograph below, so that negative attitudes or remarks of others could be avoided.

Photo 39: Plaster on a CL sore on the arm of a CL patient at the Dermatology Service



Source: Collection Ramdas, S., Dermatology Service, June 2010

Sores were also covered because the majority of CL patients (161, 79%) self-treated their sores with medicines that required bandaging.

Strikingly, on this topic, many people in the hinterland commented that they believed that CL sores should not be covered because this would supposedly hinder a quick cure; some CL patients at the Dermatology Service also mentioned this. Covering the sore only for the purpose of covering it would cause the sore to secrete more fluid. Ideally, therefore, CL sores should be left open to stimulate quick healing. However, since many flies are attracted to open sores, for hygienic purposes CL patients and those in the hinterland said that sores – preferably after applying some kind of bush medicine to it – should be covered. The inquiries indicate that covering sores to avoid stigma was thus not (per se) *the* reason to cover sores.

In Afghanistan, however, because lesions appear so much on the faces of people “affecting prominent features such as nose or ears” (Kassi et al. 2008:e259), and because CL patients stay with CL sores for many years (ibid), concealment of the condition is more difficult. Kassi and colleagues (ibid) even reported on the case of a 28-year-old woman who had had CL lesions on her face continuously since she was twelve years old. It is imaginable that growing up with destructive lesions on the face, visible to everyone, such patients will experience severe stigmatisation.

8.9.6 CL has a low prevalence

The relatively low prevalence of CL is another aspect contributing to why CL may not be a severely stigmatised illness in Surinamese society. As people in the hinterland remarked, sometimes the illness is ‘absent’ and sometimes many people are seen with it. At Donderskamp, a 53-year-old hunter, said: “It is varying. Let’s say this year you’ll see two or three persons with it, and then maybe in three or five years you’ll see it again. It is not that often”. Van der Meide and colleagues (2008:192) note that “CL is not a notifiable disease” (i.e. it is not a disease that is required by law to be reported to government authorities), it does not occur on a wide scale, and is therefore less prominently present in people’s lives. The illness is foremost present in the hinterland, where only about ten percent of the total Surinamese population (i.e. 541.638 people) lives (Algemeen Bureau voor de Statistiek 2013:23).

The situation is quite different in Afghanistan, for example. As Reithinger and colleagues (2005:634) reported: “For almost a decade, Kabul, Afghanistan, has had the highest incidence of CL in the world, with an estimated 67,500-200,000 cases each year”. Furthermore, the number of leishmaniasis cases has been increasing “in South Asia, particularly in Afghanistan” (Reithinger et al. 2010:2). The last estimations of the annual incidence of CL in Suriname were made between 1979 and 1985 where a mean annual incidence of 4.9 per 1000 inhabitants in the hinterland and 0.66 per 1000 for the whole country was reported (Burgus & Hudson 1994); furthermore, according to Hu (2013:13), about 300 new CL cases were registered at the Dermatology Service in 2011.

8.9.7 Because of gender, profession, age, and cultural differences

As remarked earlier, the majority of 205 CL patients in the study at the Dermatology Service (183, 89.3%) were men. Most of them are used to working in and exploring the harsh Amazonian rainforest (where infected Phlebotomine sand flies thrive), and their professional background as gold diggers, woodcutters, construction workers, or their hobbies such as hunting and fishing in the woods, make them vulnerable for – and at the same time nonchalant towards – all kinds of cuts, bruises, and sores, many of which they may experience almost on a daily basis. Having a CL sore, therefore, may not quickly be considered as something very serious (especially in the beginning).

In Afghanistan, however, where “severe stigma and trauma are associated with the disease” (Reithinger et al. 2008:635), women are found to be “at greater risk for contracting CL” than men (ibid). Unlike CL in Suriname, in Afghanistan it is “anthroponotic (i.e. humans are the reservoir)” (Reithinger et al. 2003:727) and the risk of contracting CL “is associated with household construction (i.e. brick walls) and design (i.e. proportion of windows with screens)” (Reithinger et al. 2010:e639). With Afghan women (as well as children and the elderly) staying indoors more than men, they are more likely to be infected with CL. Afghan and colleagues (2011:2) reported that in Pakistan, “women and children are particularly affected”. Kassi and colleagues (2008:e259) mention that in Afghanistan and Pakistan, women with CL are particularly “victimized, as they are considered unacceptable for marriage, sometimes by their own families”. Velez and colleagues (2001) report that in

Colombia, women with cutaneous ulcers are also stigmatised; their spouses sometimes leave them, using their condition as a pretext.

In my study in Suriname, the group of young CL patients was, in general, very small. Of the 205 CL patients, there were only twenty patients (9.8%) below 19 years of age. Only two children younger than four years were infected with CL; most likely because their mothers took them along to their plots while they worked. In Kabul, Afghanistan, however, Reithinger and colleagues (2010:e659) noted that of 10,596 CL patients, the median age was fifteen years. Khan and Muneeb (2005:4) also reported that of 738 cases of CL in the Northwest Frontier Province of Pakistan registered by the WHO, these were “mostly in children under the age of fifteen”. Children also experience CL stigma. As Reithinger and colleagues (2005:635) described, “children felt disfigured because of lesions or scars ... or because they were excluded from play with other children”.

In Suriname, inquiries in the hinterland villages revealed that social exclusion of children with CL did not happen: they could go to school “without any problems” and were allowed to play with others. Two factors should not be overlooked here: 1) that close proximity with others does not lead to contamination with CL in Suriname, unlike in Afghanistan (Reithinger et al. 2010:e639) and Pakistan (Khan & Muneeb 2005:4), where because of its anthroponotic character, this is the case; and 2) that in Suriname CL sores appeared more on the upper and lower extremities and less on the face, unlike in Afghanistan where most lesions appear on the face and hands (Reithinger et al. 2003). These differences in the primary location of the sores between Afghanistan and Suriname is likely related to clothing, since in Afghanistan women and girls wear clothing that covers most of the body except for the hands and face, whereas in Suriname men usually walk around (and work) in the forest with bare arms, legs, and even torsos due to the heat and humidity. These two key factors probably contribute to the non-stigmatising attitude of others towards CL patients in general.

Gender, and related to that profession, age, and culture, may therefore be important aspects contributing to less CL stigma in Suriname than in other countries in the world, in particular Afghanistan. Maybe, if CL affected more women in Suriname, or if it affected women with a different cultural background (for example Hindustanis and Javanese as opposed to Maroon women), those living in a city environment (as opposed to the hinterland), those with an aesthetic oriented profession (especially commercial sex workers), or finally children, the picture of overt and aesthetic stigma during and post CL illness would be different.

8.10 Conclusion

The WHO (2007, 2008, 2013) and researchers involved in CL studies (Kassi et al. 2008; Yanik 2004; Reithinger et al. 2005, 2010; Afghan 2011) have increasingly highlighted CL as a stigmatising illness because of its disfiguring capabilities and the great social impact it has on patients' lives. Investigation into CL stigma in Suriname was therefore an important component of this current research. The aim was to assess the extent of CL stigma in Suriname, and the way(s) in which stigmatisation happens (enacted, perceived or felt, anticipated or internalised). The multi-dimensional model of Jones and colleagues (1984) was used as a theoretical

framework to assess six key dimensions relevant in stigmatisation: concealability (of CL sores), course (of the illness), disruptiveness (of social interaction due to CL), aesthetic qualities (of CL sores and their role in experiencing stigma), origin (of the illness), and peril (related to contamination with the illness). The findings of this research suggest that CL is a low stigmatised illness in Suriname.

The study shows that of 205 CL patients, 125 (61%) did not experience *any* negativity due to their illness, and 172 CL patients (83.9%) did not experience enacted stigma. The findings suggest that people with CL encounter relatively little discrimination or other overt acts of negativity solely based on the presence of CL lesions on their bodies. The majority reported that they were treated as “normal” or “not differently” by those in their social environment. Patients disclosed their illness without hesitation to those in their social environment, could speak freely about the illness, and were often advised to “go to the doctor”. This ‘normal’ or ‘as usual’ attitude of the community, family members, friends, and colleagues reflects the general experience that people have with CL as a well known, non-contagious, and curable disease. Patients generally receive support and compassion from those their social environment, and families tend to be concerned or worried about patients’ conditions.

A group of 66 CL patients (32.2%) out of the total of 205 did, however, experience enacted, anticipated, internalised, and aesthetic stigma, which affected their lives and socio-psychological being in a negative way. The encountered or anticipated reactions included physical and social distance in relation to others (either enacted by others, or by the CL patient him- or herself), avoidance of public places and social activities, and concealment of sores. In terms of aesthetics, patients felt uncomfortable with the sores on their bodies, and suffered from feelings of shame and ugliness. Strikingly, these feelings seemed to be of a temporary nature. Upon healing of the sores, the experienced negative feelings or attitudes from those in their social environment also disappeared; and marks left by the sores were not perceived as particularly important.

Closer investigation of these experiences and their influence on patients’ personal feelings, daily lives, and activities revealed that in nearly all cases, stigmatisation – in the sense of ‘spoiling the patient’s identity’ – did not occur. CL sores are not “an attribute [that is] deeply discrediting” (Goffman 1963) for CL patients, marking them as essentially and morally bad individuals (Dijker & Koomen 2008); most likely, this is because CL is considered to be contracted through something of nature and not from person to person, and therefore a ‘moral’ dimension related to contracting the illness is lacking (Jones et al. 1984; Estroff 1993).

Based on the findings of this chapter – and those discussed in the previous chapters – stigma most likely does not hamper biomedical treatment, nor does it reduce treatment adherence or favour resort to traditional medicine. For public health authorities in Suriname, undoubtedly this conclusion contributes to at least one less ‘burden’ in their fight against CL. Their efforts and energies can instead be focused on increasing treatment adherence, case findings, and prevention of CL.

Nevertheless, overt, anticipated, or internalised negativity due to CL was experienced by about one third of the 205 CL patients. Public health authorities should be aware of – and act upon – the different types of CL stigma, since they may require specific suitable health education and stigma sensitisation programmes.

Since lack of (biomedical) information about the illness aetiology and biology are important aspects that contribute to fear of contamination with the illness and a cautious attitude towards CL patients, the research findings suggest that illness education programmes (in particular those aimed at the target population) will most likely be beneficial in combating the overt, anticipated, and internalised stigma that are experienced by some. Public health authorities in Suriname should initiate such programmes as soon as possible. CL patients experiencing problems with aesthetics because of CL should be offered proper information, guidance, and counselling at health clinics, in particular at the Dermatology Service.

Strikingly, this research reveals a relative absence of CL stigma in Suriname compared to other countries in the world (Afghanistan, Pakistan, Turkey, countries in the Eastern Mediterranean region), where CL patients are severely stigmatised (WHO 2013; Kassi et al. 2008; Reithinger 2005; Yanik 2004; Afghan 2011). This relative absence of CL stigma in Suriname can be understood as a result of several different aspects related to: lay perceptions; aetiological explanations; biological, parasitological, and epidemiological characteristics of the illness; and socio-cultural (gender and age related) differences cross-culturally.

Findings of this study suggest that lay perceptions of CL as a curable, non-chronic, non-lethal, and non-contagious illness are related to low stigmatisation of CL. In Suriname, this is the case, as has also been found elsewhere (e.g. Aleppo, Syria, Abazid et al. 2012; and Bahia, Brazil, Llanos-Cuentas 1984). If CL is believed to be contagious, in particular caused by physical person-to-person contact, as it is in some countries (Afghanistan, Pakistan), CL stigmatisation seems more likely (Reithinger et al. 2005; Kassi et al. 2008).

The difference in parasite species, leading to less severe or more dramatic disfigurement, especially in the face, is a crucial aspect contributing to harsh CL stigmatisation (as it is in some countries – cf. WHO 2013; Afghan 2011; Kassi et al. 2008; Reithinger 2005) or the relative lack of it (as is the case in Suriname – cf. Hu et al. 2012; Van der Meide et al. 2008). The increased incidence of CL lesions on the face compared to on other body parts (which is not the case in Suriname, in contrast to other countries such as Afghanistan and Pakistan) also makes it harder to conceal the illness and its symptoms, most likely leading to greater stigma.

Added to this, the fact that in Suriname more men than women are at risk of CL, and a smaller group of children are affected, unlike in Afghanistan and Pakistan (Kassi et al. 2008; Reithinger et al. 2010; Afghan 2011) most likely contributes to lower stigma. In Afghanistan and Pakistan, women and children in particular are severely stigmatised (Reithinger et al. 2005:635; Kassi et al. 2008). In Suriname, this is not the case. Moreover, the number of people affected by the illness in Suriname is far smaller, with a mean annual incidence of 4.9 per 1000 inhabitants in the hinterland and 0.66 per 1000 for the whole country (Burgus & Hudson 1994); compared to Afghanistan, where in Kabul alone, annual incidence is estimated between 67,500 and 200,000 cases (Reithinger et al. 2005:634). The combination of CL as a low prevalence illness in Suriname and its curable (non-lethal and less severely damaging) character makes it a 'low priority' illness in the country, and this in turn makes it understandable why there is a relative absence of CL stigma.

The attempt to provide insights into the dynamics of CL stigma in Suriname, as compared to some other countries in the world, reveals that relatively little is known about CL stigma, or lack thereof, worldwide. Stigma and CL stigmatisation

remain very complex processes that take shape and are shaped by a multitude of aspects; and thus require careful investigation. Efforts of researchers focusing on CL stigmatisation and its devastating effects are applauded; however, the different types of stigma – enacted, felt or perceived, anticipated, internalised, and self-stigma – and its many dimensions should be taken into consideration when conducting CL stigma research. Currently, these are lacking, but being aware of them and including them in future CL research will contribute to more detailed insights that can be helpful in combating CL stigma more effectively on different fronts.

Chapter 9 **Prevention of cutaneous leishmaniasis in Suriname: different perspectives**

Despite the widespread view that prevention is better than cure, the concept of prevention has received scant attention within medical anthropology (Krumeich 1989; Van der Geest & Krumeich 1989:39-40). Krumeich (1989:72-73) points out that medical anthropological studies tend rather to illuminate the more striking, exotic aspects of traditional healing systems. Prevention, according to her, 'belongs' to the unobtrusive everyday life of people. It is therefore easily neglected and barely referred to (Müllen 1983).

Krumeich criticises medical anthropologists (e.g. Foster 1962; Lieban 1966; Paul 1955) for their ethnocentric approach to prevention when comparing 'non-Western' and 'Western' cultures. The former are portrayed as 'primitive', fatalistic, passive, and therefore lacking true preventive efficacy, while the latter are seen as scientific, active, and future-oriented. However, with her research among the Carib people of the Bigi Poika village in Suriname, Krumeich describes a 'non-Western' culture that, though very different from a 'Western' system, *was* future-oriented and *had* an active preventive health care system.

Using Krumeich's data, Van der Geest and Krumeich (1989) – following Douglas and Wildavsky (1982) – added that the concept and practice of prevention is culture bound. 'Dangers', they note, do not exist 'just like that'; they are identified and selected on the basis of cultural premises (Van der Geest & Krumeich 1989:45). This study reinforces this idea that 'lay' perceptions of prevention are culture dependant: in the case of CL, lay prevention is context bound in multiple ways. This chapter focuses on perceptions of CL prevention and explores how these perceptions are linked to local concepts of CL aetiology, 'not knowing', plus ideas and practices derived from biomedicine, such as public health campaigns and curative treatments.

These insights into lay ideas about CL prevention arose from investigations into how (according to CL patients) CL could be prevented, and what their perceptions and ideas concerning CL reflect. This study shows that CL patients have ideas about prevention that are based on their own perceptions of the illness, as they are intertwined with public health perspectives. Although the concept of treatment seeking refers to prevention (see Chapter Two), this research shows that concepts of CL prevention are hardly part of 'treatment seeking'.

9.1 How to prevent CL: lay perspectives

Because "prevention and maintenance are based on the identification of dangers" (Krumeich & Van der Geest 1989:45), the way in which dangers are identified is, logically, key to prevention. The obvious 'dangers' to CL patients are everything that can cause CL. As discussed in Chapter Four, several such dangers have been identified. For example, in the perception of CL patients, certain lianas are labelled dangerous, since they are viewed as having the power to 'give' CL. This chapter shows that the variety of identified dangers results in a variety of possible solutions

or ways to prevent the contraction of CL. In what follows, these solutions, i.e. CL patients' thoughts on CL prevention, are presented and discussed.

9.1.1 'I don't know': mysterious disease, puzzling prevention

The majority of people approached in this study responded to the question of how CL could be prevented in a similar way to Hardy, a 40-year-old hunter at Donderskamp:

Well... That's a good question, because you don't really know what causes it. Whether it's a liana, bacteria, a fly, a mosquito, you can't see... So, to prevent it, well... that's a difficult question. And, it's [CL] not something that happens every day...

'I don't know' was by far the most common answer given by CL patients in response to the question of how CL could be prevented (see Table 10 below), acknowledging the unknown aetiology of the illness. Many patients simply said "I don't know [how to prevent CL], because I don't know what causes it". Not knowing the aetiology of the illness causes patients to be concerned about its prevention. So CL is described as a 'mysterious' disease, leaving those who are vulnerable to it wondering how to avoid it. Mokko, a 30-year-old CL patient and a woodcutter, answered:

I have to be careful even though it's hard for me to be so careful, since I have no idea how I got it. Was it a mosquito, a tree, a leaf? I'm not sure. I don't know... I would not know how to prevent it.

The 'invisibility' of the illness's origin and its unknown causative agent confuses patients. As Kumar, a 36-year-old CL patient and Hindustani truck chauffeur, reacted:

I have no idea [how to prevent CL]; because you won't see it coming, it doesn't announce its arrival. Most people run [in] to it by accident. I have no idea what I can do; I'm not even sure where I got it...

Because CL is a vector-borne disease, environmental changes influence outbreaks of the disease. Thus during the rainy season, more people are infected with the *Leishmania* parasite than during the dry season (Van der Meide et al. 2008:192). These fluctuations are noted by CL patients and others in the hinterland. A 60-year-old Maroon woman at Godo-olo said: "The people here [in the hinterland] have to do with *Busi Yasi* during certain seasons, especially the rainy season". In another conversation with three gold diggers at Paaston, they reported:

A: In May, or [during the] big rainy season, you have a lot more [cases of CL]. In those times, it's the *Sunna* [Au] that's flying around everywhere. Those are yellow-black flies.
B: Yes, you get *Busi Yasi* in certain periods. Most of the time you get it when you're in the woods.

C: Yes, right... It's a very bold disease, because it doesn't consider any kind of a planning you have. It does as it wishes. And if you come to the interior, you'll get *Busi Yasi*.

There are, however, others who are oblivious to the seasonality of CL. Sudden outbreaks leave people wondering about the illness: when it comes and when it goes, what causes it, and how to prevent it; one simply does not know. Roy, a 40-year-old CL patient, puzzled:

Because you don't know how it's caused, you don't have any idea of how to prevent it. Maybe something bit you and you haven't paid attention. The illness has its season. Now [September 2009, dry season], for example, there is nobody with it. But when exactly you see people with it, I don't know, it's only that sometimes you see a lot of people with it.

An often heard explanation of given by CL patients was that they did not know how to prevent the illness because there was no public health information about it. Especially in the past decade, people have been receiving health education about malaria through campaigns aimed at those living and working in the hinterland. In 2006 and again in 2008, malaria control programmes were successfully implemented in Suriname by the Medical Mission and the Bureau of Public Health (BOG) respectively. As Breeveld and colleagues (2012:5) report, among the main interventions were "Active Case Detection (ACD) campaigns, distribution of nearly 70,000 long-lasting impregnated nets (LLINs), the protection of more than 5,000 individuals by additional indoor residual spraying (IRS), and information and communication meetings", all of which implied a huge involvement of the local population.

Being accustomed to receiving such intensive information and education about malaria makes people wonder why, in the case of CL, there is no public health information at all. A 47-year-old military man and hunter said:

We have to know what caused it, that's what we have to know. And there must be information and education on the television, and then only we can avoid it [CL], prevent it...

Some CL patients thought that BOG should make CL "a priority" and provide proper information, because "why so much information about malaria, but nothing about *Busi Yasi*?"

Though 'I don't know' was an often heard answer, the research also shows that there were CL patients at the Dermatology Service who did have ideas of how to prevent CL. In the following table an overview is provided of the most mentioned – and sometimes grouped – ideas, and the number of times they were mentioned.

Table 10: Ideas on CL prevention and the number of times they were mentioned by 205 CL patients (multiple answers were possible)

Ideas about CL prevention	Frequency
I don't know	87
Sleep under mosquito nets, use insect repellents, wear protective clothing (long sleeves, trousers, boots, thick clothes) so whole body is covered up.	37
Avoid going to the same place where illness was caught or do not go to the bush; avoid hunting, working, or walking in the bush.	33
It is unpreventable.	24
Injections; the injections of the doctor are like a vaccination.	24
Knowing what causes the illness, getting more information about it, going to the Bureau of Public Health and getting advice on how to prevent it.	16
Use of home remedies: - Smear <i>Krapa</i> oil on the body before entering the bush. - Drink bitter things in order to embitter the body and blood, and wash the body with [bitter] leaves. - Smear diesel/gasoline on the body. - Avoid certain foods, do not eat certain wild meat.	14 (6) (5) (1) (2)
Once you get CL, you don't get it again.	9
If possible, a vaccination, swallowing the right medicine. - Swallowing amoxicillin to get a stronger body.	6 (1)
Spray the bush with insecticide (malathion), either by individuals or the Bureau of Public Health, similar to malaria eradication programmes.	4
Keep the working area or hunting area clean where camps are made, keep body clean, be careful in the woods.	4
Stay away from someone with CL; not to discriminate, just [to] be careful.	2

9.1.2 Adopting a public health perspective to prevent CL

As the table above shows, CL patients had multiple ideas of how to prevent CL. Among these, the most frequently mentioned prevention strategy was to sleep under mosquito nets and use insect repellents or wear protective clothing, such as thick clothes, clothes with long sleeves, and trousers to cover up the whole body (including wearing boots and flexible gloves). This finding shows that the perceptions that CL patients have about CL prevention mostly reflect a public health or biomedical perspective based on the prevention of other vector-borne diseases (i.e. malaria, dengue).

Aside from the recent successful malaria control programmes of the Medical Mission and the Bureau of Public Health, in 1982 the Bureau of Public Health in Suriname ran nationwide campaigns against the dengue epidemic in the capital city Paramaribo. Apart from the use of different media (newspapers, television, radio) to inform the population about the disease (and how to prevent it), 95 trucks sprayed the chemical malathion in low dosages over an area of 70km² and 552km of roads (Hudson 1987:21).

This research shows that the information provided on malaria and dengue, with mosquitoes as the vector for both illnesses, has been well internalised both by people in the city and those working and living in the hinterland. Ganga, a 29-year-old taxi-driver, answered: "Try to prevent [CL] with good clothing, long sleeves, or use mosquito gel". Eduardo, a 41-year-old civil servant, said: "Sleeping under a mosquito net if you go to the bushes, just like with malaria". Priti, a 45-year-old hunter, thought that the following actions would help prevent CL: "If I'll go hunting

the next time, I'll smear mosquito gel on my body, and I will light a mosquito candle in the place I'll sleep". As with dengue and malaria, the idea of spraying the bushes with insecticide or pesticide in order to work and to keep camping areas clean so as not to attract flies were brought up as preventive measures against CL.

Many gold diggers and others living in the villages in the hinterland thought the same. During a chain interview with gold diggers at Paaston, on the question of how they thought CL could be prevented, one of the gold diggers mentioned:

Well, maybe with a similar system as with malaria or with mosquito nets etcetera, [especially] the impregnated ones. Because it's most of the time a mosquito, or insect kind of things, [that give you the disease], I think.

Due to the internalisation of this prior illness prevention information about malaria and dengue, associative reasoning (as similarly discussed in Chapter Six in terms of the identification of 'suitable' medicine) also happens in the domain of prevention. CL is mostly believed to be a 'bush related' and 'fly or insect related' illness (see Chapter Four). Hence, CL patients come up with ideas to prevent CL in ways similar to dengue or malaria.

9.1.3 'Can't prevent it'

Aside from not knowing either the cause of CL or the place of contamination, another frequent answer given by respondents was that CL is unpreventable. A gold digger, 41-year-old Gregory, almost desperately articulated:

I wouldn't go anywhere. There's nothing one can do to prevent it; you're just going to get it. Unless we exactly know what is the cause of the disease. Where does it come from? What is it exactly? Nobody knows for sure.

As with Gregory, many CL patients reasoned that avoiding the supposed infection location in the bush could help prevent the disease. This was the third most common answer. Avoiding hunting, working, or walking in the bush was also mentioned.

Even as patients suggested avoiding the bush, they also concluded that this was not a viable option to prevent CL. People in the hinterland villages agreed. As they said, even wearing protective clothing all the time would not work, something confirmed by observation. The reality of life is that despite all of the 'dangers' in the woods, people must work in it on a daily basis. In the photograph below, a group of people clearing their plot in the Tapanahony region with unprotected arms and legs are taking a break.

Photo 40: Sitting in a wooded area with unprotected arms and legs



Source: Ramdas, S., Godo-olo area, 2009

On the question of prevention, 25-year-old CL patient Sado, a technician, smiled as he gave an impossible solution: “Then you must not go to the jungle”. Gilly, a 24-year-old construction worker remarked, “[You] can’t stop it [CL], it’s not preventable. Because you can’t know for sure how you get it. If you travel to the hinterland you will get it”. Another patient, Hubby, a 30-year-old gold digger, answered:

You can’t [prevent it]. Even if you’re here in the city, you can contract it. People [medical doctors] must discover what the cause is of *Bus’ Yasi* and take actions to prevent it; like [for example] spraying [to kill mosquitoes], like in the case of dengue.

Hubby’s answer also clearly shows the lack of information in general about CL. Redjo, a 61-year-old prospector, replied:

You can’t prevent it [CL]. The bush is so big and if these flies come from rotten woods, it is not preventable; because you know how many trees are cut down every day?

The invisible spread of the illness across the huge Amazonian rainforest, the infection’s ‘mysterious’ origin, the necessity to keep working (and living) in the woods for income, and to visit the woods in order to pursue one’s leisure activities, all contribute to the pragmatic lay viewpoint that CL is very difficult – or perhaps even impossible – to prevent.

9.1.4 Preventing CL with injections

A striking – and rather worrisome – finding was that some CL patients believe that biomedical treatment can prevent them from contracting CL again. According to these patients, the biomedical drug, once injected into the body, acts as “some kind

of a vaccination” that provides either temporary or long lasting immunity to CL. Brian, an 18-year-old painter of mixed cultural background, thought that a good way to prevent CL would be to “take the injection before going to the bush”. Jeremio, a 36-year-old Brazilian gold digger, remarked: “I don’t think I can get it [CL] again, I took a lot of medicine in my body; I’m immune to the illness I think”. Kromo, a 53-year old worker at an agricultural company, reasoned that CL can be prevented “by taking the injections. The injections [I took] secured my blood, they make me immune, the injection secures everything”. A 35-year-old Hindustani gardener, Anil, explained:

I think that when I go to the hinterland I’ll buy a shot [of Pentamidine] I need one week before leaving. And I will ask the doctor to inject me. In that way I can make sure the mosquito won’t be able to do me anything. Then I am assured of my safety, you know...

Renfrum, a 21-year-old Maroon gold digger, also believed that he was protected against CL by the injections: “No, I can’t get it anymore due to the injections. My father told me that every man should get an injection at least once”. Another 29-year-old gold digger also believed that he could not contract CL twice: “I don’t think I will get it [CL] again; the injections form a kind of a vaccination and I will use mosquito gel”.

Others were not sure, but had heard or hoped that the injection worked as some kind of vaccination. A 36-year old Maroon cook, Frans, mentioned that if he took good care of himself, he would probably not contract CL again; as he believed, CL could be prevented by the injections: “they might be some kind of vaccine”.

The idea also existed that the injected biomedical drug could provide protection against CL for a period of several years. Royke, a 31-year-old Maroon gold digger, hoped that he would never contract CL again, and added: “Some say that the injection will keep you safe from the *Bus’ Yasi* for three to four years”. Cedoc, a 27-year-old Maroon gold digger, was convinced of the lasting protective qualities of the biomedical drug: “If you get that injection, then it will keep you safe for about ten years. You must get all three injections though”.

Some CL patients did not know how CL could be prevented, but thought that a vaccination or medical treatment (swallowing pills, like for malaria), if available and possible, would be a great solution for CL prevention. One patient thought that swallowing amoxicillin pills would make the body stronger and that this would prevent CL.

9.1.5 Once CL has been contracted, the body is ‘protected’

Similar to the idea that injections could be some kind of vaccination, some CL patients also believed, or heard from others in their environment, that once a person has been infected with CL – as with diseases such as chickenpox – immunity is achieved, thereby preventing infection for a second time. A 26-year old Maroon gold digger, Leo, explained: “I heard that if you’ve got *Bus’ Yasi* once already, you’ll never get it again, because your body is stronger. But I don’t know it precisely”. Djosi, a 19-year-old Maroon man, also a gold digger, thought that he would not get infected with CL again because “people say you only get it once”.

9.1.6 Prevention of CL using home remedies

Also mentioned by patients was the use of several home remedies or some chemicals as pre-treatment before entering the woods to prevent CL infection. Most often mentioned among the home remedies was smearing the body with *krapa* oil (made from the seeds of *Carapa guianensis* Aubl. (Meliaceae), see Chapter Five, section 5.2.1.1). Tidjo, a 57-year-old technician, reported: “I think that by using *krapa* oil the flies won’t sit on you”. With evident confidence, a 25-year-old Indigenous man, a farmer, recommended: “Use *krapa* oil on your skin if you go hunting, my father said. That is very bitter and small insects won’t bite you”. Jeremy, a 30-year-old military man, thought home remedies could prevent CL and regretted not having used them:

Some home remedies, like *krapa* oil [can prevent CL]; it can prevent small insects to crawl on your body... I think I am going to do that. Every time I go to the hinterland I should do that. I did take it with me, the *krapa* oil, but didn’t use it. I wished I had done so...

Drinking bitter concoctions made from bitter plants or herbs or taking herbal baths with several bitter leaves were also mentioned as possible effective preventive measures against CL. Jonny, a 30-year-old Javanese technician, shared his ideas:

There is a liana, bitterer than the *kwasibita* (Sr), you can drink that with water, and your body will become very bitter... so you can prevent this disease. So I heard and I am going to try that too.

The 32-year-old assistant forest manager Banio thought: “Before going to the bush and after coming from there, you should wash with medicinal soap and drink bitter. [Then] You won’t get it [CL]”.

Avoiding certain foods, such as wild animals and other food products, to prevent CL were only mentioned a few times by CL patients. However, these ideas about CL prevention reflect assumptions about the aetiology of disease. At Tepu, for example, some people believed that after having sex with other population groups, a certain diet should be kept to avoid CL. A 65-year-old mother reported:

If you had sex with other people, like with the Wayana, white people, [or] Maroons, you should not eat apes, piranhas, and other animals and you can avoid *kaasa* [CL] by fasting for about two to three months.

9.1.7 Perceived ‘contagiousness’ is not an issue for CL prevention

Finally, this study reveals another striking and contradictory finding: despite the belief by some that CL is a contagious disease (see Chapter Four), prevention of CL by avoiding people with CL sores was rarely mentioned. Only two CL patients mentioned this. As one of these patients said: “The biggest question is how you got it. If someone has it, stay away from the person; not to discriminate, but just [to] be careful...”.

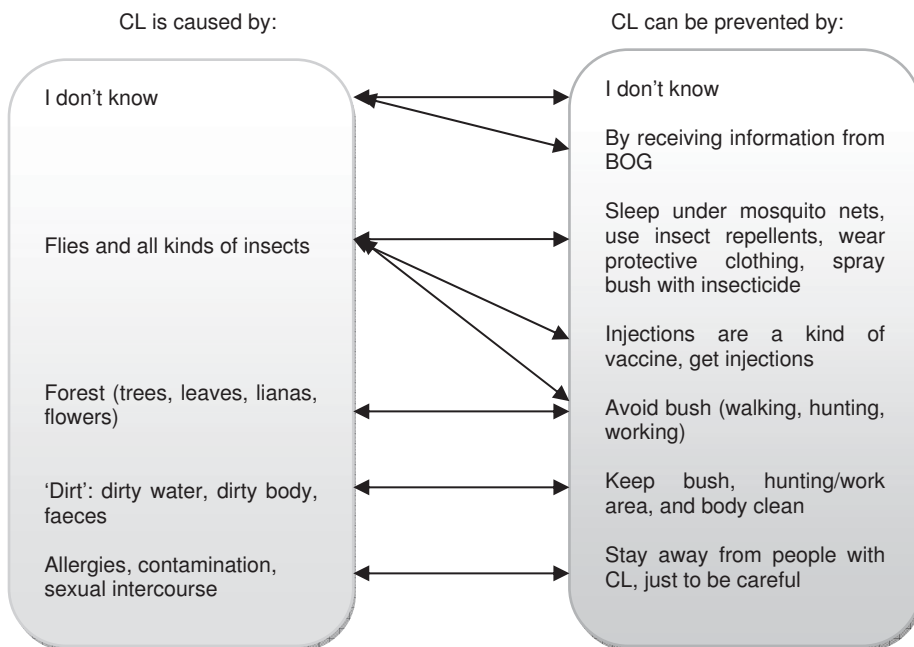
This finding implies that ‘not knowing’ the aetiology and development of the illness keeps in place uncertainty about prevention strategies. Though CL is believed to be contagious by a group of patients, experience shows that it probably is not. Because one does not know for sure either way, keeping a distance from CL patients would be logical to prevent CL. But the fact that very few CL patients (only two out of 205) mentioned ‘avoiding people with CL’ as a way to prevent CL suggests that they rely on experiential knowledge that shows that CL is probably not contagious.

9.2 Prevention theories are related to lay aetiological explanations

The findings in the sections above clearly show that ‘not knowing’ the cause of the condition frames ‘prevention’ efforts. In illnesses where the cause is known, people undertake necessary actions to protect themselves. With a ‘mysterious’ illness like CL, its prevention also becomes puzzling, resulting in a spectrum of disease causation theories that fuel diverse prevention theories. This is how ideas about the origin and prevention of the illness are related.

The schema below provides an overview of the relationship between illness causation and prevention theories. The one ‘feeds’ the other: when lay perception is that CL is “caused by the forest”, theory of prevention is to “avoid the forest”. Conversely, a theory of how to prevent CL is related back to lay perceptions of CL causation: “to keep one’s body clean”, because “dirt” is thought to cause the disease. This is how thoughts about prevention and cause correlate.

Figure 8: Relationship between (lay) illness causation and prevention theories



The 'dangers' (Krumeich & Van der Geest 1994:45) that CL patients and others in the hinterland identified are motivated by their hope of avoiding CL. Their operative premise is that their perceptions, observations, and experiences with the aetiology of the illness are correct.

9.3 Adding lay perspectives to public health perspectives on prevention

From a public health perspective, in the 1960s prevention was defined as “averting the development of a pathological state”, including taking “all measures – definitive therapy among them – that limit the progression of disease at any stage of its course” (Clark 1967, cited in Starfield et al. 2009:580). In addressing disease prevention, the WHO stated that prevention “covers measures not only to prevent the occurrence of disease, such as risk factor reduction, but also to arrest its progress and reduce its consequences once established” (WHO 1998, cited in Starfield et al. 2009:580). In the past decades, the public health concept of prevention has expanded to encompass primordial, primary, secondary, tertiary, and quaternary prevention (Reinherz 1980; Starfield et al. 2009).

Primordial prevention means “preventing the emergence of predisposing social and environmental conditions that can lead to causation of disease” (National Public Health Partnership 2001, cited in Starfield et al. 2009:580). *Primary* prevention refers to “activities undertaken prior to the onset of disease with the goal of avoiding its occurrence and building immunity in a potentially vulnerable population... [It also] includes the promotion of positive health through promoting healthful life-styles” (Reinherz 1980:5) and “promotes health prior to the development of disease and injuries” (Starfield et al. 2009:580). *Secondary* prevention concerns early diagnosis and treatment in the asymptomatic stages of illness, for example by conducting screening programmes to identify a variety of health problems in the early stages of the illness (Reinherz 1980:5). *Tertiary* prevention consists of “rehabilitative programmes aimed at reducing the after effects of illness” (ibid) or to “improve function, minimize [illness] impact, and delay complications” (Stoltenberg 2005, in Starfield et al. 2009:580). *Quaternary* prevention is defined as “an action taken to identify a patient at risk of over-medicalization, to protect him (*sic*) from new medical invasion, and to suggest to him (*sic*) interventions which are ethically acceptable” (Brenzen 2003, cited in Starfield et al. 2009:581). Only recently has this latter dimension been added to the concept of prevention, which includes the identification of “risk factors” (Starfield et al. 2009:580).

Given the scope of the different levels of prevention from a public health perspective, preventive measures corresponding to these levels are required to combat CL. This is especially so since CL risk factors are due to human practices such as migration, deforestation, and urbanisation (Desjeux 2001:239), or biological and environmental risk factors such as “changes in the human host’s susceptibility to infection such as immune-suppression and malnutrition”, and “natural change in environment” (ibid). Other “manmade” factors such as colonisation (because of which target populations in Suriname have come to live in the hinterland) and the current increase in deforestation and occupation of the forest, as findings of earlier

studies (Van der Meide et al. 2008:192, Hu 2013:15) and this study suggest, contribute to the constant exposure of certain groups of people to an environment in which CL infections can easily occur. Global factors include the high price of gold – currently US\$1,577,00 per troy ounce⁷⁸ – on the world market, which has prompted an estimated thirteen to fifteen thousand people to work as small scale gold miners in Suriname (Heemskerk & Duijves 2012:5). Because people are willing to go deeper and further into the Suriname woods in search of gold, they encounter and disturb the ecological habitat of (infected) phlebotomine sand flies; this contributes greatly to the vulnerability of this group to CL.

To make CL prevention in Suriname effective, more studies into matters that concern primordial, primary, secondary, tertiary, and quaternary CL prevention are needed. The current multidisciplinary research project 'Leishmaniasis in Suriname', of which this study is part, can only partly contribute to the design and execution of future CL prevention programmes.

This chapter underscores how public health authorities can benefit from considering lay socio-cultural perspectives as an integral part of the concept of prevention. Being aware of these perspectives will enable collaboration with the affected people and communities, thereby enhancing the success of illness prevention programmes. These findings suggest that public health authorities can build upon the earlier success of malaria eradication and dengue control programmes, given the positive attitudes of people working and living in the hinterland towards these programmes. Vector control has been one of the main foci of Surinamese public health authorities for both malaria and dengue. For CL, the vector is the female phlebotomine sand fly that lays "its eggs in the burrows of certain rodents, in the barks of old trees, in ruined buildings, in cracks in house walls, in animal shelter[s], in household rubbish" (WHO 2008), or in any environment that provides the larvae with organic matter, heat, and the humidity necessary for survival (Ashford 1999:331). One of the main international foci to prevent CL, from a public health perspective, has been vector control, with measures involving "spraying houses and adjacent areas with insecticide, placing screens on windows, and using uniforms or top sheets impregnated with insecticides" (Kassi et al. 2008:1). Sometimes the entire outfits of military soldiers, such as shirts, undershirts, pants, socks, and hats, have been impregnated (Kassi et al. 2008; Soto et al. 1995). These types of public health interventions – spraying with insecticides, and impregnating clothing or bed sheets with insecticides – are likely to be well received among those living and working in the hinterland of Suriname, due to their associations with previous successful measures to control malaria and dengue.

Despite the lack of biomedical (or scientific) knowledge about CL and its risk factors, this study shows that lay perspectives on prevention are closely related to the public health perspective on prevention. Moreover, patients are eager to receive information about CL and the different aspects of the illness. At the end of each interview, CL patients were asked if they had any questions that they would like to pose; of the 205 CL patients, 140 (68.3%) said that they did not have any. A group of 65 patients (31.7%), however, had various kinds of questions. In the table below,

⁷⁸See web reference number 38. The troy ounce is most commonly used to measure the mass of precious metals. One troy ounce is defined as exactly 31.1034768 g.

these questions are categorised, and the number of times the questions were posed is given.

Table 11: Questions posed by 65 CL patients at the end of the interviews at the Dermatology Service ⁷⁹

Questions posed by CL patients	Frequency
Concerning aetiology	6
<i>What causes the disease?</i>	5
<i>Can you get the disease only in the hinterland or also in Paramaribo?</i>	1
Concerning severity and contagion	8
<i>Is it a dangerous disease?</i>	1
<i>Will it spread all over the body?</i>	1
<i>Is it contagious?</i>	4
<i>Is it a coincidence that so many people are here at the Dermatology Service now when I am here?⁸⁰ Or is it that[many] people [do have the illness, but they] simply don't show up [come for treatment at the Dermatology Service?</i>	1
<i>What's the next step [what to do] when you get it [CL] the second time?</i>	1
Concerning cure/biomedical treatment	21
<i>When will it heal/how long does it take to cure?</i>	9
<i>Is it a heavy treatment?</i>	1
<i>Can only injections cure this illness / does the injection help?</i>	3
<i>Will I get cured with three injections?</i>	1
<i>How many injections will I get?</i>	1
<i>Can my pregnant wife get injections?</i>	1
<i>Aren't there any other medicines than injections for it?</i>	1
<i>Is fast diagnosis and fast medication of Busi Yasi possible?</i>	1
<i>Can Pentamidine cure this disease?</i>	1
<i>Can I be on Pentamidine treatment and continue to use bush medicine?</i>	1
<i>How can I speed up cure?</i>	1
<i>Will the virus or bacteria continue to stay in the body after the treatment?</i>	1
Concerning prevention	20
<i>Isn't there a vaccine for it or medicine against it like against malaria?</i>	4
<i>Is there medicine to prevent it?</i>	3
<i>How can I prevent it?</i>	3
<i>Shouldn't BOG / clinics have to provide information?</i>	3
<i>Is there any information about it?</i>	2
<i>Aren't there insecticides to prevent this disease?</i>	1
<i>Is the injection a vaccine?</i>	1
<i>When can you come [when is one eligible] for these injections?</i>	1
<i>When will they [medical doctors] provide information after this research?</i>	2
Concerning diet and other 'rules'	5
<i>What's a good diet [to keep] going together with the treatment?</i>	1
<i>Can I drink alcohol after I get the injection?</i>	1
<i>Can I drink alcohol and eat pepper while I'm on treatment?</i>	1
<i>Can I have sex after the injection?</i>	2
Concerning costs of biomedical treatment	3
<i>Isn't there free medical treatment?</i>	1
<i>What about those who can't pay for the treatment?</i>	1
<i>Why is CL not treated free of charge here [in Suriname], while they do so on the French side?</i>	1
Concerning self-treatment	2

⁷⁹It was possible to pose multiple questions.

⁸⁰The patient was surprised to see relatively many (more than three) patients with CL on that particular day that he visited the Dermatology Service, so he asked me whether it was only a coincidence or whether it was the case that many patients were out there, but that they usually did not come at the Dermatology Service for treatment.

<i>Should I do self-treatment [i.e. can the doctor advise it]?</i>	<i>1</i>
<i>How to treat the illness when I have it in the bush?</i>	<i>1</i>
Other types of questions	2
<i>Can I donate blood if I am a donor, and after what period after treatment can I donate blood?</i>	<i>1</i>
<i>Does the information [during the interview] I gave to you [the interviewer] make sense?</i>	<i>1</i>

The wide variety of questions that patients had about the illness can be a valuable tool in the design of future CL prevention programmes. Most of the questions asked were about medical treatment and prevention of CL, followed by questions about the origin and development of the illness. Four CL patients explicitly mentioned that the Bureau of Public Health (BOG) should prioritise CL, and remarked that they would visit it and ask for advice and information on CL prevention.

9.4 Conclusions

Illness prevention is based on the identification of dangers (Douglas & Wildavsky 1982; Krumeich & Van der Geest 1989:45). But what if dangers and ways to avoid illness are misidentified? This study shows that in terms of CL: 1) by not knowing the dangers (i.e. the origin(s) of the illness), people also do not know how to prevent it; 2) just as the aetiology of the illness is not known, prevention is also not known to most patients; and, 3) just as not knowing gives rise to a wide variety of lay illness causation theories (Chapter Four), not knowing is also related to a wide variety of prevention theories.

This study shows how both areas – cause and prevention – are crucial for treatment seeking and control of CL, which are largely unknown to CL patients and others vulnerable to the illness in the hinterland. At the same time, when flies are thought to be the main culprit of the illness, spraying insecticide or sleeping under mosquito nets are considered accepted ways to prevent the illness. If ‘walking in the bush’ causes CL, ‘avoiding the bush’ is thought to be a preventive measure.

The success of community health awareness programmes (Kendall 1998; Crabtree et al. 2001) can be enhanced by awareness of lay theories of illness causation and socio-cultural beliefs, perceptions, and attitudes regarding illness. Lay perceptions, ideas, and actions at both the individual and community level concerning causation and prevention should inform the design and implementation of prevention programmes. As Van der Geest and Krumeich (1994) put it, prevention is culture dependant. My research adds that perceptions of prevention are also rooted in and shaped by the multiple contexts in which illness occurs.

This study accentuates how a variety of contexts contribute to the formation of the concept of prevention of CL. ‘Not knowing’ the roots of the illness or lack of biological information about CL is reflected in lay perceptions about prevention. Previous public health education campaigns for other illnesses in the hinterland are associated with prevention: measures to prevent these other illnesses are adopted and used as possible measures to prevent CL. The occupational, environmental, and habitual contexts contribute to a pragmatic perspective: the illness is viewed as a condition that is non-preventable; a risk attached to living and working in or visiting the rainforest. The socio-cultural context also shapes prevention ideas, for instance

the use of home remedies or the keeping of food taboos as CL prevention measures.

My research reveals how certain aspects of CL patients' associative reasoning about CL prevention may be especially 'worrisome' for public health authorities; in particular, because of the perceived 'strength' of the biomedical medicine – its entrance 'straight in the blood' – CL injections are incorrectly viewed as offering a protective barrier or immunity against CL. Patients even provided timeframes (e.g. three years, ten years) for the assumed protection of CL injections. This reasoning may be potentially harmful to patients themselves. The mistaken perception that CL injections function as a regular vaccine that is effective for a period of years could mean that people will expose themselves to contracting CL once again.

The research suggests that, theoretically, public health authorities should consider lay (socio-cultural) perceptions on prevention as an integral part of the public health concept of prevention; in particular on the level of primary prevention. Such socio-cultural perceptions can inform the activities that public health authorities undertake in order to prevent illness and build immunity in a population that is potentially vulnerable (Reinherz 1980:5). The promotion of healthy lifestyles, including "health prior to the development of disease and injuries" (Starfield et al. 2009:580), may also benefit from lay perceptions.

Public health campaigns should start by informing the general public about CL: the cause of the illness, its development, the available biomedical treatment, and how it can be prevented. The list of questions presented in Table 11 can be used as a 'guideline tool' to shape the information provided to the target population. In these campaigns, health professionals could most effectively present sand flies as the vector for CL. Drawing upon the malaria and dengue campaigns, public health authorities can make good use of visual materials (folders, drawings of the sand fly and the cycle of contamination) to present the sand fly as the vector. Furthermore, in collaboration with the heads of villages in the hinterland, public health professionals should organise meetings in the hinterland where people are informed about the illness in their local language. Such information can acknowledge and counter, where appropriate, lay explanations about the cause(s) of CL. For example, if lianas are viewed as a possible cause of CL, the discussion could clarify how (infected) sand flies could possibly be sitting on those lianas and that, upon being disturbed, they may bite, thus infecting the person with the *Leishmania* parasite. If ticks are believed to be the cause of CL, the information provided can discuss how ticks have been scientifically discarded as possible vectors for the *Leishmania* parasite. If dirty water is thought to be the main culprit, then once again the correct information should be stressed about the cause of the illness. When educating the population, by discussing lay perceptions – during community meetings, for instance – public health authorities will acknowledge lay theories about the cause of the illness, thereby fostering an atmosphere of respect in which local people see their viewpoints reflected. Specific and clear information about prevention can then be provided; in particular, information about the duration and effect of the biomedical treatment.

Emic explanations and perspectives can shape meanings of and measures for prevention. As shown above and throughout this whole thesis, it is crucial that lay perceptions, ideas, and actions concerning CL prevention are considered carefully

by public health authorities prior to implementation of CL prevention programmes. Being aware of these perspectives can help to frame meaningful and context sensitive health education campaigns, which are needed to stop further spread of CL and to encourage the uptake of effective biomedical treatment.

Chapter 10 Conclusion

The findings of this research paint a ‘thick’ (Geertz 1973) and complex picture of the socio-cultural aspects related to the perception and treatment of CL in Suriname. Rather than a straightforward biomedical treatment seeking trajectory (i.e. noticing a sore, visiting a medical doctor, and adhering to biomedical treatment), CL patients exhibit seemingly chaotic behaviour that involves self-treatment practices rooted in the multiple contexts of their daily lives. In this concluding chapter, the rich variety of relevant contexts is presented and discussed, in order to achieve more transparency in terms of the practical consequences of this ethnographic study and the theoretical reflections presented in the foregoing chapters. First, the study findings are laid out in a somewhat “thinned” version (Van der Geest 2010:91),⁸¹ following the research questions of the study (see Chapter One). Subsequently, a more detailed theoretical, methodological, or applicability oriented reflection follows, outlining five remarkable findings and research experiences.

10.1 Thinned study findings

10.1.1 Patients’ perceptions of the illness

Striking is the lack of knowledge among CL patients and others about the aetiology and development of the illness and the large variety of medicines used to cure CL in self-treatment. CL is viewed as a cruel illness, with a cause unknown to many, though it is mainly believed to be an illness of nature. Because of the illness’s harsh character, the belief among hinterland people exists that equally harsh treatments should be used to cure it, such as acidic, poisonous, and bitter plants, hot treatments and harsh non-biomedical (household and industrial) chemicals. Fear of biomedical treatment is remarkable; biomedical treatment is often viewed as an option of last resort. CL related stigma hardly occurs. Furthermore, several contradictory health seeking behaviours are noted; these are further discussed in section 10.2.

10.1.2 The role of traditional healers in treating CL

While few CL patients reported having sought out a traditional healer for their illness, inquiries among the traditional healers in the different hinterland villages revealed that many CL patients do seek their help; whether for care or for advice concerning a specific medicine, often a plant type, that can cure the sores.

People in the hinterland generally trust the medicinal knowledge of traditional healers and the medical advice given to treat CL is often followed up. There appears to be a thin line between self-treatment and treatment seeking from

⁸¹“For the non-anthropologist, the adjective ‘thick’ may assume the same meaning as it has in connection with forest or thicket: dense and difficult to penetrate. Practical-minded people often see anthropologists as producers of highly complex and theoretical texts that resist ‘translation’ into concrete action. As a consequence, anthropological descriptions tend to be regarded as irrelevant and paralyzing to policymakers because they merely complicate matters” (Van der Geest 2010:91).

traditional healers, because the illness can often be managed by patients themselves (or their family members); the key is to find the 'right' medicine.

10.1.3 Traditional and biomedical health practitioners in the treatment of CL

The research shows that, in general, traditional healers have a high social status in their communities. Despite this position, healers do acknowledge the power of biomedical professionals to cure illnesses, because, as they say, their own (traditional) knowledge and means to cure illnesses are limited. For example, biomedical doctors have x-ray machines at their disposal, which can see internal problems occurring in a patient's body; traditional healers do not. Specifically in terms of treating CL, traditional healers view their own medicines as effective. However, when their own treatment options fail, traditional healers do not hesitate to refer patients to biomedical doctors. Or, as they also reported, they might first advise people to visit a medical doctor, but if they are unable to find a cure there, patients can then seek their help again.

Although traditional healers' diagnosis, treatment, and prevention of CL certainly differs from biomedical methods, certain aspects do overlap. Just as health workers at the Medical Mission are trained to clinically diagnose CL by looking at the symptoms, traditional healers diagnose CL in a comparable manner. Furthermore, in both cases, treatment of CL is painful: whether it is injections or the various 'harsh' traditional treatments. The main difference is that the biomedicine used for treatment of CL has been extensively tested in randomly-controlled clinical trials and found to be effective; the traditional and other types of medicines used for self-treatment of CL in Suriname have not. Because traditional healers do not know the (biomedical) aetiology of the disease, their advice for prevention is also inadequate.

Biomedical health professionals are aware of the position of traditional healers within communities and the preferred choices of patients. According to medical doctors, the tendency of patients to ask a traditional healer for advice or to engage in self-treatment is understandable given the long distances and expenses related to seeking biomedical care. Biomedical professionals express concern, however, about those healers whose medical advice aggravates the illness instead of healing it. Thus while traditional healers generally have trust in biomedical healing, this seems relatively absent among biomedical health professionals concerning traditional healing. Medical doctors view patients as being responsible for their treatment choices. In short, medical doctors and traditional healers do not communicate about or cooperate in the treatment or prevention of CL.

10.1.4 Exploring and understanding stigma related to CL

This study found that people with CL encounter relatively little discrimination or other overt acts of negativity based solely on the presence of CL lesions on their bodies. Many patients said that they were treated "normally" or "not differently" by those in their social environment. Indeed, they received support and compassion from others and their families tended to be concerned or worried about their condition.

Of the 205 CL patients interviewed at the Dermatology Service, a group of 66 CL patients did, however, to some extent experience negative reactions that adversely affected their lives and socio-psychological well being. Encountered or anticipated reactions contribute to physical and social distance towards others,

avoidance of public places or social activities, and concealment of sores. In terms of aesthetics, patients feel uncomfortable with the sores on their bodies, and suffer from feelings of shame and ugliness. These feelings, however, seem to be of a temporary nature. Once the sores heal, negative feelings or attitudes experienced from those in the social environment also disappear. Marks left by the sores are perceived as unimportant.

Close investigation of these experiences and their influence on patients' personal feelings, daily lives, and activities reveal that, in nearly all cases, stigmatisation in Goffman's sense of 'spoiling the patient's identity' does not occur. It can also be concluded that there is no CL stigma that hampers biomedical treatment, reduces treatment adherence, or favours resort to traditional practitioners. For public health authorities in Suriname, this represents one less 'burden' to worry about in their fight against CL. Their efforts can instead turn to other aspects that need to be targeted to increase treatment adherence, early case detection, and prevention of CL.

10.1.5 Why is CL in Suriname not stigmatised, in contrast to some other countries?

The near absence of CL related stigma in Suriname, in contrast to some other countries in the world where CL patients can be severely stigmatised, can be understood through the unique features of the local (lay) perceptions and aetiological explanations, the biological, parasitological, and epidemiological characteristics of the illness, and certain socio-cultural (gender and age related) differences. CL is a complex disease and this complexity is reflected in the experience of the illness, which differs cross-culturally.

10.1.6 (Non-) adherence to biomedical treatment

The study shows that of 205 CL patients, most (161) did not use biomedical health care services in the initial phase of the illness: they tried to self-medicate instead. This tendency towards self-treatment is related to many aspects. Only after self-treatment fails do CL patients (78.5% in this study) seek help at biomedical health care services. Of the 205 CL patients, many (67.8%) adhered to the biomedical treatment at the Dermatology Service, while 32.2% did not. According to medical doctors at the Dermatology Service, a rate of 32.2% of non-adherence among CL patients is quite high, especially considering the fact that the treatment – when completed – is effective in most cases. This study reveals how non-adherence to biomedical treatment among this group of patients is due to a variety of factors: weak economic position (and high costs of biomedical treatment seeking in the capital city), work obligations (in combination with long infrastructural distances between work site and the capital city), fear of injections and their side-effects, confined spread of CL lesions on the body (especially having only one lesion), and the possibility for CL patients to take medication back to the hinterland to complete treatment there.

10.1.7 CL prevention from various perspectives

CL patients and others living and/or working in the hinterland do not know the origin of the illness, and so they do not know how to prevent it. Lay aetiological theories are, however, abundant. The preventive ideas that CL patients and others have are based on these theories. Although CL patients and others wonder about how to prevent CL, they find it more interesting to know the cause of the illness.

According to a group of patients and others in the hinterland, one aspect that emerges as possibly contributing to the spread of CL is skin-to-skin contact, with the wound fluid infecting either oneself or another person. Another striking finding is that some CL patients mistakenly think that the biomedical drug acts as a vaccine against CL; receiving biomedical treatment, they think, enables them to be risk free for a period of years.⁸² Such incorrect perceptions may contribute to risky behaviour among cured patients, exposing them to future infection.

For biomedical health professionals, many issues concerning CL prevention still have to be researched. Because the cause of the illness is known, however, biomedical professionals do have several ideas of how to prevent CL, such as wearing protective clothing when in the forest, the use of repellents, keeping areas clean, and avoiding being in the woods at dawn and dusk since these are the times when sand flies are most active. From a biomedical point of view, aspects contributing towards the spread of the illness in Suriname are related to manmade and other environmental factors, many of which still have to be investigated

10.1.8 Interrelatedness of various aspects of health seeking

Lay perceptions, explanations, treatment preferences, and practices are closely related to, and reflected in, the experience of illness and treatment seeking. Treatment preferences and practices influence the experience of CL. Initial treatment is mostly sought in the (close) social environment of patients, but when it comes to biomedical treatment, adherence or non-adherence is related to the larger socio-economic, socio-psychological, and professional context. As mentioned before, there is no stigma that hampers biomedical treatment or reduces treatment adherence. Reasons for non-adherence include lack of biomedical knowledge about the drug Pentamidine, fear of injections, and the (less aggressive) appearance of the illness on the body (number of sores, places where sores occur, size of sores). Lay perceptions, aetiological explanations, and treatment preferences and practices in particular affect early treatment seeking, but seem unrelated to adherence or non-adherence to eventual biomedical treatment.

The presentation above of the main findings once again shows the complexity of health seeking and the interrelatedness of various aspects of treatment seeking. To continue, some of the most important findings are discussed in more detail and related to the discussions in the literature; some theoretical and methodological, and some more practical and policy related.

⁸²According to biomedical professionals, it is possible, however, that having had a CL infection may provide a certain extent of protection against a new infection (Schallig, personal communication, 2014).

10.2 Knowing, not knowing, and contradictions in explaining illness

The aetiology of illness is a central element of medical systems (e.g. Young 1976; Kleinman 1980; Nichter 2008) inherently related to the diagnosis, treatment, and prevention of illness. Several researchers have tried to understand illness aetiologies and health seeking behaviour by classifying them into different systems. Foster (1976) distinguished between “personalistic” and “naturalistic” systems, the former being viewed as a medical system in which illness is caused by “*active and purposeful intervention of an agent*” – human, non-human, or supernatural – while in the latter illness is thought to be caused by “*natural forces or conditions*” (Foster 1976:775, original emphasis). Young (1976) distinguished between “internalising” (i.e. emphasising patho-physiological processes that explain ill health) and “externalising” (i.e. focusing on forces outside the body, thus witches, spirits, and ghosts, etc.) factors associated with illness. It is clear from my findings that most CL patients and others in the hinterland view CL as being caused by naturalistic elements (such as insects, trees, plants, juice of lianas, etc.). However, there are some lay illness theories that place the origin of illness in the supernatural world; in this case, CL can be caused by bush spirits or other unexplained supernatural forces. Nevertheless, a clear coherent system through which CL patients and others understand and explain CL is lacking.

Striking is that many people are uncertain about the cause of CL. Based on their observations, they only *suspect* what CL is caused by. Many CL patients and others in the hinterland say that they do not know the origin of the disease, but can only speculate about it. Research in the last four to five decades has pointed at the importance of ‘not knowing’ and its consequences for medical practice in non-Western societies (see Littlewood 2007). Last (1981) illustrated that culture is not a systematic body of ideas and practices, but a diffuse whole, full of contradictions and ignorance, whereby assumptions about ‘reality’ are hardly – if at all – well reasoned. As he stated:

...under certain conditions not-knowing or not-caring-to-know can become institutionalized as part of a medical culture and that it is inadequate, then, simply to claim there is still at work an unconscious system embedded, for example, in the language. (Last 1981:1)

Last conducted his research among the Muslim Hausa population in northern Nigeria, and found that on questioning local people and healers about their own traditional Hausa medicine, they often did not know much about it. Pool (2003), in his research among the Wimbun people in the Western Grassfields of Cameroon, recorded fragmentation, inconsistencies, and indeterminacy related to illness and illness aetiology. He showed how, in dialogue, people built on a coherent system of thought about illness and illness aetiologies. Pool (2003:25) argued that “the way in which knowledge about illness is produced and constituted and the essentially negative character of that knowledge” is not deviant from the norm. Instead, “fragmentation, inconsistency and indeterminacy are seen as the normal state of affairs” (ibid). These and many other anthropological observers have emphasised that medical action is not always the logical consequence of pre-existing knowledge

or ideas, but that 'knowledge' may well follow from action or comes into being *in* the action (e.g. Moerman 2011).

Regarding people's explanations of the aetiology and other aspects of CL in my research, such apparent 'contradictions' are also noted. On the one hand, for example, CL seems to be a rather well known and familiar illness, both to CL patients and others. The illness is known by different vernacular names by different cultural groups – *Busi Yasi* (Sr), *Bos Yaws* (SD), *Azo* (Au), *Kaasa* or *kaasa piye* (Tr), *Tatay yassa* or *Matu yassi* (Sa), *Ferida brava* (Po), *Leisho chorao* or *Leisho seco* (Po), a leishmania (Sa), and *dala soro* (Sr) – reflecting the illness's symptomatic characteristics, its (assumed) aetiology, and its associations with another illness (Framboesia or Yaws) that previously existed in the rainforest. The illness is also often recognised and diagnosed by lay people, based on the way the sores look and progress. Further, inquiries show that many are aware that the incidence of CL seems to increase during the rainy season, that everybody, regardless of age and sex, can contract the illness, and that different types of CL occur.

On the other hand, CL remains a 'mystery' illness. While being familiar with the illness, people still do not seem to *know* it. The origin of the illness, its biomedical traits in terms of spread, contamination, side-effects of the biomedical treatment, and prevention of CL are key aspects that CL patients do not know how to explain. Patients and others in the hinterland thus wonder about the original cause of CL. Because nobody seems exactly to know how the illness is caused, people produce a wide variety of aetiological explanations. Such 'multiple causality' beliefs imply that "any one of several or a combination of causal factors can be thought to cause illness" (Nichter 2008:42).

CL patients and others are also puzzled about whether or not the illness is contagious; many do not know and opinions are divided about the topic. Because of the observation that people can sometimes have multiple CL sores spread over the body, some think that a person with one sore can infect him- or herself further. Another group of people who believe that CL is a contagious illness reason that the wound fluid leaking from the sore can, upon bodily contact, infect another person. Those who view CL as a non-contagious disease argue, however, that if it were a contagious illness, others in close proximity to the CL patient, maybe even the whole village, would be infected as well. But this, they argue, does not occur.

With regard to the biomedical treatment, even though CL patients know that the biomedical drug is efficacious, they do not know exactly how it works, and wonder whether it functions as a vaccine. Much obscurity thus surrounds many aspects of the illness, and in producing lay aetiological theories, indeterminacy and not knowing prevail. But rather than accepting this gap in medical knowledge as part of their culture, and viewing it as a "normal state of affairs" (Pool 2003:25), CL patients and others confronted with the illness in the hinterland are troubled and at a loss, and want to know more.

The study reveals contrasting feelings of fear concerning CL. Because of its aggressive development from small to large (sometimes deep) sores and the possibility of its spread over the body, coupled with the perceived risk of amputation of infected body parts and its gruesome appearance, CL is viewed as a very serious and dangerous illness and feared by many patients. The reputation of the biomedical treatment to cure CL also contributes to this fear. But because almost all

patients and others view CL as a medically treatable and curable illness, it is also considered to be an illness that one should not really fear.

Opinions are also divided about certain beliefs related to CL. In the Maroon villages, a pregnant woman looking at a CL sore is believed to worsen the condition of the sore. Sexual intercourse is also thought to 'spoil' medicine and hinder cure, so it is advised by some to restrain from sex until after the illness is cured. In the Indigenous villages, as well as among Brazilian gold diggers, intake of certain foods is advised against once one has contracted CL. The extent to which these beliefs influence (self-) treatment seeking and their role in biomedical treatment seeking requires further research.

10.3 Contradictions and ambivalences in medical choice

The majority of CL patients attempt self-treatment prior to visiting the Dermatology Service; only when self-treatment fails do they seek biomedical treatment. Why did CL patients do so? In her study about medical knowledge and practice among Bolivian peasants in the Andean highlands, Crandon-Malamud (1993) shows how knowledge about medical efficacy is not the prime reason upon which people choose or combine indigenous medicine and biomedical treatment. In a society where medical boundaries are fluid, and subject to economic, social, political, and historical changes, she states:

The patient suddenly emerges from this complex, constantly changing, and politically charged situation as a kind of decision maker that most scientists want to avoid: he is not Rational Man looking for medical efficacy; rather, he is a social and political animal who at times may be looking for meaning through efficacy which becomes a validation of some sociopolitical or economic proposition, but more often is looking for efficacy through meaning in a sociopolitical and economic context. This view also explains how the patient, and even the healer, can maintain contradictory ideologies at the same time (Crandon-Malamud 1993:32-33).

Similarly, for CL patients their medical choice is based on different concerns and contextual factors. Patients self-treat because of several reasons, related to: 1) their living environment; 2) their working conditions; 3) large geographical distances between the hinterland and the capital city; 4) their (poor) economic position; 5) socio-psychological factors (in particular, fear of biomedical treatment); and 6) socio-cultural understandings of illness and cure that include generational use of bush medicine and knowledge of medicines that cure CL. In line with Crandon-Malamud (1993), CL patients thus have more to gain from self-treatment than only health.

The contradictory explanation of illness (knowing, yet not knowing the illness) in particular, and cultural beliefs (that harsh illnesses require harsh treatments) influence the type of medicine used. Self-treatment practices, advised by many significant others, comprise 'cruel' treatments such as herbal treatments with strong and/or poisonous plants and leaves, 'hot' treatments such as dripping hot liquids onto the sore, and harmful treatments with household and industrial chemicals, insecticides, and a poisonous herbicide. The cultural belief that harsh

illnesses require harsh treatment is striking. Among Brazilian gold diggers in particular, self-injection practices with the biomedical drug Pentamidine Isethionate or Pentacarinate is common. Only after failure of self-treatment practices do CL patients visit the Dermatology Service.

It can be concluded that several contradictions and ambivalences emerge in the perceptions, attitudes, and health seeking behaviours that CL patients and others confronted with the illness in the hinterland have about (or towards) the illness. To list a few:

- Patients think of CL as a dangerous and hard to cure disease, yet they keep on pursuing self-treatment.
- Patients view CL as a serious illness (because of its rapid spread and flesh eating character), yet they do not consider it a priority.
- Patients are very afraid of CL injections, yet they do not fear their own 'cruel' treatments.
- Patients know biomedical treatment is free in the hinterland Medical Mission clinics, yet they hardly visit these clinics.

These ambivalences and seeming contradictions are, in a similar way as Crandon-Malamud suggests, understandable when one takes into consideration the different contexts in which patients live and work, their reasoning related to treatments, and certain biological traits of the illness (see also Kleinman 1980; Moerman 2002). At the same time, they mirror the lack of a coherent illness knowledge system (see Last et al. 1981; Littlewood 2007), through which medical actions can be understood: experimenting with different treatments produces (temporary) knowledge that leads to yet another action and knowledge. Knowledge and action interact with each other, portraying health seeking behaviour (in particular with self-treatment practices) as being based on ambiguous expectations about the effectiveness of medicines; in other words, patients undertake medical action without the certainty or guarantee that the medicines used in self-treatment will actually work.

10.4 The importance of distinguishing stigma or no stigma

This study points to the caution that social scientists, clinicians, and health workers need to adopt when using the concept of stigma. Before even considering whether stigma hampers biomedical treatment seeking or adherence, more important is to identify whether one can speak of stigma in the (classic) 'Goffmanian' sense or not; the variety of forms in which stigma occurs and its dimensions (see Jacoby et al. 2007; Jones et al. 1984; Scambler 2004; Weiss & Ramakrishna 2004) developed post-Goffman should therefore also be considered. This study has attempted to do just this, and the findings highlight that despite the fact that CL is clinically often linked to stigma, in the majority of cases the CL patients did not encounter reactions that could be regarded as stigma.

The near absence of CL stigma can be understood in terms of the in-depth exploration of different contextual aspects, which outline why this is the case in Suriname in contrast to some other countries in the world. It also supports an understanding of CL stigma among those CL patients in Suriname who did

encounter negative experiences. In assessing stigma, therefore, questioning *why* people experience the illness in the way they do is equally as important as investigating *how* they experience it. Exploring the concept of stigma in such a way contributes to purposeful insights that can inform future health policies. As Ribera and colleagues (2009:e445) state in their article 'A word of caution against the stigma trend in neglected tropical disease research and control':

Stigma is a powerful element in determining health behaviour and is one reason for social isolation and exclusion. But be careful: it is not the only one... Whether or not it is stigma that limits health-seeking behaviour or leads to a delay in treatment or to social isolation, this has important implications for health interventions. If stigma *is* relevant, sensitization campaigns are justified. If stigma is not or of little relevance, other interventions should be prioritized.

It is crucial indeed to distinguish the thin line between stigma and lack thereof, and the impact of stigma on health seeking, because of the practical implications that research findings can entail for the development of future health policy, as well as education and awareness programmes.

10.5 Challenges and collaboration in multidisciplinary research

Viewing one illness from multiple disciplinary angles may prove challenging, especially when each discipline holds a certain 'ethnocentric' point of view through which they try to understand a health condition (Köbben 1991). In his article 'Ethnocentrism and medical anthropology', Van der Geest (2005) writes about the negative sides of ethnocentrism, pointing to, among other matters, ethnocentrism as an obstruction in multidisciplinary settings:

... ethnocentrism ... plays a part in the (lack of) communication between scientists from different disciplines. Indeed, it is clarifying to regard scientific disciplines as cultural traditions with which one identifies oneself, not only socially but also 'religiously'. That is to say that the basic ideas of the scientific field assume the air of statements on reality, of doctrines with far-reaching, meaning-giving implications. The belief in those doctrines is, amongst others, preserved by shutting off the 'messages' from other disciplines or showing contempt for scientific work outside of one's own field (Van der Geest 2005:8).

The situation described by Van der Geest in the excerpt above is very different from the multidisciplinary setting in which this anthropological study took place. Rather than "shutting off the 'messages' from other disciplines", the different teams in this research – clinical, biological, and anthropological – appreciated and used the messages (i.e. research results) from the other disciplines. Instead of "showing contempt", the teams showed deep interest in the findings of each other's research.

The collaboration between the different disciplines, as elaborated in the sections below, and the mutual efforts to make the 'Leishmaniasis in Suriname' project a successful one, was not affected by ethnocentrism and other (related) challenges (e.g. division of the budget, prioritising research areas, providing

feedback on each other's research projects) known to many multidisciplinary projects (Nichter 2008; Strober 2003; Trotter 2011). Results of the scientific work of all teams were viewed as useful and complementary, in accordance with the set-up of the project.

10.5.1 Shaping research and reducing costs

The clinical research (Hu 2013) focused on treatment, quality of life, and the cost aspects of CL in Suriname, while the biological research (Kent 2013) investigated aspects related to the biology (e.g. parasite types, reservoirs) of CL. These studies contributed to a clinical and biological understanding of the illness, which partly shaped the anthropological research questions. For example, because of the biological information that *Leishmania* parasites exist in several zoonotic reservoirs, hinterland people were asked if they also saw animals that had similar skin conditions as that of CL. For the anthropological exploration, this provided deeper understanding of the knowledge of inhabitants of the hinterland about the illness. Furthermore, clinical information facilitated interpretation of certain answers. For example, information about how the biomedical drug is administered to patients (i.e. through injections) and how it works in the body helped me to understand patients' 'horrible' experiences with biomedical treatment (Ramdas 2012). Similarly, anthropological investigations helped to shape the biological study. Questions about possible vectors and reservoirs were asked to the people in the hinterland villages during the anthropological fieldwork, and the biological team was updated on this information; based on this information, possible locations in the hinterland were pointed out where the biological study could be carried out.

The complementary nature of the CL project furthermore concerned logistical collaboration. To reduce costs, exchange of relevant information occurred between all three teams: whenever necessary, photographic material collected by this study was shared with or provided to the clinical study (see Hu 2013:16-18). In this way, superfluous expensive and time consuming visits to the hinterland were avoided.

10.5.2 Complementary data

In relation to both the clinical and biological study, the anthropological study provided in-depth understanding about the emic perspectives of CL patients and others confronted with the illness, providing answers to many questions posed by medical doctors concerning CL patients' health seeking behaviour. The qualitative nature of the research produced rich descriptions of various aspects of health seeking, including adherence to biomedical treatment, health related stigma, and prevention, which complemented certain aspects of the clinical and biological research. For example, clinical quantitative investigation into the quality of life of CL patients was conducted (amongst other methods) with the use of Skindex-29 and EQ-5D-33L questionnaires. The Skindex-29:

is a three-dimensional, dermatology specific Health Related Quality of Life (HRQL) questionnaire ... [combining 29 questions to form] three domains: symptoms, emotions and functioning ... [whereby] domain

scores and overall scores are expressed in a 100-point scale... The EQ-5D is a widely used method of generic HRQL containing five domains (mobility, self-care, usual activities, pain/discomfort, and anxiety/depression) ... [with] three response levels (no problems, some problems, extreme problems). (Hu et al. 2013:74-75)

This quantitative investigation provided valuable information in the form of scores about lower or higher quality of life of CL patients in different domains. However, to contextualise certain scores, in-depth qualitative analysis was required; this was provided by the medical anthropological study (*ibid*). Perhaps, when viewing both the biological and clinical studies (see Hu 2013; Kent 2013), more of the anthropological material provided by this study could have been used or referred to. But due to a difference in planning, outcomes of the research results from all three branches could not be synchronised by the time of publishing the biological and clinical studies. Nevertheless, future collaboration (see next section) among all three teams of the 'Leishmaniasis in Suriname' project will probably do (more) justice to the complementary nature of this project.

10.5.3 Future studies

The clinical and biological teams were informed about all of the anthropological research results at several key points in the five year research period, when joint team meetings were held to discuss and compare research findings. In addition, this study contributed to details and insights concerning non-biomedical treatments. The information on different botanical treatments gathered in the medical anthropological study is part of a study currently in preparation by biological and parasitological researchers to investigate the in-vitro efficacy of Surinamese medicinal plants against CL (Kent, personal and email communication 2013; Mans & Schallig, email communication 2013).

The individuality of each research project and the interrelatedness between all three projects may best be reflected in the articles that have been published (Ramdas 2012; Hu et al. 2012; Kent et al. 2013a, 2013b) as well as those currently being prepared for future publication.

10.6 Why medical anthropological research matters: practical implications

The usefulness of medical anthropological research in changing health seeking behaviours is illustrated by numerous studies (e.g. Langwick 2007; Malik et al. 1992; Nichter 1995; Lakshman & Nichter 2000; Cassell et al. 2006), especially since they often entail practical implications for health policy and practice. Similarly, the findings of this research – as set out below – can be beneficial for follow-up education, treatment, control, and prevention programmes on Leishmaniasis in Suriname.

10.6.1 Practical implications for public health authorities

First of all, by providing insights into lay knowledge of CL, this study identified the necessity for national information and education programmes about the aetiology of

CL, illness characteristics and development, and the biomedical treatment that public health authorities should develop and implement. Public health campaigns should thus include information concerning the medication provided, its side-effects, and the necessary period of treatment.

Second, the research shows that the majority of CL patients were living and working in the hinterland. Therefore, in particular, information and education programmes should be prepared and aimed specifically at the hinterland communities and other working groups. The importance of involving the Medical Mission in this regard should be underlined. As with the malaria and dengue campaigns (Breeveld et al. 2012), when presenting sand flies as the CL vector, public health authorities can make good use of visual materials (folders, drawings of the sand fly and the cycle of contamination) and in collaboration with the heads of villages in the hinterland organise meetings where people are informed about the illness in their local language. Such information can acknowledge and counter, where appropriate, lay explanations about the cause(s) of CL. Additionally, collaboration should be sought with companies and organisations that predominantly have employers working in the hinterland (such as in the gold and wood sector).

Third, the study found that self-treatment is often applied in the quest to cure CL. Hinterland programmes should, therefore, highlight the advantages and disadvantages of self-treatment practices versus biomedical treatment. Collaboration with local community health experts (if applicable) is hereby recommended. Health workers, when discussing the negative effects of self-treatment practices, should do so in an open, non-judgemental way with hinterland communities and working groups, since – as this study shows – different contexts create conditions in which potentially harmful self-treatment practices occur. Harmful self-treatment practices should be discouraged and early case registration stimulated, which would render self-treatment with harmful medicines unnecessary.

Fourth, the research identified fear of biomedical treatment as a very important aspect in late biomedical treatment seeking. For this reason, this aspect needs to be addressed, both in national and hinterland specific programmes. Side-effects of the biomedical drug, its functioning, and the necessity of adherence to biomedical treatment should be properly discussed. At the clinics (both in the hinterland, as well as the Dermatology Service), CL patients should be counselled before receiving CL treatment. Again, the Medical Mission should be actively involved because of their focus on and expertise with the hinterland communities (see Chapter Three, section 3.2.2.1).

Fifth, the study finding that the biomedical drug Pentamidine for the treatment of CL is considered a vaccine is alarming. Particularly for the hinterland communities, early registration and treatment should be encouraged, where it should also be stressed that the biomedical drug for treatment of CL is not a vaccine. To enhance reporting of new cases, health workers of the Medical Mission in particular could try to detect new cases as early as possible. One way would be the snowball method: inquiries among CL patients (and other villagers) may lead to others who have also contracted CL but have not yet sought biomedical treatment.

Sixth, in Chapter Nine, Table 11 presents a list of questions asked by CL patients. This list could be used by public health authorities as a 'guideline tool' to shape the information provided to the target population at the clinics and during information campaigns. This list (adapted if necessary and potentially elaborated),

with the corresponding answers, should also be posted online for those seeking CL information.

Seventh, the study shows that CL related stigma is not a problem in Suriname. However, there are groups of patients who do encounter negative reactions because of their condition. Public health authorities should be aware of this, since it may require specific education and sensitisation programmes. CL patients who experience distress related to their appearance should be offered proper information, guidance, and counselling at health clinics, both in the hinterland and at the Dermatology Service.

Eighth, the research underlines the problem of adherence. The importance of early registration, treatment, and adherence to biomedical treatment should therefore be highlighted. Specific attention should be paid to conveying information about the severe complications of non-adherence, and the lack of other medicines in case resistance to the biomedical drug Pentamidine occurs. Different aspects of self-treatment (see previous Chapter Six), and fear of biomedical treatment and its side-effects, need more attention.

Ninth, the research shows the importance of multiple contextual factors in influencing CL patients' treatment seeking. Public health authorities should, on the one hand, be aware of the practical and logistical problems that CL patients face, and search for pragmatic solutions that cause less disruption in patients' daily lives in order to stimulate adherence to treatment. Specifically, the already existing 'informal policy' whereby medical doctors prescribe medicines which patients take with them to the hinterland to continue treatment there could be recognised and enhanced to a more 'formal policy'. For this to work, more collaboration between the Medical Mission and the Dermatology Service is needed, in particular setting up sustainable structures to 'follow' CL patients so that continued treatment and outcomes are registered and monitored. On the other hand, CL patients should also be informed about the restrictions that public health authorities face, so that an open platform for mutual understanding can develop.

Certain outcomes of the study entail particular policy implications for the Ministry of Health. First, the study has ascertained that the biomedical drug Pentamidine Isethionate (or Pentacarinate) is often under-stocked or completely lacking, both in the hinterland and in the capital city, and it is furthermore relatively expensive for most of those in need of it. The Ministry of Health should therefore undertake appropriate action to ensure the availability and affordability of the medicines.

Second, the research has produced a long list of non-biomedical treatments, in particular botanical treatments, used by patients in self-treatment. The Ministry of Health, through the Bureau of Public Health, should initiate collaboration between local healers and biomedical health professionals for the identification and production of safe and painless (herbal) medicines to treat CL.

Third, this study is part of the larger multi-disciplinary programme 'Leishmaniasis in Suriname', and all three studies have provided insights into different aspects of the illness and treatment seeking. Therefore, the Ministry of Health must be aware – and be fully informed – of these results prior to developing policies and strategies aimed at early case detection, treatment, control, and management of CL.

A fourth point is that cognitive, infrastructural, and financial barriers to seeking timely biomedical treatment are problematic issues that should be addressed on a macro level. The Ministry of Health should initiate discussion and seek collaboration with policy makers responsible for such issues (Ministry of Finance, Ministry of Public Works, Ministry of Labour, Technological Development and Environment). Such an approach requires a well thought out plan of action and will need some time to take shape. Efforts will be necessary from different stakeholders, but once set up, a tailor-made CL plan of action could be beneficial for both CL patients and biomedical authorities.

10.6.2 Practical implications for health researchers engaged with CL research in Suriname

A third party for whom practical implications are identified are health researchers engaged in CL research in Suriname.

First, as remarked previously, this study contributes extensive insight into the self-treatment practices of CL patients and has identified a wide variety of botanical medicines. Clinical investigations should therefore be developed – as is currently being done – to study these Surinamese botanical medicines and their potential in the treatment of CL.

Second, the study points out that in self-treatment, many potentially harmful chemicals are used. The theme of self-treatment should be investigated further and clinical investigation into the efficacy of non-biomedical chemicals and their interaction with the biomedical drug Pentamidine are urgently needed.

Third, the various ‘hot’ treatment methods, in particular treating CL sores with hot charcoal, as reported at Tepu, require more attention. This treatment method should be further clinically observed and investigated for its benefits in treating CL patients.

Fourth, the study has established that regarding prevention, and especially on the level of ‘primary prevention’, lay (socio-cultural) perceptions are hardly considered. Health researchers working on prevention studies for CL should consider lay (socio-cultural) perceptions as an integral part of the public health concept of prevention; in particular, on the level of ‘primary prevention’.

10.7 Closing remarks

The ‘Leishmaniasis in Suriname’ programme, in which various disciplines presented their vision on cutaneous leishmaniasis, has ended after a five year research period. The programme has provided extensive and unique biological, clinical, and socio-cultural information that can be used for follow-up programmes. Some of the findings have led to recommendations that can be used in the short term to alter existing CL health policy and practice, while other recommendations require more time and careful planning before execution will be possible. It is important to acknowledge that changing health seeking behaviour is a long process in which not only the patient but all other actors (at the local and national level) play decisive roles. Undoubtedly, further CL research is needed on various aspects, as the studies of the ‘Leishmaniasis in Suriname’ programme show. Continuing multi-disciplinary research about awareness – and acting upon – the multiple contexts that lead to

(harmful) self-treatment, late biomedical treatment seeking, and poor adherence to biomedical treatment is crucial for the successful development, implementation, and evaluation of future CL treatment and prevention programmes.

References

- Abazid, N., C. Jones & C. R. Davies
2012 Knowledge, attitude and practices about leishmaniasis among cutaneous leishmaniasis patients in Aleppo, Syrian Arabic Republic. *Eastern Mediterranean Health Journal* 18(1): 7-14.
- Addo, E. & T. Poon-King
1986 Leukocyte suppression in treatment of 72 patients with paraquat poisoning. *Lancet* 327(8490): 1117-20.
- Afghan, A.K., M. Kassi, P.M. Kasi, A. Ayub, N. Kakar & S.M. Marri
2011 Clinical manifestation and distribution of cutaneous leishmaniasis in Pakistan. *Journal of Tropical Medicine*, ID 359145: 1-8.
- Agency for Toxic Substances and Disease Registry (ATSDR)
1997 *Toxicological profile for chlordfenvinphos*. Atlanta, G.A.: United States Department of Health and Human Services, Public Health Service.
- Ajzen, I. & M. Fishbein
1980 *Understanding attitudes and predicting social behaviour*. Englewood Cliffs, NJ: Prentice-Hall.
- Akendengue, B., E. Ngou-Milama, A. Laurens & R. Hocquemiller
1999 Recent advances in the fight against leishmaniasis with natural products. *Parasite* 6(1): 3-8.
- Albrecht, G.J., R. Fitzpatrick & S. Crimshaw
2003 *The handbook of social studies in health and medicine*. London: SAGE.
- Algemeen Bureau voor de Statistiek
2013 Definitieve resultaten Achtste Algemene Volkstelling (Vol.1). Paramaribo: Algemeen Bureau voor de Statistiek/Censuskantoor.
- Alonso, L.E. & J.H. Mol (eds.)
2007 *The RAP Bulletin of Biological Assessment*. Arlington: Conservation International.
- Andersen, R. & J.F. Newman
1973 Societal and individual determinants of medical care utilization in the United States. *Milbank Memorial Fund Quarterly* 51(1): 95-124.
- Anon
1997 *Working party from compliance to concordance: achieving shared goals in medicine taking*. London: Royal Pharmaceutical Society of Great Britain.
- Arboleda-Flórez, J.
2002 What causes stigma? *World Psychiatry* 1(1): 25-6.
- Aronson, N., R. Coleman, P. Coyne, E. Rowton, D. Hack, M. Polhemus, G. Wortmann, K. Cox, P. Weina & B.L. Herwaldt
2003 Cutaneous leishmaniasis in U.S. military personnel – Southwest/Central Asia, 2002-2003. *Morbidity Mortality Weekly Report* 24(52): 1009-12.
- Ashford, R.W.
1999 Cutaneous leishmaniasis: strategies for prevention. *Clinics in Dermatology* 17(3): 327-33.

- Baer, H.
2004 Medical pluralism. In: C.R. Ember & M. Ember (eds) *Encyclopedia of medical anthropology – Health and illness in the world's cultures*. New York: Kluwer Academics / Plenum Publishers, pp.109-16.
- Baer, H.A., M. Singer & I. Susser
2003 *Medical anthropology and the world system*. London: Praegers Publishers.
- Bailey, M.S. & D.N.J. Lockwood
2007 Cutaneous leishmaniasis. *Clinics in Dermatology* 25(2): 203-11.
- Bañuls, A., M. Hide & F. Prugnolle
2007 *Leishmania* and the leishmaniasis: a parasitic genetic update and advances in taxonomy, epidemiology and pathogenicity in humans. In: J.R. Baker, R. Muller & D. Rollinson (eds.) *Advances in Parasitology*. Amsterdam: Academic Press.
- Bellinger, D.C. & A.M. Bellinger
2006 Childhood lead poisoning: the torturous path from science to policy. *Journal of Clinical Investigation* 116(4): 853-57.
- Bennet, S.
1992 Shame, stigma, and mental illness in Ancient Greece. In: P.J. Fink & A. Tasman (eds.) *Stigma and mental illness*. Washington: American Psychiatric Press, Inc., pp. 29-37
- Bern, C., J.H. Maguire & J. Alvar
2008 Complexities of assessing the disease burden attributable to leishmaniasis. *Plos Neglected Tropical Diseases*: e313.
- Berry, D.
2007 *Health communication: theory and practice*. Maidenhead, Berkshire, England, New York: Open University Press.
- Bharat, S., P. Aggleton & P. Tyrer
2001 *India: HIV and AIDS-related discrimination, stigmatization and denial*. Geneva: UNAIDS.
- Birungi, H.
1994 Injections as household utilities: Injection practices in Bugosa, Eastern Uganda. In: N.L. Etkin & M.L. Tan (eds.) *Medicines: meanings and contexts*. Amsterdam / Quezon City: Medical Anthropology Unit / Health Action Information Network, pp. 17-32.
- Boelaert, M., B. Criel, J. Leeuwenburg, W. Van Damme, D. Le Ray & P. Van der Stuyft
2000 Visceral leishmaniasis control: a public health perspective. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 94(5): 465-71.
- Boonmongkon, P.
1994 *Khi thut, "The disease of social loathing": an anthropological study of the stigma and leprosy in rural North-East Thailand*. Geneva: WHO.
- Breeveld, F.J.V., S.G.S. Vreden & M.P. Grobusch
2012 History of malaria research and its contribution to the malaria control success in Suriname: a review. *Malaria Journal* 11(95): 1-7
- Brockhoff, A., M. Behrens, A. Massarotti, G. Appendino & W. Meyerhof
2007 Broad tuning of the human bitter taste receptor hTAS2R46 to various sesquiterpene lactones, clerodane and labdane diterpenoids, strychnine, and denatonium. *Journal of Agricultural & Food Chemistry* 55(15): 6236-43.
- Broslov, L. (ed.)
2002 *Encyclopedia of public health*. New York: Macmillan Reference USA.

- Burgos, A.M. & J.E. Hudson
1994 Annotated list of the phlebotominae (Diptera) of Surinam. *Memorias do Instituto Oswaldo Cruz* 89(2): 171-78.
- Callard, F., F. Myers, L. Main & A. Pyonnen
2009 *Mapping and analyzing anti-discrimination and anti-stigma projects across the WHO European region*. Conference paper- Fourth International Stigma Conference. London: Royal College of Physicians.
- Camden Electronics LTD
2006 *Requirements-hazards and disposal of batteries*. Hertfordshire: Camden Electronics LTD.
- Camargo, L.B. & H. Langoni
2006 Impact of leishmaniasis on public health. *Journal of Venomous Animals and Toxins including Tropical Diseases* 12(4): 527-48.
- Cascon, V. & B. Gilbert
2011 Characterization of the chemical composition of oleoresins of *Copaifera guianensis* Desf., *Copaifera duckei* Dwyer and *Copaifera multijuga* Hayne. In: T. Van Andel & S. Ruyschaert *Medicinale en rituele planten van Suriname*. Amsterdam: KIT Publishers, p. 223.
- Chrisman, N.J.
1977 The health seeking process: an approach to the natural history of illness. *Culture, Medicine, & Psychiatry* 1(4): 351-77.
- Conner, M. & P. Norman
1996 *Predicting health behaviour. Search and practice with social cognition models*. Ballmore, Buckingham: Open University Press.
- Coradetti, A.
1952 The epidemiology and control of oriental sore in Abruzzo, Italy. *American Journal of Tropical Medicine and Hygiene* 1(4): 618-22.
- Corrigan, P.W. & A.C. Watson
2002 Understanding the impact of stigma on people with mental illness. *World Psychiatry* 1(1): 16-20.
- Crabtree, S.A., C.M. Wong & F. Mas'ud
2001 Community participatory approaches to dengue prevention in Sarawak, Malaysia. *Human Organization* 60(3): 281-87.
- Crandon-Malamud, L.
1991 *From the fat of our souls. Social change, political process, and medical pluralism in Bolivia*. Berkeley, Los Angeles, Oxford: University of California Press.
- Crocker, J., B. Major & C. Steel
1998 Social stigma. In: D. Gilbert, S.T. Fiske & G. Lindzey (eds.) *The handbook of social psychology*. New York: McGraw-Hill, pp: 504-53.
- Das, V.
2001 *Stigma, contagion, defect: issues in the anthropology of public health*. Background paper for the National Institute of Mental Health conference on stigma. Maryland: Bethesda.
- De Groot, S.W.
1974 *Surinaamse granmans in Afrika*. Utrecht, Antwerpen: Het Spectrum.
- Department of Community Health
2004 *Chlorine public fact sheet*. Michigan: Department of Community Health.

- Desjeux, P.
2001 The increase in risk factors for leishmaniasis worldwide. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 95(3): 239-43.
- Desjeux, P.
2004 Leishmaniasis: current situation and new perspectives. *Immunology, Microbiology & Infectious Diseases* 27(5): 305-18.
- Deutsch, H. & F. Nussbaum (eds.)
2000 *"Defects": engendering the modern body*. Ann Arbor: University of Michigan Press.
- Dijker, A.J.M. & W. Koomen
2007 *Stigmatization, tolerance and repair*. Cambridge: Cambridge University Press.
- Diniz, J.L., M.O. Costa & D.U. Gonçalves
2011 Mucocutaneous leishmaniasis: clinical markers in presumptive diagnosis. *Brazilian Journal of Otorhinolaryngology* 77(3): 380-84.
- Douglas, M. & A. Wildavsky
1982 *Risk and culture. An essay on the technological and environmental dangers*. Berkeley: University of California Press.
- Dunbar, J.
1980 Adherence to medical advice: a review. *International Journal of Mental Health* 9(1-2): 70-87.
- Emanuel, S.L.
2003 *Kinderen in Brokopondo. Een situatie analyse*. Paramaribo: unknown.
- Estroff, S.E.
1993 Identity, disability and schizophrenia: the problem of chronicity. In: S. Lindebaum & M. Lock (eds.) *Knowledge, power and practice*. Berkeley: University of California Press, pp. 247-86.
- Etkin, N.L.
1994 The negotiation of 'side' effects in Hausa (Northern Nigeria) therapeutics. In: N.L. Etkin & M.L. Tan (eds.) *Medicines: meanings and contexts*. Amsterdam / Quezon City: Medical Anthropology Unit / Health Action Information Network, pp. 17-32.
- Etkin, N.L. & M.L. Tan (eds.)
1994 *Medicines: meanings and contexts*. Amsterdam / Quezon City: Medical Anthropology Unit / Health Action Information Network.
- Evans-Pritchard, E.E.
1937 *Witchcraft, oracles and magic among the Azande*. Oxford: Clarendon Press.
- Fabrega, H., Jr.
1972 The study of disease in relation to culture. *Behavioural Science* 17(2): 183-203.
- Francis, J.J., M.P. Eccles & M. Johnston
2004 *Constructing questionnaires based on the theory of planned behaviour: a manual for health services researchers*. Newcastle: Centre for Health Services Research.
- Frézard, F., C. Demicheli & R.R. Ribeiro
2009 Pentavalent antimonials: new perspectives for old drugs. *Molecules* 14(7): 2317-36.
- Flu, P.C.
1911 Die aetiologie der in Surinam vorkommende sogenannten "Boschyaws" einer der aleppobeule analogen. *Centralblatt für Bakteriologie, Parasitenkunde und Infektionskrankheiten Orig* 60: 624-37.

- Foster, G.M.
1962 *Traditional cultures and the impact of technical change*. New York: Harper.
- 1976 Medical anthropology and international health planning. *Medical Anthropology Newsletter* 7(3): 12-8.
- Foster, G.M. & B.G. Anderson
1978 *Medical Anthropology*. New York: Wiley & Sons, pp. 243-53.
- Fournet, A., A.A. Barrios & V. Munoz
1994 Leishmanicidal and trypanocidal activities of Bolivian Medical plant. *Journal of Ethnopharmacology* 41(1-2): 19-37.
- Garro, L.
1998 On the rationality of decision-making studies: part 1: decision models of treatment choice. *Medical Anthropology Quarterly* 12(3): 319-40.
- Geertz, C.
1973 *The interpretation of cultures: selected essays*. New York: Basic Books.
- Geijskes, D.C.
1954 De landbouw bij de Bosnegers van de Marowijne. *West-Indische Gids* XXXV (3): 135-53.
- Gerrits, G.J.E.
2008 *Clinical encounters: dynamics of patient-centred practices in a Dutch fertility clinic*. Amsterdam: Amsterdam Institute for Social Science Research.
- Glick, L.B.
1967 Medicine as an ethnographic category: the Gimi of the New Guinea Highlands. *Ethnology* 6(1): 31-56.
- Goffman, E.
1963 *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- González, U.
2013 Cochrane reviews on neglected diseases: the case of cutaneous leishmaniasis. *Cochrane Database of Systematic Reviews* 28(3): ED000055.
- González, U., M. Pinart, L. Reveiz & J. Alvar
2008 Interventions for Old World cutaneous leishmaniasis (Review). *The Cochrane Library* 4: CD005067.
- Good, B.J.
2011 *Practicing in a multicultural milieu: listening for stories*. Milwaukee, Wisconsin: conference IBS-the Global Perspective April 6-7, pp. 1-22.
- Good, B.J., M.M.J. Fischer, S.S. Villen & M. Del Vecchio-Good (eds.)
2010 *A reader in medical anthropology. Theoretical trajectories, emergent realities*. Oxford: Blackwell Publishing Ltd.
- Good, C.M.
1987 *Etnomedical systems in Africa*. New York: The Guilford Press.

- Green, G.
2009 *The end of stigma? Changes in the social experience of long-term illness*. New York: Routledge.
- Green, J. & N. Thorogood
2006 *Qualitative methods for health research*. London, Thousand Oaks, New Delhi: SAGE Publications.
- Guernaoui, S., A. Boumezzough, B. Pesson & G. Pichon
2005 Entomological investigations in Chichaoua: an emerging epidemic focus of cutaneous leishmaniasis in Morocco. *Journal of Medical Entomology* 42(4): 697-701.
- Guernaoui, S., A. Boumezzough & A. Laamrani
2006 Altitudinal structuring of sand flies (Diptera: Psychodidae) in the High-Atlas mountains (Morocco) and its relation to the risk of leishmaniasis transmission. *Acta Tropica* 97(3): 346-51.
- Guicherit, H.
2005 *Piki-Nengre fu Sipaliwini. Situatie analyse van kinderen in district Sipaliwini*. Paramaribo: Culconsult.
- Haily, A., A.M. Musa, C. Royce & M. Wasunna.
2005 Visceral leishmaniasis: new health tools are needed. *PLOS Medicine* 2(7): e211.
- Hardon, A.
1992 That drug is hiyang for me: lay perceptions of the efficacy of drugs in Manila, Philippines. *Central Issues in Anthropology*: 10(1): 86-93.
- Hardon, A., P. Boonmongkon, P. Streefland, M.L. Tan, T. Hongvivatana, S. Van der Geest, A. Van Staa, C. Varkevisser, C. Acuin, M. Chowdhury, A. Bhuiya, L. Sringeryuang, E. Van Dongen & T. Gerrits
2001 *Applied health research. Anthropology of health and health care*. Amsterdam: Het Spinhuis.
- Harrison, J.A., P.D. Mullen & L.W. Green
1992 A meta-analysis of studies of the Health Belief Model with adults. *Health Education Research* 7(1): 107-16.
- Hausmann-Muela, S., J.M. Ribera & I. Nyamongo
2003 *Health-seeking behaviour and the health system response*. Disease Control Priorities Projects - working paper no. 14. Washington: Population Reference Bureau.
- Health Assessment and Environmental Safety Department of Syngenta & the Medical Toxicology Unit
2008 *Paraquat poisoning: a practical guide to diagnosis, first aid and hospital treatment*. London: Guy's & St. Thomas' Hospital NHS Trust.
- Heemskerk, M.
2009 Kleinschalige goudwinning in Suriname. Amsterdam: Centrum voor Studie en Documentatie van Latijns-Amerika (CEDLA).
- Heemskerk, M., K. Delvoye & the Trio communities
2007 *Trio baseline study: A sustainable livelihoods perspective on the Trio Indigenous Peoples of South Suriname*. Paramaribo: Amazon Conservation Team.
- Heemskerk, M. & C. Duijves
2012 *Child labor in the small-scale gold mining industry in Suriname*. Calverton: ICF Macro, Inc.
- Helman, C.
2000 *Culture, Health and Illness*. Oxford: Butterworth/Heinemann.

- Henry, R.
2001 *Contraceptive practice in Quirino province, Philippines: experiences of side effects*. Calverton, Maryland, USA: University of the Philippines Population Institute, University of La Salette, and Macro International Inc.
- Hepburn, N.C.
2003 Cutaneous leishmaniasis: an overview. *Journal of Postgraduate Medicine* 49(1): 50-54.
- Herek, G.M.
2009 Internalized stigma among sexual minority adults: insights from a social psychological perspective. *Journal of Counseling Psychology* 56(1): 32-43.
- Herek, G.M. & J.P. Capitano
1999 AIDS stigma and sexual prejudice. *American Behavioral Scientist* 42(7): 1130-47.
- Herek, G.M., R.J. Gillis & J.C. Cogan
2009 Internalized stigma among sexual minority adults: insights from a social psychological perspective. *Journal of Counseling Psychology* 56(1): 32-43.
- Herwaldt, B.
1999 Leishmaniasis. *The Lancet* 354(9185): 1191-99.
- Heyde, H.
1987 *Surinaamse medicijnplanten*. Paramaribo: Westfort.
- Hirschberger, G., V. Florian, M. Mikulinger, J.L. Goldenberg & T. Pyszczynski
2002 Gender differences in the willingness to engage in risky behavior: a terror management perspective. *Death studies* 26(2): 117-42.
- Hoffman, B.
2009 *Drums and arrows: ethnobotanical classification and forest use by a Maroon and Amerindian community in Suriname, with implications for biocultural conservation*. Manoa: University of Hawai.
- Hu, R.V.P.F.
2013 *Treatment, quality of life and cost-aspects of cutaneous leishmaniasis in Suriname*. Paramaribo: Dermatology Service.
- Hu, R.V.P., A.D. Kent, E.R. Adams, C. Van der Veer, L.O.A. Sabajo, D.R.A. Mans, H.J.C. de Vries, H.D.F.H. Schallig & R.F.M. Lai a Fat
2012 First case of cutaneous leishmaniasis caused by *Leishmania (Viannia) braziliensis* in Suriname. *American Journal of Tropical Medicine & Hygiene* 86(5): 825-27.
- Hudson, J.E.
1987 The 1982 emergency ultralow volume spray campaign against *Aedes aegypti* adults in Paramaribo, Suriname. *Boletín de la Oficina Sanitaria Panamericana* 103(1): 21-23.
- 1988 Bloodsucking Diptera (Culicidae, Psychodidae, Ceratopogonidae, Simuliidae, Tabanidae), collected in Suriname. *Acta Leidensia* 57(1): 1-27.
- Husson, A.M.
1973 Voorlopige lijst van de zoogdieren van Suriname, *Zoologische Bijdragen* 14: 3-15.
- Hyland, J.A.
1993 *A socio-cultural study of Leprosy in Nepal: compliance, patient illness career patterns, and health education*. Ph.D. dissertation, University of Tasmania.
- Igun, U.A.
1979 Stages in health-seeking: a descriptive model. *Social Science and Medicine* 13A(4): 445-56.

- International Federation of Anti-leprosy Associations (ILEP) & the Netherlands Leprosy Relief (NLR)
2011 *Guidelines to reduce stigma*. London/Amsterdam: ILEP & NLR.
- International Monetary Fund
2011 *IMF Country Report Suriname* no. 11/256. Washington D.C.: International Monetary Fund.
- Jacoby, A., W. Wang, T. Dang Vu, J. Wu, N. Aydemir, J. Parr, R. Reis, C. Begley, H. De Boer, L. Prilipko & G. Baker
2007 Meanings of epilepsy in its sociocultural context and implications for stigma: Findings from ethnographic studies in local communities in China and Vietnam. *Epilepsy & Behaviour* 12(2): 286-97.
- Jacobson, R.L.
2003 *Leishmania tropica* (Kinetoplastida: Trypanosomatidae) – a perplexing parasite. *Folia Parasitologica* 50(n.n): 241-50.
- Janzen, J.M.
1987 *The quest for therapy in Lower Zaire*. Berkeley: University of California Press.
- Jara, F.
1996 Een mythe om te overleven. De Akuriyo Indianen van Suriname. *OSO tijdschrift voor Surinamistiek en Caraïbisch gebied* 15 (n.n.): 29-40.
- Jochems, A.A.F. & F.W.M.G. Joostens
2009 *Coëlho, Zakwoordenboek der Geneeskunde*. Doetinchem: Reed Business bv.
- Jones, E., A. Farina, A. Hastorf, H. Markus, D. Miller & T.R.A. Scott
1984 *Social stigma: the psychology of marked relationships*. New York: Freeman and Company.
- Kassi, M., A.K. Afghan, R. Rehman & P.M. Kasi
2008 Marring leishmaniasis: the stigmatization and the impact of cutaneous leishmaniasis in Pakistan and Afghanistan. *PLOS Neglected Tropical Diseases* 2(10): e259.
- Kendall, K.
1998 The role of formal qualitative research in negotiating community acceptance: the case of dengue control in El Progreso, Honduras. *Human Organization* 57(2): 217-21.
- Kent, A.D.
2013 *Studies towards an improved understanding of the biology of cutaneous leishmaniasis in Suriname*. Paramaribo: Anton de Kom Universiteit.
- Kent, A.D., P. Ramkalup, D. Mans & H. Schallig
2013 Is the dog a possible reservoir for cutaneous leishmaniasis in Suriname? *Journal of Tropical Medicine* 2013, article ID324140: 1-5.
- Kent, A.D., T.V. dos Santos, A. Gangadin, D. Mans & H. Schallig
2013 Studies on the sand fly fauna (Diptera: Psychodidae) in high-transmission areas of cutaneous leishmaniasis in the Republic of Suriname. *Parasites and Vectors* 6(1): 318-26.
- Khan, S.J. & S. Muneeb
2005 Cutaneous leishmaniasis in Pakistan. *Dermatology Online Journal* 11(1): 4.
- Kleinman, A.
1980 *Patients and healers in the context of culture*. Berkeley: University of California Press.
- 1988 *The illness narratives: suffering, healing and the human condition*. New York: Basic Books.
- Köbben, A.J.F.
1973 Unity and disunity: Cottica Djuka society as a kinship system. In: R. Price (ed.) *Maroon societies*. New York: Anchor Press/Doubleday.

- 1991 Taboes in de wetenschap. In A.J.F. Köbben: *De weerbarstige waarheid*. Amsterdam: Prometheus, pp. 9-26.
- Krienert, J.L.
2003 Masculinity and crime: a quantitative exploration of Messerschmidt's hypothesis. *The Electronic Journal of Sociology* 7(2): 1-30.
- Kroeger, A.
1983 Anthropological and socio-medical health care research in developing countries. *Social Science & Medicine* 17(3): 147-161.
- Krumeich, A.
1989 Ziektepreventie in een Karibendorp in Suriname. *Bijdragen Taal-, Land-, en Volkenkunde* 145(1): 72-86.
- Kwansa, B.K.
2013 *Safety in the midst of stigma. Experiencing HIV/AIDS in two Ghanaian communities*. Leiden: African Studies Centre.
- Lai A Fat, E.J., M.A. Vrede, R.M. Soetosenojo & R.F. Lai A Fat
2002 Pentamidine, the drug of choice for the treatment of cutaneous leishmaniasis in Suriname. *International Journal of Dermatology* 41(11): 796-800.
- Lainson, R.
2011 The neotropical *Leishmania* species: a brief historical review of their discovery, ecology and taxonomy. *Revista Pan-Amazonica de Saude* 1(2): 13-32.
- Last, M.
1981 The importance of knowing about not-knowing. *Social Science and Medicine* 15(B): 387-92.
- Lieban, R.
1966 Fatalism and medicine in Cebuano areas of the Philippines. *Anthropological Quarterly* 39(3): 171-79.
- Liefoghe, R., J.B. Baliddawa, E.M. Kipruto, C. Vermeire & A.O. Munynck
1997 From their own perspective. A Kenyan communities' perception on tuberculosis. *Tropical Medicine and International Health* 2(8): 809-21.
- Link, B.G. & J.C. Phelan
2001 Conceptualizing stigma. *Annual Review of Sociology* 27: 363-85.
- Littlewood, R. (ed.)
2007 *On knowing and not-knowing in the anthropology of medicine*. Los Angeles: Left Coast Press, Inc.
- Llanos-Cuentas, E.A., P.D. Marsden, L.D. Lago, A.C. Baretto, C.C. Cuba & W.D. Johnson
1984 Human mucocutaneous leishmaniasis in Três Braços, Bahia-Brazil, an area of *Leishmania Braziliensis Braziliensis* transmission. *Revista da Sociedade Brasileira de Medicina Tropical* 17(4): 169-77.
- López, L., M. Robayo, M. Vargas & I.D. Vélez
2012 Thermotherapy. An alternative for the treatment of American cutaneous leishmaniasis. *Trials* 13(58): 1-7.
- Lumu, R. & C. Katongole
2011 Comparative reduction of oxalates from New Cocoyam (*Xanthosoma sagittifolium*) leaves by four processing methods. *Livestock Research for Rural Development* 23: # 20.

- Mackian, S., N. Bedri & L. Hermione
2004 Up the garden path and over the edge: where might health-seeking behaviour take us? *Health Policy & Planning* 19(3): 137-46.
- Markowitz, G. & D. Rosner
2000 'Cater to the children': the role of the lead industry in a public health tragedy, 1900-1955. *American Journal of Public Health* 90(1): 36-46.
- Matthews, H.F.
1982 Illness classification and treatment choice. *Reviews in Anthropology* 9(2): 171-86.
- 1987 Predicting decision outcomes: have we put the cart before the horse in anthropological studies of decision making. *Human Organization* 46(1): 54-61.
- 1998 Illness classification and treatment choice. Decision making in medical domain. In: S. Van der Geest & A. Rienks (eds.) *The art of medical anthropology: readings*. Amsterdam: Het Spinhuis, pp. 268-81.
- May, A.F.
1982 *Sranan oso dresi. Surinaams kruidenboek*. Paramaribo: De Walburg Pers.
- Ministerie van Volksgezondheid
2006 Beleidsnota 2006-2007. Paramaribo: Ministerie van Volksgezondheid.
- Ministerie van Volksgezondheid
2011 National Health Sector plan 2011-2018. Paramaribo: Ministerie van Volksgezondheid.
- Modabber, F., P.A. Buffet, E. Torreele, G. Milon & S.L. Croft
2007 Consultative meeting to develop a strategy for treatment of cutaneous leishmaniasis. Instituut Pasteur, Paris, 13-15 June 2006. *Kinetoplastid Biology and Disease* 6(3): 1-24
- Moerman, D.
2002 *Meaning, medicine, and the "placebo" effect*. Cambridge: Cambridge University Press.
- 2011 Examining a powerful healing effect through a cultural lens, and finding meaning. *The Journal of Mind-Body regulation* 1(2): 63-71.
- Mull, J.D. & D.S. Mull
1998 Mothers' diarrhoea concepts in rural Pakistan. *Social Science & Medicine* 27(1): 53-67.
- Müllen, U.
1983 Preventieve zorg in niet-westerse culturen. *Antropologische Verkenningen* 2-3: 71-86.
- Nichter, M.
1992 *Anthropological approaches to the study of ethnomedicine*. London: Taylor & Francis.
- 2008 *Global health. Why cultural perceptions, social representations, and biopolitics matter*. Tucson: University of Arizona Press.
- Nichter, M. & M. Nichter
1996 Cultural notions of fertility in South Asia and their impact on Sri Lankan family planning practices. In: M. Nichter & M. Nichter (eds.) *Anthropology and international health: Asian case studies*. Amsterdam: Gordon & Breach, pp. 3-33.
- 1998 Cultural notions of fertility in South Asia and their impact on Sri Lankan family planning practices. In: S. Van der Geest & A. Rienks (eds.) *The art of medical anthropology: readings*. Amsterdam: Het Spinhuis, pp. 268-81.

- Nichter, M. & C. Nordstrom
1989 A question of medicine answering: health commodification and the social relations of healing in Sri Lanka. *Culture, Medicine & Psychiatry* 13(4): 367-90.
- Nichter, M. & N. Vuckovic
1994 Agenda for an anthropology of pharmaceutical practice. *Social Science & Medicine* 39(11): 1509-25.
- Obrist, B., N. Iteba, C. Lengeler, A. Makemba, C. Mshana, R. Nathan, S. Alba, A. Dilip, M.W. Hetzel, I. Mayumana, A. Schulze & M. Mshinda
2007 Access to health care in contexts of livelihood insecurity: a framework for analysis and action. *PLOS Medicine* 4(10): e308.
- Olugbuyiro, J.A.O., J.O. Moody & M.T. Hamann
2009 AntiMtb activity of triterpenoid-rich fractions from *Spondias mombin* L. *African Journal of Biotechnology* 8(9): 1807-09.
- Ostendorf, F.W.
1962 *Nuttige planten en sierplanten in Suriname*. Amsterdam: Gebroeders van Leeuwen.
- Pan American Health Organization
2002 *Health systems and services profile of Suriname*. Pan American Health Organization.
- Pardo, R.H., A. Carvajal, C. Ferro & C.R. Davies
2006 Effect of knowledge and economic status on sandfly control activities by householders at risk of cutaneous leishmaniasis in the subandean region of Huila department, Colombia. *Biomédica* 26(1): 167-79.
- Parry, K.K.
1984 Concepts from medical anthropology for clinicians. *Physical Therapy* 64(6): 929-33.
- Paul, B. (ed.)
1955 *Health, culture and community: case studies of public reactions to health programs*. New York: Russell Sage Foundation.
- Pavli, A. & H.C. Maltezos
2010 Leishmaniasis, an emerging infection in travellers. *International Journal of Infectious Diseases* 14(12): e1032-39
- Peters, W. & G. Pasvol
2007 *Atlas of tropical medicine and parasitology*. London: Elsevier Mosby.
- Plotkin, M.J.
1986 *Ethnobotany and conservation of the tropical forest with special reference to the Indians of Southern Suriname*. Boston, Massachusetts: Tufts University.
- Pool, R.
2003 *Dialogue and the interpretation of illness*. Amsterdam: Aksant Academic Publishers.
- Prasad, N., B.C. Ghiya, R.A. Bumb, H. Kaushal, A.A. Saboskar, C.M. Lezama-Davila, P. Salotra & A.R. Satoskar
2011 Heat, oriental sore and HIV. *Lancet* 377(9765): 610.
- Punwasi, W.
2012 *Doodsoorzaken in Suriname 2010-2011*. Paramaribo: Bureau voor Openbare Gezondheidszorg.

- Raeburn, P.
2006 Slow-acting: after 25 years, the EPA still won't ban a risky pesticide. *Scientific American*: 295(5): 1509-25.
- Raghoenandan, U.P.D.
1994 *Etnobotanisch onderzoek bij de Hindoestaanse bevolkingsgroep in Suriname*. Paramaribo: Anton de Kom Universiteit.
- Ramdas, S.
2008 *Treatment of the umbilical stump within the Maroon community*. Paramaribo: Pan American Health Organization Country Office Paramaribo.
- 2012 Cruel disease, cruel medicine: self-treatment of cutaneous leishmaniasis with harmful chemical substances in Suriname. *Social Science & Medicine* 75(6): 1097-05.
- Raveles, R.
1973 *Flowers must not grow today*. Paramaribo: Afi-Kofi.
- Reeler, A.V.
2000 Anthropological perspectives on injections: a review. *Bulletin of the World Health Organization* 78(1): 135-43.
- Reinherz, H.
1980 Primary prevention of emotional disorders of children: mirage or reality. *Journal of Prevention* 1(1): 4-14.
- Reis, R.
1996 *Sporen van ziekte: medische pluraliteit en epilepsie in Swaziland*. Amsterdam: Het Spinhuis.
- Reithinger, R., K. Aadil, J. Kolaczinski, M. Mohsen & S. Hami
2005 Social impact of leishmaniasis in Afghanistan. *Emerging Infectious Diseases* 11(4): 634-36.
- Reithinger, R., M. Mohsen, K. Aadil, M. Sidiqi, P. Erasmus & P.G. Coleman
2003 Anthroponotic cutaneous leishmaniasis, Kabul, Afghanistan. *Emerging Infectious Diseases* 9(6): 727-29.
- Reithinger, R., M. Mohsen & T. Leslie
2010 Risk factors for anthroponotic cutaneous leishmaniasis at the household level in Kabul, Afghanistan. *PLOS Neglected Tropical Diseases* 4(3): e639.
- Republic of Suriname and European Union
2008 *Country strategy paper and national indicative program for the period 2008-2013*. Paramaribo: Government of Suriname.
- Reyburn, H., M. Rowland, M. Mohsen, B. Khan & C. Davies
2003 The prolonged epidemic of anthroponotic cutaneous leishmaniasis in Kabul, Afghanistan: 'bringing down the neighbourhood'. *Transactions of the Royal Society of Tropical Medicine and Hygiene* 97(2): 170-76.
- Ribera, J.M., K.P. Grietens, E. Toomer & S. Hausmann-Muela
2009 A word of caution against the stigma trend in neglected tropical disease research and control. *PLOS Neglected Tropical Diseases* 3(10): 1-4.
- Robson, M.C., J.P. Heggers & W.J. Hagstrom
1982 Myth, magic, witchcraft or fact? *Aloe vera* revisited. *Journal of Burn Care & Research* 3(3): 157-62.

- Rolander, D.
2008 Daniel Rolander's journal, the Suriname journal: composed during an exotic journey. In: L. Hansen (ed.) *The Linnaeus apostles: Global science & adventure*. London: IK Foundation & Company, pp. 1215-76.
- Rosenstock, L.M.
1966 Why people use health services. *Milbank Memorial Fund Quarterly* 44: 94-121.
- Rotoreau, B.
2006 Ecology of the Leishmania species in the guianan ecoregion complex. *The American Journal of Tropical Medicine and Hygiene* 74(1): 81-96.
- Ruysschaert, S., T.R. Van Andel, K. Van de Putte & P. Van Damme
2009 Bathe the baby to make it strong and healthy: Plant use and child care among Saramaccan Maroons in Suriname. *Journal of Ethnopharmacology* 121(1): 148-70.
- Rüsch, N., P.W. Corrigan, A.R. Todd & G.V. Bodenhausen
2010 Implicit self-stigma in people with mental illness. *The Journal of Nervous and Mental Disease* 198(2): 150-53.
- Saliba, E.K. & O.Y. Oumeish
1999 Reservoir hosts of cutaneous leishmaniasis. *Clinical Dermatology* 17(3): 275-77.
- Sanches, R.M.
2011 Endemic (Non-Venereal) Treponematoses. In: K. Wolff, L.A. Goldsmith, S.I. Katz, B.A. Gilchrist, A.S. Paller & D.J. Leffell (eds.) *Fitzpatrick's dermatology in general medicine*. New York: McGraw-Hill, Chapter 2: fig 201-4, unknown
- Scambler, G.
1984 Perceiving and coping with stigmatising illness. In: R. Fitzpatrick, J. Hintos, S. Newman, G. Scambler & J. Thompson (eds.) *The experience of illness*. London: Tavistock, pp. 203-26.
- Scambler, G. & A. Hopkins
1986 Being Epileptic. Coming to terms with stigma. *Sociology of Health & Illness* 8(1): 26-43.
- 1998 Stigma and disease: changing paradigms. *Lancet* 352 (9133): 1054-55.
- 2004 Re-framing stigma. Felt and enacted stigma and challenges to the sociology of chronic and disabling conditions. *Social Theory & Health* 2(1): 29-46.
- 2011 The stigma of epilepsy and its impact. Papers from the epilepsy & society symposium. Brisbane, Australia.
- Scheerder, G., S. Van den Broucke & H. Saan
2003 *Projecten voor gezondheidspromotie: praktische handleiding voor kwalitatieve werken*. Apeldoorn: Garant.
- Scheider, J., R. Seiger & M. Mahon
2008 Leishmaniasis – case report with current diagnostic and treatment strategies. *Journal of American Osteopathic College of Dermatology* 11(1): 11-6.
- Scheper-Hughes, N. & M. Lock
1998 The mindful body. In: S. Van der Geest & A. Rienks (eds.) *The art of medical anthropology: readings*. Amsterdam: Spinhuis, pp. 347-68.
- Sciortino, R.
1987 *Yang menyembuhkan Tuhan, tetapi lewat dukun, arts, konidin, Jamu... (Wie geneest is God, maar Hij manifesteert zich door en/in de dukun, arts, konidin Jamu...)*. Doctoraalscriptie Culturele Antropologie/NWS. Amsterdam: Vrije Universiteit.

- Silveira, F.T., R. Lainson & C.E.P. Corbett
2004 Clinical and immunopathological spectrum of American cutaneous leishmaniasis with special reference to the disease in Amazonian Brazil – a review. *Memórias do Instituto Oswaldo Cruz* 99(3): 239-51.
- Simonsen, L., A. Kane, J. Lloyd, M. Zaffran & M. Kane
1999 Unsafe injections in the developing world and transmission of bloodborne pathogens: a review. *Bulletin of the World Health Organization* 77(10): 789-800.
- Singer, M.
2004 Critical medical anthropology. In: C.R. Ember & M. Ember (eds.) *Encyclopedia of medical anthropology – Health and illness in the world's cultures*. New York: Kluwer Academics / Plenum Publishers, pp. 24-30.
- Singer, M. & H.A. Baer
2007 *Introducing medical anthropology: a discipline in action*. Lanham: Rowman & Littlefield Publ. Inc.
- Slagveer, J.L.
1990 *Surinaams groot kruidenboek: Sranan oso dresie*. Paramaribo: De West.
- Slikkerveer, L.J.
2006 The challenge of non-experimental validation of MAC plants. In: R.J. Bogers, L.E. Craker & D. Lange (eds.) *Medicinal and aromatic plants*. Wageningen: Springer, pp. 1-28.
- Snijders, E.P.
1946 In memoriam Prof. Dr. P.C. Flu. *Nederlands Tijdschrift voor Geneeskunde* 90(40): 40.
- Soo Han, G.
2002 The myth of medical pluralism: a critical realist perspective. *Sociological Research Online* 6(4): U92-U112.
- Soto, J., F. Medina, N. Dember & J. Berman
1995 Efficacy of permethrin-impregnated uniforms in the prevention of malaria and leishmaniasis in Colombian soldiers. *Journal of Clinical Infectious Diseases* 21(3): 599-602.
- Stahel, G.
1942 De nuttige planten van Suriname. *Bulletin Departement Landbouwproefstation in Suriname* 57(unknown): 1-197.
- Starfield, B., J. Hyde, J. Gervas & I. Heath
2009 The concept of prevention: a good idea gone astray? *Journal of Epidemiology and Community Health* 62(7): 580-83.
- Steward, W.I., G.M. Herek, J. Ramakrishna, S. Bharat, S. Chandy, J. Wrubel & M.L. Ekstrand
2008 HIV-related stigma: adapting a theoretical framework for use in India. *Social Science & Medicine* 67(8): 1225-35.
- Strober, H.M.
2003 *Habits of the mind: Challenges for multidisciplinary engagement*. Stanford: Stanford University.
- Suchman, E.
1965 Social patterns of illness and medical care. *Journal of Health and Human Behaviour* 6(1): 2-16.
- Sussman, L.K.
2008 The role of culture in illness interpretation and therapy. In: U.P. Gielen, J.G. Draguns & J.M. Fish (eds.) *Principles of multicultural counselling and therapy*. New York: Routledge, pp. 37-69.

- Synnott, A.
1990 The beauty mystique: ethics and aesthetics in the Bond genre. *International Journal of Politics, Culture and Society* 3(3):407-26.
- 1993 *The body social: symbolism, self and society*. New York: Routledge.
- 2006 The beauty mystique: ethics and aesthetics in the Bond genre. *Facial Plastic Surgery* 22(3): 163-74.
- Terborg, J.
2001 *Sexual behaviour and sexually transmitted diseases among Saramaka and Ndjuka Maroons in the hinterland of Suriname*. Paramaribo: Medische Zending/Prohealth.
- Terborg, J., S. Ramdas & D. Eiloo
2006 *ICPD + 10. 10 years Programme of Action of the International Conference on Population and Development (ICPD) in Suriname 1994-2004*. Paramaribo: ProHealth.
- Titjari, W.
1985 *Famiri-encyclopedia Foe da Natura Dresi-Fas: Gezinskruidenboek van de natuurgeneeswijzen, natuurgeneeswijzen uit het zonnige Suriname*. Amsterdam: Sangrafoe.
- Tjong Ayong, G.
1989 *Het gebruik van medicinale planten door de Javaanse bevolkingsgroep in Suriname*. Paramaribo: Instituut voor de Opleiding van Leraren.
- Trotter, R.T.
2011 Applied medical anthropology: praxis, pragmatics, politics and promises. In: M. Singer & I. Erickson (eds.) *A companion to medical anthropology*. United Kingdom: Blackwell Publishing Ltd., pp. 49-68.
- Turner, V.
1967 *The forest of symbols: aspects of Ndembu ritual*. New York: Cornell University Press.
- Uiterloo, M.
2012 *Pre-study of the efficacy of Sipuinuime: a local indigenous treatment for CL in Suriname*. Paramaribo: Amazon Conservation Team.
- Ul Bari, A.
2006 Chronology of cutaneous leishmaniasis: an overview of the history of the disease. *Journal of Pakistan Association of Dermatologists* 16: 24-7.
- United Nations Development Programme
2014 *Human Development Report 2014*. New York: United Nations Development Programme.
- Van Andel, T. & S. Ruyschaert
2011 *Medicinale en rituele planten van Suriname*. Amsterdam: KIT Publishers.
- Van Andel, T.R., S. De Korte, D. Koopmans, J.A. Behari-Ramdas & S. Ruyschaert
2008 Dry sex in Suriname. *Journal of Ethnopharmacology* 116(1): 84-8.
- Van Arkel, Z.
2006 *De kunst van het vertellen*. Doctoraal scriptie Culturele Antropologie: Universiteit Utrecht.
- Van Brakel, W.
2003 Measuring leprosy stigma – A preliminary review of the leprosy literature. *International Journal of Leprosy and other Mycobacterial Diseases* 71(3): 190-97.
- 2006 Measuring health-related stigma – a literature review. *Psychology, Health and Medicine* 11(3): 307-34.

- Van der Geest, S.
1987 Self-care and the informal sale of drugs in South Cameroon. *Social Science & Medicine* 25(3): 293-305.
- 1995 The efficacy of traditional medicine (and biomedicine). In: K. Van der Velden, J.K.S. Van Ginneken, J.P. Velema, F.B. De Walle & J.H. Van Wijnen (eds.) *Health matters: public health in North-South perspective*. Houten/Diegem: Bohn Stafleu van Loghum, pp. 360-65.
- 2005 Ethnocentrism and medical anthropology. In: S. Van der Geest & R. Reis (eds.) *Ethnocentrism: reflections on medical anthropology*. Amsterdam: Het Spinhuis, pp: 1-24.
- 2010 Thick and thinned description. How useful can anthropology be? In: R. Park & S. Van der Geest (eds.) *Doing and living medical anthropology*. Diemen: AMB Publishers, pp. 91-106.
- Van der Geest, S. & A. Krumeich
1989 Preventie en cultuur: een voorbeeld uit Suriname. In: S. Van der Geest & G. Nijhof (eds.), *Ziekte, gezondheidszorg en cultuur*. Amsterdam: Het Spinhuis, pp. 39-48.
- Van der Geest, S. & A. Hardon
1990 Self-medication in developing countries. *Journal of Social & Administrative Pharmacy* 7(4): 199-204.
- Van der Geest, S. & A. Meulenbroek
1993 Metaphors, metonyms and homeopathy: terms of illness and therapy among Mossi people in Burkina Faso. *Curare* 16(3/4): 285-90.
- Van der Geest, S. & G. Nijhof (eds.)
1989 *Ziekte, gezondheidszorg en cultuur*. Amsterdam: Het Spinhuis.
- Van der Geest, S. & R. Reis (eds.)
2005 *Ethnocentrism: Reflections on medical anthropology*. Amsterdam: Het Spinhuis Publishers
- Van der Geest, S. & S.R. Whyte
1989 The charm of medicines: metaphors and metonyms. *Medical Anthropology Quarterly* 3(4): 345-67.
- Van der Meide, W.
2008 *Cutaneous leishmaniasis: new developments in diagnosis and treatment evaluation*. Amsterdam: KIT Publishers.
- Van der Meide, W.F., H. de Vries, F. Pratlong, A. Van der Wal & L.O.A. Sabajo
2008 *Leishmania, (Leishmania) amazonensis* infection, Suriname. *Emerging Infectious Diseases* 14(5): 857-59.
- Van der Meide, W.F., A.J. Jensema, R.A.E. Akrum, L.O.A. Sabajo, R.F.M. Lai A Fat, L. Lambregts, H.D.F.H. Schallig, M. Van der Paardt & W.R. Faber
2008 Epidemiology of cutaneous leishmaniasis in Suriname: a study performed in 2006. *The American Journal of Tropical Medicine and Hygiene* 79(2): 192-97.
- Van der Meide, W., L.O.A. Sabajo, A.J. Jensema, J.P. Peekel, R.W. Faber, H.D. Schallig & R.F. Fat
2009 Evaluation of treatment with pentamidine for cutaneous leishmaniasis in Suriname. *International Journal of Dermatology* 48(1): 52-58.
- Van Praag, S.
1977 Algemene gezondheidstoestand. In: A. Helman (ed.) *Cultureel mozaiek van Suriname*. Zutphen: De Walberg Pers Zutphen, pp. 41-50.

Van 't Klooster, C.I.E.A.

2009 *Medicinal, Aromatic and Cosmetic (MAC) plants for local health care and bio-cultural diversity conservation in the Saramaccan village Pikin Slee in Suriname*. Amsterdam: University of Amsterdam/ Master thesis Medical Anthropology.

2011 Het belang van medicinale, aromatische en cosmetische planten voor de Saramaccaners in het binnenland van Suriname. *OSOTijdschrift voor Surinamistiek en het Caraïbisch gebied* 30(10): 248-66.

Van 't Klooster, C.I.E.A., J.C. Lindeman & M.J. Jansen-Jacob.

2003 *Blumea Index of vernacular plant names of Suriname*. Leiden: Nationaal Herbarium Nederland.

Vermeire, E., H. Hearnshaw, P. Van Royen & J. Denekers

2001 Patient adherence to treatment: three decades of research. A comprehensive review. *Journal of Clinical Pharmacy and Therapeutics* 26(5): 331-432.

Verpoorte, R. & P.P. Dihal

2011 Medical plants of Suriname I V. Antimicrobial activity of some medical plants. In: T. Van Andel & S. Ruyschaert *Medicinale en Rituele planten van Suriname*. Amsterdam: KIT Publishers, p. 252.

Verpoorte, R., T.A.A. Tsoi, H. Van Doorne & A. Baerheim Svendsen

2011 Medical plants of Suriname I. Antimicrobial activity of some medical plants. In: T. Van Andel & S. Ruyschaert *Medicinale en rituele planten van Suriname*. Amsterdam: KIT Publishers, p. 119.

Wagner, M.K.

2001 Behavioral characteristics related to substance abuse and risk-taking, sensation-seeking, anxiety sensitivity and self-reinforcement. *Addictive Behaviors* 26(1): 115-20.

Waldram, J.B.

2000 The efficacy of traditional medicine: current theoretical and methodological issues. *Medical Anthropology Quarterly* 14(4): 603-25.

Ward, H., T.E. Mertens & C. Thomas

1997 Health seeking behaviour and the control of sexually transmitted diseases. *Health Policy & Planning* 12(1): 19-28.

Weigel, M.M., R.X. Armijos, R.J. Racines, C. Zurita, R. Izurieta, E. Herrera & E. Hinojsa

1994 Cutaneous leishmaniasis in subtropical Ecuador: popular perceptions, knowledge and treatment. *Bulletin of PAHO* 28(2): 142-55.

Weigel, M.M. & R.X. Armijos

2001 The traditional and conventional medical treatment of CL in rural Ecuador. *Review Panam Salud/ Pan American Journal of Public Health* 10(6): 395-404.

Weiss, M.G.

1998 Ethical reflections: taking a walk on the wild side. In: N. Scheper-Hughes & C. Sargent (eds.) *Small wars: the cultural politics of childhood*. Berkely: University of California Press, pp. 139-62.

2008 Stigma and the social burden of Neglected Tropical Diseases. *PLOS Neglected Tropical Diseases* 2(5): e237.

Weiss, M.G. & J. Ramakrishna

2004 *Health-related stigma: rethinking concepts and intervention*. Background paper. Amsterdam: Royal Tropical Institute (KIT).

Weiss, M., J. Ramakrishna & D. Somma

2006 Health-related stigma: rethinking concepts and interventions 1. *Psychology, Health & Medicine* 11(3): 277-87.

- Weller, S.C., T.R. Ruebush II & R.E. Klein
1997 Predicting treatment-seeking behaviour in Guatemala: a comparison of the health services research and decision-theoretic approaches. *Medical Anthropology Quarterly* 11(2): 224-45.
- White House Commission
2002 *White House Commission on complementary and alternative medicine policy, final report*. Washington D.C.: White House Commission.
- Whyte, S.R. & S. Van der Geest
1994 Injections: issues and methods for anthropological research. In N.L. Etkin & M.L. Tan (eds.) *Medicines: meanings and contexts*. Amsterdam / Quezon City: Medical Anthropology Unit / Health Action Information Network, pp. 17-32.
- Whyte, S., S. Van der Geest & A. Hardon
2002 *Social lives of medicines*. Cambridge: Cambridge University Press.
- Wijers, D.J.B. & R. Linger
1966 Man-biting sandflies in Suriname (Dutch Guiana): *Phlebotomus anduzei* as a possible vector of *Leishmania brasiliensis*. *Annals of Tropical Medicine & Parasitology* 60: 501-08.
- Willard, R.J., A.M. Jeffcoat, P.M. Benson & D.S. Walsh
2005 Cutaneous leishmaniasis in soldiers from Fort Campbell, Kentucky returning Operation Iraqi Freedom highlights diagnostic and therapeutic options. *Journal of the American Academy of Dermatology* 52(6): 977-87.
- World Health Organization
1999 *Safe and effective use of household insecticide products. Guide for the production of educational and training materials*. Washington: WHO.
- 2000 *General guidelines for methodologies on research and evaluation of traditional medicine*. Geneva: WHO.
- 2002 Cutaneous Leishmaniasis, Afghanistan. *Weekly Epidemiological Record* 77(29): 241-48.
- 2004 *Report on leishmaniasis*. Geneva: WHO.
- 2005 *National policy on traditional medicine and regulation of herbal medicines. Report of a global WHO survey*. Geneva: WHO.
- 2007a *Cutaneous Leishmaniasis: Why are you neglecting me? A WHO initiative to control Cutaneous Leishmaniasis in selected Old World areas*. Geneva: WHO Document Production Services.
- 2007b *Joint fact sheet WHO/OHCHR/323*, August 2007. Geneva: WHO.
- 2008 *Report of the consultative meeting on CL, Geneva, Headquarters 30 April to 2 May 2007*. Geneva: WHO Document Production Services.
- 2009 *Neglected tropical diseases*. Geneva: WHO.
- 2013 *Draft manual for case management of cutaneous leishmaniasis in the WHO Eastern Mediterranean Region*. Geneva: WHO.
- Yanik, M., M.S. Gurel, Z. Simzek & M. Kati
2004 The psychological impact of cutaneous leishmaniasis. *Clinical and Experimental Dermatology* 29(5): 464-67.

- Young, A.
1976 Internalizing and externalizing medical belief systems: an Ethiopian example. *Social Science & Medicine* 10(3-4): 147-56.
- Young, J.C.
1981 *Medical choice in a Mexican Village*. New Brunswick: Rutgers University Press.

Web references

1. <http://www.emro.who.int/press-releases/2012/cutaneous-leishmaniasis-still-highly-prevalent-in-the-region.html> (last entered 21.05.2014).
2. <http://www.irinnews.org/report/78674/afghanistan-no-medicine-for-leishmaniasis-in-badakhshan-province> (last entered 21.05.2014).
3. <http://www.enotes.com/public-health-encyclopedia/health-belief-model> (last visited 08.08.2009).
4. http://www.12manage.com/methods_ajzen_theory_planned_behaviour.html (last visited 03.06.2009).
5. http://www.cw.utwente.nl/theorieenoverzicht/Theory%20clusters/Health%20Communication/theory_planned_behavior.doc/ (last visited 08.09.2009).
6. http://www.medischezending.sr/cms/data/images/1/overzicht_juni2011.pdf (last visited 31.07.2012).
7. <http://www.dermasur.org/joomla/index.php/geschiedenis> (last visited 20.11.2011).
8. http://www.medischezending.sr/index.php?option=com_content&view=article&id=218&Itemid=261&lang=nl (last visited 29.07.2014).
9. http://www.medischezending.sr/index.php?option=com_content&view=article&id=67&Itemid=258&lang=nl (last visited 29.07.2014).
10. <http://www.act-suriname.org/over-ons/> (last visited 29.07.2014).
11. http://www.medischezending.sr/index.php?option=com_content&view=article&id=40&Itemid=381&lang=nl (last visited 29.07.2014).
12. http://www.medischezending.sr/index.php?option=com_content&view=article&id=40&Itemid=381&lang=nl (last visited 29.07.2014).
13. <http://www.bogsur.sr/index.php/ct-menu-item-13> (last visited 29.07.2014).
14. <http://www.bogsur.sr/index.php/ct-menu-item-3> (last visited 29.07.2014).
15. <http://accessmedicine.net/content.aspx?aID=2962644&searchStr=yaws> (last visited 17.11.2011).
16. <http://www.theplantlist.org/about/> (last visited 13.08.2011).
17. <http://www.theplantlist.org/tpl/search?q=allium+sativum> (last visited 13.08.2012).
18. <http://www.e-gezondheid.be/knoflook-allium-sativum/gids/981> (last visited 13.08.2012).
19. http://www.dbnl.org/tekst/benj004ency01_01/benj004ency01_01_0016.php#a2401 (last visited 23.10.2013).
20. <http://www.theplantlist.org/tpl/search?q=Geonoma> (last visited 13.08.2013).
21. <http://www.westloo-timber.com/hoepelhout.htm> (last visited 27.08.2012).
22. <http://www.aroma-pure.com/teatree.htm> (last visited 27.08.2012).
23. <http://www.theplantlist.org/tpl/search?q=allium+sativum> (last visited 13.08.2012).
24. <http://www.fao.org/docrep/T0646E/T0646E0o.htm> (last visited 27.08.2012).
25. <http://www.medicines1.com/supplier/bedrijf-geneesmiddelen-voorziening-suriname-bgvs.html> (last visited 2.07.2013).
26. <http://fish.mongabay.com/data/Suriname.htm> (last visited 05.09.2012).
27. <http://www1.nhl.nl/~ribot/ned/pscr.htm> (last visited 05.09.2012).
28. <http://www.westloo-timber.com/hoepelhout.htm> (last visited 27.08.2012).
29. <http://www.theplantlist.org/tpl/search?q=allium+sativum> (last visited 13.08.2012).
30. <http://www.organicfacts.net/organic-oils/organic-coconut-oil/health-benefits-of-coconut-oil.html> (last visited 27.08.2012).
31. <http://www.vicks.com/products/vapo-family/vaporub-topical-ointment/> (last visited 31.05.2013).
32. <http://www.vicks.com/products/vapo-family/vaporub-topical-ointment/> (last visited 31.05.2013).
33. <http://www.maxnature.com/shilingoil.html> (last visited 31.05.2013).
34. http://www.medischezending.sr/index.php?option=com_content&view=article&id=32&Itemid=261&lang=nl (last visited 5.6.2013).

35. http://odanyjewa.com/index.php?option=com_content&view=article&id=90&Itemid=139 (last visited 06.08.1012).
36. http://www.who.int/csr/resources/publications/CSR_ISR_2000_1leish/en/index.html (last visited 12.02.2013).
37. <http://www.emro.who.int/press-releases/2012/cutaneous-leishmaniasis-still-highly-prevalent-in-the-region.html> (last visited 27.08.2013).
38. <http://www.cbvs.sr/523/> (last visited 22.2.2013).
39. <http://www.westloo-timber.com/hoepelhout.htm> (last visted 27.08.2012).
40. <http://www.theplantlist.org/tpl/search?q=Geonoma> (last visted 13.08.2013).

Appendix 1: Informed Consent

Surinamese Dutch version

Informed Consent (Informatie en Toestemming)

Titel van het onderzoek: Sociale en culturele factoren in de perceptie en behandeling van cutaneous leishmaniasis in Suriname

Onderzoeker: Drs. Sahienschadebie Ramdas, M.A.

Promotor: Prof. dr. Sjaak van der Geest

Co-promotors: Prof. dr. Ria Reis, Dr. Henk Schallig

Voordat u akkoord gaat om te participeren in dit onderzoeksproject is het belangrijk dat u de volgende uitleg over deze studie goed leest.

Deze studie gaat over: de ziekte cutane leishmaniasis in Suriname, hoe mensen die daaraan lijden met die ziekte omgaan en hoe dat gerelateerd is aan het volgen van medische behandeling zoals aangegeven door dokters.

Onderzoeker: Ik ben Sahienschadebie Ramdas, PhD student aan de Amsterdamse School voor Sociaal Wetenschappelijk Onderzoek, Universiteit van Amsterdam, en ik doe dit onderzoek als deel van mijn PhD opleiding in de Medische Antropologie.

Doel van deze studie: om inzicht te verschaffen in de manier waarop mensen denken over de ziekte en hoe ze hulp zoeken om te genezen. Dit inzicht kan waardevol zijn voor betere en tijdige behandeling van de ziekte en om verdere verspreiding van de ziekte te voorkomen.

Uw participatie houdt in: dat u geïnterviewd zult worden over uw ziekte, hoe u het ervaren hebt of hoe u het ervaart, uw ideeën en gedachten over de ziekte, hoe er binnen uw cultuur gedacht wordt over de ziekte en wat u allemaal gedaan hebt om de ziekte te behandelen/genezen, dus hoe u vanaf het begin tot nu toe omgegaan bent met de ziekte.

Enkele andere zaken wat ook besproken zal worden is onder andere uw sociaal-economische positie (b.v. wat voor werk u doet, hoe is uw situatie thuis, hoe ziet uw dagelijks leven eruit), hoe volgens u de mensen om u heen reageren op de ziekte en hoe dat en het “man” of “vrouw” zijn in uw gemeenschap invloed heeft op de manier waarop u omgaat met de ziekte. Ook hoe u omgaat met de behandelingsmethoden die dokters gebruiken, wat u denkt van traditionele of culturele manier van genezen van de ziekte en hoe u denkt dat deze ziekte voorkomen kan worden.

Duur van het interview: ongeveer 1 tot 1,5 uur duren. U kunt gevraagd worden om meerdere malen te worden geïnterviewd. De interviews zullen opgenomen worden door middel van een cassette recorder, maar alleen met uw toestemming. Dit is noodzakelijk om het gesprek op een later tijdstip beter uit te schrijven voor een betere analyse. De interviews zullen afgenomen worden op een plek waar u zich op uw gemak voelt. Privacy is gegarandeerd. Uw identiteit zal nooit bekend gemaakt worden aan derden.

Foto's: kunnen gemaakt worden van de laesies/ wondjes op uw gezicht of lichaam, maar nooit zonder uw toestemming. Foto's zijn soms nodig om bepaalde theoretische argumenten of stellingen te onderbouwen en kunnen gebruikt worden in mijn proefschrift. We benadrukken dat ook hierbij uw identiteit nooit bekend gemaakt zal worden of afgeleid kan worden van de foto's die genomen zijn.

Vertrouwelijkheid/ anonimiteit en privacy: De door u gegeven informatie zal geheel confidentieel behandeld worden en opgeslagen worden op een beveiligde manier. Het zal toegankelijk zijn alleen voor mij persoon en, alleen de uitgeschreven versie, ook voor mijn studie begeleiders. Er zullen geen enkele identificeerbare namen op de tapes of uitgeschreven stukken staan en uw naam zal, op geen enkele manier, doorgegeven worden aan derden. Anonimiteit is gegarandeerd.

Resultaten: De resultaten van het onderzoek zullen gepubliceerd worden in de vorm van een proefschrift. Ze kunnen ook gepubliceerd worden in vakbladen, in kranten of gepresenteerd worden tijdens professionele bijeenkomsten, discussies, seminars of workshops.

Toestemming om mee te doen: Participatie in deze studie is geheel vrijwillig. U bent vrij om uw toestemming in te trekken en te stoppen met participatie in dit onderzoek op elk moment. Uw beslissing om te participeren of niet te participeren zal op geen enkele manier de behandeling die u krijgt van gezondheidsdiensten beïnvloeden. Er zijn geen kosten verbonden aan participatie in dit onderzoek. Deelnemers zullen ook niet betaald worden om te participeren.

Indien u nog informatie nodig heeft of andere vragen heeft gerelateerd aan dit onderzoek mag u dat stellen op elk moment voor, gedurende en na het interview.

Hierbij geeft u aan dat u een kopie ontvangen heeft van dit formulier (Informed Consent). Uw handtekening hieronder geeft aan dat u vrijwillig en geïnformeerd uw toestemming geeft om te participeren in deze studie.

Handtekening participant

Datum

De onderzoeker,

Drs. S. Ramdas, M.A.
PhD student Medische Antropologie
ASSR/UVA
Tel: xxxxxxxx
Email: SRamdas@uva.nl

Informatie nanga primisi (Informatie en toestemming)

Titel fu a project: Sociale nanga kulturu sani ini a fasi fa den sma e dresi noso denki abra cutane leishmania ini Sranan

Onderzoeker: Drs. Sahienschadebie Ramdas, M.A.

Promotor: Prof. dr. Sjaak van der Geest

Co-promotors: Prof. dr. Ria Reis, Dr. Henk Schallig

Fosi yu agri fu du mee nanga a project disi, a de belangrijk dati yu leysi san mi skrifi abra project dya na ondrosey.

A stuka disi e go abra a siki san datra kari '*cutane leishmaniasis*' nanga fa sma san abi a siki disi e denki abra en fa den e dresi a siki nanga fa den prakseri abra den datra dresi. Mi neng na Sahienschadebie Ramdas, mi stuka na a skore 'Amsterdamse School voor Sociaal Wetenschappelijk Onderzoek, Universiteit fu Amsterdam en leki stukaman fu Medische Antropologie, a project disi na wan pisi fu a PhD stuka ini a Universiteit. A project disi de fanowdu bika a sa sori fa sma denki abra a siki nanga fa den suku yepi fu dresi a siki bun fasi. A stuka disi kan yepi fu behandel a siki wan moro betre en fu meki muiiti taki a siki no panya moro fara.

Ini a stuka disi, mi sa aksi yu abra yu siki, fa yu e libi nanga a siki, fa yu e prakseri abra a siki, fa sma ini yu kulturu e denki abra a siki nanga ala tra sani sa yu e du fu dresi a siki wan bun fasi, fu kon betre. Ini a taki disi mi sa aksi owktu yu situatie na oso, fa yu tan, sortu wroko ye du, fa yu ibri dey libi de, kari kon. Owktu fa sma ini yu birti e taki abra a siki nanga fa den e du te den si yu, fa dati nanga yu positie leki uma noso mansma e meki yu suku yepi gi a siki fu yu. Mi sa aksi owktu fa yu e firi abra dratradresi, san yu denki abra den fasi fu meki yu kon betre, san yu prakseri abra suku yepi kulturu fasi nanga fa yu e prakseri taki a siki no musu panya moro fara.

A interview disi kan teki kande wan yuru noso wan yuru nanga afu. Kande owktu mi kan aksi yu fut aki wan tra leysi moro abra a siki fu yu. Mi sa teki op a gesprek fu unu na ini cassette recorder, ma noiti sondro yu primisi (toestemming). Dati na fu grabu ala sani moro bun fasi, sofasi mi kan skrifi moro fini. U kan du den interview ini wan presi pe yu e firi bun fu taki. A dyaranti de taki yu inibere tori sa tan inibere nanga mi. Owktu no wan sma sa sabi taki yu ben taki nanga mi.

Son leysi mi kan meki prenki fu den soro tapu yu fesi noso yu skin, ma noiti sondro yu primisi. Son leysi a prenki de fanowdu fu sori moro bun fasi a problema, fu skrifi moro krin fasi dati ala lerisma kan grabu san na a tori. Den prenki mi kan kebroiki ini mi rapport. Ma owktu djaso mi e gi a dyaranti taki no wan sma sa sabi taki yu na de a sma ini a prenki.

Leki fa mi ben taki keba, ala sani san yu ferteri mi, sa de inibere tori. Ala informatie san yu e gi mi mi sa poti bun fasi taki no wan sma kan feni yu informatie. Mi wawan sa abi a informatie ma den tra stukaman fu mi kan leysi ala sani sa mi skrifi. Mi no o skrifi yu nen tapu den papira en no wan sma man kisi yu nen.

Baka te a heri ondosuku klari, sma kan leysi a resultaat ini wan buku. Kande a ondosuku disi kan kon ini koranti tu noso ini tra buku san skrifi abra a siki disi. Kande mi sa taki abra a ondosuku disi ini workshops noso tra konmakandra.

Yu kan du mee nanga a ondosuku disi efu yusrefi firi fu du so. Kande yu gi primisi fu taki abra a siki fu yu, ma yu firi fu stop nanga a taki, dan yu kan kenki yu besroiti ala momenti. Yu besroiti fu du mee efu no du mee nanga a ondosuku no sa abi tere gi a behandelings sa yu e kisi na den datra-oso. Yu no abi fu pay fu du mee nanga a stuka disi en yu no o kisi moni efu yu e du mee nanga a stuka disi.

Te yu wani aksi tra sani abra a ondosuku disi noso te yu wani sabi moro sani abra a ondosuku disi, yu kan aksi fri iniwan ten fos un taki, te un e taki noso baka te un taki.

Nanga disi wi e meki mofo taki yu kisi wan kopi fu a papira disi (Informatie nanga Primisi). Yu handtekening ondrosey wani taki yu kisi a informatie abra a ondrosuku disi fini fini en yu wani du mee nanga a ondrusuku fri.

Handtekening participant

Datum

Onderzoeker

Drs. S. Ramdas, M.A.
PhD student Medische Antropologie
ASSR/UVA
Tel: xxxxxxx
Email: SRamdas@uva.nl

Informed Consent⁸³

Title of the research: Social and cultural factors in the perception and treatment of cutaneous leishmaniasis in Suriname

Researcher: Drs. Sahienschadebie Ramdas, M.A.

Promoters: Prof. Dr. Sjaak van der Geest, Prof. Dr. Ria Reis

Co-promotor: Dr. Henk Schallig

Before you agree to participate in this research project it is important for you to carefully read the following information about this study.

This study is about: the illness cutaneous leishmaniasis in Suriname, how people infected with it deal with their condition and how that is related to the biomedical treatment provided by medical doctors.

Researcher: I am Sahienschadebie Ramdas, PhD student at the Amsterdam Institute for Social Science Research, University of Amsterdam, and I am conducting this research as part of my PhD study in Medical Anthropology.

Aim of this study: to provide insights into the way people think about the illness and how they seek treatment. These insights can be valuable for a better and timely treatment of the illness and to prevent further spread.

Your participation means: that you will be interviewed about your illness, how you experienced it or how you experience it, your ideas and perceptions about the illness, how the cultural community in which you live think about the illness, and all the activities/steps you have undertaken to cure your illness, thus how you dealt with the illness from the start.

Some other matters that will also be discussed are, amongst others, your social-economic position (e.g. what kind of work you do, how your living situation is, how you manage your daily life), how people around you react to your illness and how being a man or woman in your community influences the way you deal with your illness.

Duration of the interview: about 1 to 1.5 hours. You can be asked to be interviewed multiple times. The interviews will be recorded by cassette recorder, but only with your permission. This is necessary to listen back to the conversation and to write it out for a better analysis. The interviews will be done in a place where you feel at ease. Privacy is guaranteed. Your identity will never be revealed to others.

Photographs: can be taken of the sores on your face or body, but never without your permission. Photographs are sometimes needed to support certain theoretical arguments or statements and can be used in my dissertation. Here too your identity will never be revealed to others, or be derived from the photographs taken.

Confidentiality/anonymity and privacy: the information you provide will be treated confidentially and be stored in a safe way. It will only be accessible to me, and for my supervisors only the written version. Tapes or transcribed parts of conversations will not be given any identifiable names and your name will in no way be given to others.

Results: the results of the research will be published in the form of a dissertation. They can also be published in scientific journals, newspapers or presented during professional meetings, discussions, seminars or workshops.

⁸³This is a freely translated version of the Surinamese Dutch Informed Consent form in English. The Informed Consent was read and explained to the participants in either Surinamese Dutch or Sranan. Participants could choose a copy in Surinamese Dutch or Sranan.

Permission to participate: participation in this study is totally voluntary. You are free to withdraw your permission and to stop with participation in this study at any moment. Your decision to participate, or not, will not influence the treatment you are receiving at biomedical health care services in any way. There are no costs involved in participating in this study. Participants will also not be paid to participate.

In case you need further information or you have more/other questions related to this research, you can ask at any moment before, during or after the interview.

Hereby you declare that you have received a copy of this form (Informed Consent). Your signature below signifies that you have given voluntary and informed permission to participate in this study.

Signature participant

Date

The researcher,

Drs. S. Ramdas, M.A.
PhD student Medical Anthropology
AISSR/UVA
Tel: xxxxxxxx
Email: SRamdas@uva.nl

Appendix 2: Research instruments

1. Topic guide interviews (on multiple levels)

A. Socio-demographic characteristics (all informants):

Age, sex, marital status, education, occupation, ethnic background, living area

B. Topic list

Levels →	CL patients at medical clinics	CL patients at traditional health clinic	Self-diagnosed CL patients	"Significant others"	Community members	Traditional healers	Medical doctors
Topics ↓							
Illness experience and description							
Lay perceptions	x	x	x	x	x	x	
Knowledge of disease	x	x	x	x	x	x	
Vernacular names	x	x	x	x	x	x	x
Aetiology / disease explanation	x	x	x	x	x	x	
Cultural and social beliefs	x	x	x	x	x	x	x
Timing and mode of onset symptoms	x	x	x				
Illness experience (change in body, feelings etc.)	x	x	x				
Natural history and severity of illness	x	x	x				
Stigma	x	x	x				
Behaviour change towards partner or change in food pattern	x	x	x				
(Lay) consultation and decision making							
Undertake actions after discovery	x	x	x				

symptoms							
Consulta- tion (social network, significant others)	x	x	x				
Role of stigma (thoughts on stigma prevention)	x	x	x	x	x	x	x
In case no treatment (why?)			x				
Self- treatment (how?)	x	x	x				
Treatment preferen- ces	x	x	x				
Known treatment practices (cultural, traditional, local/ household remedies)	x	x	x	x	x	x	x
Most appropriate treatment methods	x	x	x	x	x	x	
Decision treatment method	x	x	x				
Use of biomedical health care / traditional health care facility							
Motivations for use health facility (also role of stigma)	x	x					
Accessib- ility (geogra- phical distance, travel, housing facilities)	x	x	x	x	x	x	x
Availability						x	x
Affordab- ility (gender differences , social situation, position in household)	x	x	x	x	x	x	x

Adequacy	x	x		x	x	x	x
Adherence	x	x				x	x
Views traditional healers/bio - medical workers						x	x
Evaluation visits clinics							
Adherence	x	x				x	x
Status illness	x	x	x				
Efficacy medication	x	x	x			x	x
Views on possible scar forma- tion	x	x	x	x	x	x	x
Reinterpretation illness							
Labelling patient (chronic or cured)	x	x	x			x	x
Decisions regarding follow-up treatment and treatment methods	x	x	x				
Perception s cured patients	x	x	x				
Views on Prevention	x	x	x	x	x	x	x

C. Topic list interviews with health authorities

<ul style="list-style-type: none"> • (Government) health policy regarding CL • Access to health care services • Collaboration with traditional healers (existing policy) • Strategies on prevention

2. Checklist for observations

A. In health care clinics (both biomedical and traditional clinic):

- Physical/geographical distance between CL patient and other patients on the benches in the waiting rooms
- Communication between CL patients and other patients in the waiting rooms
- Communication between patients and health workers/medical doctors

B. Checklist participant observations in the homes/villages of CL patients

- Communication between CL patient and family members / community members
- Attitudes of community members/villagers towards CL patient
- Sharing meals/drinks/household items/clothes with CL patient
- Participation of CL patient in social activities (social gatherings, parties, etc.)
- Name calling
- School attendance and attitude of schoolmates towards CL patient
- Attitudes towards and communication with CL patient by colleagues at work

3. Topics focus group discussions in selected communities

- Illness perception
- Local (socio-cultural) beliefs
- Vernacular names
- Illness causation theories
- Illness experience: issues of stigma (influence on health seeking, marital status, etc.)
- Community attitudes towards person with CL
- Role of social network in treatment seeking
- Treatment methods (local, traditional, household remedies)
- Identification of possible 'dangerous/hazardous' treatment methods and reasons for use
- Knowledge of and views on possible traditional Indigenous CL healing products
- Access to biomedical health care services
- Perceptions regarding health workers in the hinterland (trust, competence)
- Role of economic activities (gold mining, lumber sector, etc.) on spread of CL
- Perceived risks for CL contamination
- Views/ideas on prevention and possible prevention strategies

4. Short questionnaires

A. Short questionnaire for CL patients at the Dermatology Service

1. Socio-demographic characteristics

- Age
- Sex
- Ethnicity
- Occupation
- Education
- Living area
- Working area

2. Knowledge of illness (aetiology)

- How do you call this disease? (Vernacular name)
- What, according to you, caused it? (How did you get this disease?)
- What do you know about this disease? (If nothing, what have you heard about it?)

3. History of illness, steps in treatment seeking

- How long ago did you discover the sores?
- What did you do after you discovered them?

4. Self-treatment

- What did you treat your sores with?
- Why with those medicines?
- On whose advice?
- What other types of medicines did you hear of?
- If you tried to self-medicate, why did you do so?
- Why only now did you go to the doctor?

5. Stigma and illness perceptions

- How did you feel when you discovered the sores?
- How do you yourself feel about having these sores on your body now?
- Why did/do you feel that way?
- How do those in your social environment (family, neighbours, friends, acquaintances, colleagues, co-students, etc.) react when they see the sores? (Probing: *How are you treated by others? (As usual, differently, nicely or not? In what ways?) What do they say? How do they behave with you? Can you tell a bit about what you experienced?*)
- Do you think you are treated differently? If yes, how, in which way? If no, why do you think so?
- Do you think the disease is serious? If yes, how serious?
- Do you think the disease is contagious? If yes, how, in which way?
- Do you think the disease is dangerous? If yes, why?
- Do you think the disease is lethal? If yes, why?

7. Dietary or other behavioural changes

- Did you change anything in your food pattern since you are infected with this disease?
- Are there certain (other) things you do or avoid because of these sores?

8. Accessibility of biomedical care

- Was it easy to get to this clinic? If yes, why? If no, how come?

9. Prevention

- How do you think you can prevent this disease? (So that you will not get infected with it once again?)

10. Patients' concerns and fears

- What is your biggest concern related to this disease?
- What is your biggest fear related to this disease?

11. Choice of medication

- If you had the choice between using bush medicines or (biomedical) pills, ointments, powder or injections (provided at the Dermatology Service), what would you choose and why?

12. Closing remarks

- Is there anything else you want to add or share?

B. Short questionnaire close family member of CL patient/support group of CL patient

1. Socio-demographic characteristics

- Age
- Sex
- Education / occupation
- Ethnicity
- Living area
- Family ties / relationship with the CL patient

2. Knowledge of illness (aetiology)

- How do you call this disease? (Vernacular name)
- What according to you caused it?
- Have you ever heard of this disease?

3. Stigma

- How did you feel when you discovered your ...(son, daughter, husband, wife, friend, etc.)...had this disease?
- Are you anxious about this disease?
- What are you worried most for now your ...(son, daughter, husband, wife, friend, etc.)...has this disease?
- How do surrounding people react to him or her having the disease?
- How do you feel about people's attitudes towards him or her?
- What treatment method did you suggest to your ...(son, daughter, husband, wife, friend, etc.)... Why?

4. Support and prevention

- How did you support him or her?
- How do you think this disease can be prevented?

5. Closing remarks

- Is there anything else you want to add or share?

Appendix 3: Statistics total research population

Table 12: Total research population Dermatology Service and hinterland by village and sex (in numbers)

Location	Male	Female	Total
<i>Dermatology Service Paramaribo</i>	183	22	205
<i>Hinterland villages</i>			
Godo-olo	42	24	66
Tepu	16	21	37
Donderskamp	18	15	33
Brokopondo Centrum area	41	17	58
Benzdorp	71	56	127
(Sub-total Hinterland)	(188)	(133)	(321)
Total research population	371	155	526

Appendix 4: Socio-demographic statistics of CL patients at the Dermatology Service

Table 13: Socio-demographic characteristics of all CL patients (n=205)

Characteristics	Number and percentage of patients					
	Male		Female		Total (M+F)	
	#	%	#	%	#	%
<i>Age (in years)</i>						
≤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
<i>Cultural background</i>						
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
Mix	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
<i>Educational level</i>						
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
(Junior level - VOJ)	(84)	40.9	(9)	4.3	(93)	45.3
(Senior level - VOS)	(19)	9.2	(0)	0	(19)	9.2
Tertiary	3	1.4	1	0.5	4	2
Total	183	89	22	11	205	100
<i>Living area</i>						
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 Guiana	2	0.9	0	0	2	0.9
Total	183	89	22	11	205	100

Table 14: Socio-demographic characteristics of CL patients who self-medicated (n=161)

Characteristics		Number of patients		Percentage	
		Male	Female	Male	Female
<i>Age (in years)</i>					
<19		12	4	7.5	2.5
20-29		45	2	28	1
30-39		44	8	27.4	5
40-49		26	4	16.2	2.5
≥ 50		15	1	9.3	0.6
<i>Sex</i>					
Sex		142	19	88	12
<i>Cultural background</i>					
Maroon		76	11	47.3	6.8
Hindustani		25	0	15.7	0
Creole		6	1	3.7	0.6
Javanese		18	0	11.3	0
Mix		11	0	6.8	0
Brazilian/Dominican		2	6	1	3.7
Indigenous		4	1	2.5	0.6
<i>Educational level</i>					
No formal education		11	4	6.8	2.5
Primary		51	6	32	3.7
Secondary		78	8	48.5	5
(Junior level - VOJ)		(67)	(8)	(41.7)	(4)
(Senior level - VOS)		(11)	(0)	(6.8)	(0)
Tertiary		2	1	1	0.5
<i>Profession</i>					
<i>Males</i>	<i>Females</i>				
Gold digger	Commercial sex worker	42	2	26	1
In gold sector (as goldsmith, administrator of gold company)	-	2	-	1	-
Machine operator / mechanic	Housewife / petty farmer	4	6	2.5	3.7
Security services / guard (gold sector)	Student	6	4	3.7	2.5
Taxi and truck driver (goods and oil transport), bus driver	Hairdresser	10	1	6.2	0.6
Woodcutter or working in the wood sector	Cook / beauty salon worker	17	2	11	1
Construction worker (building houses in hinterland/city, welder, painter, carpenter)	-	20	-	12	-
Prospector / technical worker / electrician	Development worker	10	1	6.2	0.6
Petty farmer, gardener	Shop worker	6	1	3.7	0.6
Student or in training (military)	-	9	-	6	-
Vendor / coal seller		4	-	2.5	-

No permanent job / jobless	Bus ticket checker	3	1	1.8	0.6
Other: Teacher, civil servant, car salesmen, salesmen, tourist, retired	Jobless	9	1	6	0.6
<i>Living area</i>					
Capital city or surrounding districts		110	11	68.3	6.8
Hinterland		26	7	16.2	4.3
Both hinterland and capital city		4	2	2.5	1
French Guiana		2	0	1	0
<i>Reason to visit hinterland</i>					
<i>Males</i>	<i>Females</i>				
Occupational	Occupational	92	3	57	2
Visit family (wife, kids) and friends	Visiting family (parents)	10	4	6	2.5
Recreational (fishing, hunting, vacation)	Live in the forest / work on plot	38	6	24	4
-	Recreational (vacation)	-	4	-	2.5
Other	-	2	2	1	1

Table 15: Socio-demographic characteristics of CL patients who sought only biomedical treatment (n=44)

Characteristics		Number of patients		Percentage	
		Male	Female	Male	Female
Sex		41	3	93	7
Age (in years)					
≤19		3	0	7	0
20-29		14	2	31.8	4.5
30-39		15	1	34	2.3
≥ 40		9	0	20.4	0
Cultural background					
Maroon		18	2	41	4.5
Hindustani		6	-	13.6	-
Creole		4	-	9	-
Javanese		3	-	6.8	-
Mix		6	-	13.6	-
Brazilian/Dominican		3	1	6.8	2.3
Indigenous		1	-	2.3	-
Educational level					
No formal education		6	1	13.6	2.3
Primary		10	0	22.7	0
Secondary		24	2	54.5	4.5
(Junior level - VOJ)		(14)	(2)	(31.8)	(4.5)
(Senior level - VOS)		(10)	(0)	(22.7)	(0)
Tertiary		1	0	2.3	0
Profession					
Males	Females				
Gold digger	Petty farmer	10	1	22.7	2.3
Mechanic / technician / prospector	Hairdresser	6	1	13.6	2.3

Plumber / stonemason / all kinds of jobs	Working in gold sector	3	1	6.8	2.3
Security work / military	-	4	-	9	-
Machine operator	-	2	-	4.5	-
Farmer	-	3	-	6.8	-
Transporter of wood / truck driver	-	2	-	4.5	-
Student	-	1	-	2.3	-
Car salesman / salesman	-	2	-	4.5	-
Buy and sell gold	-	1	-	2.3	-
Graphic worker	-	1	-	2.3	-
Warehouse worker	-	1	-	2.3	-
Fisherman	-	1	-	2.3	-
Retired teacher	-	1	-	2.3	-
Jobless	-	1	-	2.3	-
Cook	-	1	-	2.3	-
Woodcutter	-	1	-	2.3	-
<i>Living area</i>					
Capital city and nearby districts	-	36	2	81.8	4.5
Hinterland	-	5	1	11.3	2.3

Appendix 5: Socio-demographic statistics of research population in the hinterland villages

Table 16: Socio-demographic statistics research population at Godo-olo (in numbers)

Characteristics	Male	Female
<i>Sex</i>	42	24
<i>Age (in years)</i>		
<19	0	0
20-29	9	4
30-39	10	12
40-49	15	5
50-59	2	3
60-69	6	0
>69	0	0
<i>Education</i>		
No formal education	6	5
Primary	29	15
Secondary	7	4
(Junior level - VOJ)	(2)	(3)
(Senior level - VOS)	(5)	(1)
Tertiary	0	0
<i>Profession – Males</i>		
Gold digger	25	
Government administration supervisor (<i>Bestuursopzichter</i>)	1	
Captain	2	
Basya	3	
Shopkeeper at Godo-olo	3	
Shopkeeper in the goldfields	1	
Constructing boats	1	
Traditional healer	1	
Mechanic / selling fish	1	
Carpenter	1	
Retired	1	
Owner of gold digging company	1	
Jobless	1	
<i>Profession – Females</i>		
Housewife / petty farmer / selling fish		18
Teacher		2
(School) Cleaning lady		2
Small shopkeeper		1
Selling bread		1

Table 17: Socio-demographic statistics research population at Tepu (in numbers)

Characteristics	Male	Female
<i>Sex</i>	16	21
<i>Age (in years)</i>		
<19	1	0
20-29	1	4
30-39	3	4

40-49	5	4
50-59	1	1
60-69	5	8
>69	0	0
<i>Education</i>		
No formal education	5	8
Primary	10	11
Secondary	1	2
(Junior level - VOJ)	-	-
(Senior level - VOS)	(1)	(2)
Tertiary	-	-
<i>Profession – Males</i>		
Hunter / fisher	6	
Woodcutter	1	
Birdcage builder, catches and sells birds	1	
Teacher	1	
Captain	1	
Basya	2	
Shaman	1	
ACT health worker	2	
Jobless	1	
<i>Profession –Females</i>		
Housewife ⁸⁴		18
Teacher		2
Selling weaved hammock		1

Table 18: Socio-demographic statistics research population at Donderskamp (in numbers)

Characteristics	Male	Female
<i>Sex</i>	18	15
<i>Age (in years)</i>		
<19	0	1
20-29	2	1
30-39	3	4
40-49	5	3
50-59	3	0
60-69	2	5
≥69	3	1
<i>Education</i>		
No formal education	3	2
Primary	10	11
Secondary	5	2
(Junior level - VOJ)	(4)	(2)
(Senior level - VOS)	(1)	(0)
Tertiary	0	0
<i>Profession – Males</i>		
Hunter / fisher / small scale planter	9	
Woodcutter	1	

⁸⁴See section 3.3.1 for more information on the activities that women undertake at Tepu.

Catches and sells birds	1	
Government administration supervisor (<i>Bestuursopzichter</i>)	1	
Works on maintenance of the airstrip Donderskamp	1	
Station boss (<i>stationschef</i>) airstrip Donderskamp	1	
Basya	1	
Captain of Donderskamp	1	
Traditional healer	1	
Jobless	1	
<i>Profession – Females</i>		
Housewife / planter		12
Souvenir seller		1
Basya		1
Government administration supervisor (<i>Bestuursopzichter</i>)		1

Table 19: Socio-demographic statistics research population at Brokopondo Centrum area (in numbers)

Characteristics	Male	Female
<i>Sex</i>	41	17
<i>Age (in years)</i>		
<19	5	0
20-29	10	3
30-39	10	7
40-49	7	5
50-59	7	0
60-69	1	1
>69	1	1
<i>Education</i>		
No formal education	4	5
Primary	27	8
Secondary (Junior level - VOJ)	10 (10)	4 (1)
(Senior level - VOS)		(4)
Tertiary		
<i>Profession –Males</i>		
Gold digger	23	
Government worker	4	
Wood craftsmen	3	
Wood cutter	3	
Jobless	3	
Retired (one is a local health expert)	2	
Security guard	1	
Operator	1	
Hunter (and local health expert)	1	
<i>Profession – Females</i>		
Housewife / petty farmer / selling vegetables		10
Craftswomen		3
Nurse		1
Cleaning lady		1
Saleslady		1
Teacher		1

Table 20: Socio-demographic statistics research population at Benzdorp (in numbers)

Characteristics	Male	Female
<i>Sex</i>	71	56
<i>Age (in years)</i>		
<19	5	1
20-29	21	16
30-39	22	19
40-49	19	11
50-59	4	7
60-69	0	2
>69	0	0
<i>Education</i>		
No formal education	50	44
Primary	16	8
Secondary	5	3
(Junior level - VOJ)	(unknown)	(unknown)
(Senior level - VOS)	(unknown)	(unknown)
Tertiary	0	1
<i>Profession – Males</i>		
Gold digger	41	
ATV driver and other transportation	7	
Mechanic	5	
Goldsmith	3	
Doing all kinds of small jobs in gold sector	3	
Owner of gold digging machine	2	
Machine operator	2	
Working in a pharmacy	1	
Working in a restaurant	1	
Wood craftsman	1	
Teacher	1	
Nurse	1	
Shop / bar owner	1	
Owner of gold digging company	1	
Student	1	
<i>Profession – Females</i>		
Commercial sex worker		12
Cook		9
Housewife		9
Owner of drugstore, clothing or other small shops		10
Owner of gold digging machines		3
Restaurant owner		3
Working in a small pharmacy		2
Beauty specialist (manicure, pedicure, etc.) and hairdresser		4
Biologist (Pastor's wife)		1
Owner of cabaret		1
Owner of a motor taxi		1
Jobless		1

Table 21: Number of interviewed Medical Mission health workers by location, sex, position, and work experience

Location clinic Medical Mission	Number of health workers interviewed (either individually or in group)						Number of years of work Position experience as health worker			
	Male	Female	Position				Position			
			GZA in charge	Other GZAs or trainees	M	P.A.	GZA in charge	Other GZAs or trainees	M	P. A
Godo-olo	0	3	1		1	1	21	-	7.5	5.5
Tepu	0	1	1		0	0	30	-	-	-
Brokopondo Centrum area	0	2	1	1	0	0	25	20		
Klaaskreek	1	0	1	0	0	0	33	-	-	-
Brownsveg	1	7	1	7	0	0	33	Between 1.5 to 7 years (one with 31 years)		
Donders-kamp	1	0	1		0	0	25	-	-	-
Total	2	10	5	8	1	6				

M = Microscopist

P.A. = Polyclinic Assistant

Appendix 6: Number of CL patients according to Medical Mission files in the hinterland villages

Table 22: Number of CL patients at poly-clinic Godo-olo, according to the surveillance register, from 2006-2009

Month	Number of CL patients per year (2006-2009)				Total
	2006	2007	2008	2009	
January	0	1	0	1	2
February	2	1	3	0	6
March	0	0	5	0	5
April	0	1	1	0	2
May	0	2	2	0	4
June	2	4	0	0	6
July	0	0	0	0	0
August	0	0	0	0	0
September	0	0	0	0	0
October	0	0	0	0	0
November	0	0	0	0	0
December	0	0	0	1	1
Total	4	9	11	2	26

Source: Poly-clinic Godo-olo, Medical Mission

Table 23: Number of CL patients at poly-clinic Tepu according to memory of GZA and patient files from 1997-2010

Year	Number of CL patients
1997	2
1985	2
2007	1
2010	1
Unknown	1
Total	7

Source: Patient files according to memory of GZA⁸⁵ and patient files, poly-clinic Tepu, Medical Mission

Table 24: Number of CL patients at poly-clinic Donderskamp, according to surveillance register, from 2006 - April 2010

Month	Number of CL patients per year (2006 - April 2010)					Total
	2006*	2007**	2008	2009	(April) 2010	
January	-	-	0	0	0	0
February	-	-	0	0	0	0
March	-	-	0	0	2	2
April	-	-	0	0	-	0
May	-	-	0	0	-	0
June	-	-	0	0	-	0
July	-	-	0	0	-	0

⁸⁵ According to the healthworker in charge at Tepu, during the time of the research the registering of CL patients through monthly reports was lacking. Unlike the Medical Mission policy of registering CL patients in a special notebook, this did not happen at Tepu. The number of CL patients was therefore only found through the patient files, which, according to the healthworker, were also sometimes not updated. The health worker said that she knew by heart all of the CL patients starting from 1990. She had been working at Tepu for the past three decades.

August	-	-	0	0	-	0
September	-	-	0	0	-	0
October	-	-	0	0	-	0
November	-	-	0	0	-	0
December	-	-	0	0	-	0
Total	-	-	0	0	2	2

Source: Poly-clinic Donderskamp, Medical Mission

* For the year 2006, CL was not noted separately and therefore CL cases could not be identified.

** Registration of CL patients for the year 2007 were, according to the health worker, somehow missing.

Table 25: Number of CL patients at poly-clinic Klaaskreek, according to surveillance register, from 2008 - April 2010

Month	Number of CL patients per year (2006 - April 2010)					Total
	2006*	2007*	2008	2009	April 2010	
January	-	-	0	2	2	4
February	-	-	1	1	0	2
March	-	-	1	0	0	1
April	-	-	0	0	2	2
May	-	-	0	0	-	0
June	-	-	0	0	-	0
July	-	-	1	0	-	1
August	-	-	0	0	-	0
September	-	-	0	0	-	0
October	-	-	0	0	-	0
November	-	-	0	0	-	0
December	-	-	0	0	-	0
Total	-	-	3	3	4	10

Source: Poly-clinic Donderskamp, Medical Mission

* For the years 2006 and 2007, CL was not registered separately.



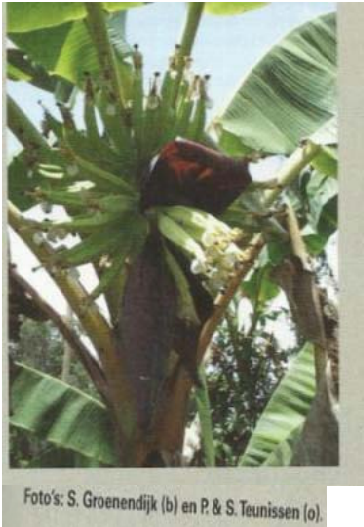

Appendix 7: Number of CL patients according to traditional health clinic at Tepu

Table 26: Number of CL patients according to registers of the traditional health clinic *Kapi*

Month	Number of CL patients per year (2006 - February 2010)					Total
	2006	2007	2008	2009	(Feb) 2010	
January	0	0	0	0	1	1
February	0	0	0	0	1	1
March	0	3	0	0	-	3
April	0	1	0	0	-	1
May	0	0	1	0	-	1
June	0	0	0	0	-	0
July	0	0	0	0	-	0
August	0	0	0	0	-	0
September	0	0	0	0	-	0
October	1	0	0	0	-	1
November	0	0	0	0	-	0
December	0	0	0	0	-	0
Total	1	4	1	0	2	8

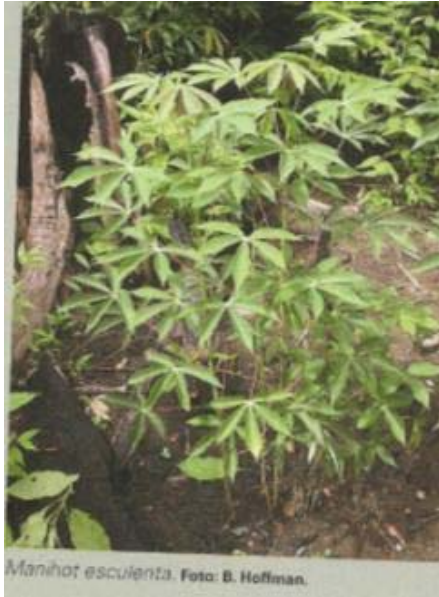
Source: *Kapi*, traditional health clinic, Tepu

Appendix 8: Photographs and/or drawings of plants listed by CL patients and traditional healers to cure CL⁸⁶

<p>1. Local plant name: Aloe vera (SD.), Sempre wisi (Sr.) Scientific name: <i>Aloe vera</i> (L.) Burm.f. (Xanthorrhoeaceae)</p>  <p>Aloe vera. Foto: H. Rypkema.</p> <p>Source: Van Andel & Ruysschaert 2011:92</p>	<p>2. Local plant name: Báibái lopu (Sa.), Popokai nangra (Sr.), Opumaka (Au.) Scientific name: <i>Uncaria guianensis</i> (Aubl.) J.F.Gmel. (Rubiaceae)</p>  <p>Uncaria guianensis: bloeiende tak, bloem en vruchten. Illustratie: H. Rypkema.</p> <p>Source: (ibid:426)</p>
<p>3. Local plant name: Banana (Sr.), bana (Sr.) Scientific name: <i>Musa x paradisiaca</i> L. (Musaceae)</p>  <p>Foto's: S. Groenendijk (b) en P. & S. Teunissen (o).</p> <p>Source: (ibid):345</p>	<p>4. Local plant name: Bisangula (Au) Scientific name: <i>Maprounea guianensis</i> Aubl. (Euphorbiaceae)</p>  <p>Maprounea guianensis: bloeiende tak, en vrucht</p> <p>Illustratie: H. Rypkema.</p> <p>Source: (ibid:209)</p>

⁸⁶There were more plants listed by CL patients and others in this study, however not all of them could be identified. The plants that were identified, and of which photographs or drawings were available, are displayed in this list.

5. Local plant name: Bita ksaba(Sr.), bittere cassava (SD.)
Scientific name: *Manihot esculenta* Crantz.
 (Euphorbiaceae)



Source: (ibid:207)

6. Local plant name: Bitatiki (Au)
Scientific name: *Banara Guianensis* Aubl.
 (Salicaceae)



Source: (ibid:435)

7. Local plant name: Bredebon (Sr.)
Scientific name: *Artocarpus altilis* (Parkinson ex F.A. Zorn) Fosberg (Moraceae)



Artocarpus altilis: zaadvormende cultuurvorm. Bg de mannelijke bloeiwijze, onder de vrouwelijke bloeiwijze met jonge vrucht. Foto's: H. Rypkema.

Source: (ibid:338)

8. Local plant name: Brokobaka (Sr.)
Scientific name: *Mikania micrantha* Kunth.
 (Asteraceae)



Illustratie: H. Rypkema.

Source: (ibid:105)

9. Local plant name: (Uma) Busipapaya (Sr.)
Scientific name: *Cecropia peltata* Linnaeus.
 (Cecropiaceae)



Cecropia peltata: a. bloeiende tak; b. manne...

Illustratie: H. Rypkema.

Source: (ibid:152)

10. Local plant name: Diatitei (Sr.), Fayatatái (Sa), Schuurpapier (SD.)
Scientific name: *Davilla kunthii* A. St.-Hil.
 (Dilleniaceae).



Davilla kunthii: stam en twigen. Illustratie: H. Rypkema.

Source: (ibid:191)

11. Local plant name: Donke (Sr.)
Scientific name: *Dieffenbachia seguine* (Jacq.) Schott. (Araceae).



Dieffenbachia seguine. Foto: S. Groenendijk.

Source: (ibid:62)

12. Local plant name: Jáffi (Sr.)
Scientific name: *Jacaranda copaia* (Aubl.) D. Don (Bignoniaceae).



Jacaranda copaia: blad, bloeiwijze, bloemen, vrucht (vers en droog), zaailing. Illustratie: H. Rypkema.

Source: (ibid:121)

13. Local plant name: Kaapà (Sa)
Scientific name: *Carapa guianensis* Aubl.
 (Meliaceae)



Source: (ibid: 334)

14. Local plant name: Kakanoto (Au)
Scientific name: *Jatropha curcas* L.
 (Euphorbiaceae) (According to a traditional healer, a kakanoto tree)



Source: (ibid:205)

(14 con'd) Kakanoto tree according to villagers at Plata kampu, Paaston



Source: Collection S. Ramdas, Platakampu, Paaston, 2009

15. Local plant name: Kalebas (SD.)
Scientific name: *Crescentia cujete* L.
 (Bignoniaceae).



Source: Van Andel & Ruysschaert 2011: 118

16. Local plant name: Kasyu (Sr.) [Cashew]
Scientific name: *Anacardium occidentale* L.
 (Anacardiaceae)



Source: (ibid:31)

17. Local plant name: Kokosnoot (SD), Kronto (Sr.)
Scientific name: *Cocos nucifera* (L.) (Araceae)



Source: (ibid:80)

17 (con'd)
 (A small coconut tree at Godo-olo)



Source: Collection S. Ramdas, Godo-olo, 2009

18. Local plant name: Kwassibita (Sr.)
Scientific name: *Quassia amara* L.
 (Simarubaceae).



Source: (ibid:442)

19. Local plant name: Lemmetje (SD.) [Lemon]
Scientific name: *Citrus aurantifolia* (Christm. & Panzer) Swingle (Rutaceae).



Citrus aurantifolia: bloem (b), blad en vruchte (c). Foto's: R & S. Teunisse

Source: Van Andel & Ruysschaert 2011:429

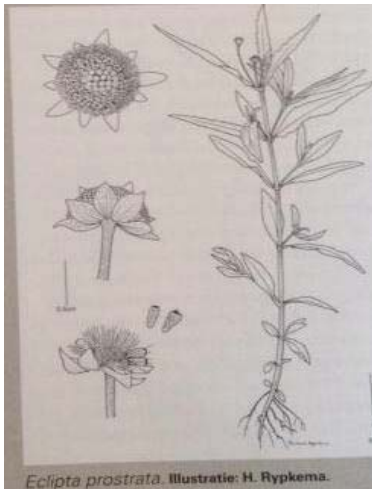
20. Local plant name: Loksi (Sr.)
Scientific name: *Hymenaea courbaril* L. (Fabaceae).



Illustratie: H. Rypkema.

Source: (ibid: 233)

21. Local plant name: (Uma) Luisawiwiri (Sr.), Bhangraiya (Sarn.), Tótobiá (Sr.)
Scientific name: *Eclipta prostrata* L. (Asteraceae).



Source: (ibid:101)

22. Local plant name: Manja (Sr), manyan (Au)
Scientific name: *Mangifera indica* L. (Anacardiaceae)



Source: (ibid:33)

23. Local plant name: Mopé (Sr.)
Scientific name: *Spondias mombin* L.
 (Anacardiaceae)



Illustratie: H. Rypkema.

Source: (ibid:35)

24. Local plant name: Ngobaya (Au), gujave (Sr.)
Scientific name: Myrtaceae, *Psidium guajava* L.



Photos: P. & S. Teunissen (b) en R. Tjon (o)

Source: (ibid:357)

25. Local plant name: Niem (Sr.)
Scientific name: *Azadirachta indica* A. Juss
 (Meliciaceae)



Azadirachta indica: habitus, bloeiende tak, bloem en vrucht. Illustratie: H. Rypkema.

Source: (ibid:332)

26. Local plant name: Noni, didibri-apra (Sr.)
Scientific name: *Morinda citrifolia* L. Rubiaceae



Illustratie: H. Rypkema.

Source: (ibid: 418)

27. Local plant name: Okro (Sr.), oker (D.)
Scientific name: *Hibiscus esculentus* L.
 (Malvaceae)



Source: (ibid:301)

28. Local plant name: Opro-udu (Sr.),
 Hoepelhout (SD), Copaieba⁸⁷ (Po.)
Scientific name: *Copaifera guyanensis* Desf.



Source: (ibid: 223)

⁸⁷ See web reference number 39.

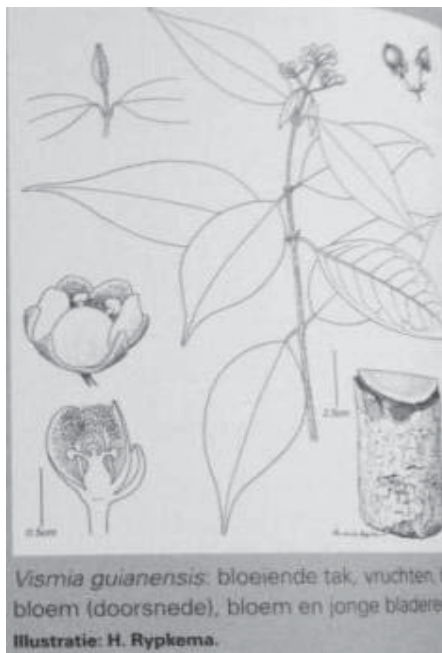
29. Local plant name: (Uma) Parabita (Sr.), Mananga (Au.)
Scientific name: *Solanum leucocarpon* Steud. (Solanaceae)



Illustratie: H. Rypkema.

Source: (ibid:456)

30. Local plant name: Pinja wiri (Sr.), Pikin pindya (Sa.)
Scientific name: *Vismia guianensis* (Aubl.) Choisy (Hypericaceae)



Source: (ibid:268)

31. Local plant name: Redi katun (Sr.)
Scientific name: *Gossypium barbadense* L. (Malvaceae)




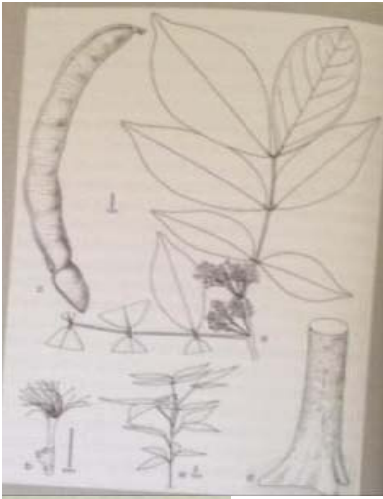


Source: (ibid:306)

32. Local plant name: Slabrikiwiri (Sr.), Sakoor (Sarn.)
Scientific name: *Senna alata* (L.) Roxb. (Fabaceae)

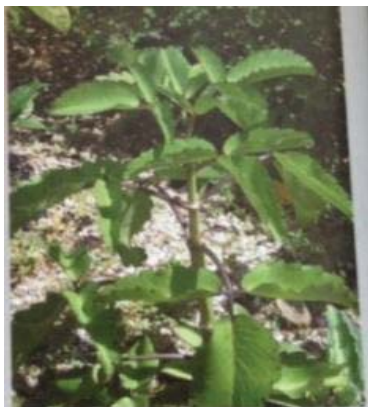


Source: (ibid:250)

<p>33. Local plant name: Suikerriet (SD) Scientific name: <i>Saccharum officinarum</i> L. (Poaceae)</p>  <p><i>Saccharum officinarum</i>. Illustratie: F. Köhler.</p> <p>Source: (ibid:401)</p>	<p>34. Local plant name: Tassi (Sa) Scientific name: <i>Geonoma baculifera</i> (Poit.) Kunth (Arecaceae)⁸⁸</p>  <p>Source: Ramdas 2008: 47</p>
<p>35. Local plant name: Tayablad (Sr.) Scientific name: <i>Colocasia esculenta</i> (L.) Schott. (Araceae)</p>  <p>Foto's: P & S. Teunissen.</p> <p>Source: Van An del & Ruysschaert 2011:60</p>	<p>36. Local plant name: Waki (Sr), Abonkini waki (Sa) Scientific name: <i>Inga alba</i> (Sw.) Willd. (Fabaceae) (Van 't Klooster et al. 2003: 297)</p>  <p>Illustratie: H. Rypkema.</p> <p>Source: (ibid:236)</p>

⁸⁸ See web reference number 40.

37. Local plant name: Wonderblad (SD.)
Scientific name: *Bryophyllum pinnatum* (Lam.)
 Kurz (Crassulaceae)



Bryophyllum pinnatum: habitus (b); bladrand met jonge plantjes (p. 179).
 Foto's: T. van Andel (b); C. van der Hoeven (p. 179).

Source: (ibid:178)

38. Local plant name: Yorkapesi (Sr.)
Scientific name: *Senna occidentalis* (L.) Link.
 (Fabaceae)



Source: (ibid:252)

39. Local plant name: Zoete patat (SD.), or switi patata (titei) (Sr.)
Scientific name: *Ipomoea batatas* L.
 (Convolvulaceae).



Source: (ibid:173)

40. Local plant name: Tupuru (Car.)
Scientific name: **Unidentified** (According to villagers, this is what the plant and its roots look like)



Source: Collection S. Ramdas, Donderskamp, 2010

Summary

This study is about the perceptions and treatment of the disease cutaneous leishmaniasis (CL) in Suriname, from the perspective of medical anthropology. How do people in Suriname with CL, and others confronted with the disease, perceive CL? What is their knowledge and understanding about the disease and how do CL patients treat the infection? What medicines do they use in self-medication, and why? How do traditional healers diagnose, explain, and treat CL, and how are the traditional treatments for CL experienced and appreciated by local people and CL patients? When seeking treatment at biomedical health services, are CL patients adherent to the treatment that doctors offer? How do medical doctors view CL treatment by traditional healers and vice-versa? Does stigma play into the illness experience and the process of health seeking? How do CL patients, their families, community members, traditional healers, and biomedical health professionals perceive CL prevention, and which aspects (in the socio-cultural, economic, and environmental contexts), according to them, possibly contribute towards the spread of the disease? These were the main questions of the study, which was part of a multidisciplinary programme 'Leishmaniasis in Suriname'.

Chapter 1 (*Introduction*) presents the epidemiology and biology of CL, the background of the set-up of the study, its objectives, research questions, and the relevance in the academic and social context. CL is clinically considered to be an important dermatological disease causing skin damage and mutilation; despite this, it is a widely neglected disease. Departing from this context, prominent health, research, and education institutions in the Netherlands and Suriname joined forces to study and combat CL in Suriname. During 2007 and 2008, they set up a multidisciplinary research program 'Leishmaniasis in Suriname'. The main aim was to contribute towards better treatment, prevention, and control of CL in Suriname. Data was collected from three perspectives: clinical, biological, and medical anthropological. The clinical research involved a treatment trial, in which two different regimes of the medicine pentamidine isethionate were compared and evaluated for treatment outcome, side-effects and drug toxicity, compliance to treatment, cost-effectiveness, and quality of life of patients. The biological research aimed to provide better insights into the infecting *Leishmania* species, vectors and reservoirs, and epidemiology of the disease. The medical anthropological study examined CL perceptions and treatment within the wider socio-economic, cultural, occupational, and geographical contexts.

Chapter 2 (*Sketching the theoretical framework*) provides the study's theoretical position and working hypothesis. The focus is on lay perceptions and explanations of CL and its treatment. Both the interpretative and critical perspectives are used to show how the behaviour of people experiencing CL, and their decisions regarding self-medication, traditional treatment, and non-use or non-compliance with biomedical treatment, can be understood from their point of view and within the larger historical, social, economic, environmental, and geographical contexts. Using middle-ranged theory, the study built upon concepts that have been widely used in social science research on health seeking: 1) health or treatment seeking in the context of medical pluralism; 2) adherence to biomedical treatment; and 3) health related stigma. Rather than making predictions, in this study an attempt has been made to contextualise, analyse, and provide understanding of the complex process

of health or treatment seeking among people with CL. Taking into account the exploratory and qualitative nature of the study, a multidimensional pathway model to investigate health or treatment seeking was designed.

Chapter 3 (*Contexts and reflections on methodological matters*) is divided into two parts. First, the different contexts of the research are discussed: the geographical, demographic, and socio-economic background of Suriname, the field locations that were selected for the research, and the key partners that facilitated the fieldwork. The second part presents the methodology of the research. In total, 205 CL patients (183 males, 22 females) seeking biomedical treatment at the Dermatology Service in the capital city Paramaribo and 321 people in the hinterland participated in the research. Semi-structured and open interviews (using questionnaires and topic lists), in-depth interviews, focus group discussions, informal individual and group conversations, and observation of CL patients (where possible) were the main methods for collecting data. Literature research, secondary analysis of national statistics and other written sources, analysis of patient files, and a personal diary were also part of the methodological package. Thematic content analysis helped in the analysis of the data and extracting relevant relationships between research findings. All study participants have been made anonymous in this study and all information is treated as confidential.

Chapter 4 (*'Not knowing': lay perceptions and explanations of cutaneous leishmaniasis*) presents and discusses research findings on local (lay) knowledge of the disease. This study shows that CL patients and others confronted with the disease in the hinterland know much about the symptomatic development and progress of the illness, yet are puzzled about its aetiology. Many think that CL is contagious but fear the disease mostly because of its biomedical treatment and the risk of amputation should the sore not heal. The discussion about the findings in this chapter is influenced by the concept of 'not knowing' in the anthropology of medicine, introduced by Murray Last (1981), whereby informants may often respond to a question without actually knowing the answer. This study reveals that not knowing (and knowing) is rooted in the specific contexts of people's daily lives and reflects historical, socio-cultural, occupational, educational, biological, environmental, and public health related conditions.

Based on the ethnographic material, Chapter 5 is the first in a series of three (including Chapters 6 and 7) that present the health seeking patterns of CL patients and describe how, upon noticing the sore(s), CL patients go on their quest for a cure. The three chapters illuminate and analyse the health seeking trajectory of CL patients, starting with self-treatment and ending with biomedical treatment seeking at the Dermatology Service.

Chapter 5 (*Seeking therapy: self-treatment, local healers, and the abundance of medicine*) focuses on self-treatment. The study shows that the majority of CL patients (161) attempted self-treatment with a wide variety of often painful or even harmful medicines: bush medicines and hot treatments, chemicals, and self-injecting practices. Dietary restrictions and 'cultural rules' are also part of the complex quest for a cure. Few CL patients reported seeking treatment from local healers, but inquiries in the hinterland suggest that local healers are often consulted for treatment. Collaboration between biomedical and local healers regarding treatment and prevention of CL is absent. Advice from those in a patient's social environment plays an important role in the choice of medicine for self-treatment. A

contradiction is also observed: despite viewing CL as a dangerous and stubborn illness, the dazzling variety of self-treatments and medicines are used either alone, often successively, or in combination, and no self-treatment experiments are spared in the effort to find the 'right' medicine.

Chapter 6 (*'Suitable' medicines: a closer look at self-treatment*) analyses the variety of medicines that CL patients used. The study shows that regardless of the type of medicine used, patients looked for medicines with certain qualities. Despite their variety, the medicines have specific characteristics in common: most are powerful medicines, consisting of corrosive, sharp, bitter, spicy, astringent, even poisonous components. The belief that a cruel disease needs a cruel treatment plays an important role in identifying a 'suitable' medicine. This chapter also discusses the impact of multiple contexts on self-treatment. Despite the provision of free biomedical treatment by the Medical Mission in the hinterland, most patients turn to self-medication. This therefore raises the question of why patients self-medicate if free medical treatment is available? The study reveals a variety of other contexts (historical, socio-cultural, personal, socio-economic, occupational, geographical, infrastructural, environmental, and health policy related) that contribute to patients seeking self-treatment first. Biomedical professionals find self-treatment "understandable", but nevertheless discourage the taking up of dubious self-treatment advice.

Chapter 7 (*Biomedical treatment and (non-) adherence*) highlights health seeking at biomedical services. Most CL patients sought biomedical treatment after failed self-treatment, while early detection and treatment are, according to the WHO, the most important measures to control CL. Only 44 patients sought early (or only) biomedical treatment, and this chapter shows how multiple – socio-personal, geographical, educational, cultural, socio-psychological – contexts may impact biomedical treatment seeking. Paradoxically, some of the aspects that contribute to self-treatment become the reasons for seeking only biomedical treatment. This study confirms that non-adherence to biomedical treatment is a problem.

Chapter 8 (*Cutaneous leishmaniasis and stigma in Suriname*) describes and analyses negative experiences related to CL in Suriname, in particular stigma. The findings suggests that people with CL encounter relatively little discrimination or other overt acts of negativity solely based on the presence of CL lesions on their bodies. Those who do encounter some form of stigma seem to experience this only temporarily. In nearly all cases, stigmatisation in the sense of 'spoiling the patient's identity' did not occur. The study further reveals that the relative absence of CL stigma in Suriname, compared to some other countries in the world, is especially related to the parasite type in Suriname, which affects the facial area much less severe.

Chapter 9 (*Prevention of cutaneous leishmaniasis in Suriname: different perspectives*) contextualises and discusses the preventive ideas of CL patients and others confronted with the illness. This study reveals how ideas about cause and prevention are crucial for treatment seeking and the control of CL. Perceptions of prevention are rooted in and shaped by the multiple contexts in which illness occurs. CL injections are incorrectly viewed as a vaccine against CL. Public health authorities should consider lay perceptions of prevention as an integral part of the public health concept of prevention; in particular, on the level of 'primary prevention'.

The final chapter (*Conclusions*) summarises and discusses the rich variety of relevant contexts, in order to achieve more transparency regarding the practical consequences of this ethnographic study and the theoretical reflections in the former chapters. In the end, the practical implications of this research are presented. The study contributes to the increase of knowledge and insights about CL, at both a national and international level, because of its anthropological approach. For Suriname, this study is unique because medical anthropological research on health seeking behaviour in relation to CL has never before been conducted. Its results may contribute to follow-up CL information and prevention campaigns that can benefit all people suffering from CL, in particular communities living and working in the interior of Suriname and medical experts and organisations involved in treatment of the disease. The in-depth insights can also inform health policy and practice for effective and early case detection, guidance of CL patients, treatment, control, and management of the disease in Suriname.

Samenvatting (Dutch Summary)

Deze studie geeft inzicht in de perceptie en behandeling van de ziekte cutane leishmaniasis (CL) in Suriname vanuit medisch-antropologisch perspectief. Wat zijn de ideeën over de ziekte bij mensen die geïnfecteerd zijn met CL? Wat weten ze erover, hoe verklaren ze de ziekte en hoe behandelen ze de infectie? Welke medicijnen gebruiken zij bij zelfmedicatie, en waarom? Hoe denken anderen in het binnenland die geconfronteerd worden met de ziekte erover? Hoe diagnosticeren, verklaren en behandelen traditionele genezers de ziekte? En hoe worden traditionele behandelingen van CL ervaren door lokale mensen en CL patiënten? Zijn CL patiënten die biomedische behandeling ondergaan trouw aan de door de arts voorgeschreven therapie? Hoe denken artsen over traditionele genezers en omgekeerd? Speelt stigma een rol bij ziekte ervaring en in het hulpzoekproces? Wat zijn de percepties van CL patiënten, hun familie, mensen binnen de gemeenschap, traditionele genezers en artsen over CL preventie? En welke aspecten (in sociaal-culturele, economische, milieu gerelateerde contexten) dragen volgens hen bij tot verspreiding van de ziekte? Dit zijn de hoofdvragen van de studie die onderdeel was van een multidisciplinair programma 'Leishmaniasis in Suriname'.

Hoofdstuk 1 (*Introductie*) presenteert de epidemiologie en biologie van CL, de achtergrond van het programma, de doelen, de onderzoeksvragen, en de relevantie in academisch en sociaal opzicht. Biomedici beschouwen CL als een belangrijk dermatologische ziekte die beschadiging of verminking van de huid veroorzaakt, maar die internationaal gezien nog weinig aandacht krijgt. Om die reden hebben prominente gezondheids-, onderzoeks- en onderwijsinstututen in Nederland en Suriname getracht om deze ziekte in Suriname te bestuderen en te bestrijden. In de periode 2007-2008 hebben zij gezamenlijk het multidisciplinair programma 'Leishmaniasis in Suriname' opgezet. Het hoofddoel was om zo bij te dragen aan betere behandeling, preventie en controle van de ziekte in Suriname. Data werden verzameld vanuit klinisch, biologisch en medisch-antropologisch perspectief. Het klinisch onderzoek betrof een test waarbij twee verschillende behandelingsregimes met het medicijn pentamidine isethionate werden vergeleken en geëvalueerd op effectiviteit, bijwerkingen en toxiciteit, therapie trouw, kosten en kwaliteit van het leven van patiënten. Het biologisch onderzoek had als doel meer inzicht te verkrijgen in de infecterende *Leishmania* parasieten, vectoren, reservoirs, en de epidemiologie van de ziekte. Het antropologisch onderzoek bestudeerde CL percepties en behandeling binnen de ruimere sociaaleconomische, culturele, beroeps en geografische context.

Hoofdstuk 2 (*Een schets van het theoretisch raamwerk*) beschrijft het theoretisch perspectief van de studie. Zowel een interpretatief als – antropologisch – kritisch kader zijn gebruikt om hulpzoekgedrag van mensen met CL en beslissingen aangaande zelfmedicatie, traditionele en biomedische behandeling, en therapie-ontrouw te begrijpen. De studie is theoretisch gefundeerd op vertrouwde concepten in sociaal-wetenschappelijk onderzoek naar hulpzoekgedrag: 1) hulpzoekgedrag in de context van medisch pluralisme, 2) therapie-trouw, en 3) gezondheid-gerelateerd stigma. In deze studie is gepoogd hulpzoekgedrag te contextualiseren en te analyseren. Gelet op het exploratief en kwalitatief karakter van deze studie is een multi-dimensionaal stappen model ontworpen om hulpzoekgedrag te bestuderen.

Hoofdstuk 3 (*Contexten en reflecties op methodologische zaken*) is opgedeeld in twee delen. In het eerste deel worden de verschillende contexten van het onderzoek besproken: de geografische, demografische, en socio-economische achtergrond van Suriname, de veldwerk locaties, en de belangrijkste partners die het veldwerk gefaciliteerd hebben. Het tweede gedeelte presenteert de methodologie van het onderzoek. In totaal hebben 205 CL patiënten (183 mannen, 22 vrouwen) die biomedische behandeling zochten bij de Dermatologische Dienst en 321 mensen in het binnenland geparticipeerd in het onderzoek. Semi-gestructureerde en open interviews (door middel van questionnaires en een lijst van onderwerpen), diepte interviews, focusgroepdiscussies, informele individuele en groepsconversaties, en observatie van CL patiënten waren de belangrijkste methoden van dataverzameling. Literatuur onderzoek, secundaire analyse van nationale statistieken en andere geschreven bronnen, inclusief patiënten dossiers, en een persoonlijk dagboek waren ook onderdeel van het methodologisch arsenaal. Thematische inhoudsanalyse is gebruikt om relaties tussen onderzoeksbevindingen te leggen. Alle participanten hebben toegestemd in het onderzoek; zij zijn geanonimiseerd en alle informatie is vertrouwelijk behandeld.

Hoofdstuk 4 (*'Niet weten': leken percepties en verklaringen van cutane leishmaniasis*) presenteert en bediscussieert onderzoeksbevindingen over lokale (leken) kennis van de ziekte. De studie wijst uit dat CL patiënten en anderen die geconfronteerd worden met de ziekte in het binnenland veel weten over de symptomatische ontwikkeling en verloop van de ziekte, maar dat de oorzaak veelal een mysterie is voor hen. Velen denken dat CL besmettelijk is, maar zijn het meest bang voor de ziekte vanwege de biomedische behandeling en het risico op amputaties indien de wonden niet genezen. De discussie in dit hoofdstuk richt zich op het begrip 'niet weten' zoals dat geïntroduceerd is door Murray Last (1981). Informanten geven vaak antwoord zonder het antwoord te kennen op de gestelde vragen. De studie toont dat weten en niet weten geworteld zijn in de specifieke context van het dagelijks leven van de betrokkenen en waarin historische en sociaal-culturele condities gereflecteerd worden zoals werk, onderwijs, milieu en openbare gezondheidszorg.

De hoofdstukken 5, 6 en 7 vormen het etnografisch hart van deze studie. Ze belichten en analyseren het hulpzoektraject van CL patiënten, beginnende met zelfmedicatie en eindigend met het zoeken van biomedische hulp bij de Dermatologische Dienst.

Hoofdstuk 5 (*Behandelingszoektocht: zelfmedicatie, lokale genezers en overvloed van medicijnen*) focust op zelfmedicatie. De studie wijst uit dat de meerderheid van de CL patiënten (161) zelfmedicatie geprobeerd heeft met een grote variëteit aan – vaak pijnlijke of zelfs schadelijke – medicijnen: bosmedicijnen en hete behandelingen, chemicaliën en zelfinjecties. Dieetbeperkingen en 'culturele regels' zijn ook onderdeel van de complexe zoektocht naar genezing. Slechts enkele patiënten gaven aan behandeling te zoeken bij lokale genezers, maar navraag in het binnenland suggereert dat lokale genezers ook vaak geraadpleegd worden. Samenwerking tussen biomedische en lokale genezers bij de behandeling en preventie van CL is zeldzaam. Adviezen uit de omgeving spelen een belangrijke rol bij de keuze van een medicijn voor zelfmedicatie. Men gebruikt een duizelingwekkende variëteit aan behandelingen en medicijnen en geen enkel

experiment met zelfmedicatie wordt gespaard in de poging om het 'juiste' medicijn te vinden.

Hoofdstuk 6 (*'Geschikte' medicijnen: een nadere kijk op zelfmedicatie*) analyseert de variëteit aan medicijnen die CL patiënten gebruikten om zichzelf te genezen. De studie wijst uit dat patiënten medicijnen zochten met een bepaalde eigenschap. Ondanks de grote verscheidenheid hebben de medicijnen specifieke karakteristieken gemeen: de meeste zijn agressief en hebben bijtende, scherpe, bittere, hete, wrange, en zelfs giftige componenten. Het geloof dat een gruwelijke ziekte ook een gruwelijke behandeling behoeft, speelt een belangrijke rol in de identificatie van 'geschikte' medicijnen. Het hoofdstuk bespreekt ook de invloed van meerdere contexten op zelfmedicatie. Ondanks gratis biomedische behandeling in het binnenland door de Medische Zending proberen vele patiënten zichzelf te genezen. De vraag daarom was: waarom onzekere zelfmedicatie als gratis professionele behandeling beschikbaar is? De studie onthult een variëteit aan contexten die bijdragen tot aanvankelijke zelfmedicatie. Biomedische professionals vinden zelfmedicatie "begrijpelijk"; maar raden af hulp te zoeken bij dubieuze adviseurs.

Hoofdstuk 7 (*Biomedische behandeling en therapie (on) trouw*) gaat in op het hulp zoeken bij biomedische diensten. De meeste CL patiënten zochten biomedische hulp na het falen van zelfmedicatie, terwijl vroege detectie en behandeling, volgens de WHO, de belangrijkste maatregelen zijn voor de strijd tegen CL. Slechts 44 patiënten zochten onmiddellijk biomedische behandeling; dit hoofdstuk suggereert dat meerdere condities – sociaal, persoonlijk, geografisch, onderwijs, cultuur, emotie – een belangrijke rol spelen bij het zoeken naar biomedische hulp. Sommige aspecten die aanvankelijk leiden tot zelfmedicatie worden later redenen om alleen biomedische hulp te zoeken. Deze studie bevestigt dat biomedische therapie-ontrouw bij de behandeling van CL een probleem is.

Hoofdstuk 8 (*Cutane leishmaniasis en stigma in Suriname*) beschrijft en analyseert negatieve ervaringen gerelateerd aan CL in Suriname, in het bijzonder stigma. Het onderzoek suggereert dat mensen met CL relatief weinig discriminatie of andere vormen van negatieve bejegening ondervinden en als dat gebeurt, is dat slechts tijdelijk. Er is nauwelijks sprake van stigmatisering in de zin dat de identiteit van de patiënt aangetast wordt. De studie komt tot de conclusie dat de relatieve afwezigheid van CL stigma in Suriname – vergeleken met andere landen – vooral samenhangt met het type van de ziekte in Suriname die minder gezichtsverminking veroorzaakt.

Hoofdstuk 9 (*Preventie van cutane leishmaniasis in Suriname: diverse perspectieven*) contextualiseert en bespreekt preventieve ideeën van CL patiënten en anderen die geconfronteerd worden met de ziekte. Ideeën over oorzaak en preventie zijn cruciaal voor het zoeken van behandeling en controle van CL. Preventie percepties zijn geworteld in de verschillende contexten waarin de ziekte zich manifesteert. CL injecties worden ten onrechte gezien als vaccinatie tegen CL. Uitvoerders van Openbare Gezondheid moeten leken percepties serieus nemen in hun preventiebeleid.

Het laatste hoofdstuk (*Conclusies*) biedt een beknopte samenvatting en theoretische reflectie op enkele bevindingen. Tot slot worden de praktische implicaties van dit onderzoek gepresenteerd. De antropologische benadering van deze studie draagt bij tot een beter inzicht in CL zowel op nationaal als

internationaal niveau. Deze studie is voor Suriname uniek; medisch-antropologisch onderzoek naar hulpzoekgedrag bij CL is nooit eerder gedaan. De resultaten dragen bij aan de verspreiding van kennis en preventie campagnes die ten goede zullen komen aan CL patiënten, vooral in het binnenland en aan medische experts en organisaties die betrokken zijn bij de behandeling en bestrijding van de ziekte. Hopelijk leiden de verkregen inzichten tot een vroege opsporing van CL gevallen, een betere begeleiding van CL patiënten, en een effectievere behandeling, controle en management van de ziekte.

Sumário (Portuguese Summary)

Este é um estudo sobre as percepções e o tratamento da doença leishmaniose cutânea (LC) no Suriname a partir da perspectiva da antropologia médica. Como é que as pessoas no Suriname com LC e outras com ela confrontadas percebem a doença? Qual é o seu conhecimento e compreensão acerca da doença e como é que pacientes com LC tratam a infecção? Quais os remédios que eles usam na automedicação e porquê? Como é que os curandeiros tradicionais diagnosticam, explicam e tratam a LC e como são os tratamentos tradicionais de LC vistos pela população local pelos pacientes com LC? Ao procurarem tratamento em serviços biomédicos, os pacientes com LC aderem ao tratamento disponibilizado pelos médicos? Como veem os médicos o tratamento da LC pelos curandeiros tradicionais vice-versa? A estigmatização influencia a experiência da doença e o processo de procura de tratamento? Como é que os pacientes com LC, membros da família, da comunidade, curandeiros tradicionais e profissionais de saúde percebem a prevenção da LC e que aspectos (no contexto sociocultural, económico e ambiental) estão, de acordo com eles, possivelmente a contribuir para a disseminação da doença? Estas foram as principais questões do estudo, que fez parte de um programa multidisciplinar “Leishmaniose no Suriname”.

O Capítulo 1 (*Introdução*) apresenta a epidemiologia e biologia da LC, os antecedentes do estudo, seus objetivos, questões de pesquisa e a relevância no contexto académico e social. A LC é clinicamente considerada uma doença dermatológica importante, causando danos à pele e mutilação, mas é amplamente negligenciada. Partindo deste contexto, instituições proeminentes ligadas à saúde e pesquisa na Holanda e no Suriname uniram esforços para estudar e combater esta doença no Suriname. Durante 2007-2008 elas estabeleceram um programa de pesquisa multidisciplinar “Leishmaniose no Suriname”. O principal objetivo foi contribuir para um melhor tratamento, prevenção e controle da LC no Suriname. Os dados foram coletados a partir de três perspectivas: clínica, biológica e antropológica médica. A pesquisa clínica envolveu um ensaio de tratamento em que dois regimes diferentes do fármaco isotionato de pentamidina foram comparados e analisados para efeitos do tratamento, efeitos secundários, toxicidade, adesão ao tratamento, custo-eficácia e qualidade de vida dos pacientes. A pesquisa biológica teve como objetivo proporcionar melhor compreensão sobre as espécies infetantes de *Leishmania* e seus vetores e reservatórios, e da epidemiologia da doença. O estudo antropológico analisou as percepções e o tratamento da LC dentro de contextos socioeconómicos, culturais, profissionais e geográficos mais amplos.

O Capítulo 2 (*Desenhando o quadro teórico*) fornece a posição teórica do estudo e a hipótese de trabalho. O foco foi em percepções e explicações não científicas da LC e do seu tratamento. Ambas as perspectivas interpretativa e crítica são utilizadas, mostrando como o comportamento das pessoas que vivem a LC e decisões sobre a automedicação, tratamento tradicional e não utilização ou não adesão ao tratamento biomédico podem ser entendidos a partir do seu ponto de vista e dentro de contextos mais amplos: histórico, social, económico, ambiental e geográfico. Usando uma teoria de médio alcance, o estudo baseou-se em conceitos que têm sido amplamente utilizados na pesquisa de ciências sociais sobre a procura de cuidados de saúde: 1) procura de saúde ou tratamento no contexto de pluralismo médico, 2) adesão ao tratamento biomédico, e 3)

estigmatização relacionada com a saúde. Mais do que prever, neste estudo é feita uma tentativa de contextualizar, analisar e fornecer uma compreensão do complexo processo de procura de saúde ou tratamento por pessoas com LC. Tendo em conta a natureza exploratória e qualitativo estudo, é projetado um modelo de índole multidimensional para investigar a procura de saúde ou tratamento.

O Capítulo 3 (*Contextos e reflexões sobre questões metodológicas*) é dividido em duas partes. Primeiro os diferentes contextos da pesquisa são discutidos: o enquadramento geográfico, demográfico e socioeconómico do Suriname, os locais que foram selecionados para a pesquisa e os principais parceiros que facilitaram o trabalho de campo. A segunda parte apresenta a metodologia da pesquisa. No total, 205 pacientes com LC (183 homens e 22 mulheres) à procura de tratamento biomédico no Serviço de Dermatologia e 321 pessoas no interior país participaram da pesquisa. Entrevistas semiestruturadas e abertas (por meio de questionários e listas de tópicos), entrevistas aprofundadas, discussões em grupo, conversas informais ao nível individual ou coletivo, e observação de pacientes com LC (quando possível) foram os principais métodos de coleta de dados. A revisão da literatura, análise secundária de dados estatísticos nacionais e outras fontes escritas, a análise de registos clínicos e um diário pessoal fizeram também parte da metodologia. Uma análise de conteúdo temático ajudou a analisar os dados e a extrair relações relevantes entre os resultados da investigação. Todos os participantes do estudo são mantidos anónimos nesta dissertação e toda a informação é tratada confidencialmente.

O Capítulo 4 (*"Não saber": percepções e explicações não científicas da leishmaniose cutânea*) apresenta e discute os resultados da investigação sobre o conhecimento local (não científico) da doença. Este estudo mostra que pacientes com LC e outras pessoas confrontadas com a doença no interior do país sabem bastante sobre o desenvolvimento sintomático e a progressão da doença, mas ainda se encontram confusos sobre sua etiologia. Muitos pensam que a LC é contagiosa, mas temem a doença principalmente por causa de seu tratamento biomédico e risco de amputação se a ferida não cicatrizar. A discussão sobre as conclusões deste capítulo é influenciada pelo conceito de "não saber" na antropologia da medicina introduzido por Murray Last (1981). Os respondentes geralmente respondem sem realmente saberem a resposta às perguntas efetuadas. O estudo revela que não saber (e saber) está enraizado nos contextos específicos de vida diária das pessoas e reflete condições históricas, socioculturais, profissionais, educacionais, biológicas, ambientais e relacionadas com a saúde pública.

Com base no material etnográfico, o Capítulo 5 é o primeiro, de uma série de três (incluindo os Capítulos 6 e 7), que apresenta padrões de procura de saúde de pacientes com LC e descreve a forma como, após detectarem a(s) ferida(s), os pacientes com LC foram em busca de cura. Os três capítulos esclarecem e analisam a trajetória de procura de saúde em pacientes com LC, começando com o autotratamento e terminando com a procura de tratamento no Serviço de Dermatologia.

O Capítulo 5 (*Buscando terapia: o autotratamento, os curandeiros locais e a abundância de remédios*) concentra-se no autotratamento. O estudo mostra que a maioria dos pacientes com LC (161) tentou autotratamento com uma grande variedade de remédios, muitas vezes dolorosos ou mesmo prejudiciais: remédios

da floresta e tratamentos quentes, produtos químicos e práticas de autoinjeção. Restrições dietéticas e "regras culturais" também fazem parte da complexa busca para curar. Poucos pacientes com LC reportam tratamento pelos curandeiros locais, mas inquiridos do interior do país sugerem que os curandeiros locais também são frequentemente consultados para o tratamento. A colaboração entre biomédicos e curandeiros locais em relação ao tratamento e prevenção da LC é, no entanto, inexistente. O aconselhamento do ambiente social desempenha um papel importante na escolha do remédio para o autotratamento. Uma contradição é observada: apesar de verem a LC como uma doença perigosa e persistente, a imensa variedade de tratamentos e remédios é usada ou isoladamente, muitas vezes sucessivamente, ou em combinação, e tentativas de autotratamento não são poupadas no esforço para encontrar o remédio "certo".

O Capítulo 6 (*Remédios "apropriados": um olhar atento para o autotratamento*) analisa a variedade de remédios que os pacientes com LC utilizam. O estudo revela que, independentemente do tipo de remédio usado, os pacientes procuraram remédios com determinadas qualidades. Apesar da sua variedade, os remédios têm características específicas em comum: a maioria são produtos potentes, consistindo em componentes corrosivos, penetrantes, amargos, picantes, adstringentes e mesmo venenosos. A crença de que uma doença cruel precisa de um tratamento cruel desempenha um papel importante na identificação de um remédio "apropriado". Este capítulo também discute o impacto de múltiplos contextos no autotratamento. Apesar do tratamento biomédico gratuito no interior do país por meio da Missão Médica, a maioria dos pacientes se virou para a automedicação. Por conseguinte, a pergunta foi: porquê se automedicar, se está disponível tratamento médico gratuito? O estudo revela uma variedade de outros contextos (históricos, socioculturais, pessoais, socioeconômicos, ocupacionais, geográficos, infraestruturais, ambientais e relacionados com a política de saúde) que contribuem para que os pacientes procurem autotratamento em primeira instância. Os profissionais biomédicos consideram o autotratamento "compreensível", mas desencorajam os conselheiros duvidosos.

O Capítulo 7 (*Tratamento biomédico e (não) adesão*) destaca a busca de saúde em serviços biomédicos. A maioria dos pacientes com LC procurou tratamento biomédico após falha de autotratamento, enquanto a detecção e o tratamento precoce são, de acordo com a OMS, as medidas mais importantes para controlar a LC. Apenas 44 pacientes procuraram cedo (ou somente) tratamento biomédico e este capítulo mostra como contextos múltiplos – sociopessoal, geográfico, educacional, cultural, sociopsicológico – podem ter impacto na procura de tratamento biomédico. Paradoxalmente, alguns dos aspectos que contribuem para o autotratamento tornam-se os motivos para procurar apenas tratamento biomédico. Este estudo confirma que a não adesão ao tratamento biomédico é um problema.

O Capítulo 8 (*Leishmaniose cutânea e estigmatização no Suriname*) descreve e analisa experiências negativas relacionadas com LC no Suriname, em particular da estigmatização. Os resultados sugerem que as pessoas com LC encontram relativamente pouca discriminação ou outros atos explícitos de negatividade e unicamente com base na presença de lesões de LC em seus corpos. Aqueles que encontraram alguma forma de estigmatização pareceram senti-la temporariamente. Em quase todos os casos, a estigmatização no sentido de

“prejudicar a identidade do paciente” não ocorreu. O estudo revela ainda que a relativa ausência de estigmatização por LC no Suriname, em comparação com alguns outros países no mundo, está especialmente relacionada com o tipo da doença no Suriname causando menos mutilação facial.

O Capítulo 9 (*Prevenção da leishmaniose cutânea no Suriname: diferentes perspectivas*) contextualiza e discute idéias preventivas de pacientes com LC e outras pessoas confrontadas com a doença. Este estudo revela como idéias sobre a causa e a prevenção são cruciais para a busca de tratamento e para o controle da LC. Percepções de prevenção estão enraizadas e são moldadas pelos vários contextos em que a doença ocorre. As injeções para a LC são erroneamente consideradas como uma vacina contra a doença. As autoridades de saúde pública devem considerar as percepções de prevenção como parte integrante do conceito de saúde pública da prevenção; em particular no nível de “prevenção primária”.

O último capítulo (*Conclusões*) sintetiza e discute a rica variedade de contextos relevantes para se alcançar mais transparência sobre as consequências práticas deste estudo etnográfico e as reflexões teóricas nos capítulos anteriores. No final, as implicações práticas desta pesquisa são apresentadas. O estudo contribui para o aumento do conhecimento e percepções sobre a LC, tanto a nível nacional como internacional, devido à sua abordagem antropológica. Para o Suriname, esse estudo é único porque pesquisas antropológicas médicas no comportamento de busca de saúde em relação à LC nunca haviam sido realizadas. Os resultados podem contribuir para monitorizar campanhas de informação e prevenção da LC que podem beneficiar todas as pessoas que sofrem de LC, em determinadas comunidades que vivem e trabalham no interior do Suriname e médicos especialistas e organizações envolvidas no tratamento da doença. As percepções aprofundadas podem servir para informar as políticas e práticas de saúde para a detecção rápida e eficaz de casos, para a orientação de pacientes com LC, e para o tratamento, controle e manejo da doença no Suriname.

Curriculum Vitae

Sahienshadebie Ramdas was born on the 24th of July 1976 in Paramaribo, Suriname. In 1992, she attended the Mr. Dr. J. C. De Miranda Lyceum 1 and obtained her diploma in 1995. In the same year, she enrolled in a preparatory year for the Anton de Kom University. She started her Masters in Sociology at Anton de Kom in 1997 and finished in 2005. While studying sociology, she also followed a two-year course (1998-2000) to obtain her Pedagogical Certificate at the 'Instituut voor de Opleiding van Leraren' (Teachers Training College) and worked from 2001-2006 at Prohealth, a community health development institute.

From 2005-2006, she worked as a researcher at the Social Science Research Unit (IMWO) of the Anton de Kom University on an International Exhibition and Research project 'Bidesia', on the dynamics of migration, social development, and cultural identity in the Bhodjpuri region of India, Suriname, and the Netherlands.

In 2006, she received a NUFFIC fellowship from the Netherlands Fellowship Program (NFP) for an Advanced Masters in Medical Antropology (AMMA) at the University of Amsterdam, the Netherlands. She graduated in August 2007, and later in the same year became engaged in research projects in Suriname. In early 2008, she conducted a medical anthropological study on the treatment of the umbilical cord of newborns among Saramacca and Ndjuka Maroons in Suriname for the Pan-American World Health Organization.

In November 2008, she started her PhD project at the Amsterdam Institute for Social Science Research, University of Amsterdam, on the Integrated Programme 'Leishmaniasis in Suriname', financially supported by the Netherlands Organization for Scientific Research / Foundation for the Advancement of Tropical Research – Science for Global Development (NWO-WOTRO). During her PhD studies, she conducted fieldwork at the Dermatology Service and hinterland villages in Suriname, and in a rural community of Corte de Pedra in Bahia, Brazil; she attended different symposiums and could present her study findings in Suriname (Paramaribo, during the Second Suriname/Dutch Conference on Tropical Dermatology) and the Netherlands (University of Amsterdam, the Amsterdam Medical Centre, Sociëteit de Waterkant in The Hague), as well as at the University of Warsaw (Poland), Université de Paris 8 in France, and the Hospital Universitarios Professor Edgar Santos in Bahia, Brazil.

List of publications

Published full papers and abstracts related to the 'Leishmaniasis in Suriname' programme

Hu, R., **S. Ramdas**, P. Nieuwkerk, R. Reis, L.O.A. Sabajo, R.F.M. Lai A Fat & H.C.J. De Vries.

- 2013 The effect of body location of "New World" cutaneous leishmaniasis lesions on the quality of life in Suriname. In: R. Hu. (ed.) *Treatment, Quality of Life and cost-aspects of cutaneous leishmaniasis in Suriname*. Paramaribo: Dermatology Service, pp. 71- 86.

Ramdas, S.

- 2012 Cruel disease, cruel medicine: Self-treatment of cutaneous leishmaniasis with harmful chemical substances in Suriname. *Social Science & Medicine* 75(6): 1097-1105.

Schallig, H., A. Kent, R. Hu, **S. Ramdas**, D. Mans, S. Van der Geest, L. Sabajo, H. De Vries & R. Lai A Fat

- 2013 Leishmaniasis in Suriname. *Abstract book British Society for Parasitology Spring Meeting* (9-11 April 2013, Bristol, United Kingdom), pp. 2-3.

Schallig, H., R. Hu, A. Kent, **S. Ramdas**, L. Sabajo, D. Mans, S. Van der Geest, H. De Vries & R. Lai A Fat

- 2013 Leishmaniasis in Suriname – an integrated programme. *Tropical Medicine and International Health* 18, suppl. 1: 136.

Schallig, H., R. Hu, **S. Ramdas**, A. Kent, D. Mans, S. Van der Geest, L. Sabajo, H. De Vries & R. Lai A Fat

- 2013 Leishmaniasis in Suriname. *Abstract book Fifth World Congress on Leishmaniasis* (13-17 May 2013, Porto de Galinhas, Brazil), O 98.

Other publications

Ramdas, S.

- 2007 *Secrecy and disclosure: How women with Sexually Transmitted Infections manage their steady relations*. Master thesis, AMMA, University of Amsterdam.

- 2007 *Overspel binnen de orthodoxe Hindoegemeenschap in Suriname*. Paramaribo: VACO.

- 2008 Liefde, leugens en religie: overspel binnen de orthodoxe Hindoegemeenschap in Suriname. *OSO Tijdschrift voor de Surinamistiek en het Caraïbisch gebied* 27(1).

2008 *Treatment of the umbilical stump within the Maroon community: A medical anthropological study on traditional practices of the Maroon population (mainly Saramaka and Ndjuka) in the hinterland and some suburban areas in Suriname regarding the treatment of the umbilical cord of newborns.*
Paramaribo: Pan-American Health Organization.

Terborg, J., **S. Ramdas** & D. Eiloo

2006 *ICPD + 10 report. 10 years program of action of the international conference on population and development (ICPD) in Suriname 1994-2004.*
Paramaribo: St. ProHealth.

