



*Perceptions and treatment of cutaneous leishmaniasis in Suriname.
A medical-anthropological perspective*

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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.