



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



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ARTICLE INFO

Article history:

Received 19 May 2015

Received in revised form

29 December 2015

Accepted 30 December 2015

Available online 2 January 2016

Keywords:

Suriname

Stigma

Cutaneous leishmaniasis

Ethnography

Illness experience

Skin disease

South America

ABSTRACT

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

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

Goffman (1963:167)

1. Introduction

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

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

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

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

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

1.1. Cutaneous leishmaniasis and stigma globally

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

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

1.2. Types of stigma

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

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

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

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

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

2. Research program

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

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

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

3. Methods

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

At the Dermatology Service, a total of 205 clinically diagnosed

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