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#### Abstrac

The Hospital-Colónia Rovisco Pais was inaugurated in Portugal in the 1940s for the treatment, study and prophylaxis of leprosy based on the compulsive internment model, whose configuration reflects the total institution concept proposed by Goffman. It concerns an important hygiene project of the Estado Novo. Its educative paradigm combined elements inspired in European social medicine and the ideology of the paternalistic Portuguese dictatorial regime. The Hospital Colony here will be thought of as a disciplinary dispositive, developing considerations regarding the confrontation between disciplinary power and experience. Memory emerges as a contingent instrument to access the practices and interstitial meanings woven into the Hospital Colony's daily life, seeking to find out about the experience of its former patients as political subjects.

Keywords: Leprosarium; Disciplinary power, Moral regeneration; Experience; Agency

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In 1947 Portugal saw the birth of the National Leprosarium, which was named the Hospital-Colónia Rovisco Pais (the Rovisco Pais Hospital-Colony) and conceived to fill a structural lacuna in the treatment, prophylaxis and study of leprosy. This institution, supported by the dictatorial regime of the Estado Novo (or New State, as the Salazar government in Portugal was known), can be understood as a hygiene project for the regulation and regeneration of the Portuguese population.

Celebrating its 60<sup>th</sup> anniversary in 2007, the Hospital Colony was transformed in the 1990s into the Centro de Medicina de Reabilitação da Região Centro–Rovisco Pais, retaining a Hansen's Disease Service in which 25 former such patients still live, ranging from 71 to 96 years of age.

We conducted ethnographic research in the Service that sought to illuminate the historical trajectory of the institution and reveal the constellations of meaning produced during the course of the lives of the former patients interned in the Hospital Colony.<sup>2</sup> The lengthy time period involved constituted this ethnographical context as a historical object as well, motivating the adoption of a hybrid methodology, with recourse to participant observation, interviews, gathering life histories and an analysis of documents from varied sources.

Here we try to trace the contours that defined the Hospital Colony as a space to segregate leprosy patients, bringing to light at the same time how its internees lived and were made to live.

The specificity of this institution in the national context at the time it was built engenders an analysis that highlights its bio-political matrix, to which is allied the singular vision of an oligarchical elite regarding the popular classes in Portugal. It is important to place the Hospital Colony within both the paternalistic ideology of the Estado Novo in Portugal and the transformation and political regulation movement that galloped through European societies in the 19<sup>th</sup> century, through such mechanisms as social medicine, and in which the modern leprosariums germinated, the model for which was agreed upon in 1897 at the 1<sup>st</sup> International Leprosy Conference in Berlin.

In this respect, the Hospital Colony can be read as a dispositive, recurring to Foucault's formulation (1977) on disciplinary power, which sought to implement a project for the moral regeneration of the Portuguese population. This leads to questioning the experience of the patients interned in the Hospital Colony not only as individuals afflicted with such a highly stigmatized disease as leprosy, but also as political subjects, confined within the walls of an institution intentionally shut off from the public space. This will be the analytical focus pursued here, leaving aside the experiential universes intimately related to the disease.

The narratives of former patients of the Hansen's Disease Service were fundamental to access the universe of practices and the creation of meaning generated within the Hospital Colony. The internment experience emerged in the telling of their stories. In effect, approaching a disease as an object produced in the labyrinth between the body and the story arises from the fact that, as Maciel explains (2004, p.124): "the diseases are not solely a set of physical signs and symptoms, nor are health policies the univocal result of how the State reacts to them. They are, instead, historically determined plural aspects, the

products of diverse intermediations, such as social structures, fields of knowledge and individual or collective identities".

The testimony, characterized by the intertwining of personal biography with the history of the community (Gugelberger, Kearney, 1991) agrees, offering a field of intelligibility that articulates the social, political and epistemological processes involved in the construction of a given disease with the phenomenological universes that are contiguous to them. So much so that, as Maciel reflects (2004) in the case of leprosy, the prophylactic policies of a segregationist inclination that were in effect during the first half of the 20<sup>th</sup> century, consolidated public fear and the social responses of stigmatization and exclusion for those having the disease, contributing to the silencing of their experience in the public space. Consequently, rescuing the memory of sanitary banishment in the modern leprosarium is crucial for understanding the modern history of leprosy.

Effectively, memory imposed itself in this research as an unavoidable methodological and epistemological presence, forcing the abandonment of a positivist view that sees memory as a limpid surface upon which the past is reflected, while primarily assuming its plastic nature, which consitutes oral memory as an imprecise portal for the daily events that have transpired. Memory results from a dialectic between what is remembered and what is forgotten in the continuous process of constructing the individual and collective identity (Lambek, Antze, 1996). On the other hand, the practices, as Bourdieu demonstrates (1990), are indivisible from the discourse. In the case of the former Hansen's Disease Service patients, we found a deep cleavage between their discourse on the Hospital Colony and their personal and collective histories regarding the institution, as they spontaneously revealed during the ethnographic research. The histories configure a mode of cultural expression which recalls ways of producing meaning that arise during the course of experience and simultaneously shape it, such Turner pointed out (1986). Memory results, in this way, as performance, and the self of the former patients enables establishing a center of narrative gravity (Dennett, 1992). In this respect, the factual veracity of the narratives is less important than the meanings they weave. Thus, it is as a way of creating the world, rather than as a representation of the world, that the memory of the former patients is here retrieved.

# The Hospital-Colónia Rovisco Pais and the biomedical utopia of Fernando Bissaya Barreto

The Hospital Colony was built in the coastal village of Tocha in the district of Cantanhede on rural property of some 140 hectares, with a capacity for a thousand leprosy victims. The architectural project was entrusted to Carlos Ramos (1897-1969), one of the most renowned Portuguese hospital architects at the time (Coutinho, 2001). Several factors contributed to the choice of this geographical location, highlighted by the high incidence of the disease in Portugal's central region, its isolation from population concentrations and local climatic and soil conditions, considered fundamental to both leprosy therapeutics and agricultural development (Silva, 1962; Barreto, 1938a).

Its construction was made possible by funds from an inheritance left by José de Rovisco Pais to the civilian hospitals of Lisbon. The Estado Novo attributed a large portion of the social welfare responsibilities to civilian society, in particular sectors connected with the Catholic church, (Rosas, Brito, 1996) - which originated what Boaventura de Sousa Santos (1993, p.46) designated as the welfare society, seeking to highlight the role of the community in the creation of social support networks, a consequence of the debility of State welfare in Portugal. The welfare policy of the Estado Novo combined charitable elements with others of a repressive nature, generating an idiosyncratic model, symbolized by personages of the Catholic Church and the Public Security Police (Bastos, 1997). At the time, the Ministry of the Interior was responsible for projects of a welfare nature as well as internal security, an unequivocal overlapping of welfare and maintenance of social order (Rosas, Brito, 1996). The community served as an empirical substrate of these projects, but also as a paradigm for the moral regeneration of the social fabric that they postulated. Family, work and the rural life thus constituted the matricial signs of that model (Bastos, 1997). On the other hand, social action, having its origins in a welfare society (Santos, 1993, p.46), tended to be decentralized and assume local singularities, making it possible to recognize specificities within the national context. An example of this is the vast welfare project of Fernando Bissaya Barreto (1886-1974), professor and surgeon at the Universidade de Coimbra and the principal ideologue and creator of the Hospital Colony.

Bissaya Barreto's political project, supported by the Estado Novo, had its origins in several institutions found in the central region of the country.3 Bissaya Barreto distanced himself from the charitable assistance that was practiced in Portugal, approaching modern European hygienics by stipulating the disease, in the broadest meaning, as a social problem and defending changing the living conditions of the populace as a means to combat it in the community (Sousa, 1999, p.164). His personal and political project for social medicine was stated in 1934 at the 1st Congress of the National Union, defining the strategy as: "1) The detection of the sick; 2) Sanitation measures that protect the individual against the contagious, that provide healthy and hygienic housing, that promote disinfection, etc.; 3) Family education; 4) Assistance of all types for the sick, their families and children" (Barreto, 1936, p.6). In the same program, he defends the idea that "the social doctor cannot avoid thinking about the social value of those assisted and proceeding as an educator. It is thus necessary to provide physical, intellectual and moral assistance, i.e., assist-educating, educate-treating" (p.7; italics in the original). The figure of the doctor emerges as that of an educator, signaling the twin actions of medicine on sick and social bodies. In effect, Bissaya Barreto's work conciliated adverse elements, some of a modernist inspiration, others of a fascist mold, reflecting both the progressivism of his thinking, evidenced by his permanent scientific interchange with the rest of the world (unusual in the autistic context of the Estado Novo), as well as his political commitment to that regime's authoritarian reformism and its moralizing overtones. .

Bissaya Barreto (1938b, p.3) initiated his campaign, entitled *Pelos Leprosos, Contra a Lepra* (For the Lepers, Against Leprosy), in the pages of a publication devoted to sanitary education, *A Saúde*, which called attention to the need for an articulated and concerted plan in the struggle against this disease. This lacuna had been pointed out since the middle of the 19<sup>th</sup> century, a period coinciding with the apparent resurgence of the disease in Portugal (Carvalho, 1932; Silva, 1962). Thereafter, the isolation of the sick in colonies constructed for that purpose

had been defended as a prophylactic measure. Among the protagonists, Doctor Zeferino Falcão stands out for the clinical studies he conducted in Portugal, presenting the results in 1897 at the 1st International Leprosy Conference, where he was appointed a member of the International Commission for the Study and Combat of Leprosy (Carvalho, 1932). The growing concern of the medical profession was shown in 1906 at the International Congress of Medicine in Lisbon, which Gerhard E.A. Hansen, the Norwegian doctor who identified the agent causing leprosy in 1873, attended. Those then present concluded that governments had to assume responsibility for containing this disease (Carvalho, 1932). In the 1930s, the Ministry of the Interior appointed a commission to study leprosy, which reported the existence of 1,127 cases in the country (Silva, 1967). During the same period, the hospitals of the Universidade de Coimbra decreed the end of internment for leprosy patients, leaving only two hospital services in the country for this purpose, the Curry Cabral Hospital in Lisbon and the Joaquim Urbano Hospital in Porto (Silva, 1967). This deficiency was a determining factor for Bissaya Barreto's political involvement in the fight against leprosy in Portugal, giving the problem greater public visibility.

In the texts published in *A Saúde*, Bissaya Barreto identified leprosy as "the dirty and filthy disease of ancient times", encouraging the formation of an "anti-leprosy arsenal", that would simultaneously treat the disease and prevent contagion firmly and compassionately. Bissaya Barreto located the occurrence and spread of leprosy in the lower classes, especially rural, of the Portuguese population and considered the lack of a strategic plan to combat the disease a national shame, incompatible with Portugal's coveted status as a civilized country:

HEALTH has existed at one remove from this momentous subject, but the time has come for it to take its place in the fight to defend the health of our working classes, our rural people, who are unfortunately the victims of this cursed disease, which has castigated the human soul across the centuries. Portugal, a civilized country, which thanks to circumstances, occupies a preponderant and justly prominent position in the world, can no longer remain indifferent to the solution that this public health problem requires and that, as elsewhere, has been and continues to be the subject of studies, investigations and enormous expenditures (Barreto, 1938b, p.3).

His appeal encouraged, on the one hand, the detection of leprosy patients and, on the other, their treatment within the framework of a medical model that rejected the religious representation of leprosy as a divine punishment, pointing out poverty and unhealthiness as its causes. Bissaya Barreto (1938c, p.3-4) idealized a model based on the dispensary, a public space for medical attention that would proceed to identify the disease, and on the asylum colony, which would segregate the sick. The leprosarium he envisioned differs from the medieval one, which qualified as a prison, conceptualizing, on the contrary, a pleasing and harmonious community:

Do not suppose that we want a leprosarium of the penitentiary type .... We want the leprosarium to be a cheerful village, happy, full of hygiene and even a certain beauty. Simple modest houses, but with considerable charm, nurseries, gardens, lots of flowers and trees, plenty of water, a house for recreation, commercial establishments, workshops, in short, a combination of circumstances that make the sick forget about their misfortune and misery (Barreto, 1939c: p.4).

Bissaya Barreto's biomedical utopia hoped that the sick, instead of resisting isolation, would seek it voluntarily: "We want the sick to flee to the leprosarium, we don't want them to flee from the leprosarium" (Barreto, 1938d, p.4).

Keeping in mind, on the one hand, the incipient scientific knowledge of the disease at that time and, on the other, its relative incidence in the country (Silva, 1962, 1967), Bissaya Barreto's alert produced a regime of truth, in other words, "domains of objects and rituals of truth" (Foucault, 1977, p.194), delineating a field for the construction of knowledge in synchrony with the exercise of power. By focusing the view on those having Hansen's disease, structurally invisible, as sick people difficult to diagnose medically<sup>4</sup>, Bissaya Barreto gave them visibility, creating a category of individuals that had yet to be named and a public health problem that remained to be faced.

His bio-political project was inspired by European social medicine, which allied social assistance for the poorest people to medical control by the public health services, which included vaccination, the registration of infectious and contagious diseases and fighting against unhealthiness. Europe in the 19th century saw the state implement intervention in the housing and bodies of its subjects, selecting hygienization of the population as a mechanism of political regulation, overseeing and rationalizing social space through the continued production of knowledge regarding individuals (Foucault, 1998). Thus, the welfare state arrived and, with it, the intertwining of assistance and social control. The individual body and the social body were constituted as an object of scientific knowledge and of biomedical intervention, the latter ordering itself by a thorough examination that established and regulated the first. Foucault (1977) called this form of exercising power disciplinary, conceived to increase the productive force of the bodies concomitantly with the reduction in their political force. It was in this context that the institutional model that brought together exclusion and discipline was disseminated, in other words, the segregation from the public space of individuals who constituted a threat to the social order (among them those sick from infectious-contagious diseases, the mentally ill and criminals) and their physical and moral regeneration within these institutions through the application of scientific knowledge.

The introduction of biomedical practice and knowledge in the space in which Hansen's disease patients were segregated is one of the factors that differentiate the modern leprosariums from the medieval, in a process that can be described as the medicalization of leprosy. This is not the place to explore more thoroughly the nature of medieval leprosariums in Portugal, but rather to refer to their vocation being more residential than therapeutic (Carvalho, 1932, p.26-37). In this respect, the place of exclusion inhabited by those having leprosy emerged as somewhere to apply scientific knowledge, inseminating the possibility of their regeneration. The leprosariums thus took on the role of healing machines, in accordance with the conception of a modern hospital (Providência, 2000), and, simultaneously, of scientific investigation laboratories, Two historic moments contributed decisively to this: the discovery of the agent causing leprosy, the *Mycobacterium leprae*, by Hansen in 1873 and the 1st International Leprosy Conference. The discovery of the bacillus signified a breakthrough in the history of leprosy, refuting the contemporary theories that defended the hereditary nature of the disease (Monteiro, 2003; Gould, 2005) and the Conference, by

majority vote, acclaimed Hansen's theory of the contagion and the proficiency of the 'Norwegian model' in combating leprosy (Pandya, 2003). This model, which had been structured in Norway under Hansen's influence and officialized in the acts of 1877 and 1885 that ordered the domicile or hospital isolation of those having Hansen's disease (Gould, 2005), seemed to explain the decline of the disease in that country. The Conference resulted in a set of resolutions that indicated registration, control and compulsory isolation of those having leprosy as urgent prophylactic measures to be taken by the governments of western countries (Pandya, 2003). Thereafter, the forefront of the fight against leprosy would be the responsibility of the medical profession. Considered throughout the West as the most 'repugnant' of all diseases, the internationalization of the fight against leprosy and the ambitious universalization of the measures employed to that end reflected the colonial project and all the fears that arose from it: "As some historians have pointed out, the West's «rediscovery» of leprosy in the late nineteenth century was a product of the flourishing imperial enterprise and the alarming presence of the disease in the conquered territories in Asia, Africa and elsewhere. In keeping with the global dimensions of imperialism, and as a consequence of the advances in bacteriology, attempts to internationalize the leprosy question were to be expected" (Pandya, 2003, p. 162).6

In effect, at the end of the 19th century, leprosy was considered an 'imperial threat' (Gould, 2005), due to population mobility. The death of Padre Damião, of Belgian origin, after he contracted the disease in the Molokai colony in Hawaii, was a determinant in the reappearance of the specter of leprosy and the medieval leper in the western imagination (Pandya, 2003; Gould, 2005).

Described in terms of a residual disease, a civilizational step backward, leprosy was recorded, at that time, in the colonized territories and the poorest fringes of metropolitan societies. In the 1950s, the prevalence of the disease in Portugal continued to be attributed to imperial expansion: "Portugal, by virtue of its mission to discover new worlds, new continents... had to endure a new invasion of the epidemic, after having abolished it from its nosological map, an invasion occasioned by the coming and going of emigrants and immigrants ..." (Ribeiro, 1958, p.1).

Bissaya Barreto resorted to this civilizing argument when instigating the State to implement sanitary measures that resulted in the creation of the Hospital Colony. Its model recalls the resolutions introduced in Berlin in 1897, discussed and updated in subsequent conferences (Silva, 1962). Leprosariums such as Carville (in the United States), whose pavilions, control mechanisms and internal recreational activities were reproduced in other colonies for Hansen's disease patients (White, 2003; Gaudet, 2004), or those that made up the São Paulo model (in Brazil), the benchmark for which was the Santo Ângelo colony (Araújo, 1956; Monteiro, 2003), constituted by the "trinity of leper colony, dispensary and prevention center" (Monteiro, 2003, p.104), represented important spaces for organizational reference and scientific change. Manuel Santos Silva, the first clinical director of the Hospital Colony, made a series of trips before and after its construction that included visits to leprosariums in Brazil and Carville and participation in international leprology congresses (Santos, 1970). Along with this interchange with the prophylactic and therapeutic model of modern leprology, the Hospital Colony propagated a paradigm of

moral regeneration for those having leprosy that reflected the paternalistic and rural ideology of the Estado Novo regime.

On the occasion of its inauguration, Portugal put aside the humiliation leprosy had provoked and proudly presented itself as a nation that had produced the "best leprosarium on the Peninsula and one of the most notable in Europe...thanks to which the problem of leprosy in Portugal could be resolved within 20 years" (In the inaugural act..., 8 September 1947, p.1).

# The creation of an aseptic community to contain an impure disease

The Hospital Colony was based on a model of compulsory internment of the contagiously ill and treatment on an outpatient basis of those who were not contagious, aiming at isolation and segregation to contain the disease.

The clinical intervention of biomedicine on the body of the sick individual was founded on the State's repressive action on the collective body, blending disciplinary power and legal power. Foucault (1977) described the action of these models for exercising power as one based on disparate logics, the first having the individual as its object, appreciating the detail that produces differentiation and enables hierarchization, and the second focused on the population, regulating it in accordance with a body of binary laws that demanded the obliteration of particularities. Contagion had given rise to both, on the one hand motivating a species of authoritarian medicine and, on the other, legitimizing measures of control and political ordering of the public space. Agreeing, Douglas (1991) proposes thinking about the diagnosis of a transmittable disease as an accusation that results in the loss of civil rights.

In the case of the Hospital Colony, the sick were sent there under a seizure order and escaping was punishable. The compulsory internment, which resulted in the loss of citizenship for the sick, transformed the Hospital Colony into a mediator of their relationships with the State. In effect, for them, the diagnosis signaled social death, and internment, civil death. With internment, the exclusion that they often experienced in their communities gave way to a disciplinary seclusion rendering them invisible. Which is what led them to describe the diagnosis as an accusation that converted them into 'criminals' and the Hospital Colony as a 'prison'.

The idea of the Hospital Colony as a prison concerns not only a forced enclosure, but also a residential space that encloses all of the daily activities of the individuals within a detailed and hierarchically ordered organization. Goffman (1961, p.XIII) defined this model using the total institution concept: "A total institution may be defined as a place of residence and work where a large number of like-situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life". The author describes the following characteristics, also verified in the Hospital Colony:

First, all aspects of life are conducted in the same place and under the same single authority. Second, each phase of the member's daily activity is carried on in the immediate company of a large batch of others, all of whom are treated alike and required to do the same thing

together. Third, all phases of the day's activities are tightly scheduled, with one activity leading at a prearranged time into the next, the whole sequence of activities being imposed from above by a system of explicit formal rulings and a body of officials. Finally, the various enforced activities are brought together into a single rational plan purportedly designed to fulfill the official aims of the institution (Goffman, 1961, p.6).

As White affirms (2003, p.135) regarding Carville: "...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".

Although total institutions presuppose self isolation, they nourish themselves in permanent dialectic with the outside world. It is precisely by closing themselves off from society that they act on it, fulfilling political objectives of state regulation, confining the individuals who rend the social fabric and promoting their regeneration inside. In this respect, the internal structuring of these institutions is based on an educative model for the subjects interned that combines the scientific representation of these subjects, taken as an ontological explanation, with the values and norms sanctioned by the political ideology in force (Goffman, 1961).

The educative model underlying the Hospital Colony project was designed with a spatial and organizational configuration. Thus, the following structures were built on the former Fonte Quente estate (an extensive property of agricultural lands, previously belonging to the Crúzios de Santa Cruz de Coimbra monks of the Santo Agostinho Order): a central hospital with four internment services, medical consultation offices, an operating theater, a central dispensary (which housed the examination, consultation and social action services) and a highly sophisticated clinical analysis laboratory specialized in the diagnosis of leprosy (Photo 1); two large pavilions that sheltered the sick able to work; two asylums to hold the invalid ill (Photo 2); six smaller pavilions, called worker houses; five family nucleuses that integrated a complex of two family dwellings, each housing a family unit, with a small garden and vegetable patch; a laundry, workshops and a kitchen (Photo 3); a pavilion that housed those having other contagious diseases, such as tuberculosis or disturbances of a psychiatric nature, as well as internees who infringed the norms of internal operation; a chapel with two naves that separated the sexes and an interior wall that separated the sick from the healthy (Photos 4 and 5); an open air cinema and a soccer field.

The design of this architectonic complex combined the modernist model of hospital architecture, whose concerns relate to salubrity and prophylaxis (Providência, 2000), with the revivalist style celebrated by the regime (Bandeirinha, 1996).

The lay out of the buildings reflected one of the most significant characteristics of the Hospital Colony's internal organization: the division of the sexes. A central axis, which united the central hospital, the chapel and the only original building, the former convent of the Crúzios monks, symmetrically separated the space destined for women from that of the men. Socializing between the sexes was not only expressly prohibited, but also severally punished, permitted only in the family nucleus areas (Photo 6), where the moralizing ideas of a modest and orderly Portuguese home were promoted.

The buildings were surrounded by agricultural areas and luxurious gardens. The internees permanently took cared of these gardens, constituting one of the most valuable attributes



Photo 1: The central hospital, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)



Photo 2: The asylum for the invalid patients, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)



Photo 3: The kitchen, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)



Photo 4: The chapel, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)



Photo 5: The interior of the chapel, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)



Photo 6: A family nucleus, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)

for the Hospital Colony's external image. In effect, the aesthetic quality of these areas motivated the visit of excursion groups that flocked there to admire them. Although these incursions did not include interaction with the internees, they mitigated their isolation and, more importantly, constituted a positive factor that offset the negativity of their identity status.

But the aesthetization of the Hospital Colony space figured primarily as the central element for the biomedical and political intervention that was carried out. On the one hand, the social medicine of Bissaya Barreto was inspired by a naturalist philosophy which identified health with education that was both physical and moral (Sousa, 1999); on the other, it reflected the Estado Novo's rural apologia. Agricultural development was the matrix of a project conceived to embrace a population that was primarily rural. In effect, most of the sick came from the rural and poor spheres, which is not to say that the disease did not occur in other social strata. The class differentiation was verified in the distinction between the compulsory internment of individuals of the popular classes and the outpatient treatment of those having greater economic and political capital.

In addition, the enormous distances between the different pavilions and family nucleuses, along with the prohibition of free circulation between them (restricting the movements of the internees to their residential and work areas) promoted a rural day-to-day existence.

The Hospital Colony thus has a disciplinary bent linked to scientific knowledge, as well as a paternalistic ideology, which emanated from the values that underpinned the fascist regime, in the triad known as family, religion and work, constituting, simultaneously, a hospital and an agricultural colony. As a healing machine, it included the treatment of leprosy, epidemiological investigation, laboratory analysis, a surgery and a pharmacy. As a



Photo 7: The shoemaker's workshop, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)

residential area for Hansen's disease patients, it was intended to be a self-sufficient community, sustained by the labor of the internees, organized into brigades of workers that performed diverse jobs; there was someone, for example, who acted as the internees' secretary. There were agricultural workers, masons, shoemakers (Photo 7) and seamstresses; others performed cleaning services and the so-called special services, such as teachers in the curricular schools, aids for blind patients and many others.

The circulation of money within the Hospital Colony was not permitted, the salaries being retained and subsequently paid either to the families of the internees or to them on the occasion of leaves and temporary or definitive release. In addition, goods not made available by the internal services, particularly alcohol, were not authorized to circulate in the Hospital Colony, since all food, clothing and other necessities were supplied by these services.

Work was imposed as a necessity, but also as a fundamental element in the therapeutic process. Bissaya Barreto defended ergotherapy, having equally in mind professional training for social reinsertion after definitive release from the hospital. Educational rehabilitation also included teaching literacy in the curricular schools and the learning of hygienic habits. It was not only the impurity found in the diseased body that was being fought, but also the social impurity arising from the improbity of behavior and lack of productivity of those bodies. Thus, the terms 'order' and 'discipline' were encountered throughout the legislative body of this institution (Portugal, Nov. 15, 1938, Aug. 2, 1947).

The internal organization of a total institution presupposes a rational model that integrates all of its elements in an ordered fashion (Goffman, 1961). Managing order at the Hospital Colony was the responsibility of the staff – administrative personnel, doctors, nurses and social assistants, but also the sisters of the Order of São Vicente de Paulo, entrusted with the nursing functions and the organization of various maintenance services. The Hospital Colony also had a group of civil guards.

The existence of two hierarchically distinct bodies at the Hospital Colony, that of the internees and that of the employees, manifested itself empirically in the prohibition of physical contact between them. During the first decades of the institution's activity, the employees avoided touching the sick, which contributed to strengthening the internal hierarchy, in sinuous overlapping with reiteration of the stigma. Sterilization was a transversal procedure to life in the great healing machine of the Hospital Colony.

Surveillance was also constant, employed as a fundamental mechanism to be insinuated throughout the community, whether through civil guard patrols, which made nightly rounds inside the pavilion, or by encouraging accusations among internees and using architectural devices, such as the insertion of a glass pane in room doors, a 'Judas window' that allowed constant peering inside, or a sound device that aired the speeches given by the clinic director throughout the pavilions.

Emblematic of the uninterrupted control exercised was the physical and symbolic place, called isolation by the administration and 'jail' by the internees, where those who disobeyed the Hospital Colony's internal regulations were sent, the most frequent being escapes and disobeying the ban on socializing between the sexes. The confinement could last up to 120 days. Unlike other Estado Novo closed institutions (Bastos, 1997), physical violence

was not applied as a punishment measure at the Hospital Colony, a contribution of the humanist ideology of Bissaya Barreto, but the stigma associated with leprosy was, transforming the sick person into an untouchable.

The internal regulations also provided for the separation of parents and children as a prophylactic measure. A prevention service was built nearby to house the children of the internees and those born in the Hospital Colony. The latter were given to the sisters of the Order of São Vicente de Paulo and periodically visited their parents in an area constructed in the entranceway to the Hospital Colony, which separated the sick from the healthy by double glass panes with asymmetrical openings to enable sound to pass through.

Despite its authoritarian bent, the conception of the Hospital Colony was designed to provide the sick interned therein with living conditions that were far superior to those existing in most of Portugal, such as supplying electric lights or constructing basic sanitation. In addition, recreational activities were developed in an ambit that was designated for ludotherapy, including soccer (Photo 8), cinemas, shows organized by the internees and others put on by national artists who visited the Hospital Colony. They also formed religious associations, singing, sewing, embroidery and dance groups, internee entertainment areas, such as their bar, and places to meditate or write, including their newspaper *A Luz*. Collective activities, such as religious processions, profusely celebrated, and gardening or nativity contests between the different pavilions, were developed as well.

The utopia of a disciplined and healthy community was embellished by the inflection on harmony, in a vision that sought to dissipate the conflict inherent to compulsory internment. Perhaps the summer Sunday trips to the lake located within the Hospital Colony area was a time to relax the prohibitions, one that best represented the promotion



Photo 8: The soccer team, the 1960s. The Estate of Carlos Ramos. (Photographer unknown)

of a community which, although segregated from the world, was intended to be internally self-sustained and added to (Photo 9).

The boundary between the Hospital Colony community and the outside world was delineated empirically and symbolically by a thorny hedge that circumscribed the entire perimeter. However, the educative model implemented within was extended beyond the boundaries that defined the Hospital Colony as a closed institution by the other dispositives on which the model for combating leprosy outlined by Bissaya Barreto was founded, namely the central dispensary and the mobile brigades. The first, installed in the Hospital Colony, monitored the outpatient sick and their families in free consultations regarding leprology and other infirmities. The mobile brigades, normally a team that consisted of a doctor, an analyst and a social agent, traveled throughout the country to identify leprosy suspects based on prior denunciations, generally made by local doctors, neighbors or even the sick interned in the Hospital Colony. They were often accompanied by the Republican National Guard, which assured compliance with the seizure order. They proceeded to detect the disease, examined the communicators of contagious diseases, treated the noncontagious sick on an outpatient basis, conducted epidemiological and social investigations and monitored the social situation of the families of the sick. In this way, an epidemiological and social mapping of the Portuguese population was conducted that also enabled a hygienic intervention in it.



Photo 9: A walk on the lake, the 1950s. The Estate of Carlos Ramos. (Photographer unknown)

Foucault (1977, p.198) identified that model with a political dream that recalls a city: "traversed throughout with hierarchy, surveillance, observation, writing; the town immobilized by the functioning of an extensive power that bears in a distinct way over all individual bodies – this is the utopia of the perfectly governed city".

It is worthwhile asking if the Hospital Colony really was a perfectly governed utopian space? The response to this question will be found more in those who made it pulse, than in the political project that underlay it,.

# Personal stories and daily life at the Hospital Colony

Several of the former patients' narratives tell of arriving at the Hospital Colony during the night, describing their entrance into an unfamiliar place, anxious about being alone and abandoned in forced confinement. Amália<sup>7</sup>, interned when she was 27, describes it like this: "I saw myself in the midst of people I didn't know, far from my family, I didn't even know which way was north and which south. I had to see where the sun rose to know where my home was".

Coming from different parts of the country, on arrival the sick were sent to one of the pavilions, depending on the state of their health. Many only then discovered the worst face of leprosy, mirrored in the bodies of the oldest patients. Since a large number of the sick entered the Hospital Colony bearing only the initial symptoms of the disease, their internment brought a terrible discovery, namely what could happen to them. This moment signaled the initiation process to a new identity, that of internees at the institution (Goffman, 1961).

Those whose internment was voluntary, because "they were told that the disease could be cured there" and because people were 'afraid' of them where they came from", often regretted it, but it was too late, because "now they wouldn't let us leave". Those who were brought by the mobile brigades deeply resented being separated, often abruptly, from their families and at first isolated themselves from the others. Many thought they had come there to die. On the one hand, the fact that leprosy was a little known disease gave rise to its being thought to be fatal. On the other hand, in the areas contiguous to the Hospital Colony, frightening rumors circulated that the sick were burned alive there, symbolically announcing the idea of internment as a death sentence:

Adelina tells of an item in the newspaper that, in her opinion, was placed by the Hospital Colony's administration to encourage internments. It said that leprosy was contagious up to 7 meters. She was working in the rice fields and this news led her boss to separate her from the rest of the workers; she was forced to walk in front and couldn't drink the same water the others did. She was often very thirsty and suffered a great deal from the segregation. She and her brother convinced their father to go together with them to the Hospital Colony. Someone had told them that they would be cured there in three weeks. They left home in a small truck bound for Figueira da Foz. There they were refused transportation to Tocha, being told that there were no seats available that day or the next. They went on foot. When they got to Tocha, they contacted an individual who, when he learned where they were going, became very alarmed because, according to what he told them, whoever went to the Hospital Colony was not cured, but died, which horrified them (Field diary).

Entrance into the Hospital Colony was somewhat ameliorated for those who came from other hospitals, namely from the former Curry Cabral Hospital in Lisbon, where they had already had contact with advanced stages of the disease, or who learned from other patients already transferred to the Hospital Colony of the 'discipline' that people experienced there. These came already determined not to make life easy for the Hospital Colony administration:

Duarte, interned at the former Hospital do Rego, on the eve of being transferred to the Hospital Colony, wrote to a sick woman who had already been transferred there. Having learned the mail was "censored" and that the letters were read by "censors", he began to include insults in them. His correspondent received thoroughly disgusting letters without understanding why, but his objective of contesting the invasion of his privacy was thus met (Field diary).

In effect, the discourse of the formerly ill emphasizes the repressive and authoritarian character of the model in effect at the Hospital Colony, interiorizing the characteristics of the dictatorial regime of that era, accusing the clinic's director of being a dictator and calling the internal regulations fascist. Similarly, the former patients attribute to the Hospital Colony staff responsibility for the discrimination to which they were subjected as Hansen's disease patients. Amílcar, who was treated as an outpatient for many years, recalls:

There was no fear of the disease until the social assistants arrived and infected everyone. They said leprosy was highly contagious, which is not true. No one in the Hospital became contagious, even the Sisters made the beds without gloves and some of the nurses dressed wounds without gloves. They said everything in the homes of the sick had to be disinfected. After that, one day when I went to a tavern, the owner broke the glass after I finished my drink.

This is a discourse widely disseminated in the context of the Hospital Colony. On the one hand, the social rupture introduced by the disease had its origin, in many cases, in the production of the diagnosis and the information circulated by the mobile brigades regarding the ways the disease was transmitted. On the other hand, the formerly sick, having symbolically transposed the causality of the social exclusion and segregation experienced by them from leprosy to the Hospital Colony, could sum up the self-rejection provoked by the stigma of the disease in a strategy also described by Goffman (1961) for this type of institution. According to him, the fear, or the 'terror' that the employees implanted in the populace was designed to gather together the largest number possible of sick people. Cândida was seven years old when the disease appeared. Several times she hid from the mobile brigades to escape internment: "They spread the terror, they told people that leprosy was a terrible disease that you could catch. They told people to stay away from us, because they wanted to fill the Hospital".

Conceived to constitute a harmonious community, the Hospital Colony proved to be, first and foremost, to be an object of profound contestation on the part of the internees. Stories of community life go hand in hand with stories of subjection to an authoritarian power, such as punishment in 'jail'. The very generation of a community feeling seemed to be compromised by the surveillance and the exercise of constant power over their bodies as Hansen's disease patients and internees. Duarte, considered the historical leader of the internees, recalls:

The family nucleuses were a small village, but subject to the restrictive laws here. It was already different. A cadet in the nucleus had a harmonica. Some people got together and began to dance. I don't know if someone appeared outside, but anyway there in the street the phone rang in the afternoon. The telephone in those days was in the bandaging room, in the so-called manor house. It was the administrator: "What's going on out there?" "Here, sir? Some girls are dancing with each other." "But how can that be?"

Someone had gone to tell him, maybe one of the snitches [an internee informer]. Can you see it? This was in a wide-open area, but nevertheless, there were still those nitpickers, who went to call him. These little things happened all the time.

We were subjected to the regimen, go have a test, go to the doctor, get undressed and so forth, it was called doing the dummy, there was a manikin there. They sketched the sores observed during the exam on the human body pictured on our exam form. We had to put up with all these things.

Experienced as an ordeal, the clinical analyses constituted a decisive moment that determined the future of the internees. Depending on whether the lab results were positive or negative, temporary leaves and provisional or definitive releases were granted or refused. Significantly, it was employees of the analysis laboratory with whom the internees had the least contact. Their job, hermetic and unintelligible and, at the same time, extremely important to the life of the internees, produced a profound anxiety and was the object of enormous suspicion. In this regard, Felipe, a former patient who, after being definitively released, wound up returning to the Hospital Colony because of ocular sequelae that produced a severe loss of vision, declares: "They ruined the analyses so that we couldn't leave".

The clinical practice itself was closely scrutinized and the incapacitating effects from progress of the disease are often attributed to the medication administered over the years, as in the case of Amália: "We entered here perfect and later became like this. Where I come from, they ask me: 'What kind of hospital are you in, you went there in perfect health, you left here perfect and now you look like this?'".

Despite the strictness of the internal regulations, the internees actively constructed their life styles within the Hospital Colony, which, as a dispositive, was subject to the practices of appropriation, contestation and subversion, but was also transformed by the agency of the internees itself. Cândida and Augusto, two former patients, relate:

- Every night we went out.
- To Tocha?
- What do you mean, Tocha! Why Tocha? I went to Nucleus 1, where my girl was.
- So, you weren't caught by the guards?
- Oh, miss, they guarded the guards!

The prohibition of relationships between men and women, interpreted by the internees as a strategem aimed at elimination of the disease, was intentionally ignored, as they developed strategies to avoid the watchful eye of the civil guards. Duarte, the first internee to contest this prohibition, speaking in public with the woman who would become his wife, recalls: "On the way to the chapel, we took three steps forward and two back. While doing this, the guys, pretending to read the newspaper, chatted with the girls".

Many relationships began in the Hospital Colony, resulting in secret marriages (escaping the Hospital Colony to get married and returning with the *fait accompli*) and the birth of

illegitimate children. With the passage of time, the accumulation of internee protests and the inefficiency of the repressive measures, the relationships were at first actively ignored and finally authorized. Augusto relates: "One guy dressed up as a woman and took a rope because the asylum was high. The skirt belonged to a colleague and he covered his head with a shawl. He stayed there all night and knew the women would go to early mass in the morning, so he had to get up early, but often he was a little late and when he had to leave, the old ladies saw him and yelled. He began to run and they said 'Hey, an old lady can run like that?" The escapes, although severely punished through capture and isolation, were also constant and varied. Some internees successfully fled, completely refusing to remain in the Hospital Colony; others, having permission to visit their families, opted to prolong their stay. Still others fled because they wanted to do something specific, such as going to the Nossa Senhora de Fátima sanctuary or to buy something, often to sell as contraband within the Hospital Colony. Finally there were those who, having families living near the Hospital Colony, went to spend the night at home and returned in the morning:

They told me, amused, about their escape to Fátima. Four girls got together, all workers in the central hospital. They agreed with a colleague to wait for them by to the hedge with clothes to replace their work uniforms and they left in a taxi. When they got back, they were called to the director's office and held. They objected to being prisoners just for having gone to the Fátima sanctuary, as if the escape was something innocuous or even noble. Nevertheless, the prison order was maintained, but only for two at a time so that the central hospital would not be short of workers for cleaning up. The first two secretly took a radio to the prison and spent the time dancing and singing. Maria was one of them and told me "I even enjoyed being a prisoner!" (Field diary).

The escapes were made by internees helping each other or using other stratagems. Cândida tells: "He raised a dog and taught her to bark at the guards. He incited the dog against the guards. The guards couldn't enter the nucleus because she attacked them. So, when he wanted to go outside to get wine, or even go home, he lived nearby, the little dog would go with him. The dog sniffed out the entire hedge up to Nucleus 3. If she saw a guard, she barked and he knew the guy was walking close by. If she didn't see one, he relaxed and left to go outside".

But transgressions were not the only form of contestation; it also occurred through political struggle. One of the most significant changes at the Hospital Colony, with profound consequences at the internal regulation level, was brought about in the mid 1960s by a group of internees who succeeded in smuggling correspondence circuitously to the Ministry of the Interior, demanding an inspection that resulted in the replacement of the administration. The former patients today call the transformation that occurred in the course of this change "our April 25", referring to the 1974 Carnation Revolution.

The internal organization of the Hospital Colony itself demonstrated more porosity with the agency of the internees than would have been predicted. The rules governing the circulation of money, foodstuffs and alcoholic beverages, gambling and the obligatory curfew were successively subverted by the internees, often with the help of the staff. Due to the scarcity of nursing personnel, many internees assumed these functions, namely the

administration of medication or changing bandages. Eurico worked for many years as a nurse's assistant and claims: "I can change a bandage as well as any nurse".

Indubitably, the long coexistence of the internees with the biomedical model significantly influenced the universes of meaning generated in the Hospital Colony. If in the past the biomedical discourse produced regarding the patients resulted, for them, in the dissemination of 'terror', today the formerly ill appropriate it, with inverse logic, as a controversial instrument vis-à-vis the concept of contagion itself. Thus, the former patients hotly contest the idea of the transmitability of leprosy, even denying it in some cases. They attribute the fear of some people to ignorance and the lack of information. Cândida states, with immense irony, that, for them, "leprosy has wings".

The word "leprosy" itself is identified with something that is ugly and embodies the threat of pollution that inevitably contaminates social contact. For that reason, it is only uttered among those with whom one has some degree of intimacy. Otherwise, the former patients mention the 'disease', most of them still not having assumed the expression Hansen's disease. As Augusto says: "leprosy is an ugly word, no one likes to hear it. Now it's not called leprosy, is it?'.

The Hospital Colony, as an object of profound contestation, is equally an aesthetic product whose authorship the former patients claim. A large part of the construction work was done by the internees, who built a significant portion of its infrastructures, leading them to claim the right to remain in what today is the Centro de Medicina de Reabilitação da Região Centro–Rovisco Pais (The Central Region Rehabilitation Medicine Center - Rovisco Pais) and, concomitantly, receive medical and social assistance. Felipe recalls and affirms: "This was a garden. People came from outside to admire it. The sick people did it all, we also made it. They locked us up here, now they can't send us away".

In fact, the successive transformations of the Hospital Colony closely tracked not only the political transformations in Portugal, but also the progress in curing Hansen's disease. After the end of the dictatorship, internment was no longer compulsory and the Hospital Colony was progressively emptied in the following decades, until it became obsolete, demanding reconfiguration during the 1980s and consolidated in the 1990s. Renamed the Centro de Medicina e Reabilitação da Região Centro–Rovisco Pais, the old Hospital Colony definitively closed its doors to leprosy.

# Conclusion

The stories outlined here illustrate the identity ambivalence imposed by the appearance of a disease that, more than being unavoidably associated with the idea of stigma, itself became an allegory for stigma, or as Sontag formulated (1991), to transform itself into an adjective densely imbued with shameful meanings.

The narratives of the former Hansen's Disease Service patients suggest that, from a structural invisibility, motivated by the social exclusion to which they were consigned by their communities, they were consituted an object of disciplinary seclusion by their compulsory internment in the Hospital Colony. Their stories enable examining experience within a closed institution and, through it, a glimpse of the ways in which the educative

model imposed there was received. The emergence of their voices, silenced by stigma and exile from the public space, points to a problematization of the domestication process of the subjects conducted in the leprosarium that Bissaya Barreto envisioned.

Here memory outlines not only the mundane life that otherwise would be lost in the webs of time, but especially the place for enunciation of the subject that it records. Thus one understands the dysphony between the emphasis that the former patients discursively place on the authoritarianism of the Hospital Colony's internal regulations and the autonomy, however contingent, of their way of life within it, aired in their stories.

In effect, the Hospital Colony, constructed as a dispositive, was transformed into an object of dispute by the practices of appropriation, subversion and contestation of the internees. The boundaries that, as a total institution (Goffman, 1961), it raised between the sick and the public space, as well as in the breast of the internal hierarchy, configured interstitial spaces. The paradox between the social representation of Hansen's disease patients and their experience requires shifting our view beyond power as a dialectic relationship. It may be more revealing to observe the interstitial spaces of the contingency, such as post-colonial criticism points out:

There is truly a growing conviction that the affective experience of social marginality – as it emerges in non-canonic cultural forms – transforms our critical strategies. It forces us ... to deal with culture as the irregular and incomplete production of meaning and worth, frequently comprised of incommensurable demands and practices produced in the act of social survival" (Bhabha, 1998, p.240).

Not only did the internees maintain contact with the social spaces contiguous to the Hospital Colony, but their agency within it also progressively transformed it. It could be said that, if the leprosy patients were the object of disciplinarization by the combined action of biomedicine and the State, the dispositive created for this purpose was also transformed into a object of domestication by the patients. The very educative model that the Hospital Colony constituted was incorporated by the internees in a way that can be described as strategic and selective. Thus, many benefited from acquiring literacy and professional training, rejecting, at the same time, subordination to the authoritarian hierarchy.

By highlighting the oppression of the compulsory internment experience in the past, the former patients demand today, in counterpart, the right to remain in the Hansen's Disease Service and to receive continued medical care and social assistance. In large measure, their discourse regarding the idea of prison is, more than a discourse on what victimizes them, an important strategy of revindication. Remaining in the Hansen's Disease Service itself (interpreted by the technicians of this Service as being motivated by the fragility of their affective and social networks) is explained, according to the former patients, by the fact that they will get financial and clinical support there that is unfeasible outside. In other words, residence in what was formerly the Hospital Colony, more than reflecting the incorporation of the stigma or the shutting down of disciplinary intervention, is most of all an option for the improved conditions that are offered to them there, relative to those that they would have were they to return to where they came from.<sup>8</sup> Thus, it is as agents that they opt to stay.

The Hospital Colony constituted itself as a hybrid space, irreducible to hospital or home. Today, the Hansen's Disease Service assumes this ambivalent condition, joining geriatric care to the treatment and prevention of the consequences of Hansen's disease. The liminarity does not configure here a moment of ontological transformation and structural transition (Turner, 1967), but rather an identity condition, subject to the processes of social marginalization and disciplinary exile, in which the subjects remain structurally invisible. Nevertheless, the interstitial spaces constituted by the boundaries that delimit the margins show themselves to be fertile spaces of social production, in which practices endowed with symbolic and political intentionality were woven. The former Hansen's disease patients have inhabited, throughout their lives, a social contingency that, although making them invisible to the public space, did not eliminate them as historical subjects.

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#### **NOTES**

- <sup>1</sup> The word "leprosy" is so much associated with stigma that it has been replaced by the contemporary designation "Hansen's disease" in an attempt to transform its social representation. However, given the historical context of the individuals to which this text refers, and since the name Hansen's disease was not incorporated by them, the word "leprosy" will be used here, except when referring explicitly to present times.
- <sup>2</sup> This research, conducted between February 2006 and May 2007, was inserted within the scope of an interdisciplinary investigation project entitled The Hospital-Colónia Rovisco Pais: Anthropology and History in Context, carried out by the Anthropology Investigation Center, part of the Universidade de Coimbra's Department of Anthropology, and financed by the Instituto de Investigação Interdisciplinar of the Universidade de Coimbra.
- <sup>3</sup> These include psychiatric hospitals, sanitariums, a vast network of pre-school instruction, maternities, nursing and social assistance schools and the Hospital-Colónia Rovisco Pais (Sousa, 1999).
- <sup>4</sup> In agreement, most of the former Hansen's Disease Service patients tell of the difficulty local doctors had in producing a diagnosis for the set of symptoms that they presented, which left many of them for several years without a precise diagnosis and treatment.
- <sup>5</sup> By medicalization is understood "defining a problem in medical terms, using medical language, adopting a medical format to understand it or using medical intervention to 'treat it'. This is a socio-cultural process that may or may not involve the medical profession, determine medical social control or medical treatment or have resulted in the intentional expansion of the medical profession" (Conrad, 1992, p.211). A number of authors refer to the leprosy medicalization process, among them Pandya, 2003; Monteiro, 2003; Benchimol, Sá, 2003; and Gould, 2005.
- <sup>6</sup> A free translation was made of this and text citations in languages other than Portuguese. [Translator's note: The translation of the main text's English citations uses the original English]
- <sup>7</sup> At the request of the former Hansen's Disease Service patients, their names have been changed to protect their identities.
- <sup>8</sup> The stigma associated with Hansen's disease tends to conceal the agency of the sick. Staples (2005) discusses how, in the south of India, the physical incapacity provoked by the disease is transformed by those who suffer from it into an emancipatory means for their subsistence.
- <sup>9</sup> Fairchild (2006, p.1-2) writes about Carville: "Carville stood at the crossroads of subjugation and freedom: despite the existence of institutionally unprecedented housing arrangements, because of the

reality of compulsory confinement it was too hospital-like to be a home; despite its penal features, because of the unusual autonomy the patients enjoyed, it was too home-like to be a hospital". Similarly, the former Hansen's Disease Service patients of the old Hospital Colony, despite decades of residence in its facilities, where they developed their lives, established affective relationships and worked, still refused to consider that space as their home.

<sup>10</sup> Concerning the relationship between liminarity and marginality, Turner says (1974, p.233): "Marginals, like ritual liminars, are betwixt and between, but unlike ritual liminars, they have no cultural assurance of a final stable resolution for their ambiguity".

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