

Oral history and memories of Hansen's disease patients in two Colombian leper colonies: life trajectories, conflicts and resistance strategies

Natalia Botero-Jaramillo

Professor, Facultad de Medicina/Universidad de Antioquia.
Cra. 51d, n.62-29
Apartado aéreo 1226
Antioquia – Medellín – Colombia
natalia.boteroj@gmail.com

Jessica Mora-Blanco

Professor, Facultad de Medicina/Departamento de Humanidades/
Universidad El Bosque.
Av. Cra 9, n.131A-02
Bogotá – Cundinamarca – Colombia
jpmora@unbosque.edu.co

Nelson Daniel Quesada-Jiménez

Professor, Facultad de Medicina/Departamento de Humanidades/
Universidad El Bosque.
Av. Cra 9, n.131A-02.
Bogotá – Cundinamarca – Colombia
nquesada@unbosque.edu.co

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Abstract

The paper examines the oral history of Hansen's disease in two Colombian communities that were leper colonies until 1961. The oral history around the disease allows us to connect individuals' memories with collective memory. This history remains an oral one, and few academic studies have documented it. We use oral history as a qualitative research method in order to analyze how the patients and those who lived alongside them positioned themselves in terms of the disease and how it permeated their entire existence, re-signifying the concepts of health and disease, normality and abnormality. We examine how, over the course of their lives, they engaged in resistance strategies that allowed them to get closer to normality, in their own sociocultural terms.

Keywords: Hansen's disease; oral history; resistance; memory; normality.

...that's how God repaid him, just as he repaid Uncle Luis, who went off to be a chaplain in Agua de Dios, the Colombian leper colony in a town in Cundinamarca, where he caught the disease he eventually died of, with strips of his back peeling off, and pieces of his fingers falling off.

Excerpt from *El olvido que seremos* (Abad, 2006, p.108)

Hansen's disease is a disease with a strong historical and cultural component. It is recognized as a medical entity, but in addition, a series of beliefs and meanings has been constructed around it that highlight its sufferers' body image, the connection to divine punishment and the ostracism to which they were subjected (Obregón, 2002, p.22-24). Ever since it was first reported, Hansen's disease was perceived as special, and it became the object of various myths and beliefs generated by the concepts of normality and abnormality, which set in motion their own social dynamics. By the twentieth century, when Colombia aspired to ideals of progress, the state became concerned with controlling incidence of the disease; therefore, in order to protect society, three leper colonies were established to isolate patients in strategic locations around the country. These were Caño de Loro in the department of Bolívar, Agua de Dios in Cundinamarca, and Contratación in Santander (Obregón, 2002, p.206; Platarrueda, 2009, p.70).

Inside these leper colonies, various surveillance measures were enacted not only to insure that patients remained isolated but also how they were to live, measures that were based on the religious and public health beliefs of the time. However, these institutions only continued as leper colonies until 1961, when mandatory isolation was abolished; a year later, they became municipalities. This was due to the expense of maintaining them as colonies and the implementation of treatment with sulfones, which guaranteed recovery under the biomedical paradigm (starting in the 1940s); this modified strategies for managing the disease and attitudes to it in the medical and political sphere (Obregón, 2002, p.360-361).

Throughout history, an oral tradition has built up around Hansen's disease that has been passed on from one generation to the next. However, these stories have remained purely oral, and few studies of scientific literature have collected them. Some research studies in Colombia have relied on oral history and qualitative research methodologies: interviews, ethnographic observation and collection of documentary sources, as seen in Obregón (2002), Platarrueda (2009), Sevilla (1995) and Botero (2009; Botero, Polo, Sinuco, 2015). On an international level, the Global Project on the History of Leprosy, run by the International Leprosy Association (ILA), is of great relevance in connecting oral history with the disease. This project is based on the idea of guaranteeing that a patient with Hansen's disease will be listened to so as to document individual perspectives, "empowering people and letting them take their proper place in history" (Platarrueda, 2009, p.214). Bearing in mind that approaches to oral history and health have not been extensively explored, we need more extensive studies of the construction of the oral history of diseases and its importance in the historical context of the period.

The goal of this article is to examine the oral history of Hansen's disease patients and those who lived alongside them in the historical context of Colombia in the twentieth century,

and to analyze discourses about notions of normality, abnormality and the health-disease process. We use oral history as a qualitative research method, supported by consultation of primary sources and secondary bibliography, in order to understand the internal history of leper colonies, beyond the policies established for patients. Using interviews, field trips and ethnographic observation, we attempted to reconstruct the memory of inhabitants of the former leper colonies in Contratación and Agua de Dios, and to trace how patients resisted the pressures caused by their abnormal status, which reinforced the ostracism long used to control the disease. We also looked at the isolation mechanisms mandated by the State, at medical and public health policies and at administrative issues relating to leper colonies (Obregón, 2002, p.205-210). We analyzed how Hansen's patients viewed their condition, how medical diagnosis labeled them as diseased, how the medical institution of hostels and leper colonies controlled their lives, and how patients engaged in practices and discourses that undermined the concepts of disease and abnormality so as to re-signify themselves as ordinary subjects.

Our data collection centered on oral history, based on interviews with inhabitants of the towns of Contratación and Agua de Dios, which allowed us to reconstruct various facts and describe the conditions pertaining to them. We sought to understand the status of Hansen's disease patients in twentieth-century Colombia; the isolation mechanisms mandated by the State; medical and public health policies; and administrative issues relating to leper colonies and control of the disease.

We performed two field trips. The first was to the town of Contratación in the department of Santander, where we approached patients and their families directly and carried out interviews. The second took us to the town of Agua de Dios in Cundinamarca, where we interviewed Hansen's patients in nursing homes. Our criteria for inclusion involved elderly people who agreed to the terms of our research and who had lived in the leper colonies in Agua de Dios and Contratación for at least a year; either patients with the disease or those who lived with them under the same conditions.

We carried out a total of 20 life-story interviews of relatives and patients with Hansen's disease from July 2013-March 2014; we also used interviews from 2007-2009, and studies by one of our researchers on memory and oral history relating to leprosy. The interviews were semi-structured and thematic, and audio recordings of people's life histories were made. Afterwards, we organized the information, transcribing the interviews and generating categories based on the life histories collected and the phenomena described. For ethical reasons, the interviews were carried out with informed consent, and the people interviewed will remain anonymous. The total number of interviews was determined by whether we felt we had enough information, based on prior research we had carried out.

In this article, we review the methodology of oral history, highlighting its importance for health sciences. In our results, the various life histories were pieced together in an account that covers the most significant aspects of the process of living with the disease inside the leper colonies. Lastly, our discussion offers an analysis of these life histories in terms of the concepts of normality and abnormality as opposing but also connected concepts that allow us to see Hansen's disease as an experience that, although it marked the life of the patients and those who lived with them, also led to methods of resistance.

Overview of oral history

The term “oral history” began emerging in academia after Second World War. Allan Nevis was the first to use oral history as a major research source for constructing history and generating archival records. As a result, the Columbia Center for Oral History Research was founded in 1948 at Columbia University, New York. Initially, it was only intended to record and make available experiences related to local history (Dunaway, Abelló, 1995, p.27-38).

Technically, oral history consists of preplanned recordings of people’s narratives; it involves a series of technological and analytical procedures aimed at obtaining a complete description of the subjects one wishes to study. Thus, oral history helps promote analysis of social processes occurring in the present, facilitating first-hand knowledge of the environment, which is useful for studying identities and cultures.

Oral history is an innovative tool, since its principal source lies in spoken narratives rather than written documents. We can see oral history not only as a series of simple thematic interviews, but as a resource that helps fill gaps in our knowledge of certain acts and social actors in a meaningful way. It arises from social participation, in that it gives visibility not only to people whose voice is heard in history but also to subaltern subjects, facilitating our understanding of identities. It means that any person can be a source for broadening our knowledge, and that in itself allows for academics and working-class sectors to come together to retrieve and preserve memories of communities and of the health-disease process (Meihy, 2005).

An important characteristic of oral history is that the researcher has to deal with subjectivity, since “for the oral historian, subjectivity is part of the material aspect of history, just like economic data, police documents, or the mass media.” Oral sources tell us not just what the subjects did but what they wanted to do, what they thought they were doing or what they think now about what they did, which gives a different kind of credibility than other types of sources used by researchers (Meihy, 2005).

While testimonial interviews were granted new value in the 1960s as a means of obtaining information that was not recorded in any written medium, in Latin America oral history came out of the drive to give voice to outcasts, peasants, the poor, and the excluded. The rise of oral history in Latin America has been particularly strong in Brazil, where we find a large number of articles on it in the literature (Martins, Caponi, 2010). In addition, oral history studies of disease have involved various social actors, such as doctors, nurses, patients’ relatives and patients themselves (Boff, Caregnato, 2008; Guimaraes, et al., abr.-jun. 2013; Visentin, Labronici, Lenardt, 2007).

Oral history and memory

Oral history is “the product of a movement for progressive change in the social sciences that is centered on rescuing collective memory, both social and individual” (Pozzi, 2012, p.61). There is an important connection between oral history and memory: since memory is oral history’s main foundation, it is seen as a space where versions of the past have not yet

gained a written dimension – whether individual, social or collective – a process affected by the processes of remembrance and forgetting.

Hardly any of what was observed in the past is remembered; hardly any of what is remembered is recorded; hardly any of what was recorded survives; hardly any of what survives gets historians' attention; hardly any of what gets attention is credible; hardly any of what is credible is perceived; hardly any of what is perceived can be apprehended or narrated by a historian (Louis Gottschalk, quoted in Meihy, 2005, p.63).

According to Julio Aróstegui, memory has two main functions: the ability to retrieve past perceptions and experiences and bring them to the present (extending and keeping them alive); and to provide a foundation for history and a vehicle for transmission. However, within the field of memory, it has been pointed out that both collective memory and individual memory exist. Neither excludes the other; on the contrary, they complement one another, although they can come into conflict and contradiction.

Rescuing memory allows forgotten scenes to be recreated, and events that were recorded in a biased way to be investigated; it allows people to retrieve, value and share biographies. It represents a way of understanding the past, without which it would not be possible to construct oral sources (Pozzi, 2012, p.65). Individual memory is the most intimate way of recreating oral history. It is exclusive to every individual, which does not mean that it cannot be shared, since many memories are related in time-periods, contexts or conditions that are similar. Furthermore, collective memory is a phenomenon affected by the strength of the external factors and power relations characterizing a given group, which shaped its identity; this type of memory is marked by collective actions and thoughts and is established when there are thematic affinities. It is a very elaborate cultural construction.

Memory belongs in the oral domain; it is both an individual and a social process, since each history that is recounted complements another, analogous one, creating a sense of belonging and identity. Memory allows people to construct social history, which involves common places, and this also applies to oral history. José Sebe Bom Meihy (2005) sees the process of constructing a collective memory as being based in oral history; he compares oral history to a law of economics – the law of diminishing returns – explaining that at some point in any research study, oral histories become so similar, with places and situations common to all of them, that they gain a certain redundancy in which individual accounts seem to meld into one, revealing the collective nature of individual memory.

Oral life histories

The oral life history is a process whereby the speaker assumes a place in history based on his or her own interests and under certain power relations (Platarrueda, 2009, p.191). It is a social research method that is descriptive and analytical, that seeks to reveal the dialectical relationship between utopias and realities, creation and acceptance (Charriez, 2012, p.50). It provides a phenomenological perspective that helps explain social interactions and human behavior; in this case, it sees disease both as a phenomenon and as a social construction in the life trajectories of subjects.

The life history is a research strategy aimed at generating alternative versions of social history by reconstructing personal experiences. It constitutes a first-rate resource for studying human events and facilitates understanding of the relationship between subjectivity and social institutions, with their imaginaries and representations. The life history allows everyday life to translate into words, gestures, symbols, anecdotes, and tales, and constitutes an expression of the ongoing interaction between personal and social history (Puyana, 1994, p.185-186).

The life history works with personal experiences, and while it is subjective, via those experiences it allows one to grasp the feelings of each individual and to study their private lives more closely. Both sociology and history have used life histories to record oral testimonies that help characterize what problems are relevant in terms of various conceptual, temporal and thematic categories (Cornejo, Mendoza, Rojas, 2008, p.30). Life histories allow important events to be reconstructed within an individual's life process, bearing in mind the cultural and biological changes undergone by human beings. Reconstructing each individual's history allows the speakers to appropriate their lived experience and connect it to their reality, bringing emotional components of the disease process to an objective state.

Life histories are always told to someone and constructed around a given situation. When someone is asked to recount part of their life, they take a position in terms of what to tell and are given the ability to create a concept of themselves and to subjectively appropriate their experiences. This shows how telling a story can be a dynamic process, allowing the interviewer to seek out different key points for approaching a research problem and obtaining knowledge. Thanks to oral life histories, it has been possible to interpret changes in history, societies and cultures by listening to and recording the memories and experiences of different individuals.

Life in the leper colonies

After public health measures were put in place to control Hansen's disease in Colombia in the early twentieth century, it became a topic of national attention; numerous laws were passed and large amounts of resources were invested in controlling transmission of the disease, which at that time was considered extremely infectious and untreatable (Obregón, 1998, p.130-131, 2002, p.207-209). As a result, the leper colonies of Colombia, Agua de Dios, Contratación and Caño de Loro (this last one disappeared some time later) underwent a process of medicalization in response to the need to isolate patients (Obregón, 1997, p.141).

This process of medicalization of the disease led to the creation of legislation that favored mandatory isolation, the creation of hygiene measures and medical and epidemiological oversight of them, reflecting the world-wide tendency to establish leper colonies as total institutions. In constructing a leprosarium,¹ the main consideration when choosing a location was a place that was geographically inaccessible and far away from the country's main cities. After sites were selected, the regulations for the leper colonies were drawn up; they became institutions for ostracizing and isolating people from society (República de Colombia, 1934, 1937).

Access to the leper colonies was restricted by a cordon sanitaire or isolation line² staffed by members of the National Police who did not have Hansen's disease, unlike the police on

the inside, who were known as “sick police” or “stump-fingered police,”³ whose job was to guard the inhabitants of the leper colony, creating a “carcelary and policed atmosphere” (Platarrueda, 2009, p.147; Botero, 2009, p.27). Once patients crossed the isolation boundary, their national identity cards were exchanged for new ones used only inside the leper colony, symbolizing the loss of their rights. The new card was used as a way of controlling patients' movements in and out. Another control measure put in place was the creation of a currency used only inside the colony. This was due to the belief that contact with objects touched by Hansen's disease patients could result in transmission, based on the bacteriological paradigm of disease, which helped reinforce patients' stigma and isolation (Platarrueda, 2009, p.147).

The layout inside the leper colonies consisted of two hospitals surrounded by four asylums: one for sick women, one for sick men, one for sick girls and the last for sick boys. There were also asylums for the patients' healthy children, located outside the colony (Botero, 2009). All these were run by members of the Salesian religious order, which took over these children's upkeep and care in the late nineteenth century. The medical staff building (where the doctors, nurses and bacteriologists were housed) and the administration building were located at a distance from the colony's inhabitants, next to the isolation boundary (p.27-29).

Trips outside the leper colony were only allowed with a permit from the mayor specifying the start date, length and end date for the excursion; if for any reason this rule was broken, the patient was fined.⁴ Another restriction stemming from the debate about heritability and contagion – a topic discussed in the early twentieth century by the medical and scientific community – was the ban on marriage between healthy people and Hansen's patients, which restricted healthy people from living in the leper colony; if they wished to do so, they had to be subject to the isolation rules. If for any reason such a relationship took place and children were born, they were taken away immediately and placed in asylums for healthy children⁵ (Botero, 2009, p.61-68; Obregón, 2002, p.272-273). Despite all this, these measures led to forms of resistance on the part of patients, which we will discuss shortly.

They discovered I had the disease

Oh painful days when they came after us
Those who suffered that cruel disease;
To them the police said harshly,
“Stop right there and follow me, sir.”
They walked away weeping, leaving their families,
Wrenching a last farewell from their breasts
Their faces pale, looking like the dead
All you could hear was weeping and “goodbye”
Why did they chase us down like wild animals?
Why did they snatch us from our beloved homes?
Why did they add to our bitter cup?
Why did they humiliate us in society?

(González, 2011, p.17)

A diagnosis of Hansen's disease was a gateway to discrimination, so receiving the news that one had it was a dreadful misfortune for the patient. The clinical variations in the way the disease presents meant that each person had a different experience. Living with the disease was – and still is – something only the patients themselves can describe:

And the breakouts I had on my skin, I used to say they were like boils and lies, was 'nervous leprosy,'⁶ (interview with a male Hansen's patient, Agua de Dios, 2014).⁷

What I've got on my back is I've got spots, I get like fever and dizzy spells; they did a bacillus [bacilloscopy] and it came out positive; I started getting growths on my arms and legs (interview with a female Hansen's patient, Agua de Dios, 2014).

Discrimination did not come only from society; within the family, patients had to face the various reactions caused by news of their disease. These reactions involved not only emotions such as grief, sadness and alienation produced by the imminent separation, but also condemnation, concealment and rejection.

My dad took me to see an aunt who lived in Socorro so I could say goodbye to her. She knew about my case and she took me to a place a ways from the house, where you could see quite a long way off to the south, and she pointed to the mountains, way far off and said, Son, those mountains way off in the distance, that's where they're going to take you, and anyone who goes there, they never come back again because they die. Their arms fall off, their hands fall off, their feet fall off, they're completely disfigured and they're not allowed out ever again. So we'll never see each other again here (interview with a male Hansen's patient, Contratación, 2013).

Saying farewell and the hardships of isolation

Once diagnosed with the disease, it was impossible to avoid isolation. The police tracked patients down and forced them to go to one of the leper colonies. At that point the patients had to say goodbye to their families, leave their daily lives behind, and adapt to a new situation.

I was three and a half when my mother and I got thrown out. At that time they were very tough on leprosy, you were like a criminal. We had to go to the leper colony; it took four days to get from Cúcuta to Guadalupe, because in those days there was no road. We got to Guadalupe at 6 in the evening and they wouldn't put us up anywhere because they were very strict about it back then. We had to sleep on the floor in a big old shed, where they kept farming equipment for livestock and all that shit. The next day we carried on. We left at 6 in the morning from Guadalupe; the police were supposed to come and get us. When they arrived at 7 at night to collect us – because the police were coming from Cúcuta to Guadalupe and they didn't go any further – there were 10 policemen with leprosy and another ten who were healthy, to take us to Contratación (interview with a male Hansen's patient, Contratación, 2007, cited in Botero, 2009, p.21).

The name "The Sighs" was used for two iconic places that were highly important to the history and collective memory of the leper colonies in Agua de Dios and Contratación. In Agua de Dios, "The Sighs" was a bridge over the Bogotá River, and in Contratación it was a monument – a statue of the Virgin Mary on the side of a building, where the first cemetery

was located. Each of them symbolized the problem of isolation. While "The Sighs" in Agua de Dios reflected patients' isolation from the outside, since it was the place where they had to bid farewell to their families and the "world of the healthy," in Contratación it represented a second type of isolation, an internal one, since the monument was the place where patients said goodbye to their children who were taken to asylums for healthy children of Hansen's patients.⁸

For patients, travel to the leper colonies meant a long and torturous voyage to a place of banishment. In many cases, they were taken there forcibly by the police; others went of their own free will, setting out on their own for the colonies in order to avoid being transported like prisoners. They remembered their arrival as painful moment when they first glimpsed the place where they were to spend the rest of their lives. This meant meeting the people who were their peers, since they shared the state of illness and isolation. Although arriving at the leper colony meant separating from one's family, for some it provided a chance to meet up again.

My mom left because she was ill, and since at that time they would track you down if you were sick, like they do the guerrillas nowadays, she had to go to Contratación (interview with a male Hansen's patient, Contratación, 2013).

Plodding down the mountain pass come a motley band of Hansen's patients... The scene is composed of withered elders, grown men, young mothers, nubile maidens and even babes in arms ... Various patients are carrying their belongings with them: a rush mat, a towel, a blanket; some have a thin piebald rooster, with one eye and a lopped-off spur, and a skinny dog, on its last legs. ... There are always sad and moving scenes. A mother who sees her beloved daughter in the group, a son who recognizes his father ... A paradox: the husband who refused to follow his wife when they sent her off into the deprivations of exile ... driven by prejudices and scruples, he wrongly believed he was free of the deadly disease (Ruiz, 1998, p.97-98).

Upon arrival, patients first encountered the people with whom they shared the condition of living with the disease. In many cases, even though existing residents had no social connections to the new arrivals, daily routines and the fact that they had to share space with each other on a day-to-day basis meant that in the future, they would become like family. In other cases, new patients might be meeting family members who had been diagnosed with the disease earlier, as in the case of a woman who arrived at the Agua de Dios leper colony as a girl and was reunited there with her father and siblings after many years of separation, thanks to her Hansen's diagnosis.

My arrival was dramatic. It was really painful and sad, because my dad thought I was in Popayán⁹ and a man who came to meet me at the first sentry post [where people coming into the leper colony had to report in] called the police and told them to go and get my dad ... he said, "Hey, go and get 'Chucho the partyer,' Chucho Gonzales; his daughter just got here from Popayán." My dad didn't believe them, so the policeman and one of the managers from Agua de Dios sent a driver – his name was Mr Carmona – whose hands and nose were in a bad way, but he had lovely eyes, they were as blue as can be ... When the policeman said to me, "Get in, honey, they've come to get you, ok? Your dad sent for you, he's waiting for you over there." [And they told my father] "Look, look, this is your daughter, this is your daughter," [and my father replied] "My

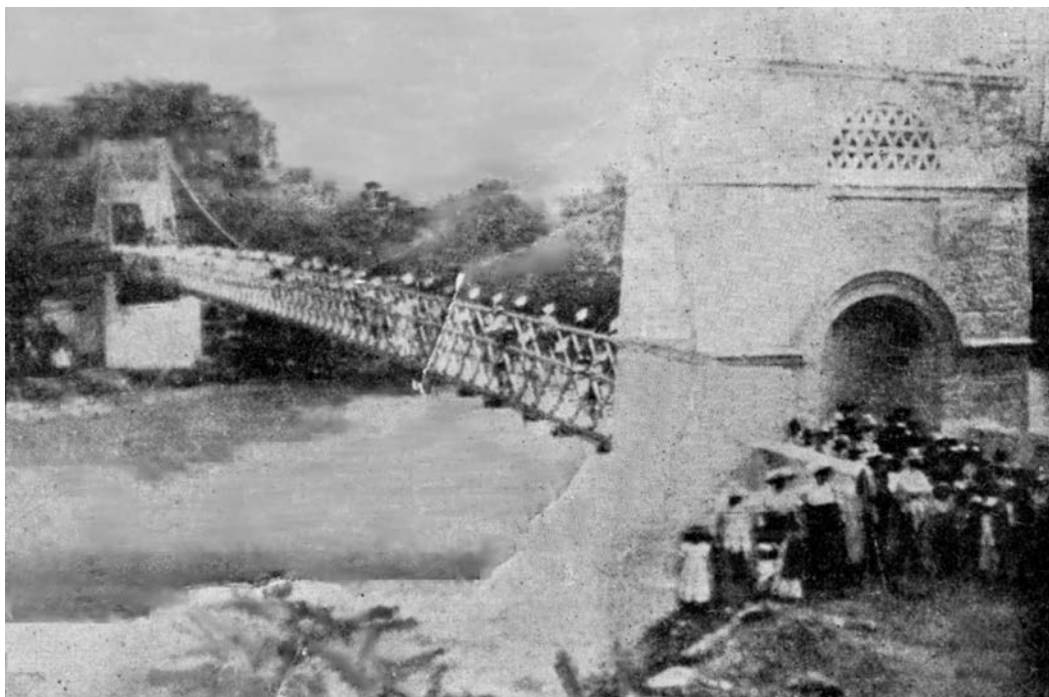


Figure 1: The Bridge of Sighs (Museo de la Lepra de Agua de Dios. Date obtained: Mar. 2016)



Figure 2: Burial at the House of Sighs – Contratación (Archivo Fotográfico, Memoria histórica del municipio de Contratación. Date obtained: June. 2013)

daughter? That skinny little thing? No, no, no. My daughters are students at Popayán. Where did you get this girl? If you brought her here, keep her, because she's not mine!" And my dad said, "Where are you from, dear?" "Can't you see she's from Popayán, from Popayán?" [they said to the father]. My sister recognized me, she hugged me through the car window, and I screamed and cried. [She said], "Dad, it's her, it's her!" And I cried and cried... [I asked him] "Why are you crying, dad?" [The father answered] "No, I'm just happy, honey, because you've come to live with us, you're going to live with us, you know." (Interview with female Hansen's patient, Agua de Dios, 2014).

Isolation within the leper colonies

Upon arrival in a leper colony, patients became subject to a series of laws passed by the Leper Colonies Board (Dirección de Lazaretos) at the Health Ministry (Ministerio de Salud), which required mandatory isolation and social control within the colonies. Trips outside the colony were only allowed with permits granted by the mayor, stating the start date, duration and end date. If patients violated this rule for any reason, they were fined. Inside the leper colonies, healthy and sick people could live together, which made it possible to have relationships and start families, despite the ban on marriage between patients and non-patients (Botero, 2009, p.50). Children in the leper colonies were classified as either "healthy" or "sick" and taken to the corresponding asylum. Thus, healthy children were taken to asylums outside the colonies that were run by Salesian monks and nuns, who provided education, food and care. One of these healthy children tells his story:

I've never forgotten the day my mother, who was sick, took me to the San Bernardo del Guacamayo-Santander Asylum for healthy children and handed me over, like Judas delivering Christ, to Father Alberto Cortés, the prison director. I cried all afternoon and part of the first night until I wore myself out and fell asleep. Perhaps in my innocence I thought I was dreaming, but it was the harsh reality. My mother wasn't beside me, and how terribly painful that was. When I woke up, I understood, and I was so lonely it felt like my heart was breaking (interview with a Hansen's patient's relative, Contratación, 2007, cited in Botero, 2009, p.66).

The asylums for healthy children were described as centers where Salesian priests provided a strict, inflexible education and discipline, justified from the national point of view by the need to train young people for agricultural work and manual arts and crafts, in the hope of creating productive adults so as to make them "useful citizens" and keep them away from the leper colonies and their sick relatives.

Just as transfer to the leper colonies was mandatory for patients, healthy children were also obliged to remain in the asylums. If this rule was broken, either because the parents did not hand their children over or because children or adolescents ran away, the patient's allowance was cut.¹⁰ This meant that healthy children who lived in a leper colony with a parent or parents who were sick, even they themselves had no Hansen's diagnosis, were subject to the isolation and surveillance laws and required to undergo mandatory internment in asylums until they reached adulthood, at which point they were allowed to leave.

What a disappointment! Two weeks after I disappeared from boarding school – that prison – my step-father was notified by the Director of the Sanatorium that I was to

return immediately to prison or the allowance that leprosy victims received would be cut. It was our family's only means of subsistence, their only source of cash for daily expenses. It was no use crying; since we had no alternatives, we were so dirt poor, I had to go back (interview with the relative of a Hansen's patient, *Contratación*, 2007, cited in Botero, 2009, p.86).

The policing of life¹¹ inside the leper colonies and resistance strategies

Over time, we managed to persuade patients to tell us what life was like inside the leper colonies. Thus we were able to uncover a common and oft-repeated story among the inhabitants of those places, who described the use of highly symbolic objects that represented the total institutional power of the leper colony in collective memory. Objects like the coins that circulated exclusively within the colonies and the identity card marked the segregation to which Hansen's patients were subjected, which was exclusive to them: "They'd give you the colony ID and take away your other one. And money, they had their own currency there, and if you went outside, away from the colony, you had to get it exchanged" (interview with a male Hansen's patient, *Agua de Dios*, 2013).

Given the apparently rigid isolation measures, the grief of saying goodbye, the painful symptoms of Hansen's disease itself and all that it involved, when we think of the leper colonies as spaces of oppression, both patients and those who lived with them were victims of an unjust and humiliating system. However, their resistance to isolation and the bans in place in the leper colonies meant that life on the inside came to resemble everyday life on the outside. We now know that a wide range of strategies was used by the patients and those who lived with them to avoid obeying the laws imposed: strategies like hiding in the trunks of cars, avoiding the sentry posts by walking around them on the old bridle paths, or (in the case of healthy children of sick parents) camouflaging themselves among the market produce. Other resistance mechanisms that, while not actually breaking the law, did give patients a sense of agency, included contests, plays, parties, and all the events involving the patient community that allowed them to develop a daily life resembling that of "healthy" people, calling into question the dichotomy between the healthy and the sick.

On holidays there were usually bazaars, sometimes there were bull-fights, and you got special food and wore special clothing on those days. For breakfast we got tamales, sponge cake, egg and potato soup, cheese and crackers. It was a great breakfast, and lunch was great too. As far as I remember, the holidays we celebrated were the Director's saint's day, the Feast of Our Lady (May 24th), Easter Week and Christmas. On the Director's saint's day, they'd set up barricades for a bull-ring and whoever wanted to go fight the bull was allowed to; the food was super-special and they'd rig up a piñata outside. It was a real ceramic one that we had to actually break, so candies and things would fall everywhere. Some kid always got thwacked on the head, but that's what made it fun. Another great holiday was the Feast of Our Lady: we had a sports day and all the winners got tickets they could exchange for a fizzy drink called Chivo Clausen (interview with a Hansen's patient relative, 2007, Botero, 2009, p.71-72).

When there were holidays, a lot of patients used to dress up in disguise; I remember Emilio Rueda [a stage actor] who was very good at everything he did, and there were lots of musicians (interview with a Hansen's patient's relative, *Contratación*, 2013).

At 16 I was “nominated” for the kindness contest; I did a good job, treating everyone kindly. Maruja Parra won a little more money than me, but I brought in a lot myself, because I was made runner-up (interview with a female Hansen's patient, Agua de Dios, 2014).



Figura 3: Drama group (Archivo Fotográfico. Memoria histórica del municipio de Contratación. Date obtained: June 2013)

Although the ban on marriage was one of the most widespread and representative, there was no effective isolation for those who wanted to marry. Patients would escape the confines of the leper colonies to marry in churches in neighboring towns, with the help of priests who preferred breaking the law to allowing families to grow up out of wedlock, which was against Catholic doctrine at the time.

Until 1950 you had to do it in secret: a patient who wanted to marry a healthy woman or a healthy man who wanted to marry a sick woman. They had to get round the sentry post, get away in secret and tell the priest, ‘I want to get married.’ Some of them got married in San Pablo, others in Guadalupe or else other places, on the edge of a ravine, or in a house or a hut. But here, here sick people and healthy people couldn't [marry] (interview with a male Hansen's patient, Contratación, 2008, cited in Botero, 2009, p.28-29).

If a sick man fell in love with you, you couldn't marry him: they wouldn't let you. To marry him, you had to take the back routes out to Guadalupe or Chima or Guacamayo, the three closest towns, and get married there. Or there was a priest, Father Bruno Orjuela, who would marry people in the village in any poor person's house, or at a sugar-cane mill. That was what they were the most against, drinking, and getting married to someone who was sick. But that's what they mostly did (interview with a male Hansen's patient, Contratación, 2009, cited in Botero, 2009, p.29).



Figure 4: Contrateña family, 1940s (Archivo Fotográfico. Memoria histórica del municipio de Contrataciónulo. Source: Consejo de Cultura Alcaldía Municipal de Contratación, Santander)¹²

Everyday life in the leper colony led to the creation of customs that are still preserved in the town, such as the game of *la hueca*,¹³ a game adapted to patients' physical condition,¹⁴ which was played with friends, laughter, drinks such as *chicha*¹⁵ and *aguardiente*,¹⁶ bets and even rows. All of this met the patients' need to reconstruct their daily life and create new social networks.

The artistic and cultural movement in Contratación and Agua de Dios was representative. It grew out of the Salesian education in art, music, theatre and crafts and spread to the whole population, who built on those skills and succeeded in perpetuating them, taking them to spaces outside schools, to carnivals, fiestas and games, extending the frontiers of the local. As a result, nowadays those two towns host international events such as the International Puppet Festival.

I learned to paint by chance because I was sick, here in a hostel down in the town, the Ospina Pérez, at that time it was run by the Presentation Sisters [Sisters of the Presentation of the Blessed Virgin Mary, a religious order] and I was pretty sick, with joint pain, an illness called neuritis – that's what we called it – terrible pains, and so while I was having those pains, whenever I would get a bit of relief from the medication they gave me, I would take my mind off it by drawing things I saw around me on any piece of paper that came to hand. It got a lot of attention, that a painter from Agua de Dios [like me] could have shows in Bogotá and of course it got attention from all the big newspapers and TV (interview with a male Hansen's patient, Agua de Dios, 2014).

Reflections on the normal and the pathological

Using oral history as a method for reconstructing patients' life stories, individual and collective memory of the disease and life in the leper colonies, we analyzed the relationship between memory and the health-disease process, based on the concepts of social interaction, memory and discourse, social processes in which patients and those who lived with them constructed notions of what was normal and what was pathological (Canguilhem, 1976, 2011; Ostachuk, 2015; Giroux, 2011).

Oral history is based on the history of human subjectivity, which determines practices and daily activities (Pozzi, 2012, p.62). Subjectivity is what constitutes the individual as more than the rational, mechanical being described by Cartesian theory, but a diverse subject full of conflict, an individual subject who belongs to a culture, who is both an individual and part of a collective. Subjectivity is thus part of the construction of identity, and through it subjects and cultures become differentiated in terms of their relationship to an Other. Memory is both individual and collective, contingent and cause, and it is reproduced in social interaction (Larrain, 2003, p.34). However, identity is not fixed, it is constantly in conflict and confrontation, experiencing "the conquest of the social" (Calderón, 2012, p.6; Restrepo, 2007, p.25-32).

In their life and memory process, patients and their relatives speak about themselves, their families, community and the period they lived through, which was circumscribed by Hansen's disease and the medical, social and police control policies designed to insure obligatory isolation of patients within the total institutions of leper colonies, in which power devices such as normativity, surveillance, currency, and identity cards determined the patients' lives and thus those of their families (Rodríguez, 1981, p.100). In this context, medicine gave María, Pablo, Carmen, and José¹⁷ a diagnosis as Hansen's patients and with it, an identity and a new meaning for their bodily experience: that of being diseased. However, that definition, based on science and provided by physicians, was necessarily recrafted in the social field by the patients themselves and those who lived with them during the illness (Canguilhem, 2011, p.137; Ostachuk, 2015, p.5). Thus, the patients defined themselves, lived their lives, and constituted themselves through their own subjectivity, sometimes silencing their memories and other times shouting them out loud. They wished to deconstruct themselves as patients, to acknowledge their condition and their bodily state through autonomy and self-determination as a principle for existence.

In other words, patients established certain social relationships and strategies which, even though limited and subject to their disease, allowed them to create a notion and practices that were valued and situated within the field of normalcy. Disease, as Canguilhem argues (2011, p.143), is a variation of health and therefore there is no self-sustaining pathology; disease has to be understood in relation to aspects of the individual, the society and the period. Although Hansen's disease might seem to permeate the subjects' entire existence, conferring the identity of patients and determining that they would end their days in a leper colony in which they were subjected to a total institution that sought to control their practices and bodily experience through rules, functions and defined spaces, patients were involved in a permanent struggle to live an ordinary life, a life that would allow them to

feel normal and follow the social conventions of their era – to be subjects who got married, had children, got drunk, partied, gambled, and lived in ways outside what was permitted by the disease and the authority of the total institution. Subjects wanted to live normally as a way of approaching existence, reproducing and re-creating their systems of belief, and feeling normative (Canguilhem, 1976, p.190, 2011, p.149-150). Within their particular context – and even despite it – they wished to construct a series of strategies that would allow them to be normal on their own terms. They entered into a game of power and resistance in which their subjectivity was debated, re-created and reconstructed on a daily basis. In their discourse, they moved between recognizing themselves as diseased and recognizing themselves as normal subjects; between the condition of having the disease and dignifying their own lives by everyday, ordinary practices. Thus they positioned themselves in a back-and-forth of possibilities, fluctuating between normality and abnormality as they signified their existence, assuming and showing others their identity and subjectivity.

Thus, the distinction between the normal and the pathological became blurred, and those who lived with Hansen's patients, despite never having been diagnosed themselves, had to put up with being treated as if they were ill. Canguilhem (1976, p.193, 2011, p.115) argues that the line between the normal and the pathological consists of quantitative variations and that disease is a deviation from the norm, as medicine has constructed it. Although anomaly is a variety of life, abnormality is inserted in a value-system. Although there is a line between the normal and the pathological that is determined by quantitative, scientific evidence that generates a medical diagnosis, the reality of social interaction is different, both for the healthy and the sick, as seen in the fact that health is a state of unawareness of the body; it is only when sick people become aware of their bodies and the disease process they are undergoing that they are considered diseased. Disease is part of normal life. However, for Hansen's patients and those who lived with them, escaping momentarily from the disease with all its history, metaphors, representations, symbols, meanings, and forms of discrimination and repression, was an attempt to establish normalcy that ended up being an outpost of resistance and even freedom for those who had to bear the burden of leprosy.

Being ill is a process of individual signification of a reality decreed by physicians, called a diagnosis; for patients this manifests in the body – the starting point, from the medical perspective, for the whole process. It is necessary to differentiate between disease for the patient and disease for the doctor; the first is signified through pain and human suffering, the second thanks to a pathological diagnosis (Ostachuk, 2015, p.5). However, these two meet in the doctor/patient relationship, in which the doctor, thanks to the social power historically and politically conferred on the profession, is the one who marks the patient as such, legitimizes the individual's illness vis à vis society and imposes a normative power system upon the person (Foucault, 2001, p.46, 2002, p.56-59).

The illness places patients in the field of difference, of the pathological. However, in disease, there is no lack of norms, since although illness represents a turn in the patient's life, it sets up another system of norms. This means that, although socially and scientifically patients are acknowledged to be in an "inferior normative" position (Canguilhem, 1976, p.196), they cannot exert agency over their own life process. Thus, everyday forms of resistance created by the sick, and those who lived with them in the leper colonies, were strategies to get closer

to normal – to the norms of others – to refashion the identity of “patient” that had been conferred by medical power by going outside the normative schema of disease. Seeing this as the only way to survive, they threw themselves into ordinary life which, given the patients' condition and the historical process of the leper colonies, was a form of resistance.

These forms of resistance can be interpreted in this context as a new normative system within the community of patients and those who lived with them, in that the condition of being a patient affected both the patients and their children, spouses etc., plunging them into the field of the pathological and subjecting them to medical and political power at the time. However, given the construction of their difference, a form of otherness that was forced on them by disease, the resistance strategies of sick people and their relatives helped set up new norms, rules and local agreements that allowed them to interpret themselves as ordinary subjects living a life that was analogous to what, in their own terms, constituted the life of a “healthy” person.

Final considerations

This article complements the historical and socio-anthropological studies of Hansen's disease by Colombian authors such as Diana Obregón (1997, 1998, 2002), Elias Sevilla (1995), and Claudia Platarrueda (2009), among others. We have set up a gaze that transcends the field of medicine and science, medical and state policies, and social representations of the disease, by turning to oral history and the memories of Hansen's patients and those who lived with them, examining their life experiences, attitudes to the disease and the conditions it imposed on their lives, as well as the forms of resistance they resorted to. In this context, we have discussed the concepts of normality, abnormality and pathology, exploring them in relation to subjects, discourses and practices.

Throughout this article, we have stressed the re-signification of the concept of disease in the life experience of patients and those who lived with them; we have shown how, through oral history and individual and collective memory, we can not only re-live and re-construct the history of the disease and the medical, political and social processes occurring in the leper colonies; we can also understand the concepts that were being constructed alongside the disease, such as abnormality-normality. These concepts, as other authors have argued, help explain how a condition that was initially a disease state marked by difference became commonplace thanks to the resistance strategies of patients and their relatives. These strategies were the initial foundation for eliminating the barriers historically associated with a diagnosis of Hansen's disease, the normative impositions involved in pathologizing those who contracted it; deconstructing the disease as a differentiating label and category, they constructed a new normative system in order to become agents of their own lives.

NOTES

¹ “Leprosarium,” the term used at the time, is synonymous with “leper colony.”

² The first official document mandating boundaries around leper colonies was Decree 372 of 1910; then, in 1926, Decree 777 reduced the area allotted to them. In 1934, with Decree 2116, the boundaries were redrawn again (República de Colombia, 1937, p.95-98, 1934, p.419-423).

³ *Policía ñoca* refers to police with Hansen's disease. *Ñoco* is a colloquial term for missing a finger, referring to the mutilation of the upper extremities caused by the disease.

⁴ We found laws prohibiting escapes by patients, and punishments for doing so in the form of fines, transfer to other colonies, withholding of rations or arrest (República de Colombia, 1937, p.223-236).

⁵ The laws on isolation and healthy people residing in the colonies were Law 32 of 1918, Decree 638 of 1930 and Resolution 60 of 1933 (República de Colombia, 1937, p.182-189). The laws that covered the treatment of healthy and sick children were Law 32 of 1918, Law 20 of 1927, Decree 812 of 1930, Resolution 174 of 1932 and Resolution 151 of 1933 (República de Colombia, 1937, p.189-193).

⁶ For Hansen's patients, "nervous leprosy" was the series of neurological effects of infection by the bacillus, mainly fainting, which was the main symptom leading to suspicion of the disease.

⁷ What follows are excerpts of interviews with Hansen's patients and those who lived with them. These excerpts were chosen – after the interviews were transcribed, categorized and analyzed – based on whether, in the researchers' view, they contained and illustrated different processes, emotions and experiences relating to the disease, the everyday forms of control and resistance, and whether they discussed the concepts of normality and abnormality. In the course of our research study, we carried out twenty semi-structured, thematic life-story interviews. Ten were done in Contratación in 2013 and ten in Agua de Dios in 2014. Overall, we interviewed 17 Hansen's patients and three people who lived with patients; nine were men and 11 were women. We also included a chronicle, an autobiographical account of a person who lived with a Hansen's patient, and interviews by one of the researchers that appeared in academic publications from 2007-2009.

⁸ Asylums for healthy children were located in Guadalupe-Santander (the Asilo San Bernardo del Guacamayo for boys and the Asilo de Guadalupe for girls).

⁹ Popayán is a city in Colombia, the capital of the department of Cauca. It is in the center of the department, in southwestern Colombia.

¹⁰ This was the financial allowance paid by the state to Hansen's patients.

¹¹ "The policing of life" refers to living under certain decrees, in this sense applied to Hansen's patients.

¹² This photograph shows the Torrado family, including Roso Torrado, Helena de Torrado, and Germán Torrado (possibly). Roso Torrado died in the political violence. Germán Vergara, Roso Torrado family and Helena de Torrado. Research statement, Project PCI 2012 319, "La enfermedad en imágenes: historia de la lepra en el Lazareto de Contratación, Santander 1930-1960" [Disease in images: the history of leprosy in the Contratación Leper Colony, Santander 1930-1960]. "Leprosy, stigma and exclusion" group, Universidad El Bosque.

¹³ *La hueca* is a board game similar to Parcheesi or Ludo. One of the most significant modifications is to the board, which has raised sides, and the way the dice are used, since they are picked up in a holder that patients can use, shaken and thrown onto the board (whose raised edges prevent the dice from falling to the ground).

¹⁴ Hansen's disease is known to affect anatomic regions such as the upper limbs, mainly the fingers, so this game allowed patients to spend time together entertaining themselves despite any manual deformities they might have.

¹⁵ *Chicha* is an alcoholic beverage produced by fermenting maize water. Consumption was illegal within the leper colonies.

¹⁶ *Aguardiente* is a type of hard liquor made from distilled sugarcane. As with *chicha* and other alcoholic beverages, sale and consumption were forbidden within the leper colonies.

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