Déjà Vu: Leprosy and Immigration Discourse in the Twenty-First Century United States

CASSANDRA WHITE
Department of Anthropology, Georgia State University, Atlanta, GA 30302, USA

Accepted for publication 09 December 2009

Summary Leprosy, or Hansen’s disease, continues to be feared and poorly understood in the United States, where knowledge of the disease is limited and prevalence is low. The presence of leprosy among immigrants, however, provides fuel for those with an anti-immigration agenda. In recent years, there have been several examples of popular media distortions of statistics and of information on leprosy’s properties and contagiousness. As in previous eras of U.S. history, public fears about leprosy seem to be related to anti-immigration or nativist sentiment, which often mask underlying concerns about the potential economic threat of immigrant populations. In this article, I analyse the role of the U.S. media and other stakeholders who may have an interest in generating public fear associated with leprosy, in presenting and at times manipulating data about the disease to create an association between leprosy and undocumented immigration.

Introduction

Leprosy, also known as Hansen’s disease, has never been a serious public health problem in the United States. Since case reporting began in 1824, the number of new cases per year has never risen above 500, and most years saw far lower numbers (166 in 2005, for example). Some of the cases are indigenous, among U.S.-born individuals who have never travelled abroad, and others are found in immigrants who have come to the U.S. from nations where the disease is more prevalent. Despite the low incidence and low transmissibility of this disease, some members of the medical community and the media have contributed to the creation of leprosy-related fear and stigma among the American populace.

The association of leprosy with immigrants in the contemporary context is a particularly effective means of generating anti-immigrant sentiment. In the West, leprosy is popularly imagined to be a disease of the past, to be highly contagious, and to cause flesh to rot and limbs to fall off. Leprosy can be a powerful metaphor, carrying with it all the ills assumed to be caused by foreign populations entering the U.S.
has observed that ‘the crossing of boundaries is essential to the creation of panic. When the edge of safety cannot be defined, people react in ways that are not necessarily rational – cordoning off suspect populations [and] creating artificial boundaries that create the illusion of safety...’1 Prior to the discovery of an effective treatment and cure for leprosy, fear associated with the disease was understandable but also quite exaggerated.

In the early twentieth century, policy and popular beliefs about leprosy in the United States were influenced not only by the characteristics and connotations of the disease itself but by the assumed foreign origin of people affected by the disease. In his book, *Leprosy, Racism, and Public Health*, anthropologist Zachary Gussow demonstrated how public health policies about this disease in the late nineteenth century in the U.S. were driven in part by Western fears of the ‘other’. Immigration and colonialism were two means through which people in the West had greater opportunities to come into contact with people from endemic regions. During this time period, xenophobia associated with Chinese immigration was quite strong in the U.S. As Gussow noted: ‘...Western fears of a leprosy pandemic coincided with the period in the nineteenth century when apprehension about the Chinese and their ‘alien germs’ were at their height and when, in the United States, the immigration of foreign populations deemed ‘undesirable’ was being restricted’.3

Fears that ‘lepers’ from other countries would ‘overtake’ America, coupled with scientific data that suggested leprosy could be transmitted from person to person, influenced leprosy policy in the United States. The decision, with a Congressional law passed in 1917, to require isolation of people affected by leprosy in the U.S., was ‘based on the premise that leprosy was highly contagious,’4 though according to Gussow, ‘[l]eprologists working in areas of the world where the disease was hyperendemic abroad had, by 1916, already agreed that leprosy was not highly infectious’.4 The number of cases reported in United States in the years before this law was passed was also extremely low – for example, only 26 cases were reported in 1916.4 However, as Gussow noted, leprosy, at this time, was ‘more than just a disease. It was also an ideological symbol of the danger that the United States faced should it abandon its philosophy of Americanism and its policy of political isolation’.5

Jane Buckingham, in her book, *Leprosy in Colonial South India*, demonstrated how politics and popular opinion played roles in late 19th century policies regarding certain groups affected by leprosy in that country as well. Despite the belief among many Indian physicians and a report by the British-sponsored Leprosy Commission that leprosy was not easily transmissible, recommendations were made by this same Commission to expand leprosy asylums for the poor. An 1889 Leprosy Bill in India focused on the confinement of ‘vagrant’ leprosy sufferers.6 In both nations, factors external to the disease itself (racism and immigration in the U.S. and class prejudice in India) prompted national isolation policies.

Prior to the passing of the law requiring confinement of people diagnosed with leprosy in the U.S., there were facilities where people diagnosed with leprosy were sometimes sent, but their confinement was not federally mandated. The administration of one such facility, the ‘Louisiana Leper Home’ in Carville, Louisiana (later known simply as ‘Carville’), came under the jurisdiction of the United States Public Health Service in 1921.7 Carville became the primary institution where people with leprosy in the continental United States were sent for confinement, and later outpatient treatment, during much of the twentieth century.

After the discovery, in the early 1940s, that sulfone drugs could be used to treat leprosy, there was no longer a valid justification for forcibly isolating patients to prevent the spread of the disease. According to Sato and Frantz, ‘[t]he last compulsory isolation was reportedly enforced in 1960,’8 and legislation that stipulated that outpatient care must be available to
people affected by leprosy in the U.S. was not passed until 1985. Sato and Frantz, in an article that details the history of policy-making associated with leprosy in both the United States and Japan, have noted that, ‘Science, although presumably a potent factor, was not in itself a major force in opening a policy window,’ in terms of leprosy:

However, many influential experts, who had been engaged in the establishment and/or expansion of leprosaria were determined to keep the policy and the institutions and played on remaining public fear of leprosy. Those conservative ‘elites’, primarily bureaucratic agency representatives in the US and medical professionals in Japan, manifested opposition to the proposed law revision, and their arguments were not critically reviewed and more or less accepted by the other actors.\(^9\)

After a multidrug therapy (MDT) regimen was introduced and implemented in most endemic countries in 1982,\(^10\) former confinement centres/leprosaria in the United States – Carville in Louisiana and Kalaupapa in Hawaii – stayed open to accommodate former patients for whom these places were home. Carville officially closed in 1999\(^7\) and Kalaupapa continues to serve as a residence for leprosy-affected individuals.\(^11\) The United States National Hansen’s Disease Program continues to operate with headquarters in Baton Rouge, Louisiana and 11 ambulatory care clinics throughout the U.S.\(^12\)

**LEPROSY’S SUPPOSED COMEBACK**

In the same year that Carville closed, major media outlets began reporting on fears about a resurgence of leprosy that were being expressed by some members of the medical community. In 1999, journalist Sharon Lerner wrote a story on leprosy for *The Village Voice*, with several quotations from Dr. William Levis, a physician with the United States Public Health Service. In the article, Lerner wrote that: ‘…leprosy is emerging – burgeoning, even – as a modern problem. While there were some 900 cases of leprosy in the U.S. 35 years ago, today 10,000 are on record, 500 of them in the tristate area’. ‘And those are cases we know about,’ says William Levis, director of SIUH’s [Staten Island University Hospital] Hansen’s programme. ‘The real number could be double or triple that easily. It probably is’.

In 2003, Lerner published a similar article in *The New York Times*. With the title, ‘Leprosy, a synonym for a stigma, returns,’ she again suggested that the disease was making a comeback in the U.S. In this article, she wrote that ‘…today more than 7000 people have leprosy’ and again quoted Levis as stating, ‘…and those are the ones we know about’.\(^13\)

According to the National Hansen’s Disease Program ‘…in the last 30 years (1975–2005), 7029 new cases have been reported. The number of cases reported per year peaked at 456 in 1983 and, since 1988, has remained relatively stable’.\(^14\) Lerner’s statement that ‘…more than 7000 people have leprosy,’ is misleading, implying 7000 active cases.

The majority of these 7000 individuals would have completed MDT long ago and most others would be in treatment and no longer capable of transmitting the disease. Lerner also wrote that many people affected by leprosy in the U.S. ‘…are immigrants from global leprosy hot spots, like Brazil, India, and the Caribbean’. The article includes the statement, based on her interview with Levis, that, ‘…the disease is now officially endemic to the Northeastern United States for the first time ever’.\(^13\)
For a case to be labeled ‘endemic,’ as defined by the National Hansen’s Disease Program, a person has to have been born in the state where they were diagnosed and living in that state when they received a diagnosis.\textsuperscript{15} There are around 30 ‘endemic’ cases of leprosy each year diagnosed in Louisiana and Texas among people born in the U.S. who have never travelled to nations where the disease is a public health problem (Dr. James Krahenbuhl, personal communication, June 3, 2008). The term ‘endemic’ can be misleading to the general public; for example, my computer word-processing programme’s thesaurus\textsuperscript{16} gives the following synonyms for ‘endemic’: ‘widespread’, ‘prevalent’, ‘common’, and ‘rife’. However, according to Dr. James Krahenbuhl, Director of the National Hansen’s Disease Program in the U.S., Levis was using ‘endemic’ to refer to the theoretical (but as yet unproven) spread of leprosy within immigrant communities living in the U.S. (personal communication, June 3, 2008). Because of the long incubation period of leprosy – ‘about five years’ but ‘as long as 20 years’ according to the World Health Organization,\textsuperscript{17} it would be difficult to determine if a person had acquired leprosy before or after they had immigrated to the U.S., or perhaps, as Dr. Krahenbuhl suggested, on subsequent visits to his/her country of origin. According to Dr. Krahenbuhl, a ‘very high burden of proof’ would be required to determine if a case is truly ‘endemic’ (personal communication, June 3, 2008).

On March 13, 2005, a story by Ben Whitford, entitled, ‘Leprosy in America: New cause for concern,’ was published online by the Columbia (University) News Service.\textsuperscript{18} Whitford emphasised immigration as a key factor in the rise in the number of cases between 2000 and 2001. The number of cases in 2001 was 110, up from 76 in 2000. However, he did not mention that the year 2000 was unusual in terms of having the fewest number of cases reported in a single year since 1962. The low numbers of reported cases in 1999 and 2000 may have been associated with the closing of Carville in 1999 and the misperception among physicians who encountered cases of leprosy in the U.S. that the National Hansen’s Disease Program was no longer in operation (thus resulting in failure to report cases to this federal programme). The figure of 110 cases is relatively low; the incidence of leprosy in the U.S. was higher (but still relatively insignificant from a public health perspective) throughout the 1980s and 1990s (with a peak in the mid-1980s associated in part with Vietnamese refugees who arrived in the late 1970s and early 1980s but whose disease did not manifest for several years).\textsuperscript{14} Whitford used the terms ‘outbreak’ and ‘epidemic’ in the article, neither of which are appropriate terms in referring to the leprosy situation in the U.S. Whitford quoted Dr. William Levis here as well, saying that leprosy ‘...is creeping into the U.S. ... This is a real phenomenon. It’s a public health threat’. Whitford’s article did contain a counter statement from Denis Daumerie at the World Health Organization, saying that there was ‘... absolutely no risk that the few immigrants who are affected by the disease, if they are diagnosed and treated, will spread the disease in the US’.\textsuperscript{18}

Neither Lerner nor Whitford’s articles seem to reflect strong anti-immigration agendas on the part of the authors or the news services for which they were writing, but Dr. Levis’ comments in both articles were quite provocative and have been recycled in a number of articles on conservative websites and blogs. For example, on the website, ‘News With Views’, an article by Frosty Wooldridge is titled, ‘Leprosy, Hepatitis, and Tuberculosis Rising Fast in the United States’. The article cites Lerner’s \textit{New York Times} article as a source and includes Levis’ statement, ‘And those are the ones we know about’, but adds his own commentary implicating immigrants. Wooldridge wrote that ‘7000 cases have been brought in on the backs of newcomers since 2001’, and, ‘Because illegal and legal immigrants are hired into food service, dish washing, cooking, hotels and day care – leprosy finds speedy
access across the country’. 19 The article ends with a plea to take action to ensure the ‘deportation of illegal aliens—slowly, methodically, and surely’.

A May 22, 2005 article, posted to WorldNetDaily, which describes itself as a ‘Free Press for Free People’ is entitled, ‘Are illegals making the U.S. a leper colony?’ (under the subject of ‘Invasion USA’). The article draws heavily on the Whitford story, but it references a story in the Business Journal of Phoenix in which Representative J.D. Hayworth is quoted as saying: ‘Americans should be told that diseases long eradicated in this country – tuberculosis, leprosy, polio, for example – and other extremely contagious diseases have been linked directly to illegals. . . For example, in 40 years, only 900 persons were afflicted by leprosy in the U.S.; in the past three years, more than 7000 cases have been presented’. 20

William Levis was the source for much of the information in both articles. An article in The Scientist entitled, ‘The Leprosy Watcher’, that is primarily about Dr. Levis, noted that Levis was in the process of fighting the policy of mandatory retirement after 30 years with the United States Public Health Service, ‘simultaneously pitting himself against the Hansen’s Disease Centre in Baton Rouge which, he says, wants the slot for his federal position transferred there’.21 Unfortunately, his comments provided fodder for those wishing to use infectious disease to underscore the alleged danger posed by undocumented immigration.

FEAR-MONGERING AND FALSE REPORTS

On April 14, 2005, on the nightly CNN program, Lou Dobbs Tonight, which frequently focused on the threats posed by undocumented immigrants (consistently referred to as ‘illegals’ or ‘illegal aliens’ to the American economy and to the middle class, correspondent Christine Romans presented a report on what Dobbs called, ‘rising fears that once eradicated diseases are now returning to this country through our open borders’.22 Dr. Madeleine Cosman was shown, stating, ‘We have some enormous problems with horrendous diseases that are being brought into America by illegal aliens,’ and she mentions leprosy among them. Romans told Dobbs, ‘. . .the woman in our piece told us that . . .there have been 7000 in the past three years’.22 Cosman, a scholar and lawyer (but not a physician or leprosy specialist) who passed away in 2006, frequently spoke and wrote about her perceptions of the damage undocumented immigrants cause to the U.S. healthcare system.23 In a non-peer-reviewed article published in the Journal of American Physicians and Surgeons, entitled ‘Illegal aliens and American medicine’, she wrote that ‘illegal aliens’ stealthy assaults on medicine now must rouse alert and alarm’.24 She included the misinformation about there being 7000 cases in ‘the past three years’,25 attributing the supposed surge in the incidence of leprosy, which she characterised as a disease that ‘horribly destroys flesh and faces’, to ‘illegal aliens and other immigrants’.25 Lerner’s Village Voice and New York Times articles were among her sources.

Two years later, on May 6, 2007, Dobbs was interviewed on the programme 60 Minutes. When correspondent Lesley Stahl questioned Dobbs about the 7000 cases in 3 years figure, he said simply, ‘If we reported it, it’s a fact’, despite Stahl’s presentation of statistics from the National Hansen’s Disease Programme that this number represented 30 years of case reporting.26 In their response to the 60 Minutes report, Romans defended her reporting, citing Cosman. Dobbs downplayed the importance of Stahl’s investigation by suggesting that the numbers of leprosy cases was hardly important: ‘. . .It’s remarkable that this – whatever confusion, or confoundment over 7000 cases, they actually keep a registry of cases of leprosy. And the fact that it rose was because – one assumes – because we don’t know for sure – but
two basic influences – unscreened illegal immigrants coming into this country primarily from South Asia, and secondly, far better reporting. After the publication of a New York Times story criticizing Dobbs’ failure to admit the errors in the original story, Dobbs called Romans’ original reporting ‘...an unscripted ad-lib, not a report’.

Although several conservative, anti-immigration bloggers admitted the flaws in Dobbs’ reporting, some bloggers dismissed Stahl’s report as an attack by the liberal media. On a website hosted by Pat Dollard, a conservative blogger and filmmaker, ‘drillanwr’ posted an article on September 20, 2008, entitled, ‘Unchecked ‘immigration’ bringing back the ancient scourge of leprosy?’; this poster wrote that ‘Lou Dobbs became alarmed by this ‘outbreak’ of leprosy in our country, but liberal groups were swift in their backhand to slap him down’.

Although Dobbs left CNN on November 11, 2009, he continues to host a national radio show, on which he has discussed entering politics at a high level (possibly running for president in 2012). Other journalists and activists may point out errors in his broadcasts, but this may not diminish the initial impact of the statements he or his correspondents. However, as demonstrated by the next example, local news stories have nearly the same potential to reach a national audience through internet repostings and other forms of media dissemination.

LEPROSY PANIC IN ARKANSAS

In February, 2008, a small city news story about a supposed leprosy ‘epidemic’ in Arkansas caught the attention of the national news media and subsequently of internet bloggers across the country. I learned about this story from a student at my university who, noticing a flyer on my door for a talk I was presenting on leprosy and stigma in Brazil, asked me if I had heard about the ‘leprosy outbreak in the Midwest’. I found, on YouTube.com, a February 7, 2008 news segment with several inaccurate and alarming statements that prompted other print and internet stories about a leprosy ‘outbreak’. This segment, which was the top story on the 10 p.m. broadcast of KFSM-TV news in Fort Smith, Arkansas, began with anchorwoman Bridget Schultz reporting that ‘...the medical community is warning the public that a leprosy outbreak in Springdale could blossom into an epidemic if something isn’t done soon’. The reporter on the story, Mary Marsh, then revealed that the source of the ‘epidemic’ was the Marshallese immigrant population in Springdale. She stated in the story that ‘...specialists say that the Marshall Islands have the most cases of leprosy in the world and the city with the largest number of Marshallese people outside the Marshall Islands is Springdale’.

Dr. Jennifer Bingham was interviewed as part of the broadcast and mentioned noncompliance with treatment as a reason for the spread of leprosy. Marsh narrated, ‘...Bingham says that without cooperation, leprosy, which has no vaccine, and is transmitted through the air, will spread, and could become an epidemic’. During this narration, a photo of a man’s chest covered in lesions was on the screen. Bingham appeared again, saying, ‘People absolutely should be concerned. What I’m afraid of is that by the time people start thinking about it enough, it will already be out of control’. Marsh then said that, ‘Bingham and others say that government’s help is the next step’.

The segment then cut to Springdale mayoral candidate Nancy Jenkins saying, ‘We just opened the borders and said, ‘Come on in! Bring your diseases! Bring ‘em!’ Why are we doing that?’ And those who have it need to be quarantined and treated, or sent back to their country’. Another quote from Bingham concluded the story: ‘The only way to truly protect our community and our economic growth is to think of this as a very important, panic mode
attempt to treat leprosy before it gets out of hand’. The reporter, Marsh, followed up with a few statements of accurate information about early symptoms and treatment.

The suggestion of an ‘outbreak’ or a possible future ‘epidemic’ was absurd, given the small number of registered cases in Springdale. The Marshall Islands has a relatively high prevalence rate of leprosy, but they are very far from having the ‘most cases of leprosy in the world’. Although illegal immigration was not mentioned in the story, there was no explanation given that, as part of a Compact of Free Association between the U.S. and the Marshall Islands, Marshallese citizens can live and seek employment in the U.S. without obtaining visas.32

The following day, an accompanying online story had been removed from the website, though it had already been copied by several blog sites (where I was also able to access it). A new story was posted that, while not a retraction, pointed out some errors in Dr. Bingham’s statements. A physician from the Arkansas Department of Health was consulted, and the story reported that an epidemic of leprosy was not occurring and that the nine reported cases of leprosy were not new cases but rather cases that have been registered and followed over the past 2 to 3 years.33

Using the keywords ‘leprosy’ and ‘Arkansas’ in Google searches conducted between May and October of 2008, I found that the first several pages contain blog sites where this story is discussed. On one site, with the title, ‘Arkansas Leprosy Outbreak Blamed on Lax Border Control’,34 the YouTube video of the KFSM broadcast is posted, followed by several posters’ comments. Though several respondents on the site noted the problems with the story and included accurate information about leprosy in their posts, one poster, ‘Sarah’, wrote: ‘...I come from Springdale. I plan on moving back. This has scared me for all my loved ones. I couldnt [sic] imagine if someone I knew contracted this. If even one case is true then it is something that should be addressed. None of this is a joking matter. Whether it be testing before they come in the country and/or quarantining the whole state and surrounding areas, something has to be done’.

The original online KFSM story stated that Marshallese immigrants came to Springdale to work in poultry processing for Tyson Foods, whose headquarters are in Springdale. Several bloggers and posters made a leap to the idea of a risk to the national food supply. On one site, in response to a post with the KFSM news story, one person wrote, ‘Just think of leprosy plagued workers preparing your food’.35 On the same site, in response to a poster who noted that illegal immigration was not an issue in the story, another poster wrote, ‘It would be unlikely that legal immigrants would have leprosy’.36 and another poster, in response to a comment about the U.S. being a ‘melting pot’, wrote, ‘Apparently one giant FESTERING melting pot’.37

The expression of fear associated with leprosy in these blogs is a surface presentation of a general fear of the ‘other’ and a broader concern that ‘illegal’ immigrants threaten the American way of life, a parallel of concerns of the late nineteenth and early twentieth century in the U.S.. Despite the emphasis on disease as a rationale for limiting immigration, this focus is often what Chirwa referred to as ‘smokescreen’ for underlying economic and political anxieties.38 In his article on the repatriation of Malawian immigrants in South Africa in the late 1980s and early 1990s, Chirwa noted that the reason given by the state for repatriation was fear of migrant worker Malawians spreading HIV; however, he suggests that this policy had more to do with concerns about foreign labour in the mining industry than about fears about HIV/AIDS.
Discussion

As Margaret Humphreys has noted, ‘Disease panic and the news media form their own generative circle. The more panic, the more rumours, the more demand for information to be supplied by the newspapers (and later CNN)’. This circle continues and information becomes further warped with the reposting of stories to websites and blogs. Although it is unlikely that poor reporting, such as that of the KFSM broadcast and the report on Lou Dobbs Tonight, is going to result in a new era of quarantine for people affected by leprosy, stories like these have the potential to cause people who are in treatment or who need treatment to go into hiding. At a seminar I attended, held on May 10, 2008 in Atlanta, Georgia, ‘Awareness and Management of Hansen’s Disease (Leprosy) in the U.S.’, Dr. Barbara Stryjewska, who works with the National Hansen’s Disease Program in Baton Rouge, Louisiana, reported that a Marshallese man with leprosy who was living in Arkansas delayed seeking treatment in the U.S. specifically because of the KFSM news story. He was afraid he would be locked up or quarantined, so he did not seek treatment until his symptoms worsened, thus putting himself at greater risk for nerve damage and serious disability. Markel and Stern have suggested that American beliefs that disease and immigration (of ‘undesirables’) go hand-in-hand ‘have deterred, rather than encouraged, many immigrants from seeking medical care’.

Concerns about leprosy that have been expressed in the media and on blogs are misplaced. Within the U.S., leprosy constitutes a health risk primarily to individual patients, rather than to the public at large. If patients do not have access to proper care, they can incur severe disabilities. This care is available in the U.S. through the National Hansen’s Disease Program, but individuals affected by the disease may encounter obstacles in receiving a diagnosis and being referred to this programme in a nation where the disease is rare and where most physicians are not familiar with leprosy. Long-term follow-up care is particularly important for patients who are cured of the disease but who experience leprosy reaction. As Jacob et al. have suggested based on a recent study with a small cohort of people affected by leprosy in the state of Georgia in the U.S., the prevalence of leprosy reaction ‘may be more common than previously thought among patients living in non-endemic areas’. Early detection of the disease is also important in terms of the prevention of permanent disabilities in patients. However, patients may hesitate to seek care if they fear stigmatisation, quarantine, or deportation.

The resurgence of public interest in leprosy in the twenty-first century, as evidenced by the media representations mentioned in this article, parallels strong negative attitudes and fears about immigration, not unlike those that existed in the late nineteenth and early twentieth century in the U.S. However, there are potentially positive aspects of this renewed public interest in leprosy. Funding for leprosy research and work has declined in recent years after various declarations by the World Health Organization that the ‘elimination’ of leprosy in endemic nations was imminent, despite evidence that the global incidence (number of new cases each year) is still high. Researchers, non-profit organisation representatives, and others who work with leprosy might take advantage of the American public’s interest to provide information on the global leprosy situation; this could ultimately lead to more funding support for leprosy projects worldwide.
Acknowledgements

I would like to thank Dr. James Krahenbuhl, Chief, Immunology Research Department of the National Hansen’s Disease Program in the U.S. for comments and suggestions he provided on an early draft of this paper. I would also like to thank Dr. David Scollard and Dr. Barbara Stryjewska, also of the U.S. National Hansen’s Disease Program and Dr. Carlos Franco-Paredes, Assistant Professor of Medicine at Emory University.

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