



## **Carville and Curupaiti: experiences of confinement and community**

*Carville e Curupaiti:  
experiências de  
isolamento e  
comunidade*

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Although Hansen's disease (leprosy) is still a significant problem in many parts of the world, the effectiveness of multidrug therapy has allowed people affected by this disease to be treated on an outpatient basis. However, throughout much of the twentieth century, people diagnosed with Hansen's disease were isolated from their families in facilities known as 'leprosaria'. This article presents a brief history of isolation policies and the development of community structures at two such facilities, Carville and Curupaiti, in the United States and Brazil, respectively. The modern dilemmas faced by the administration, staff, and residents of these institutions will also be discussed.

**KEYWORDS:** medical anthropology, leprosy (Hansen's disease), United States, Brazil, stigma.

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*Apesar de ainda ser a hanseníase um problema relevante em muitas partes do mundo, a eficácia da terapia multidrogas vem permitindo que pessoas afetadas sejam tratadas como pacientes não internos. No entanto, durante a maior parte do século XX, os diagnosticados como hansenianos eram isolados de suas famílias e internados em instituições chamadas 'leprosários'. O presente artigo apresenta uma breve história da política do isolamento e do desenvolvimento de estruturas comunitárias em duas instituições, Carville e Curupaiti, nos Estados Unidos e no Brasil, respectivamente. Os dilemas modernos frente à administração, às equipes e aos residentes destas instituições também serão discutidos.*

**PALAVRAS-CHAVE:** antropologia médica, hanseníase, Brasil, Estados Unidos, estigma.

<sup>1</sup> In this paper, I alternate between the terms 'Hansen's disease' and 'leprosy'. Hansen's disease (or *hanseníase* in Brazil) is often the preferred term among patients, but I use 'leprosy' when it seems more appropriate in terms of talking about how the disease was understood historically or how stigma is understood.

Isolation of patients with Hansen's disease,<sup>1</sup> or leprosy, was not a phenomenon that was unique to the twentieth century. Thousands of 'leprosaria', or isolation centers, were established throughout medieval Europe (Foucault, 1965). However, many of these leprosaria were closed by the end of the Middle Ages, and leprosy was temporarily forgotten by the Western world. In the United States, concerns about leprosy did not emerge until the nineteenth century, with the awareness of cases of the disease in regions of Asia and the Pacific that were controlled by the United States and with new immigrant groups arriving on American shores from endemic nations (Gussow, 1989). In the late 1800s, isolation of leprosy patients became public health policy in the United States. The discovery of the bacillus that causes leprosy, *Mycobacterium leprae*, by Gerhard Armauer Hansen in 1873, and the presence of the disease in U.S. as well as European territories and colonies seemed to have contributed to the spawning of a new leprosarium movement.

Meanwhile, in Brazil, leprosy had been a problem since the sixteenth century when it was most likely introduced to the South American continent by both Europeans and enslaved Africans. Hospitals designed for leprosy patients were first established in the 1700s in Brazil, although some people affected with leprosy were placed in hospitals alongside patients with other diseases. In the early 1900s, Oswaldo Cruz spoke in favor of the isolation of patients in leprosaria or 'leper colonies' (APPRJ, 1922, p. 1, *apud* Guimarães e Silva *et alii*, 1998, p. 57), the building and administration of which often followed the U.S. model. Carville Hospital, in Louisiana, served as one model for construction and administration of leprosaria in Brazil (Souza Araújo, 1948), although Brazil remained more liberal in many of its policies. For example, in many cases, spouses were allowed to accompany patients to the leprosaria in Brazil, whereas this was prohibited in the U.S. until the late 1940s. Also, after a cure for Hansen's disease was discovered in the 1940s, patients with the less severe, 'tuberculoid' form of the disease were no longer forced to live in the leprosaria, whereas in the U.S., all patients diagnosed with Hansen's disease were required to live in a confinement center, at least temporarily, until the 1970s (Gussow, 1989). However, there were many similarities in the daily lives and experiences of people in the leprosaria in Brazil and the U.S. during the twentieth century.

In this paper, the histories of two former leprosaria, or Hansen's disease confinement centers — Carville, in the state of Louisiana in the United States, and Curupaiti, in the state of Rio de Janeiro, in Brazil — will be discussed. Both facilities developed into closed communities where patients experienced both joys and sorrows, the latter being greatly enhanced by both the effects of their disease and the forced

isolation from society. The account presented here of the lives of former patients at Carville is more detailed than that of Curupaiti because I had a chance to spend more time at Carville, but my visits to Curupaiti gave me some insight into what daily life was like for former patients there. The current circumstances for residents of Carville and Curupaiti have proved to be extremely different, and after attempting to demonstrate what life was like at each facility historically, I discuss the modern situation in both locations.

### Carville

The Gillis W. Long Hansen's disease Center, popularly known as Carville, was open for slightly more than a century. In different times, Carville served many functions. For most of its history, it was as a confinement center for leprosy (Hansen's disease) patients, but it was also a treatment center, a research facility, a community, and a home for many people. I began visiting Carville in 1996, and I had the opportunity to work on a video-oral history project for two years while I was a graduate student in anthropology at Tulane University. For this project, I conducted twenty-nine videotaped life histories of patients, former patients, and staff, and I transcribed several other life history interviews conducted by the Public Affairs Specialist of Carville, Julia Elwood, who also initiated Carville's Oral History Project.<sup>2</sup>

<sup>2</sup> These videos and most transcriptions are available at the T. Harry Williams Oral History Center at Louisiana State University in Baton Rouge, Louisiana, USA.

As mentioned above, Hansen's disease was never a serious public health concern in the United States, except, perhaps, for the high rates of the disease among residents of the Hawaiian Islands after the disease's introduction there, prompting the establishment of a leprosarium on the island of Molokai. Still, there were several pockets of endemicity in the continental United States particularly in Texas, Louisiana, and Florida. John Trautman (1989), who once served as a physician at Carville, has suggested that there may be a genetic factor of susceptibility in descendants of French Canadians who came to Louisiana from Nova Scotia in the 1700s. Gussow (1989) mentioned the immigrants from Norway (where Hansen's disease continued to be endemic well into the nineteenth century) in the Upper Mississippi Valley as a possible font of Hansen's disease in the United States. Hansen's disease also seemed to be common in immigrant populations from Asia and in Mexican-American families living in Texas. Today, 90% of the new cases of Hansen's disease diagnosed in the United States are from other countries. The number of registered cases of Hansen's disease in the United States is around 6,500, although the U.S. includes on their registry all patients and former patients who have ever been reported and who are still alive, regardless of whether or not they have been cured. About 200-250 new cases of Hansen's disease are reported in the U.S. each year (*The Star*, 1995, p. 18).

Carville Hospital, on the Mississippi River between New Orleans and Baton Rouge in Louisiana, was established during the nineteenth century leprosarium movement. In 1894, authorities became aware that a physician was running a boarding house for Hansen's disease patients in downtown New Orleans. The existence of other cases of Hansen's disease in the city alarmed officials, and with the encouragement of Tulane University dermatologist Dr. Isadore Dyer, a bill was passed to create the Louisiana State Leper Home for these patients on the site of what was once a sugarcane plantation (Dyer, 1902; Stein *et al.*, 1963). It was located at a dead end of the road that runs alongside the Mississippi River. The first seven patients were shipped to Carville from New Orleans on a coal barge. One resident doctor was assigned to Carville, but he resigned shortly after, and the patients were left to fend for themselves for approximately two years. The patients lived in old slave cabins of the former plantation (Stein *et al.*, 1963).

In 1896, four nuns of the order of the Sisters of Charity of Saint Vincent de Paul arrived at what was then known as the Louisiana Leper Home at Carville. One of the nuns soon died of malaria, and many patients suffered from malaria as well, since Carville would virtually turn into a swamp during heavy rains. The living conditions there were very poor, but attempts to move the facility to a site closer to New Orleans, for better access to the healthcare services available there, were met with protests, and the home remained at Carville. The United States government took over the administration of the facility in 1921, although the Saint Vincent de Paul nuns, most of whom were also nurses, continued to work at Carville (Stein *et al.*, 1963). Carville remained open under the auspices of the U.S. Public Health Service until 1999, when the authority switched it to the state of Louisiana. By that time, the facility had already turned into a home for troubled teenagers.

When I began conducting life histories at Carville in 1996, there were approximately 160 patients still living there. At Carville, I interviewed thirteen former patients, two physicians, a nun, a Catholic priest, a Protestant minister, and several staff members, some of whom had worked at Carville for several decades and some who also had parents who worked at Carville. For the most part, the life histories of patients were the most profound and moving, but other staff members provided much information about Carville and helped to provide me with a more holistic understanding of the experience of daily life there.

Most of the patients I interviewed had a similar story about diagnosis with leprosy and the events that followed. Some talked about being isolated or quarantined at home or in the hospital awaiting transportation to Carville. For patients in nearby towns and states, a station wagon was often dispatched to retrieve them. One man said that because the station wagon was not available when he was brought to Carville, they picked him up in a hearse that doubled as an ambulance. Another

man who came to Carville in 1956 said that because he was living in California, he went by train with a doctor from Los Angeles to Louisiana. He said:

I remember getting in the train. He [the doctor] installed me in a sleeping compartment. ... He gave me instructions. He said: "You are going to be here until we get to New Orleans, and you are not to open this door. You are not to get out. They will bring you your meals in here. If you need anything, I'll be checking on you from time to time." So I was there in this kind of coffin-like compartment, and there was a window to the outside and nobody to talk to. I was just there wondering what was going to happen. I knew that as far as I was concerned, I was dead to the world, that I was going to this place — I didn't have an idea how it was, but that I was going to this place that I was never, never again to come out — that I would die there.

For many patients, arrival at Carville represented a kind of death for them, symbolized not only by their mode of transportation to Louisiana (a hearse, ambulance, or coffin-like train cabin), but also by the location of Carville itself, at the dead end of the Mississippi River Road. This was the literal and figurative 'end of the road' for many patients. The supervised journey also marked the beginning of their confinement. Patients entering Carville, even in the 1950s and 1960s, often were not sure if they would ever leave.

Upon arrival at Carville, new patients would be offered the chance, and were often encouraged, to take an assumed name. The change of identity also represented the end of their lives as they had previously experienced them. Patients were advised that a name change could protect their families from the stigma of leprosy. Some people mentioned that their families did, in fact, suffer because of their diagnosis. One woman said that after she was taken to Carville in 1949, at age 14, her school in her hometown in Texas burned her desk and her books. Some patients' young brothers and sisters were shunned at school when it was discovered that their sibling had leprosy.

There are also several examples that despite scientific evidence to the contrary, leprosy was considered to be highly contagious both within and outside of the community of the treatment facility. There was a sterilization machine for outgoing mail at Carville. Coca-Cola bottles brought into Carville were not picked up for recycling but rather had to remain on the grounds. When patients' families came to visit, they were not allowed to stay overnight on the grounds of Carville, and in the early days, patients could not have physical contact with their visiting relatives.

There were many other restrictions on patients' lives. Patients were not allowed to own a car before the 1970s, nor were they allowed to leave Carville without permission. Many patients and staff told me about the well-known 'hole in the fence', through which patients

occasionally escaped but more often just made short trips to Baton Rouge or New Orleans before returning. Some patients went through the hole (which was really an area where the fence could be lifted and patients could crawl underneath) just to do some fishing on the Mississippi River, which is across the road from the gates of Carville. One woman who left through the fence three times to visit her family and children in Puerto Rico would tell her doctor each time before she left, and, assuring him she would return, she never suffered any punitive consequences. However, some patients who escaped and were caught would be placed in a jail that existed, ironically, within the confinement center.

Interactions between medical staff and patients ranged from very negative to extremely positive. For years, many patients were ‘guinea pigs’ of medical trials and treatments with chaulmoogra oil and other medications that were ineffective and often painful. Stanley Stein’s autobiography *Alone no longer* (1963), written with Lawrence G. Blochman, details his experiences at Carville from the time he arrived in 1931. He gives an account of the terrible reactions Stein and other patients had to the chaulmoogra oil injections they were given at Carville. However, even after sulfones began to be used, new drugs were constantly being developed at Carville and tested on patients. One former patient told me: “I believe that every experimental drug that came in here was given to us. We were never told, I guess, being a patient here — they just automatically assumed we were going to take it ... I’m healthy, but a lot of our patients had a lot of reactions that really ruined their faces, handicapped them for life, [ruined] their eyesight.” While these disabilities were probably not the results of drug tests, these tests certainly led some patients to distrust the physicians and nurses at Carville. For the most part, however, the patients I interviewed had very good experiences with the medical staff.

Though most of Carville’s history, there were opportunities for patient activities, either organized by patients or by the staff. Stanley Stein wrote about his involvement in theater productions at Carville and how much it helped him. Stein also began the publication *The Star* in 1931, a journal for patient advocacy and for educating the public about Hansen’s disease. Work on the staff of the *The Star* also provided some of the patients I interviewed with part-time, paid employment (although the people I interviewed reported that the pay was extremely low). Patients also hunted, fished, farmed, and kept flower and vegetable gardens. There was a dairy farm operating on the grounds that had ceased operations by the mid-1950s. There was a lake with paddleboats available for patients to use. There was a patient Canteen, a small store where patients could buy snacks and cold drinks. The Canteen was also the center of social life for many years at Carville. There was also a movie theater, which, according to one of the men I interviewed, who worked as

a projectionist and electrician at Carville, would bring in most of the four hundred patients who were there in the 1950s for the two or three nights a week that movies were shown.

Daily life at Carville was different during different eras, depending not only on the treatments available and the policies of the administration but also on the opportunities for socialization. For younger people, their experience was generally a more positive one if there were other younger people there as well. During the late 1950s and early 1960s, the patient population was high and there were several teenagers. One woman who was a teenager during that time told me:

There were so many young people, girls and boys ... That made a difference, too, because they brought a lot of life into this place, a lot of activities. That began to take my mind off my misery. I remember that while I was still running around in tests and in clinics and everything, this friend of mine ... showed me all the things, activities, and entertainment about this place. He took me to the Canteen, which was always bubbling with people and people drinking. I was surprised to see, in a hospital, people drinking beer, and some of them drinking more than their daily dose. He took me to the recreation hall. There it was like entertainment at all times. At all times, there were so many people hopping in that recreation hall, people waiting their turn to play pool, and they had badminton, ping pong. There was a big jukebox, with a great collection of records of the fifties, of course. It was so good to just go and punch whatever tunes you wanted, without having to put a quarter in it. After school, in the afternoon and the evening especially, there were all these young people in there and all these activities — playing or singing or dancing or just socializing there. That was a lot of help. Little by little, I began to feel more comfortable in my new home because as far as I could tell, it was my home for the duration.

Another aspect of recreational life at Carville that was unique was their annual Mardi Gras celebrations. In Louisiana, Mardi Gras (Carnival) is an important celebration. At Carville, patients would build floats, celebrate with balls and dances, and even crown a king and queen of Mardi Gras. According to one patient who served twice as queen, they would receive costumes from organizations in New Orleans and Baton Rouge, and a company in New York sent evening dresses for the young women to wear for the balls.

There was also a Patients' Federation, an organization to which all patients automatically belonged. This Federation, founded originally as the What Cheer Club to manage funds raised by sales at the Canteen (Stein *et al.*, 1963), sponsored dances and other patient events, such as the Mardi Gras celebration. The Patients' Federation eventually became more political in nature, petitioning for patients' rights on several issues. Other organizations that had

chapters at Carville included the Lion's Club, the American Legion, and Catholic groups such as the Legion of Mary and the Holy Name Society. In the 1950s and 1960s, one of the nuns ran what was called the 'B' Natural Club for musical instrument and choir instruction and performance.

While Carville constituted a fairly tight-knit community, there were many forms of segregation throughout Carville's history. Different ethnic groups were segregated into different houses at Carville for many years; for example, there were separate houses (several patients per house) for African-Americans, Chinese, Hispanics, and French Cajuns. Men and women were also segregated for much of Carville's history. Patients were not allowed to marry each other before the early 1960s. Healthy spouses were not allowed to move into Carville until 1946, when a military officer generated national publicity and acquired a letter from general Douglas MacArthur allowing him to live at Carville with his wife, a patient (Stein *et al.*, 1963). Before that, if a patient's family wanted to live near the patient, they would have to buy a house close by, but outside of the facility.

Until the 1970s, there was a segregation of patients and staff in terms of the physical layout of the grounds. There were separate housing areas, dining areas, movie theaters, tennis courts, and golf courses. There was a staff swimming pool that patients were not allowed to use. There was segregation during church services as well. One man, who later became an activist in Hansen's disease education, took a stand against this segregation at the Catholic church at Carville: "...While there was segregation at the chapel... the staff [and] the Sisters on one side and the patients on one side. They had two chalices for giving out the host. So I went ahead and took it upon myself to just break that barrier; [I] sat on the patients' side and forced the priest to give me a host from the chalice that came from the staff side." Although it was known that leprosy was not highly transmissible, and although after the 1940s, most patients at Carville had been rendered non-contagious through sulfone treatments, the idea of leprosy as an extremely contagious disease was perpetuated through these segregation policies.

Interviewees at Carville told me they were not aware of an official policy against patients having children, but such a policy must have existed. Women who became pregnant while patients at Carville had their children taken away. One woman I interviewed, who was at Carville from 1956-1962, married another patient and became pregnant while she was there. No one had ever advised her against having the child, but when it was time for her to deliver, she was sent to a New Orleans public health hospital:

They put us in quarantine, and after I had the baby, the baby was separated from me. I never knew whether they actually put him in the



same nursery as the other children or not, but they never let me touch him. They let me see him, but they never let me touch him. My husband's mother took the baby, and he lived with her until I was able to leave the hospital and have a house in the community where I could keep him.

She did not get to touch or hold her baby until it was nine months old and she had been released from Carville. Of course, there are much more tragic stories in Carville's history. Before the days of sulfone, women who became pregnant at Carville would sometimes resort to performing abortions on themselves. Women who carried their babies to term would be forced to give them up for adoption if no family member outside of Carville was available or willing to care of the child. Although separating parents and infants was not a universal policy in Hansen's disease control in the twentieth century, this did take place elsewhere (see, for example, Gugelyk *et al.* (1986), on policies at Kalaupapa in Hawaii). Although I do not have information on this policy at Curupaiti, many leprosaria in Brazil sent infants to *preventórios*, facilities designed to isolate and 'protect' them from their parents and other potential sources of infection (Monteiro, 2002).

Although patients were confined against their will, some patients actually experienced an increase in their quality of life upon moving to Carville. Many patients came from migrant labor or other working-class Mexican-American families in Texas. Both immigrant patients and patients from rural Louisiana also generally came from very poor families. Residence at Carville meant less work, more food and better medical care than was available to their parents, siblings, spouses, or children at home. There was also an opportunity for better education. A few patients who arrived as teenagers in the 1950s and 1960s went on to college and graduate school after attending the accredited high school that was at Carville during these years. However, after many years of institutionalization, others came to depend on the institution to meet their needs. Despite the development of sulfone drugs and, essentially, a cure for Hansen's disease in the 1940s, many leprosaria did not open their doors. According to Gussow (1989, p. 22), an anthropologist who also worked at Carville, the United States "failed to develop outpatient treatment centers for Hansen's disease until the 1960s, long after such an approach was feasible." By the 1970s, leprosaria began to seem less necessary and Carville no longer required patients or former patients to live there. However, residents often found they had no place to go and no identity outside of the leprosarium, and many chose to stay.

Many of the patients in residence at Carville, whether or not they had a physical disability or disfigurement, had been institutionalized for most of their lives and did not feel able to reenter society. Some of them had been abandoned by their families or had chosen to cut off contact with family members to avoid problems for them. They had

become dependent on the medical care and other services available to them there, but they also felt that Carville was their home. By the 1990s, most of the residents had spouses or friends buried in the cemetery there, increasing a sense of connection to this place. Some patients did have family they could live with on the outside, but they felt more comfortable at Carville. As one former patient told me: “I enjoy being with the patients here because ... we’re the same; we’re all in the same boat.” While I was conducting interviews at Carville, plans were still in limbo about the future of Carville. This situation proved very stressful for residents. Some former patients were concerned not only for themselves but for others who might need diagnosis and treatment. Another woman told me: “Well, about Carville — Carville is, to me, the best place we have. Even if I don’t need to come here, we need this place for other people’s sake. I love Carville just like this was my first home because I was here when I was young. Half my life, I was here.” Some concerns seemed more trivial but were still important to residents: “Before this talk, talk, talk [plans to shut down the hospital] ... I wasn’t worried about it at all. Now I was looking forward to decorating my bathroom [in her house at Carville] and this and that ... I don’t feel like doing that anymore.”

Though originally brought to Carville against their will, many people were thoroughly invested in the lives that were shaped in part by the confinement process. For many people, their identities were intertwined with their experiences of illness. Many patients felt they did not have the skills to survive in the outside world, and many thought that the stigma against leprosy would prevent them from being accepted, although, as Gussow *et al.* (1968) pointed out in discussing their research at Carville, this was a form of self-stigmatization created by life in the institution that did not necessarily correspond with reality. However, by the 1990s (when I first visited Carville) leaving was an extremely grim, if not impossible, option for many people due to old age, infirmity, and lack of contacts on the outside.

In the early 1990s, the United States Federal Government attempted an experiment in which federal prisoners (white-collar criminals) were brought in to live at Carville. They were hoping that this would be a more economical use of the extensive area available there. At first patients and former patient residents did not like the idea because of the numerous implications of the plan. Were Hansen’s disease patients being equated with criminals? Was Carville a dumping ground for the refuse of society? Certainly it may have already seemed that way to patients, since an industrial community of chemical plants (called ‘Geismar’, part of what’s known in Louisiana as ‘Cancer Alley’) had sprung up very near to Carville in the 1980s. However, many Carville residents actually came to warm up to the federal prisoners who were brought there; the prisoners did a lot of work on the grounds and

seemed to get along with patients. Unfortunately, the experiment proved not to be economically feasible for the U.S. Federal Prison System.

The next idea was to turn Carville into a facility for troubled adolescents. At first, patients were going to be allowed to share the facility with these adolescents, but that proposal did not pass, and the Hansen's disease research and treatment center, that had been part of Carville, was relocated to Baton Rouge in 1999. Several former patients accepted an annual stipend to leave Carville, but those who had nowhere else to go were allowed to remain in residence. There are fewer than forty former patients living at Carville today. The decision by the Federal Government to close Carville was very traumatic for both residents and staff at Carville. As one former patient put it, "the government has told the patients that they're going to keep them, house them, and care for them until they die". Many residents felt doubly betrayed by a government that forced them into isolation and then, after decades of dependency, was forcing them back into the world.

### **Curupaiti**

In 1998-1999, I spent 11 months in Rio de Janeiro, Brazil, studying social and cultural aspects of Hansen's disease and Hansen's disease treatment in health posts in Rio and surrounding areas. One of the facilities where I worked was the Instituto Estadual de Dermatologia Sanitária, or the State Institute of Sanitary Dermatology of Rio de Janeiro, formerly the leprosarium of Curupaiti. Patients are no longer confined at Curupaiti, but many former patients and their families continue to live there. In addition to housing for former patients, there is an outpatient facility for treatment of Hansen's disease and of dermatological conditions. Although my research was on the outpatient treatment of Hansen's disease in Brazil, I also did some historical research for my doctoral thesis while at Curupaiti. In addition to using the small library on the grounds there, I also talked with others who had conducted historical and contemporary research at the institution. In learning about the history of Curupaiti, I noticed many correspondences between Carville and Curupaiti in terms of community formation and the experiences of patients in the past. However, there are some striking differences in the contemporary circumstances at each location.

My first visit to Curupaiti was with a Discovery Channel camera crew in March of 1999. For the documentary, *Banished: living with leprosy* (1999), producer Phyllis Ward wanted to contrast outpatient treatment with life in the leprosarium — the present and the past pictures of leprosy. Curupaiti is located in Jacarepaguá, a suburb of Rio that can be reached by bus or car from the famous beach of Ipanema via a primarily beachfront journey through the wealthy

neighborhood of Barra da Tijuca or, from downtown Rio de Janeiro, through the beautiful and steep mountain passage of the serra dos Três Rios. On this visit, we were accompanied by a volunteer from Morhan (Movement for the Reintegration of Hansen's disease patients), whose husband was also a resident of Curupaiti. During this first visit, I met the director of this clinic and I was invited to return.

The outpatient clinic there is a public health facility for Hansen's disease treatment, but it is also a general dermatology treatment center. Patients have access to the several psychologists on staff and are also allowed to use the services of the hospital of Curupaiti. When I was there, there were two social workers on staff that had recently (in early 1999) begun to implement daily waiting room groups (*grupos de sala de espera*). Social workers held discussion sessions in the waiting room, taking advantage of the numerous patients who waited there for appointments. They began these group sessions by talking about the services available at Curupaiti and about Hansen's disease specifically, allowing patients to ask questions at any point. In June and July of 1999, I spent one-two days per week at Curupaiti for approximately six weeks.

After several visits to Curupaiti's outpatient clinic, I was introduced to Regina Maria da Cruz, a social worker who assists residents of the community of Curupaiti. She had completed a Master's thesis on the history of Curupaiti, entitled *Essa história eu vivi (I lived this history, 1995)* after an extensive search through Curupaiti's archives. Some information about Curupaiti can also be found in a two volume collection entitled *A memória documental da hanseníase na cidade do Rio de Janeiro: 1697-1953*.<sup>3</sup>

Curupaiti was founded in the 1920s as part of a push towards the creation of isolation centers by then-president Epitácio Pessoa. The facility was originally supposed to house leprosy patients, but it held only tuberculosis patients until 1928, when 53 leprosy patients were transported there from the Hospital dos Lázaros, a hospital in Rio de Janeiro where doctors were concerned about leprosy patients being contaminated with other diseases. At that time, the institution was officially designated as an *Enfermaria para Hansenianos* or Hansen's disease Infirmary (Cruz, 1995).

As at Carville, Curupaiti developed the structure of a closed community. Ruth Reis do Amaral (1990, p. 14), a volunteer at Morhan who worked at Curupaiti in the past, writes about the *colônias* (colonies) for leprosy patients in Brazil in general:

The *colônias* were organized like miniature cities, with a mayor's office, businesses, clubs, churches, schools, and police, with the administration undertaken by the residents, under the 'tutelage' of the *Colônia* Hospitals... [Eventually] the majority of residents of the colonies lost all affective ties 'outside the walls' and constructed their own world within.

<sup>3</sup>While this volume had only limited information on Curupaiti, it is an excellent collection of documents that was compiled as part of a project to demonstrate how historical documentation should be done. I borrowed original copies of these volumes from the Ministry of Health Office of the Municipality of Rio de Janeiro, where they should still be available for researchers to view.

For this reason, one observes a continuation of the colonies, with no opening in the 1960s/70s, preserving even today, in some of the 33 colonies that exist in Brazil, the relics of an ancient structure.

Also like Carville, Curupaiti became what Goffman (1961) described as a 'total institution'; the lives of the patients outside the walls of the treatment facility were rendered irrelevant, and identity came to be defined by their disease and their residence within the walls of the facility.

Today, the former 'colony' of Curupaiti covers 48,000m<sup>2</sup> in the half-rural, half-urban neighborhood of Tanque in Jacarepaguá. For the residents, there is a cultural center with a literacy program and other practical courses for residents; churches (a Spiritist temple, Catholic church, Assembly of God evangelical church, and a Buddhist temple); fields for soccer, volleyball, and basketball; stores; bars; and most medical facilities (Cruz, 1995, and personal observations). There are ambulances that are available to transport residents to doctors' appointments in other parts of the city for any medical services that are not available on the grounds, but I learned in the morning waiting room appointments I attended that there is a children's dentist, a gynecologist, an ophthalmologist, and a cardiologist available on different days. Psychologists and social workers are available for residents as well.

At Carville, residence at the facility began to be discouraged by the late 1970s. In contrast, when the doors to Curupaiti were opened, more people moved in than out. By the mid-1990s, approximately seven hundred former patients lived in Curupaiti, and there was an unknown number of family members of former patients living there (Cruz, 1995). No new construction is allowed on the grounds, but the families of former patients who may have been separated from them in the past have been allowed to move in and receive all the benefits of living there, such as free, readily available health care. This fact seems to have created a situation of dependency among residents, both former patients and their families. Some residents are descendants of former patients, and I was told that some of them do not even know that Curupaiti ever functioned as a facility for Hansen's disease patients. Another phenomenon that had taken place at Curupaiti was that some patients who had been more recently diagnosed with Hansen's disease were occasionally managing to live within the community. The facility does not encourage new patients to live there, nor does it provide them with a place to stay. However, there seem to be some problems regulating the influx of new residents.

On my visits to Curupaiti, I interviewed several staff members. A psychologist, Suzana Maria Ormachea de Duran, discussed a case with me in which a patient who had been diagnosed with leprosy in

recent years had decided to become a resident. Duran also wrote a short but insightful monograph on this case. Her paper is entitled 'SER', a pseudonym for this patient's son, a play on words, as 'ser' is the Portuguese infinitive 'to be', and SER is also an acronym for Social and Economic Rehabilitation. SER's mother was a "clandestine resident," as Duran (1995, p. 21) puts it. She had moved into Curupaiti shortly after being hospitalized there for complications associated with Hansen's disease. An employee at the hospital, who may have been a former patient himself, invited her to move into Curupaiti, emphasizing that it would be much easier living inside the gates of the facility than on the outside, where the *doente* (sick person) is treated differently because of stigma. She came to think of Hansen's disease as a chronic and permanent illness. SER was also diagnosed with Hansen's disease. At nine years old, he was not following the treatment schedule of physical therapy. This was in part due to his mother's belief that Hansen's disease was incurable and that nothing could really be done to help him. Meanwhile, he was suffering stigma at school, particularly during a time when he was wearing a cast on his arm. The other children knew that he lived in Curupaiti, and they would call him *aleijadinho* (translated as 'little cripple,' but also the nickname of a famous eighteenth century sculptor in Brazil who had Hansen's disease). His teacher and the parents of other children in his class were fearful of SER attending school as well. His problem was eventually brought to the attention of the staff at Curupaiti. A group of health professionals was sent to SER's school to provide them with information about Hansen's disease. There was also an evaluation made of this case. It was found that one physician who had treated the mother when she was in the hospital at Curupaiti essentially gave up on her when she refused to comply with treatment and told him she had decided to live on the grounds of the facility (Duran, 1995).

One reason that new patients might decide to institutionalize themselves may have to do with the encounter of the past and present worlds of leprosy in one location. This encounter has taken place at leprosaria worldwide. At Carville, for example, most of the patients who arrived after 1950 did not and would never suffer severe deformities from their disease. However, when they arrived at Carville, they often encountered patients with multiple amputations, claw hands, and other disabilities associated with the advanced form of untreated Hansen's disease. Older patients occasionally would tell new ones who came in that they would be there forever and that Hansen's disease was incurable, because for them, it was. Likewise in Brazil, patients who are treated at or who visit a former leprosarium may come to have a different perspective on their disease than those who are treated at other health posts. One patient I interviewed, who had completed outpatient multidrug therapy treatment for Hansen's disease in Niterói, was

discussing the fact that she realized her disease, which doctors call *hanseníase* (Hansen's disease) was the same as the disease of the people in the leprosaria:

It is *lepra* (leprosy). I'm an Evangelical, so I was in the colony [visiting with her church]. People there would look at me, at my appearance and say, "You don't have this disease." Then I'd say, "I had it. I had it and I went through treatment. I'm always in reaction." Then they say, "No, you didn't have it. You have eyebrows, I don't. I have a mutilated nose, you don't." People have those things, right? ... You know that if you don't get treatment, you're going to be like that. It is, it *is* this disease.

This patient recognized the fact that the treatment program prevented her from having severe deformities and made the difference between the past and the present in terms of the reality of Hansen's disease. If patients do not receive adequate information that Hansen's disease is treatable and curable, they may institutionalize and stigmatize themselves as 'lepers' (*leprosos*).

Another reason for self-institutionalization is the economic situation in Brazil. Minimum wage in Brazil as of April 2002 was 200 Brazilian reals (*reais*) per month (about \$70 U.S.). Many families have just one or two wage earners to support several people. Most people in the lower socioeconomic class in Brazil cannot afford regular housing. A large percentage of the population of Rio de Janeiro and surrounding municipalities live in shantytowns, or *favelas*. Although some *favelas* have undergone urbanization (installation of electricity, paved roads, plumbing, garbage service), most have not, and living conditions are less than adequate. Violence is also very prevalent in many *favelas*, where gun battles between drug traffickers and police are everyday occurrences.<sup>4</sup> Adequate health care is difficult to come by in Brazil as well, as most of the physicians in the public health posts are underpaid and overworked. Some of the larger *favelas* have health posts, but they offer only limited services. The appeal of living on the grounds of facility where rent, health care, recreation, and food are available is obvious.

However, there are problems for former patients and others who choose to reside at Curupaiti. Within the community of Jacarepaguá, this facility is fairly well known as a leprosarium. The popular belief about Curupaiti is that it still operates as a confinement center or at least as a place of residence for leprosy patients. Thus, a stigma has been generated surrounding the facility. This stigma can present a problem for Curupaiti's residents in their interactions with people on the outside.

The stigma of the former leprosarium also affects outpatients who come there. During waiting room groups, some patients who had come there for dermatological problems had been warned by friends or family not to go to Curupaiti for treatment because of the dangers of contracting leprosy there. The social worker that usually directed

<sup>4</sup> Drug trafficking has become a problem at Curupaiti in recent years, however.

these discussions noted that it was more likely to get Hansen's disease on the outside than within Curupaiti, where everyone has been treated and is no longer contagious. Also in these meetings, I heard some of the popular models of leprosy in Brazil, most of which I had already learned from interviews with patients, health care workers, and volunteers in Rio de Janeiro. Some of these beliefs include the idea that leprosy comes from casual contact with infected individuals, contact with dogs, contact with contaminated floodwater, or consumption of fish or pork. The common belief that leprosy makes you lose limbs (*cai em pedaços*, literally 'fall to pieces') was volunteered by some at these discussions as well.

These waiting room discussions were useful in attempting to educate patients about Hansen's disease and to dispel some fears about visiting the facility. But the presence of former patients would sometimes negate the messages of the social worker leading the discussion. As in many former leprosaria or Hansen's disease confinement centers, many residents of Curupaiti still consider themselves to be 'patients' and think of themselves as 'sick', particularly if they have disabilities or deformities from Hansen's disease. At the waiting room meetings, there was often a mix of residents and outpatients with various ailments. One morning, a former patient and resident of Curupaiti, an elderly woman with swollen ankles and some sores argued with the other patients in the waiting room. In a discussion of what *hanseníase* was, she spoke up. "*Eu sou doente*" ("I'm sick"), she insisted. She talked about the stigma she had experienced in the past with this disease. Another woman said to her, "Were you released (*recebeu alta*) by the doctor?" "Yes, ten years ago." "Then," the other woman said, "you are not sick. If you had a cold, and it's gone, are you still sick? If you had a wound, and it's scarred, are you still hurt?" Eventually the former patient conceded that she was doing all right today and said that she was at the clinic that day not for any problem related to Hansen's disease, but because of an allergic reaction to shrimp. Yet her self-perception as a 'sick person', by virtue of her former status as a leprosy patient and a current resident of Curupaiti, she presents an image of Hansen's disease as an incurable disease that requires isolation.

### Conclusions

Although the confinement of Hansen's disease patients is a thing of the past, there are still thousands of individuals worldwide who are affected by twentieth-century policies of isolation. In the transition to the modern era, the problems that have arisen at Carville and Curupaiti have been very different. At Carville, former residents were encouraged to leave the place that they had come to see as their home, a place where they were once forced to reside and later felt



obliged by the government to leave. Although they were not denied financial support or long-term medical care, they were deprived of the community that would have provided them with emotional support and happiness in their later years. At Curupaiti, former patients and their families continue to live and receive government support. However, the failure in this case is related to the influx of new residents to Curupaiti and the potential for self-institutionalization of new patients diagnosed with Hansen's disease.

The Carville case was related to political decisions involving funding this facility, which, because of the extremely low incidence of Hansen's disease in the U.S., was deemed unnecessary. Although Carville did operate as an outpatient facility on a small scale, it was not considered to be economically feasible to keep it open to treat newly diagnosed cases and to care for former patients. However, in closing Carville, a lack of concern for the well being of the former patient residents at Carville was demonstrated. At Curupaiti, the problem of self-institutionalization of new patients has complex causes. Some stereotypes about leprosy might be perpetuated by the coexistence of outpatients and a permanent resident population on the same grounds. Patients in treatment for Hansen's disease may become confused by the confinement era picture created by Curupaiti and might come to see themselves as *leprosos* (lepers) or *doentes* (sick people), as some of the former patients in residence call themselves. Also, residence on the grounds has become desirable both for new patients and non-patients, largely due to the current economic situation in Brazil.

While facilities like Carville and Curupaiti are no longer necessary (and were perhaps never necessary) for Hansen's disease patients, government officials worldwide should remember that former patients may continue to be affected both physically and psychologically by having Hansen's disease and all that this entails. In the case of patients who were forced into institutionalization many decades ago, governments have a responsibility to continue to care for these patients. Long-term follow-up and appropriate care for all former Hansen's disease patients should be an important part of Hansen's disease elimination programs. Such care would not lower the prevalence or incidence of Hansen's disease, but it would improve the quality of life for many people. At the same time, it is important to make sure that in Brazil, where the incidence of Hansen's disease continues to be high (41,070 new cases were reported in 2001 [World Health Organization, 2002]), new patients receive enough information about their disease to know that there is no need for institutionalization or confinement. New patients should be provided access to services that help them maintain their independence and even improve their quality of life at home and at work, through outpatient care (including medical treatment, physical therapy, and psychological and social services), education of family members and

employers about Hansen's disease, and assistance with disability benefits if necessary. Curupaiti does provide many of these services already, so the main goal for the future might be an attempt to make sure that no one falls through the cracks. Of course, ultimately this goal is extremely difficult in an area with limited economic and educational opportunities for the population most affected by Hansen's disease today.

Through my experiences at Carville and Curupaiti, I have come to see that the legacy of the leprosarium era is still alive in the buildings and on the grounds of these facilities. I have seen the importance of documenting the rich history of the communities that developed in these and other leprosaria around the world. The memory of Carville and Curupaiti is still extant in the minds of many people who were confined there and who worked there. I have also found it important not to forget that these facilities continue to have meaning and function for many individuals. In the effort to phase out leprosaria around the world, it is important both to avoid future stigmatization of new patients while respecting the rights of older patients who were forcibly confined in the past and who now identify themselves with the confinement center. I believe this balance can be achieved through the wider dissemination of information about Hansen's disease, its treatment, and its history.

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