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Not-knowing and the proliferation of assumptions: local explanations of Cutaneous Leishmaniasis in Suriname

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ABSTRACT

Why do patients and others confronted with cutaneous leishmaniasis (CL) – a parasitic skin disease – in the hinterland of Suriname, South America, provide a dazzling variety of aetiological explanations for one single illness? And how do these explanations reflect local knowledge of and interest in the origin of illness? In this article, we explore these questions using the concept of ‘not-knowing’, as introduced by Murray Last in 1981. One of Last’s conclusions is that ‘don’t knows’ or ‘don’t cares’ reflect people’s disinterest in medicine. The aim of this article, however, is to draw attention to another aspect of not-knowing: it may lead to a proliferation of explanatory assumptions, unhindered by precise knowledge. In other words, multiple explanations mask not-knowing, which is from a methodological point of view a rarely observed element in social science research and constitutes an important addition to Murray Last’s well known argument. The paper describes findings based on anthropological fieldwork carried out between September 2009 and December 2010 at the Dermatology Service in Suriname’s capital Paramaribo and among 205 CL patients and 321 inhabitants in various communities in the hinterland. As this article shows, both knowing and not-knowing are rooted in the various contexts of people’s daily lives and reflect their historical, socio-cultural, occupational, educational, biological, environmental, and public health-related conditions. Public health authorities should explore not-knowing more seriously in their efforts to prevent illness, since knowing about not-knowing is valuable in the design of health education and prevention programmes.

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Introduction

Countless studies have emphasized the importance of explanation in the ordering and management of illness. These illness explanations have been recognized as being shaped by the social and cultural contexts, as well as lay and professional knowledge systems, that exist within a given context. Studies in the anthropology of medicine have however also pointed out that illness knowledge may be largely absent or that people simply do not care to know (Last 1981; Littlewood 2007; Dein 2007).

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The concept of ‘not-knowing’ was introduced by Murray Last in 1981, who 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 tradition. Last claimed that even healers lacked a clear and systematic idea of their own healing methods. Furthermore, he criticized anthropologists for their persistence in obtaining answers from informants, even when the informants may not have the requested knowledge. As a result of such persistence, he argued, informants are likely to provide an answer simply to satisfy the researcher. Obviously, the accuracy of such answers may be doubtful, to put it mildly. Methodologically speaking, anthropologists and other health researchers should therefore take the answer ‘Don’t know’ more seriously. Mair et al. (2012, 1) in their introduction to an edited collection of essays on ‘the anthropology of ignorance’, support this conclusion when they write that

... anthropologists have too easily attributed to the people they study the same unambiguous desire for knowledge, and the same aversion to ignorance, that motivates their own work, with the result that situations in which ignorance is viewed neutrally – or even positively – have been misunderstood and overlooked.

Knowing not-knowing

Not-knowing has made remarkable advances in the most diverse fields of academic as well as popular writing, from philosophy to moral and spiritual guidance, from art to psychology. Authors emphasize the importance of accepting or seeking not-knowing and speak of the wisdom, beauty, art, power, wonder, and courage of not-knowing. ‘Agnosticism’ is increasingly recognized as the only ‘rational’ position, not only in matters of religion.

In anthropology – and medical anthropology in particular – the interest in not-knowing finds its origin in the discipline’s unease with conceptualizing the human person as a rational being (Young 1981). Ethnomethodology, phenomenology, semiotics, and postmodernism all inspired anthropologists to pay more attention to contradiction, ‘irrationality’, emotion, and ‘chaos’ in human thinking and action. Rationality became rationalization: we do things and produce a reason afterwards. Doing thus overtook thinking in much ethnography and anthropological theorizing.

It may – for heuristic purposes – be useful to distinguish between two different types of actors involved in not-knowing, namely informants and ethnographers. To start with the former, informants or interlocutors may simply not know the answers to our questions. Last (1981) – as mentioned – pointed this out in his eloquent article. He also remarked that informants may not admit their ignorance about their illness – or any other aspect of their lives – and instead may produce information that they have never even thought about before. Mair et al. (2012, 2–3) emphasize that interlocutors of anthropological research may ‘... cautiously, regretfully, proudly, or stubbornly insist on their own ignorance.’ They argue that so-called ignorance should therefore not be treated simply as the absence of knowledge but as an ethnographic object worthy of closer attention.

That suggestion is shared in various ways by other authors who point out that people may just lie to hide their ignorance or to satisfy researchers and get rid of them in a polite way (Bleek 1987; Fainzang 2015; Nachman 1984; Salamone 1977). In his critique of over-systematization in medical anthropology, Dein (2007, 42) cites a study by Williams and Healy (2001), who observed how first-time presenters to a mental health service in Wales produced

explanations that were readily dismissed as inconsistent and incoherent by the medical staff. Dein concludes that ‘there is a large amount of data from medical anthropological research that suggests that treatment choice is determined primarily by social and political factors rather than underlying explanatory models’ (ibid., 46). The number of authors raising critical questions about the cognitive and rationalist approach to illness explanations or beliefs is very large indeed. Nijhof, a medical sociologist *and* patient, in a reflection on his own sickness, wrote:

Sociologists are trained to ask people questions, so many of them expect to get answers. And there are even those who think the answer is already in their brain, fully-formed and waiting to be uttered. Such sociologists think that a sick person knows how he is doing, that all he has to do is disclose it whenever he is asked to do so. As if there were such a thing as a state of being ill, a state that a sick person can talk about reliably and with valid answers (Nijhof 2018, 110–111).

Even doctors in clinical settings, thought to be exemplary locations of rationalist evidence-based practice, often act without proper knowledge, as various sociologists and anthropologists have observed (e.g. Fox 1998; Street 2014). In poor settings with limited staff, time, and diagnostic equipment, doctors may have no other choice than to treat patients without knowing the correct diagnosis. Alice Street (2014, 111) describes how biomedicine is enacted in an overcrowded hospital in Papua New Guinea as in ‘a space of perpetual uncertainty’. Treatment thus becomes a way of finding the true cause of a patient’s complaints as well as of hiding a doctor’s own uncertainty.

So far, we have talked about not-knowing among informants. Researchers too, however, increasingly admit or embrace not-knowing. Joel Robbins (2008, 422), writing about linguistic exchanges in Papua New Guinea, observed that ‘If speech cannot convey what speakers think or feel, how can a spoken assertion that this is the case be taken to be an accurate report of the speaker’s own experience?’ In other words, can ethnographers ever claim to know what is on other people’s minds? The colloquial trope in human communication ‘I know exactly what you mean’ is a popular example of the naiveté of the assertion that one can read another person’s mind. Critical anthropologists aim to steer clear of such simplicity and rather argue for the opposite. Cultural analysis, wrote Geertz (1973, 23), ‘is intrinsically incomplete’ and ‘essentially contestable’.

How did not-knowing present itself in our research and how did it affect the rationalization of action such as prevention and treatment seeking? In this article, we first describe people’s confusion and uncertainty about the cause of cutaneous leishmaniasis (CL). We are not the first to observe this uncertainty. Herndon et al. (2009, 8) remark: ‘Leishmaniasis [is] a condition attributed by Trio to an insect bite although they are non-specific to insect identity. Trio note that *kaasa* [CL] is frequently acquired in the course of hunting trips to particular swamp regions.’ (Interestingly, as early as the 18th century Peruvian highland groups applied the same term, *uta*, to both CL and the sandfly, an association that was only postulated by Western epidemiologists in 1924; Herrer and Christensen 1975, cited in Herndon et al. 2009, 14). Our respondents filled the absence of knowledge by producing a wide variety of explanations. These explanations are rooted in their daily living conditions in the forested hinterlands of Suriname. We then address the question of why there is no popular consensus about the cause of such a common disease as CL, while there *is* consensus about the aetiology of most other diseases. Put differently, why is there uncertainty with regard to CL and not about other diseases? We conclude with a plea for more awareness of

not-knowing as a key to understanding treatment seeking and point to some practical recommendations that follow from our research.

Study context and biomedical matters

The multi-disciplinary study (see Hu 2013; Kent 2013; Ramdas 2015) on which our article is based was conducted in Suriname, a thinly populated country with about 550,000 inhabitants in the northern part of South America. The ethnic composition of the population is very diverse, consisting mostly of Hindustanis (27.4%), Maroons (21.7%), Creoles (15.7%), Javanese (13.7%), people of mixed descent (13.4%), and other smaller groups of Indigenous peoples and others (7.6%) (Algemeen Bureau voor de Statistiek 2013, 42). Maroon and Indigenous communities have been studied extensively by anthropologists mainly because of the extraordinary impact of colonialism and slavery on their ascent and present situation (e.g. De Beet and Sterman 1981; De Groot 1969, 1977; Köbben 1979; Kloos 1971; Krumeich 1984; Price 1973, 1975, 1976; Thoden van Velzen 1966; Thoden van Velzen and Van Wetering 1991, 2004, Van Lier 1971; Van Wetering 1973). A discussion of this voluminous anthropological and historical literature on – in particular – religion, kinship, political organization, and migration falls however outside the scope of this article that focuses on a very specific aspect of their daily life: their concern about and knowledge of CL.

Maroons and Indigenous people live mostly in remote areas, deep in the Amazon rainforest that comprises 80% of the country. They are also the groups most vulnerable to CL, a skin infection caused by parasites belonging to the genus *Leishmania*, transmitted via the bite of infected female sand flies (*Phlebotomus* or *Lutzomyia* species) (Hu 2013, 8). Depending on the infecting species, different clinical symptoms can develop, ‘ranging from localized CL with single to multiple skin ulcers, satellite lesions or nodular lymphangitis’ (ibid.). CL is clinically considered ‘one of the most serious skin diseases in developing countries’ (Gonzalez et al. 2008, 1) due to the potentially extensive ulceration and scar formation. Inhabitants of the Suriname hinterland, those working in the gold mining or timber sectors, and visitors (tourists, vacationers) are most at risk for CL, since its vectors – sand flies – are primarily present in the dense vegetation of the rainforest. The abovementioned groups were therefore the target of our research.

The disease CL affects between one and 1.5 million people globally and is a growing health problem, with ten countries harbouring more than 90% of the worldwide disease incidence: Afghanistan, Pakistan, Algeria, Iran, Syria, Saudi Arabia, Colombia, Brazil, Bolivia, and Peru (WHO 2007; Bern et al. 2008; Desjeux 2004). Afghanistan, Syria, and Brazil are the main foci of CL (Pavli and Maltezou 2010). CL is endemic in Suriname, with the first case reported in 1911 (Flu 1911). Epidemiological data are, however, scattered, poorly collected, and sparsely monitored. A total incidence of 66 cases per 100,000 inhabitants was reported between 1979 and 1985 (Van der Meide et al. 2008, 192). In 2011, nearly 300 new cases were reported at the Dermatology Service in the capital city Paramaribo (Hu 2013, 13).

Existing studies of CL in Suriname and the wider Amazon region (ACT 2014; Herndon et al. 2009; Odonne et al. 2011, 2017) focus mainly on local knowledge of treatment, such as herbal medicine, without investigating people’s aetiological views which is the central topic of this article.

To contribute to improved treatment, prevention, and control, several national and international research and education institutes in Suriname and the Netherlands set up and executed the 'Leishmaniasis in Suriname' programme, which comprised three projects – one clinical, one biological, and one anthropological. The programme spanned a period of five years (2008–2013). This article is based on the third project, which focussed on perceptions and treatment of CL. National stakeholders selected the research themes during a national conference prior to starting the research. All questions brought forward by the stakeholders were brought under four main themes namely health seeking, compliance to biomedical treatment, stigma, and CL prevention. In this way we also developed the research questions. Field sites, methodological and logistical matters too were discussed during the conference.

Methods

Qualitative anthropological fieldwork was conducted between September 2009 and December 2010 by the Surinamese researcher who was fluent in Dutch and Sranan and had some command of various other languages. The research was carried out at the Dermatology Service in Paramaribo, and in the hinterland in Maroon and Indigenous villages (Godo-olo, Brokopondo Centrum area, Donderskamp, Tepu) and among Brazilian gold diggers in Benzdorp. These – from an anthropological point of view – relatively short visits to a variety of communities were carried out to get an overall picture of ideas and practices in the ethnically diverse population of Surinam. All sites were selected in close consultation with national stakeholders.

At the Dermatology Service, a total of 205 clinically diagnosed patients participated in the study – with their written or verbal informed consent – through a short (structured) questionnaire, which contained open-ended questions concerning a range of aspects regarding perceptions and explanations of the illness, health seeking, self-treatment, stigma, disease contamination, and prevention. Each interview lasted approximately 30 minutes, and in some cases 45 minutes to one hour. The answers were written down on a form, or in some cases audio-recorded and then transcribed. Medical doctors and nurses involved in the treatment of CL patients at the Dermatology Service were also interviewed. Our analytical emphasis lay predominantly on the 205 CL patients seeking treatment at the Dermatology Service, because they received a laboratory-confirmed diagnosis. However, since the majority of the patients worked in the hinterland and had family and cultural ties with communities there, complementary research was carried out in the hinterland. Findings and analysis are therefore derived from both survey-type research (at the Dermatology Service) and qualitative ethnographic inquiries (in the hinterland).

In the hinterland, a total of 321 people who claimed to have had CL or who knew others with the illness participated in the study. During field research stays of between three weeks' and three months' duration, daily life was observed and casual conversations, focus group discussions, and in-depth interviews were carried out with community members, health workers at the Medical Mission (a semi-private, non-profit, primary health care organization providing medical care in 57 village clinics in the hinterland), ex-CL patients in the villages, and key persons such as village captains, their assistants, and 'traditional' healers. These various forms of communication took place in a remarkably open, friendly and respectful way. Notes of all conversations, observations, and discussions were taken. Both Dutch (SD)

and Sranan (Sr) (the national formal and informal language, respectively) were the main languages used during interviews. In addition to Sranan, in the hinterland villages the Maroon language Aucan (Au), Saramaccan (Sa), the Indigenous language Trio (Tr), and Portuguese (Po) were also used. Audio-recorded interviews were transcribed and translated into English; photographs were taken with the permission of those involved.

With the help of research assistants, the data was processed using computer software. Information collected during the research was treated as confidential and the identities of all CL patients and people living in the field sites have been anonymized. Literature research, secondary analysis of national statistics and other written texts, the study of patient files, and a personal diary were also part of the methodology.

Research results

Socio-demographic profile of study population

Of the 205 CL patients at the Dermatology Service, 183 (89%) were male and 22 (11%) female. Most of the patients (81%) were in the working age category 20–49 years. A total of 89 patients (43%) were low educated (had received no formal education or primary education). The majority (77%) lived in the capital city or surrounding districts, but originated mainly from or worked in the hinterland. More than half (113) were of Maroon and Indigenous descent, and of these the majority were men (48%).

People in Maroon and Indigenous communities live under their own traditional authority, consisting of the head of the village, called the *cabiten* (captain), the assistants of the captain, called *basiyas*, and the village elders. The lifestyle of Maroon and Indigenous peoples is largely ‘traditional’, with tasks divided along gender lines. In Maroon communities, men are mostly engaged in the lumber and gold sectors. They are also involved in hunting and fishing, laying out plots for agricultural activities, building houses, boat construction, and making a living from tourism by offering transportation and guide services or processing wood into souvenirs. The men in Indigenous communities engage in similar activities as Maroon men, but are also involved in weaving household utensils and baskets to carry fruit or other agricultural products, training hunting dogs, or trying to make a living through the sale of wild animals.

Women in both communities are busy with planting, harvesting, and transporting products like bitter cassava and vegetables. They are also engaged in processing food, preparing and selling food products, fish, or embroidery, or they own small shops where they sell beverages and other ‘luxury’ products. Women often take care of households, children, the sick and the elderly. Similar to men, women work also as civil servants, teachers, or health workers. Overall, people in the villages try to combine different economic activities to make ends meet.

Knowing, yet not knowing: multiple disease causation theories

From the start of the inquiries among patients at the Dermatology Service and others in the hinterland it was obvious that people were puzzled about the aetiology of CL or *Busi Yasi*, as the disease was generally called. In response to the question of whether they knew the origin of the disease, 82 (40%) of the 205 CL patients at the Dermatology Service said

that they *did not know* what caused CL and 123 (60%) responded that they *did know*. Though some 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 Table 1, an overview is provided of all of the mentioned causes of CL, as categorized by CL patients, and the number of times they were mentioned.

Table 1 clearly shows, the majority attributed CL to the bite of a fly or other kind of insect. The exact type of fly, 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 (five) 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 following, the aetiological views of CL patients are discussed in depth and complemented with information on the topic gathered in the hinterland villages.

Flies and insects

CL patients referred to a variety of flies and insects known locally in villages to cause one to itch after a bite, such as *Sunna* (Au), *Honjohonjo* (Sa), *Maku* (Sa), *Kosombo* (Sa), *FongoFongo* (Au), and other types of (unidentified) flies. According to patients, their CL sores often started where a bite had been felt. Two of the frequently mentioned flies were horseflies – the *kawfree* (Sr) cow fly (i.e. *Dichelaceramarginata*) and the *Brokoston* (Sr) (i.e. *Lepiselagacrossipes*) – both of which stem from the family *Tabanidae* (Hudson 1987, 22). In the hinterland, ex-CL patients (of the Medical Mission) and other villagers emphasized in particular the *kupalimofo* (Au) – the 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). Listed in particular were ticks on turtles, white lipped peccaries (*pingos*, Sr) (Husson 1973, 11), collared peccaries (*pakiras*, Sr) (Husson 1973), deer (*dia*, Sr) (Husson 1973, 12), capybaras (*capuwa*, Sr) (Husson 1973, 13), South American Tapir or bush-cow (*tapir*, *bofru*, Sr) (Husson 1973 11), bush rabbits, agoutis (*konkoni*, Sr) (Husson 1973, 13), dogs, and the black curassow (*powisi*, Sr) (Alonso and 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.

Table 1. Aetiological explanations provided by 123 CL patients (multiple responses included).

CL patients’ explanations for cause of illness	Times mentioned (n)
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	3
Some kind of bacterium	1

Despite the fact that biomedical experts in the research team stated that sand flies are very small – almost invisible to the human eye – and that their bites go unnoticed, both current and former CL patients reported actually *feeling* the bite of some types of fly. Many even provided detailed descriptions of the bite, and when and how the sore on their body had started.

Some CL patients explained that their CL sores resulted from an earlier infection of the skin caused by – as they called it – *maskitaworon* (Sr) or *diaworon* (Sr); a disease biomedically known as cutaneous myiasis (parasitic infestation of fly larvae under the skin), which is caused by the human bot fly (*Dermatobia hominis*) (Peters and 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 to take a bath. I think I contracted something *diaworon*-like’ (GD, Godo-olo, November 2009). Another said that ‘People ... say if you’ve got *diaworon*, 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*).

Lianas, leaves, trees, and flowers

A second major explanatory category of illness aetiology, according to CL patients, has its 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 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 *fajatatai* (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 *fajatatai* 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.

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 we discussed the lay theories of lianas, trees, or leaves as being the cause of CL with biomedical colleagues in the ‘Leishmaniasis in Suriname’ project, they commented that sand flies, sitting on lianas, tree barks, and leaves probably bite 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.

Caused by other wounds

At the Dermatology Service, three CL patients explained that their sore had resulted from previous wounds on their body or was due to another form of skin damage. In the hinterland, 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 from 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-nefibanun-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, March 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.

Dirty water, unhygienic bodies, and faeces

Five CL patients at the Dermatology Service thought that dirty water was the cause of their sores. The dirty water theory was held mostly by gold diggers, who work in conditions that cause them to stand and work in muddy water in the gold fields. The majority of the researched population in Godo-olo and Brokopondo Centrum explained that the dirty water in the gold pits 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 (*tjobowatra*, Sr) in small creeks or ponds as being responsible.

Gold diggers, woodcutters, hunters, and others living in the hinterland also believed that unhygienic bodies can cause 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 explanation, especially among Saramacca Maroons, is that human faeces cause CL. Faeces are dirt, associated with bacteria and unhygienic conditions, which, according to the informants, can lead to CL.

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 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, many of his hunter colleagues had 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 [with faeces and urine of the fly] you can get the illness 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 sometimes linked to the supernatural world (as is discussed below).

Supernatural beings

In this study, the majority of the CL patients and people in the hinterland placed the origin of the disease in the natural world. However, not knowing provided room for another explanatory theory, related to the supernatural world or religious beliefs. Six CL patients attributed CL to supernatural agents, and a further six kept open the possibility that CL could also be caused by 'invisible, supernatural matters'.

The explanatory theory that CL sores could be caused by elements beyond the 'natural' was supported by several people 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). Religious beliefs were then turned to more frequently.

In our inquiries about disease causation, both bush spirits (*ampuku* or *apuku*) and snake spirits were mentioned, the former more often than the latter. *Ampukus* are believed to have their homes in trees and termite nests. A 40-year-old gold digger at Godo-olo, explained:

Sometimes you see them [bush spirits, *ampukus*], there are a lot of them here in the bush. If you cross their path or they [cross] 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 Amerindians who fled [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 *Busi Yasi*.

Ex-CL patients working deep in the jungle (gold diggers, woodcutters), and other forest inhabitants often believed that fluids dripping from bush spirits caused CL.

Defecating or urinating in certain areas – for instance, close to certain trees that function as homes for certain bush spirits – can cause CL. Many informants remarked that it is wise to keep to the rules of the bush, especially in terms of asking for permission from the spirits or gods – even if one does not know them – before relieving oneself in the bush. Furthermore, when staying in or visiting the jungle, people should also always leave the area clean.

Especially among current and former CL patients who believed that they had ‘enemies’ in their social environment – i.e. persons who were envious 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 (cf. 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’ (Harold, Dermatology Service, September 2009).

‘Allergies’, contamination, or sexual intercourse

A small group of CL patients, especially Brazilians, thought that CL could be caused by certain food allergies. One Brazilian gold digger said that CL ‘could also be caused by shrimps, if you eat them. The sore is a reaction to it’ (Roberto, Dermatology Service, July 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 Yasi*’ (Raymond, Dermatology Service, December 2009). At Tepu, some villagers thought that eating the infected meat of animals with CL sores on their bodies could cause CL.

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

If you relate [have sex] to a lot of people, Javanese, Creole, and other folks, you will get *kaasa*. I have heard it from the elderly; you should not have sex with different kinds of people.

The idea that sexual intercourse with people from other ethnic groups could cause CL may be associated with the past. With the arrival of Dutch colonizers in the 17th century in Suriname, Indigenous populations suffered significant mortality due to the introduction of infectious diseases with which they had no prior experience and therefore little or no resistance to (Van Praag 1977, 43). This legacy is still felt today upon the appearance or arrival of an outsider in (some of) the hinterland villages.

Not-knowing

The large variety of explanations for CL provided by informants in this study seemed at first dazzling and puzzling. Why this amazing variety of illness explanations? The simple answer is that people do not know exactly how CL is caused. But why this absence of *one single* widely shared explanation for CL? In the introduction, we mentioned that ‘not-knowing’ in this 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 probable cause of the absence of one single illness explanation is related to the biological context of the illness, namely its unnoticed beginning. The sand fly that causes

CL is very small, measuring approximately 3 mm in size, and its bite is hardly felt. This lack of a visible and noticeable start may be one of the explanations of the absence of a single illness cause.

Second, not-knowing is rooted in the general state of neglect in which people in the hinterland have been living for centuries. Lack of higher education in general and lack of CL health education by public health authorities are two important constraints fuelling this state of neglect. Up till now, CL itself was a neglected disease and there have been no nationwide CL health information and education campaigns conducted by public health authorities. 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 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, all contribute to the lack of a single explanation for the cause of CL.

Third, not-knowing reflects the general attitude of hinterland inhabitants about CL in terms of it being a less prioritized disease when compared with other diseases or health conditions such as malaria, HIV/AIDS, snake bites, and stingray stings. CL, as our study shows, is viewed as a curable disease; to some, CL is not even viewed as a disease, but merely a sore that should be healed (Ramdas, van der Geest, and Schallig 2016). Furthermore, the occupational context in which many in the hinterland are engaged and their (often) poor economic position keep them 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 (Ramdas 2012).

Finally, the dazzling variety of illness explanations because of not-knowing the exact cause of disease leads to the use of a similarly dazzling variety of – harsh, and potentially harmful – treatments to cure the disease (Ramdas 2012, 2015). Not-knowing thus is reflected in patients' health seeking behaviour. The explanations are speculations and uncertainties, as is the use of harsh remedies in self-treatment. Explanations as well as behaviour are however logical and understandable from the peoples' point of view.

Conclusion

Returning to Murray Last's concept of not-knowing, our aim in this article is relatively simple: through a close reading of the fieldnotes, we have explored how not-knowing affects the quality and content of ethnography. A large majority of the informants who participated in the study did not have a clear or certain explanation about the origin of CL. And yet – or as a result, we argue – they provided a wide variety of answers. We were at first puzzled as to why, given the fact that CL is a generally well-known and relatively common disease in the hinterland of Suriname, local knowledge did not seem to have a common widely shared explanatory theory about it. What did not-knowing in our study reveal, and what did 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). We, however, draw attention to another aspect of not-knowing: it may lead to a proliferation of explanatory assumptions, unhindered by precise knowledge. In addition, it may also impact treatment seeking. Both knowing and

not-knowing are rooted in the contexts of people's daily lives and are a reflection of historical, socio-cultural, occupational, educational, biological, environmental, and public health-related conditions.

Through daily experience, by observation, and through visits to biomedical health clinics, people develop 'theories' about the origin(s) of CL, which – if asked – they present (or produce) to a visiting researcher. Our research presents convincing ethnographic evidence that the absence of knowledge can indeed lead to a plethora of assumptions, often presented as knowledge. Lay understandings of illness and aetiological explanations should, however, remain topics of interest in the social and cultural study of health, because they reveal the complex processes of health seeking. They also provide valuable insights for health policy-makers, helping them to understand the quantity and complexity of barriers in the fight against illness, such as shame and stigmatization (Ramdas, van der Geest, and Schallig 2016). Public health authorities should be aware of such barriers and take them into consideration when designing health education and treatment and prevention programmes. For this same reason, the answer 'Don't know' should be taken seriously as an invitation to further exploration.

Ethical approval

Formal permission to carry out the study was obtained from Suriname's Medical Ethical Commission and the heads of the selected villages. All names of respondents have been anonymized. Formal approval by authorities does not however guarantee high ethical fieldwork. As an anonymous reviewer of this article wrote, '... ethical clearance is not the same thing as serious engagement with the ethical implications of research practice, findings and dissemination.' The researcher's positionality in Suriname's unequal and racially divided society, for example, could have intimidated her interlocutors. As mentioned before, the conversations with people in the various communities in the hinterland were open, respectful and relaxed. The fact that personal and intimate information was willingly shared bears this out. Dissemination, finally, has been a crucial concern throughout the entire research. During the research there have been several meetings and workshops with Surinamese colleagues for comments and advice. The final research findings, furthermore, were presented to relevant counterparts (amongst whom representatives of hinterland communities), academic colleagues and policy makers in the Ministry of Health. After the finalization of the project, a national press conference was held in which journalists and radio news reporters (reporting on national and local levels) were given all the major outcomes of the research. These outcomes were published in the most prominent local newspaper (*De Ware Tijd*) and through main radio stations. In short: the Surinamese people (including hinterland communities) were informed of the results. It is our intention to also produce a 'popular' summary of the whole research in a Dutch and Sranan leaflet.

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