

Stigma, deforming metaphors and patients' moral experience of multibacillary leprosy in Sobral, Ceará State, Brazil

Estigma, metáforas deformadoras e experiência moral de pacientes com hanseníase multibacilar em Sobral, Ceará, Brasil

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Abstract

In response to the call for a new Science of Stigma, this anthropological study investigates the moral experience of patients diagnosed with severe multibacillary leprosy. From 2003 to 2006, fieldwork was conducted in the so-called "United-States-of-Sobral", in Ceará State, Northeast Brazil. Sobral is highly endemic for leprosy, despite intensified eradication efforts and a 30% increase in primary care coverage since 1999. Of 329 active leprosy cases at two public clinics, 279 multibacillary patients were identified and six information-rich cases selected for in-depth ethnographic analysis, utilizing illness narratives, key-informant interviews, home visits, participant-observation of clinical consultations and semi-structured interviews with physicians. A "contextualized semantic interpretation" revealed four leprosy metaphors: a repulsive rat's disease, a racist skin rash, a biblical curse and lethal leukemia. Far from value-free pathology, the disease is imbued with moral significance. Patients' multivocalic illness constructions contest physicians' disease discourse. "Skin Spot Day" discriminates more than educates. Patients' "non-compliance" with effective multi-drug therapy is due to demoralizing stigma more than a rejection of care. "Social leprosy" in Northeast Brazil deforms patients' moral reputations and personal dignity.

Leprosy; Stereotyping; Metaphor

New science of stigma

In a 2006 *The Lancet* article, Keusch et al.¹ call for a "new science of stigma". They set an ambitious global research agenda: building a conceptual framework and an evidence base for interventions to reduce discrimination and social exclusion. Biomedical and behavioral scientists alike are invited to contribute. For Castro & Farmer², psychological factors are insufficient to explain stigma. Structural violence caused by macro-sociological forces – poverty, class disparity, illiteracy, political corruption, racism, sexism, inequitable allocation of health resources and hegemonic doctor-patient relationships – generate social inequities and sculpt stigma experiences. Decontextualized explanations blame victims for pejorative self-images³. Kleinman⁴ argues that stigma is best comprehended as moral experience, configured within a local world amidst danger and uncertainty. What is moral, he says, embodies our sense of right and wrong yet "to be understood requires ethical scrutiny from the outside and from those on the inside who challenge accepted local values"⁴ (p. 2).

Throughout history, leprosy (Hansen's disease) has been shrouded with stigma, despite being one of the least contagious human transmissible diseases⁵. Caused by a bacillus bacterium, *Mycobacterium leprae*, it is a dreaded disease, provoking peripheral nerve damage, skin sores, progressive debilitation and gross disfigurement.

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Known as the “illness of untouchability” in the ancient Indian Caraka Samhita medical text, it is attributed to moral transgressions: “untruthfulness”, “sinful acts”, and “blasphemy against the gods”⁶. In Pakistan, leprosy-affected “sinners” are abandoned by spouses, divorced, expelled from villages, left to beg on city streets and confined to animal quarters⁵. Even the 1981 introduction multi-drug therapy (Dapsone, Clofazimine and Rifampicin) – highly effective against both paucibacillary and multibacillary disease forms – has not eradicated leprosy’s stigma^{5,6}. As with infectious cholera⁷, popular resistance to control is subliminal, albeit strong^{5,6}. Some 30% of Pakistani patients dropped-out of multi-drug therapy; 54% denied ever having leprosy or proclaimed themselves “cured”, prompting Mull et al.⁵ (p. 805) to declare that: “*clearly ‘non-compliance’ relates to the stigma attached to ‘lepers’, together with the common idea that equates leprosy with deformities*”.

Brazil – second behind India in newly detected cases – reports a high prevalence of Hansen’s disease (4.6/10,000 inhabitants in 2001), climbing to 6.13/10,000 inhabitants in the Northeast⁸. While poverty, inequality, urbanization, low educational level and food shortage are known risk factors in Ceará State⁹, stigma’s influence is unknown. Qualitatively, however, the Portuguese word *lepra* (leprosy) is synonymous with grotesque deformities. The derogatory term *leproso* (leper) labels anyone ostracized by society. Even thirty years after its official name change to stigma-free Hansen’s disease (*hanseníase*), *lepra*’s pejorative connotation persists¹⁰. Queiroz & Puntel¹¹ report that 50% of *M. leprae*-affected in Campinas, São Paulo, Brazil, distinguish between the two terms, considering them separate diseases or different stages of the same disease – *lepra* the most severe. Depression, sexual impotency and suicidal thoughts are reported and dermatological symptoms are disguised as “sun” or “pregnancy spots”; informants avoid kissing children and spouses and separate their utensils^{11,12}. In São Paulo, women with leprosy, when compared with men, are more often single, separated or divorced, live with family and children rather than husbands or partners, reside at the same address for a shorter duration, work in domestic occupations without benefits, have less education and attend religious cults¹³; 37.1% reject multi-drug therapy. Leprosy, by all accounts, is a demoralizing disease.

Social theories of stigmatization

Social scientists have investigated stigma since the 1960s, yet disagree on theoretical approaches. Early classics emphasized the origin of stigma as an intersubjective, psychological process. Goffman¹⁴ postulated that stigma occurs when the construction of categories is linked to stereotyped beliefs that label and distinguish people as different or unacceptable. They either resist stigmatization with cover-up strategies or internalize a negative self-perception, “spoiling” identities and reputations. British anthropologist Douglas¹⁵ argued that stigma is symbolically constructed when personal identities are associated metaphorically with “impure” images – raising doubts about his/her integrity, honesty, sexual purity, etc. – “polluting” the moral essence of personhood. In Hong Kong, patients in treatment for schizophrenia were reportedly stigmatized by structural discrimination – inequitable health policy, resource allocation and service organization which privilege service providers’ control over users¹⁶. In a Brazilian shantytown, poverty, class disparity, police violence, and militaristic interventions shape and signify cholera stigma for infected residents⁷.

Studies of leprosy stigma have continued to target cognitive processes of infected individuals^{17,18}. Exceptionally, Opala & Boillot¹⁹ report that among the Limba of Sierra Leone, Africa, stigma varies according to social context and access to effective therapy. Stigma is severest and unresponsive to medications when onlookers view the “leper” as *morally corrupt* and fear *both* the individual and the disease¹⁹. The Limba’s various interpretations of leprosy stigma, within a single culture, suggests it is multivocalic²⁰. Indeed, stigma is complex and, we suspect, at the heart of leprosy in Northeast Brazil. How structural forces shape its moral experience in this poor, tropical setting is unclear. Through patients’ voices, we aim to reveal the semantic network²⁰ of *lepra* in an endemic community.

Methods

Status-conscious Sobral, Ceará, Brazil

Sobral, a town of approximately 200,000 inhabitants situated in the desert backlands (*sertão*) of Ceará State in Northeast Brazil, serves as an excellent locale for the investigation of stigma because of its rigid social structure, high prevalence of Hansen’s disease, model Family Health Program (FHP), and political mandate to eradicate the disease. Located 250km from Fortaleza

(the state capital with a population of nearly 2.5 million), the remote town is jokingly nicknamed "The-United-States-of-Sobral", owing to its residents' audacious, First World "triumphant posture" (*sobralidade triunfante*)²¹. Not without reason. The town proudly traces its nobility to Portugal's King, who christened it "The Distinct Royal Village of Sobral" – a settlement of European nobility on Brazilian soil²¹. Reminders of its regal past adorn the town: the aristocratic symbols decorating the city's flag, a replica of France's *Arc de Triomphe*, and scores of ornate Catholic churches. However life, today, is harder and hungrier: 54.8% of adults are unemployed and 79% of household heads earn less than US\$ 166/month, falling to less than US\$ 83/month on the city's outskirts²². Traditional families – the ruling elite – dominate local politics. Armed landowners, known as *coronels*, impose "order" through threats and violence. A Second District Judge was condemned in 2005 to 15 years in prison for murdering an unarmed night watchman at Sobral's Lagoa Supermarket – a horrific crime captured on film by security cameras²³. Wives suffer domestic violence, an epidemic in Ceará's interior, where 118 women were murdered in 2005 alone, most by intimate partners²⁴. In this authoritative, top-heavy, and hierarchically-structured system, ordinary citizens seek status and upward class mobility emulating First World trends. Imported motorcycles race through cobblestone streets. Modern Internet cafés operate in renovated colonial buildings. And teenage girls promenade in historic plazas wearing cheap copies of exclusive designer fashions.

Sobral classifies²⁵ as a "very high endemic" area for Hansen's disease with a 2002 prevalence rate of 12.7 cases per 10,000 inhabitants, of which 85% represent the severely deforming multibacillary form. And leprosy rates are rising: from 1997 to 2002, the detection rate increased from 7.6/10,000 inhabitants to 11.4/10,000 inhabitants and the prevalence rate increased from 8.9/10,000 inhabitants to 12.7/10,000 inhabitants²⁵. In 2002 alone, 205 active and 184 new cases were registered²⁵, despite a 30% increase in primary health care coverage²⁵ and the implementation of a Special Task Force for the Elimination of Leprosy. Prior to 1997, health care was provided at social security clinics, located in public elementary schools²²; referrals from Sobral, and 25 surrounding counties, were sent to a single, under-staffed clinic. In 1999, services were decentralized to family health units and a dermatological reference service was opened²². The community was mobilized by organizing a self-help group (MORHAN – *Movimento de Reintegração de Pessoas Atingidas pela Hanseníase*),

training traditional healers and sex workers to diagnose and refer suspected cases, and publicly awarding "certificates of cure" to patients adhering to treatment. Regardless, the notion that disease is fundamentally a biological phenomenon²⁰, maintains a stronghold amongst health professionals in Sobral.

Contextualized semantic interpretation

From March 2003 to January 2006, this anthropological study explored the subjective dimensions of Hansen's disease. Of the 329 active cases of Hansen's disease being treated at two public clinics providing services in Sobral (FHP and County's Public Health Dermatology Referral Unit) in June 2003, 279 patients with confirmed multibacillary Hansen's disease were identified. After reviewing cases, a key-informant (ex-patient, MORHAN organizer) was invited to select six information-rich cases²⁶ known by the community activist to present either: (1) marked social suffering or (2) stigmatizing experiences for our in-depth ethnographic investigation. All six patients' illness narratives²⁷ were elicited during clinic visits, yielding a dense description²⁸ of leprosy discourse and experience. Seven follow-up home visits (one repeat) were conducted; relevant comments by patients' family members, neighbors, community health workers and healers were also recorded. Patients were observed during a follow-up consult with their attending physician; 28 additional consultations of these doctors with other leprosy patients were made, totaling 34 observations at the two health centers. A semi-structured interview, with four open-ended questions about leprosy treatment, was conducted with the six physicians. Other key informants questioned included two nurses, three health practitioners, two dermatologists, clinic staff, authorities from the Ministry of Health and members of MORHAN.

Interviews were tape-recorded and transcribed verbatim utilizing a word processing computer program. After repeated readings of the transcriptions, 36 topics emerged, condensed into eight themes: (1) denial of leprosy, (2) social suffering, (3) physical and social disabilities, (4) everyday coping strategies, (5) lay care practices, (6) clinical approaches, (7) patient-treatment approaches and (8) health education interventions. We sought inspiration in Bibeau & Corin's²⁹ "contextualized semantic interpretation" to link individual experience with systems of significance and to actions taken, or not, within existing structural constraints. Qualitative data analysis aimed to make explicit the multiple interpretive frames and discourses (the "heteroglossia"²⁰) of leprosy,

including contested interpretations by medical professionals. Core cultural symbols and illness metaphors were interpreted against a backdrop of current events published in Brazilian newspapers, magazines (*Diário do Nordeste*, *O Povo*, *Veja*) and drug advertisements and announced at public events and political rallies. The final text prioritizes the popular word *lepra* (leprosy) over the technical term, Hansen's disease, reflecting informants' discourse. Research adheres to the Brazilian Council of Bioethics in Health Research Involving Human Subjects *Resolution n.º. 196/96*. All informants' names are fictitious.

Results

Stigmatizing leprosy metaphors

Health professionals' hegemonic, technical discourse about Hansen's disease is often absent, contested or even subverted by Cearense (inhabitants of the state of Ceará) patients' narratives about *lepra*. Popular illness stories are loaded with cultural significance and embedded in the local moral world⁴ and socio-political context of Northeast Brazil. In the individuality of informants' voices, and during dialogues with spouses, relatives, neighbors, colleagues, community health workers and medical professionals, four leprosy-related metaphors emerged. The first two metaphors – the rat's disease and a racist skin rash – we interpret with deeper insight. The second two – a Biblical punishment and lethal leukemia – are punctuated with spaces and blanks in meaning. It is clear, however, that all four metaphoric associations are pejorative, degrading and humiliating, capable of disfiguring not only patients' limbs but their moral reputations.

Roberto: repulsive rat's disease

Leprosy is interpreted as the "rat's disease", as leptospirosis is popularly called. The semantic link between a filthy rat and a patient's reputation became apparent from Roberto's narrative.

Roberto was 22-years-old when diagnosed with Hansen's disease, never suspecting that it was leprosy: "*I wasn't afraid to tell anyone I was a Hansen's disease carrier (...) I didn't know it carried, well, such a heavy weight of prejudice (...) since I didn't pay much attention to what the doctor said!*". Eating lunch with co-workers, Roberto casually downed his pills with a glass of water "*in front of everyone in the world*". But when he naively said the medication was to treat his Hansen's disease, everyone backed-off. Startled, one bystander yelled out: "*Hey, stay clear folks*

(...) stand back (...) because this rat's disease is contagious!". Roberto stood frozen in silence and shame. Later he commented: "*It was at that moment I realized that, in reality, Hansen's disease is called (...) prejudice!*".

Before this shameful cafeteria scene, Roberto believed leprosy was an innocuous, curable disease. His doctor reinforced this perception at diagnosis: "*Roberto, from this day on, we are going to be friends. I'm going to see you cured. Don't worry (...) you needn't say anything about this to anyone either. This is a simple disease*". This "simple disease", as it turned out, was rat infested! Hansen's disease was called the *doença de rato* (rat's disease), we suspect, because of the phonetic proximity of Portuguese terms *lepra* (leprosy) and *leptospirose* pronounced popularly as *lepra-spirose*. Through a semantic slip, the entirely distinct infectious disease – leptospirosis – caused by the microorganism *Leptospira interrogans* and transmitted by the common household rat is fused (and confused) with *lepra* (leprosy) and, consequently, with Hansen's disease. Transfiguring *lepto-spirose* into *lepra-spirose* instantly magnifies the microscopic *M. leprae* into a life-size rat.

In Northeast Brazil, the rat's reputation is morally suspect. Brazilians personify the rat – the *guabiru* or *rabo-de-couro* (leather tail), as an unsavory, garbage-eating rodent. For Claudio, 67, rats are synonymous with corrupt politicians: "*The biggest thief of all is the rat, the guabiru, the rabo-de-couro! (...) Doesn't he sneak into your house and steal everything (...) the cheese? The same is true with corrupt politicians. Just like the guabiru, they steal half the public's money (...) stuff it into their own pockets (...) and nobody catches them because of their impunity!*".

Newspaper headlines on December 17, 2003³⁰ read "*Saddam Hussein Captured in Iraq Inside a Hole*". The sensationalist article described the US Army-backed search and capture of Iraq's de-throned leader, Saddam Hussain. "*He was caught like a rat!*" exclaimed the military commander. A humiliating photograph of a disheveled, long-haired and bearded Saddam and a diagram of his "underground" hide-a-way – a rodent's burrow – accompanied the report. A cover photo on *Veja* magazine³¹ dated May 25, 2005 depicted a corrupt Brazilian politician personified as a rat (Figure 1). The man-size, hairy rodent is dressed in a business suit and tie, sports a shiny gold ring on his little finger and is smoking a large cigar – symbols of money, power and prestige. The caption in red capitals reads: "*THE CORRUPT ONES*". The suggestive subtitle adds: "*We're Losing the War Against this Plague*". The news-breaking story³¹ uncovers the latest political corruption scandal

Figure 1

Corrupt Brazilian politician personified as a rat. Cover photo on *Veja* magazine dated May 25, 2005.



"THE CORRUPT ONES! We're losing the war against this plague".

to rock Brazil. Leaders of the President's ruling Workers' Party (PT) are accused of embezzling large sums of government money in a "monthly allowance" (*mensalão*) scam. A follow-up *Veja* cover on August 15, 2006³², reprinted the rat-as-corrupt-politician photo denouncing another corruption scandal. The caption reads: "12 Ways to Stop Politicians from Stealing So Much". The photo also depicts an oversized, wooden rat-trap loaded with *bate* – a seductive hunk of cheese molded in an upside-down, half-dome and pillar (a replica of the Brazilian National Congressional Building) – the seat of political power, money and influence. The article³² (p. 43) reads: "The National Congress reached rock-bottom with the worst moral crisis in its 180 year history. After the scandalous episodes of the Worker's Party's (PT's) 'monthly allowance' and Serverino's 'little allowance' (another political scandal), federal Deputies and Senators were caught-up in the bloodsuckers' (Sanguessugas) mafia – a chain of direct assaults on public funds, reaching startling dimensions as each day passes". The text reports on the "shocking degree of corruption" among Brazil's highest level government officials and suggests ways to

"trap the corrupt ones!" *Veja's*³³ cover photo of August 15, 2007 depicts the rat-as-corrupt-politician behind prison bars, symbolizing "the plague of impunity". Semantic webs of meaning couple the rat's immoral image with the rat's disease, infectious *lepto-spirose*, *lepra-spirose* and leprosy. Through metaphoric associations, innocent *M. leprae*-infected persons become thieves, who deserve to be "trapped" by prejudice.

Marcos: racist skin rash

Leprosy is also perceived as a racist skin rash. Clofazimine, a reddish-brown, microcrystalline powder, is one of three drugs used in the powerful multi-drug therapy. While Clofazimine exerts a slow bacterial effect on *M. leprae*, 77.8% of 514 treated patients experienced red and dark skin pigmentation of varying intensity³⁴; reddish coloration of sweat, urine and tears also occurs. Although the drug's instructional insert downplays skin discoloration, it warns that adverse effect may last for months, even years, after cessation of therapy, cause depression and confirms two associated suicides (NOVARTIS. Lamprene (clofazimine) soft gelatin capsules: prescribing information. <http://www.pharma.us.novartis.com/product/pi/pdf/lamprene.pdf>, accessed on 02/Feb/2008). Even the World Health Organization (WHO)³⁵ declares that discoloration is not a serious problem, except for being "cosmetically unacceptable to some patients".

Nazaré, a 38-year-old domestic maid, contests these claims, reporting that skin-darkening Clofazimine contributes to color prejudice: "My uncle was 'moreno claro' [a person with lighter, bronzed-colored skin tones] before he started taking those pills [Clofazimine] (...) but afterwards he turned that dark (...) dark (...) dark (...) almost that purple-black color. What an awful thing, God forbid!". Racial issues relating to the use of Clofazimine surfaced during this clinical conversation between Marcos, 54, and his physician:

Doctor: "This is the medication you must take (...) both these black and white pills".

Marcos: "Am I going to turn dark-skinned with this treatment? What is this business anyway?".

Doctor: "No, the skin darkening is just temporary. Afterwards, with time, it will get better (...) fade away. There are ways to minimize this".

Marcos: "Doc, if it's going to mess up my body, don't prescribe these pills, no! I've heard that there's two kinds of pills – just the little white one alone (...) and the little white pill together with the little black one (...) don't give me that one, no way! I don't want to become a 'nigger' [negão], no way! Before, I was only a leper. But now, I'm going to be a nigger leper [leproso negão]!".

Ingesting this “dark skin pill” transforms a bronzed-colored *moreno* into a dark-skinned “*negão*”, (sometimes) loosely translated as “nigger”. Drug-induced skin coloration binds with pre-existing color prejudice to stigmatize patients. Although the pigmentation is usually reversible after 9-12 months, it is sufficient time to suffer racism. Patients beg doctors not to prescribe the “little black pills” (Clofazimine) and skip over the rows of dark pills on the multi-drug aluminum pill card. They prefer taking only the “little white ones”. For Marcos, becoming a “nigger leper” is doubly discriminating. In Brazil, where ethnic origins (Afro-Brazilian) become confused with “race” and “race” becomes identified as phenotype, racism takes on a distinctive characteristic: it is tied to infinite shades of skin color. Brazilian anthropologist Ribeiro³⁶ (p. 225) clarifies: “... on this scale, the negro (black) is the negro retinto (‘deep’ black), the mulatto is the pardo (half white), and if his skin is a little bit lighter, he can already be incorporated into the white community”.

The persistence of institutionalized racist attitudes and policies in Brazil, however, defies the popular myth that Brazilians of diverse colors and ethnicities live harmoniously as one people³⁶. The truth is that the life-expectancy of Afro-Brazilians is lower than that of their white compatriots³⁷, and indigenous populations suffer the poorest health indicators in the country³⁸, amongst other inequities. Lighter skin shades, however, generally confer higher social rank; while darker epidermis denotes lower status. In status-conscious Sobral, light skin indicates noble European heritage; darker tones are associated with (forcibly) enslaved Tupi-Guarani and African people, treated, historically, as inferior²¹. Leprosy patients, like Marcos, skip taking Clofazimine pills to avoid color prejudice and social enslavement.

Marta: Biblical curse

Since Biblical times, leprosy has signified more than disease. It is a “metaphor for evil” associated with notions of falling body parts, sin, transgression of social norms, and banishment³⁹. Israelites designated the person with “malignant sores” as *tsara’ath*, a Hebrew word for a state of religious impurity, translated into Greek as “leprosy”³⁹. Over time, *lepra* came to stand for all social or moral wrongs of society, including sexual impropriety. Marta, a 40 year old, Catholic woman “without family”, never married. She admits to causal sex with numerous men – a source of gossip among neighbors. Undergoing her sixth dose of multi-drug therapy and suffering reac-

tions, Marta recalls her colleagues’ social shunning and her attempted suicide: “I was diagnosed during a screening at my work (...) I almost died (...) I never thought I’d have this disease! (...) The doctor said it was Hansen’s disease (...) but I heard his nurse say ‘leprosy!’” (grifo nosso). Stunned she was “a leper”, Marta felt as if her “head was tied in knots!”. She worried incessantly: “Isn’t leprosy that ancient Biblical curse (...) where your fingers fall off?”. Colleagues pester her: “What’s-your-name, do you really have leprosy?”. A co-worker separated his cup from Marta’s. “He was trying to say something to me!”. Distraught, she “took a medicine to die!”. Marta slowly “grew to accept that I have leprosy”. She avoids saying “leprosy”, affirming: “What I have is Hansen’s disease!”. Despite supportive friends, she feels alone and depressed without a husband or children. On weekends, Marta drowns her sorrows by drinking.

Marta’s painful stigma is amplified by her religious beliefs and certainty that Hansen’s disease is leprosy. She read us a Bible⁴⁰ verse about Satan inflicting a curse of ugly sores: “So Satan went out from the presence of the Lord, and struck Job with painful sores from the sole of his foot to the crown of his head”⁴⁰ (Job 2:7). Marta then turned to the Old Testament Book of Leviticus and “the law of the leperous plague”⁴⁰ (Lev 13:2:59): “The priest shall examine the sore on the skin of the body (...) if it is a leprous sore, he shall pronounce the man unclean...his clothes shall be torn and his head bare (...) shall cry out, ‘Unclean, unclean!’ He shall dwell alone (...) outside the camp (...) you shall burn with fire that in which is the plague”⁴⁰ (Lev 13:1-3, 45, 57). Deeply ashamed, Marta isolates herself and drinks excessively, preferring to speak of the less morally-incriminating Hansen’s disease.

Joel: lethal leukemia

The final metaphoric association – leprosy as lethal leukemia – is speculative but helps explain Joel’s vehement denial of *hansemia* – a curious, “made-up” word we frequently heard in the clinic.

Joel, a 21-years-old laborer, is an *M. leprae* carrier who abandoned treatment, as did his uncle and older brother, Elias. Joel believes “nothing is wrong” with him: “I’m as good as can be (...) only these white skin patches [pano branco]”. Ten years earlier, “the doctor said I had this disease (...) hansemia” and prescribed pills, but Joel refused to take them: “They made me sicker and laid me up (...) unable to work”. He dismissed symptoms – white spots, loss of eyebrow hair, saddle nose, flaky, dry skin, claw hands, and scars on the hands, legs and feet – as childhood problems. “See this thing on my forehead and this here on my nose? I’ve had these since infancy! This scar on

my left hand is a burn (...) I burned my hand and it stayed like this!". And he blamed the skin spots on "sun exposure", contact with "hospital filth" and "eating very salty foods". While his brother – "totally done in by hansemia" – quit work, abandoned wedding plans and contemplated "doing a stupid thing [committing suicide]", Joel "enjoys life to its fullest!".

For years, Joel has disguised his white spots as *pano branco* ("white patch"), the innocuous fungal skin infection, Pityriasis Versicolor. To escape his *hansemia* he struggles to lead a normal life. From dawn to dusk, this sturdy man shovels and hauls heavy buckets of wet sand from the banks of the Acaraú River in Ceará State. His young wife admires Joel's vitality, strength and endurance, bragging that he is "a good provider (...) a family man". In his neighborhood, laboring hard to support one's family is a core masculine value – at the heart of being *macho* (manly) in Ceará's rugged *sertão*.

Joel abandoned care after a nurse visited his workplace, scolding him in front of co-workers for not "admitting his disease" or "taking his medication". Although vowing to "help when he is too crippled to work" she embarrassed and stigmatized him as a "useless creature". While the word *hansemia* is inexistent in formal Portuguese, in popular discourse the first syllable of *hans-eniase* (Hansen's disease) is grafted onto the ending of *leuc-emia* (*leukemia*), forming the hybrid: *hansemia*. The grammatical merger symbolically transforms treatable Hansen's disease into a lethal "blood disease" – leukemia. Similarities between the two distinct diseases are blurred together. Hansen's disease's "malignant sores", "dormant white spots", "falling fingers" and "*poliquemioterapia*" (multi-drug therapy) are confused with cancer's "malignant tumors", "white blood" (Greek root of the word, leukemia), "hair-falling-out" and "*quimioterapia*", respectively. As a dreaded, cancer-like disease, *hansemia* radically contests physicians' discourse that "Hansen's disease has a cure!". Terrified patients refuse to say the name of "that disease": cancer. Others complain that *hansemia* is "turning my blood into water (...) eating me up from the inside!". By rejecting the grave "blood cancer" diagnosis and fatal prognosis ("death sentence"), Joel continues to work, provide for his family and safeguard his reputation as a man.

"Skin Spot Day": educate or discriminate?

After the Brazilian Ministry of Health transformed the feared *lepra* into curable Hansen's disease, the priority became early disease detection by heightening public awareness of symp-

oms. Sobral's health workers distributed pamphlets teaching low-literacy residents how to distinguish simple dermatitis – rashes, irritations, pussy sores, nodules and infiltrations – from white, dormant leprosy lesions. Color photos of the two types of skin lesions were pictured side-by-side for easy comparison. "Skin Spot Day" (*Dia da Mancha*) was designated as a monthly massive-screening event to be held at Sobral's six family health clinics. Medical staff aimed to examine large numbers of autonomous, walk-in residents quickly and free-of-charge. Suspected cases of Hansen's disease would then be referred for intensive medical follow-up. Our observation of "Skin Spot Day" held on May 14, 2004, however, revealed that the clinic nurse's role of screening the general population for disease had been transformed into a stigmatizing event, as this field note excerpt illustrates:

"At 7:30 am, a line formed outside the clinic for spot screening scheduled to begin at 8:00 am. A poster on the wall read: 'Dormant spots can be Hansen's disease (...) Hansen's disease has a cure'. By 9:30a.m. no spots had been examined. When the nurse finally arrived, seven weary individuals – including two of our informants – were ushered into a large room. Rather than efficiently examining skin spots as I had expected, the nurse greeted and embraced each 'autonomous' person by name, clearly indicating she knew them personally. The 'residents' quickly fell out of line, taking their customary seats in a circle of pre-arranged chairs. The nurse addressed the group announcing that the aim of this 'monthly meeting' was 'to hear the patient', 'clarify his doubts about the disease and treatment', 'to avoid abandonment of therapy' and 'to better integrate patients with professionals'".

Unwittingly, the nurse (and clinic staff) had transformed the widely advertised "Skin Spot Day" into a highly-visible stigma fair. On the broadcasted day, May 14, any neighbor could gaze out of their front window and see seven "spotted lepers" lined-up outside the clinic. When she replaced the screening of Sobral's 200,000 nameless residents with a small, personalized, self-care gathering, it became easy for anyone to identify the town's "lepers", tainting their reputations. Locals with suspicious white spots, it was rumored, avoided the clinic on "Skin Spot Day" so as *not* to be mistaken for a *leper*. Discrimination, not education, marked this special day.

Discussion

This anthropological interpretation uncovers experiences of stigma narrated by patients

with severely disfiguring multibacillary Hansen's disease in Northeast Brazil. Through a litany of culturally-constructed illness metaphors – from sleazy rats to lethal leukemia – they voice stories of fears, rejection and indignation. These shared moral experiences of *lepra* are so troubling, as Kleinman⁴ says, precisely because what looks so unjust from patients' perspectives looks different from the vantage point of collaborators or perpetrators. Leprosy's webs of significance are embedded in our patients' symbolic universe and local moral world – the desert backlands of Sobral.

Two studies by Claro¹² and Oliveira et al.¹⁰ in southern, industrialized Rio de Janeiro, clarify considerably the human dimensions of Hansen's disease. Limitations in their interpretative approaches, however, truncate their full explanatory power. Claro's¹² analysis of 45 patients' illness representations adheres to a biomedical framing of the disease (cause, treatment, adhesion), distorting subjective constructions. Oliveira's et al.¹⁰ free-word-association test of 800 housewives, speculates that “the word ‘rat’ could be related to leprosy”¹⁰ (p. 44) but does not explore the association further. By penetrating into the rich semantic world²⁰ of *M. leprae*-affected patients in Brazil's Northeast, this study makes an original contribution to the new science of stigma.

Bibeau & Corins²⁹ “contextualized semantic interpretation” was a fortunate methodological choice. It challenged us to cross-cut symbolic, behavioral, social, political and economic dimensions of patients' lifeworlds. Interpreting the meaning of the “rat's disease” demanded considering the *guabiru's* corrupt image. Marta's shame and suicide attempt only made sense in light of her sexual history and the Bible's Leprosy Law. Embedding semantic analysis in the macro-sociological context illuminates cultural interpretations and avoids victim-blaming³. What matters in this critical analysis, is situating Hansen's disease squarely *within* “The-United-States-of-Sobral” – a poor, but pretentious, town with a distinctive nobel heritage and haughty First World reputation. This is the local moral world of crippling, *endemic* leprosy stigma.

Findings not only corroborate Mull et al.'s⁵ conclusion of “‘non-compliance’ to the stigma attached to ‘lepers’...”⁵ (p. 805), it makes explicit the metaphoric associations linking Clofazimine “non-adherence” to dark pills, hyperpigmentation, Brazilian race/ethnic classification and color prejudice. Although the drug's adverse effect is temporary, and downplayed by drug manufacturers (NOVARTIS. Lamprene (clofazimine) soft gelatin capsules: prescribing information. <http://www.pharma.us.novartis.com/product/pi/pdf/lamprene.pdf>, accessed on 02/Feb/2008), it provokes patients' fears of color discrimination. Meanwhile, the recent, dramatic case of argyria⁴¹ in an American man, 57 – irrevocably turning his fair skin dark, blue-purple after ingesting colloidal silver, a popular cure-all – has stirred attention⁴². Marcos, like the “blue man”, suffers stigma, isolation and social shunning.

In “The-United-States-of-Sobral”, institutionalized discrimination¹⁶ occurs when clinic staff publicly scrutinize identifiable patients' skin spots. While health professionals, elsewhere, reportedly harass, spread rumors, and refuse to treat leprosy patients⁴³, they have been shown to reduce discrimination⁴⁴ by increasing disease-related knowledge⁶, engaging community members⁶, improving access to therapy⁵, providing group counseling¹⁷, adopting a culture-sensitive paradigm³⁹, and reducing poverty⁴⁵.

Our ethnographic evidence confirms that stigmatization is a deeply moral experience⁴, expressed in a multiplicity of voices, sculpted by context and contested by hegemonic medical discourse and practice. A critical evaluation of Sobral's spot-detection-day demonstrates that improved access to services, alone, does not reduce leprosy stigma. What really matters is providing quality, non-accusatory care which empowers citizens and promotes human dignity.

Our ethnographic evidence confirms that stigmatization is a deeply moral experience⁴, expressed in a multiplicity of voices, sculpted by context and contested by hegemonic medical discourse and practice. A critical evaluation of Sobral's spot-detection-day demonstrates that improved access to services, alone, does not reduce leprosy stigma. What really matters is providing quality, non-accusatory care which empowers citizens and promotes human dignity.

Conclusions

Stigma: social leprosy of modern times

“We're all lepers!” shouts ex-patient, Jeremias, at a MOHAN rally. His protest cry is a potent reminder that leprosy stigma wounds moral reputations as much as microorganisms destroy connective tissue. *Lepra* is interpreted in culturally-contextualized ways, expressed through illness metaphors, and morally experienced in infinite ways. “Multiple-stigma” is resistant to standardized eradication efforts. Eliminating prejudice, re-moralizing affected-persons, and empowering patients to defend their rights is as critical as lowering *M. leprae* counts in their bloodstream.

Social injustice is not restricted to leprosy or to Northeast Brazil. It emerges when structural constraints channel the way we organize society, establish patterns of interaction and rank, value, and esteem one individual over another. Anyone suffering from stigma – the plague of modernity – is crippled by a kind of “social leprosy”, robbing them of their human potential. All forms of discrimination must be denounced if social leprosy is to be eradicated.

Resumo

No intuito de criar uma *Ciência do Estigma*, este estudo antropológico investiga a experiência moral de pacientes diagnosticados com a hanseníase multibacilar. De 2003 a 2006, a pesquisa foi conduzida nos "Estados Unidos do Sobral", Estado do Ceará, Brasil, altamente endêmico para hanseníase apesar da intensificação de erradicação e o aumento de 30% na cobertura de saúde desde 1999. Entre 329 casos de hanseníase, 279 foram identificados como multibacilar e seis casos "ricos em informação" foram selecionados para aprofundamento. Narrativas da enfermidade, entrevistas etnográficas, visitas domiciliares, observação-participante de consultas clínicas e entrevistas semi-estruturadas com médicos foram realizadas. A "interpretação semântica contextualizada" revelou quatro metáforas de "lepra" – uma repulsiva doença de rato, uma infecção de pele com conotações racistas, uma praga bíblica, e uma leucemia letal. Essas metáforas "multivocálicas" contestam o discurso biomédico. A lepra é repleta de significados morais. O "Dia da Mancha" discrimina mais do que educa. A falta de aderência à eficaz poliquimioterapia é causada mais pelo estigma desmoralizante do que pela rejeição ao tratamento em si. A "lepra social" no nordeste brasileiro deforma a reputação moral e a dignidade do paciente.

Hanseníase; Estereotipagem; Metáfora

Contributors

M. K. Nations participated in the research design, directed the data analysis and interpretation and wrote the article. G. V. Lira designed the research, collected data, participated in data analysis and interpretation and revised the text. A. M. F. Catrib designed the research and participated in the data analysis.

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