

# MARTOR



---

Title: "Chronic Isolation: Experiencing a Cured Disease at the Leprosarium of Tichilești"

Author: Andrei Mihail

How to cite this article: Mihail, Andrei. 2015. "Chronic Isolation: Experiencing a Cured Disease at the Leprosarium of Tichilești". *Martor* 20: 93-106.

Published by: *Editura MARTOR* (MARTOR Publishing House), *Muzeul Țăranului Român* (The Museum of the Romanian Peasant)

URL: <http://martor.muzeultaranuluiroman.ro/archive/768-2/>

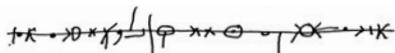
---

*Martor* (The Museum of the Romanian Peasant Anthropology Review) is a peer-reviewed academic journal established in 1996, with a focus on cultural and visual anthropology, ethnology, museum studies and the dialogue among these disciplines. *Martor* review is published by the Museum of the Romanian Peasant. Its aim is to provide, as widely as possible, a rich content at the highest academic and editorial standards for scientific, educational and (in)formational goals. Any use aside from these purposes and without mentioning the source of the article(s) is prohibited and will be considered an infringement of copyright.

*Martor* (Revue d'Anthropologie du Musée du Paysan Roumain) est un journal académique en système *peer-review* fondé en 1996, qui se concentre sur l'anthropologie visuelle et culturelle, l'ethnologie, la muséologie et sur le dialogue entre ces disciplines. La revue *Martor* est publiée par le Musée du Paysan Roumain. Son aspiration est de généraliser l'accès vers un riche contenu au plus haut niveau du point de vue académique et éditorial pour des objectifs scientifiques, éducatifs et informationnels. Toute utilisation au-delà de ces buts et sans mentionner la source des articles est interdite et sera considérée une violation des droits de l'auteur.

*Martor* is indexed by EBSCO and CEEOL.

# Chronic Isolation: Experiencing a Cured Disease at the Leprosarium of Tichilești



**Andrei Mihail**

Ph.D. candidate in Anthropology at the National School of Political Studies and Public Administration

## ABSTRACT

The inhabitants of the Tichilești leprosarium experienced medical isolation caused by a medically cured body; once an individual was diagnosed with leprosy, he would be confined for his whole life inside this institution. Thus, former leprosy sufferers had to cope with the medicalization of their daily life while making sense of a socially incurable illness that disrupted their regular life-trajectories.

## KEYWORDS

leprosy, experience, institutionalization

The leprosarium of Tichilești is located one kilometer away from the road connecting Tulcea to Brăila and Galați. The institution belongs to the administrative area of the city of Isaccea, although it is closer to Revărsarea village. To access Tichilești, you must follow a narrow road full of potholes which, according to those who live<sup>1</sup> there, has not been repaired for nearly 30 years. This road leads to the gate of the leprosarium, a place that does not look like a hospital, but rather more like a sanatorium. The institution is located at the bottom of a horseshoe-shaped valley. The most impressive buildings are located near the gate of the institution. On the left, beyond the fence, opposite a cultivated ground area, you can see a three-floor building comprising a church. On the right, there is a small house which accommodates the manager of the hospital, Răsvan Vasiliu MD, who spends most of the week here. With his help I gained access to the leprosarium, as he is trying to *open the institution a little bit, to let the world see that leprosy is not that frightful and fight the isolation a little bit*, as he puts it. The manager is one of the last European dermatologists specialized in leprosy. He is a

very active man in his mid-50s, interested in popularizing the story of Romania's lepers, in order to make others aware of the realities of this disease. Journalists, photographers or documentarists who exposed frames of the daily life of this institution preceded my visit. This is how I managed to visit the leprosarium twice, during the spring of 2013, in order to observe the daily activities of staff, inhabitants or visitors and discuss with all of them without any formal restrictions. In front of the manager's house the path splits into two, one ramp allowing access to a small building hosting the main-

1) As I will show, individuals living in the leprosarium were cured of leprosy. This is why I call them "inhabitants" of the institution.

Fig. 1. The access road for the Tichilești hospital



tenance personnel, and another one to the administrative offices. From this angle, the entire hospital resembles a *panopticon*, as the administrative staff have a good view of all the sectors. This is also the only area where you can get a cell-phone signal.

2) Due to anonymity reasons, all the names presented in this paper are fictitious. As leprosy is a highly stigmatizing disease, I preferred to change all of my informants' names in order to keep them safe from being recognized by anybody outside the leprosarium. For the same reason, photographs shown here will not show individual traits of the inhabitants of Tichilești.

The second path leads down to the area with the highest density of buildings. On the right side, there is a popular place with some benches and a gazebo where, during summer, the inhabitants can have conversations, play chess and backgammon. Towards the right side of the valley, the visitor can find some living quarters, merely wagon-shaped pavilions, where every resident inhabits two small rooms. There are two buildings located one after the other, extending to the point where the slope starts. Not all the rooms are currently occupied.

On the opposite side of these pavilions, over an area looking like a plaza, one notices medical offices and other social spaces. They include the offices of the



Fig. 2. The garden of a family house

medical staff, bathrooms and toilets, the kitchen and a club where people gather to watch TV, play games, or read books from a small library. The whole area is surrounded by wooden hills where, at different heights, some small two-room houses surrounded by gardens are located; they accommodate families created between institutionalized individuals.<sup>2</sup> On one of these hills, there is also a cemetery for the inhabitants of the leprosarium.



Fig. 3. Pavilions accommodating individuals

Today, the hospital of Tichilești hosts 18 residents and an almost equal number of employees, medical, administrative and support staff, including doctors, nurses, accountants, the manager, a fireman and a painter. Most of the former patients live there permanently; some of them moved away with their families, but are constantly returning to the hospital. The inhabitants' average age is quite advanced, the youngest one being 45 years old. In terms of contracting the disease, there are two categories: on the one hand, there are those who were born of families formed inside, on the other, those who were brought in after having been diagnosed. The last Romanian citizen diagnosed with this disease moved to Tichilești in 1977.

None of the current inhabitants of the leprosarium carry the disease anymore. Hansen's Disease, as it has been called since Armauer Hansen discovered *Mycobacterium leprae*, the bacteria causing the disease, is curable today. A cocktail of antibiotics and other drugs (Multi-Drug Therapy – MDT) can cure its two types, paucibacillary and multibacillary, in 6 to 24 months, depending on its severity. Three days after beginning the treatment one stops being contagious. The severity of leprosy varies depending on the number of bacteria that developed inside the organism, but also on the time the diseased waited until being administered MDT according to certain strict medical rules. If not properly treated, leprosy can cause severe granulomas on the nerves, skin and eyes. This can lead to a loss of sensory senses, triggering limb amputations due to unnoticed lesions, burns or frostbites causing fierce infections. Thus, leprosy is a disease that, even if cured, can leave marks on the body of the former patient.

The treatment administered from an early stage, even if not strictly followed, made the loss of feeling in certain parts of the limbs the main side effect of the illness for those living in Tichilești. Severe skin lesions are not a common effect among the

current inhabitants. From the individual's perception, this made leprosy easy to conceal. From society's point of view, the state also had its share in making leprosy invisible, as it created a single alternative for those who got a strong socially disabling disease that could have otherwise meant homelessness. I consider Arthur Frank's concept of "remission society" (1997) suitable for understanding the processes and phenomena occurring in the case of former leper victims. Frank talks about all those who are doing well after having been diagnosed with a disease, even though they are not considered cured (*ibidem*). For the inhabitants of the hospital of Tichilești, physical recovery should not be considered from strictly from a medical point of view. Skin lesions are responsible for entrenching leprosy during the individual's entire life-span and creating a permanent presence of the disease in the body. Meanwhile, the body is not affected by pathologies anymore, but by social responses to the disease.

These imprints of a medically cured disease are responsible for isolating the inhabitants of the leprosarium even after the 70s, when the MDT treatment became available in Romania. Hence, it is an isolation based on a socially constructed image of the disease that is legitimized by medical knowledge, filtered through the individuals' personal subjectivity and that

Fig. 4. The cemetery



of those composing the patient's social network. Leprosy becomes what Claire Marin calls a "non-disease", a pathology that must be hidden by sufferers, due to medical categories which worsen the patient's personal experiences (2013). Confining former lepers in a medical institution provides the background for pathologizing a current non-medical state that carries representations of the former medical condition. This fact can be responsible for perpetuating isolation, due to a medical procedure responsible for maintaining a healthy social body (Wokaunn *et alii* 2006). This policy created an enclosed space that needed to be domesticated by those inhabiting it. According to one of the former managers of the hospital, Nicolae Romanescu (2002), the institution acquired a village-type social shape as it developed its own economic activities, feasts, relationships, politics, classes or informal property rights. Agriculture and crafts were the main activities of the leprosarium inhabitants, as they provided both food and income through the commodities produced locally that were smuggled outside by the non-medical staff. Of course, these activities were violating the institution's regulations, which powered a continuous conflict between inhabitants and management. However, the years passed and the number of inhabitants constantly decreased, leading to the small, aged population accommodated today at the institution. As the number of residents dropped, the relationship between them and the management improved. None of the conflicts described above were mentioned by my interlocutors during my visit there. I would also emphasize that in the mid 90s, doctor Vasiliu removed one of the most oppressive regulations, authorizing inhabitants to leave the institution on a temporary or permanent basis. Thus, the leprosarium became a less enclosed space that improved its inhabitants' experiences.

"This is heaven, this is not just a living", Leonard asked me to send his message to those who will be interested in my work.

I was asked to describe the good living conditions and the exemplary way that people are treated by the institution for the world to know that Tichilești is not a bad place. Lepers are people like everybody else and the Wailing Valley, a place "avoided even by the birds" as it was once said, is only a senseless myth. Furthermore, Miruna tells me that "my father had a saying: lepers were cared for by the state." For Margareta the place "is great, God has placed us in a forest where it's nice. The trees bloom, we have visitors, we have bread and God cares for us through those who work here."



### The daily medicalization of the body

Being cared for means a permanent institutional control of bodies, which shapes daily experiences. It starts as the disease occurs and continues throughout hospitalization (formal status of the Tichilești residents, as in any other hospital in Romania). The treatment starts just after the admission to the hospital. It is a process of medical colonization (Frank 1997), as the institution claims control of the patient's body; it is a life-long process, as those suffering from leprosy are hardly able to leave the institution and regain full autonomy. As long as (s)he is in, the patient's health is monitored regularly. It is a strongly medicalized life with daily interactions between the individual body and that of the institution. This medicalization is responsible for an increased longevity. Eva, a nurse who has been working there since the early 90s, says that the vast majority of former lepers lived to be over 80. She attributed that to the enhanced care received by residents. A family doctor cares for them, monitors them, nurses administer treatments for different diseases, change bandages and give injections, and the ambulance of the hospital carries individuals to a bigger hospital in case of complications.



Residents also receive three daily meals in the cafeteria, clothes and other items such as towels, soap or detergent. Moreover, they earn a small allowance of 30 lei (around 7€) of which they ought to be able to cover other necessities. The medical staff controls all other processes in order to keep people as healthy as possible. Rodica, another nurse, provides a rich description of the interplay between the medical and the daily life in Tichilești:

*“They have many files here at the office. They have forms and each patient has his own chart and with those they do not even need a referral from Tulcea because he has all the records here, since the admission date. On these files you can find everything the patient has had. And when they go to Tulcea... like Camil now, his head hurts. This evening he leaves at 4 for Tulcea. At 6 he is scheduled to go. They take the files with them. They take him to the exam room, the institution pays and he’s healed. For everything. This is how it works. He goes during the night because doctors work for private clinics in the afternoon. Every year they have tests. Yes, they come from Tulcea every year... both for them and for us.*

*– Special tests for leprosy?*

*– Yes, exactly, but they also check the glucose, cholesterol and blood pressure levels. I actually don’t know if they do tests for leprosy anymore. They did a long time ago, but now, I don’t know. And if the results are not ok, than we can enforce a diet of, let’s say, polenta. No more bread. Just polenta, to get the charts back. He goes on a diet. The nurse goes to the cafeteria office when the menu is decided and says: someone is on a diet, stop giving him bread; so they receive polenta. If the following tests come out OK, the diet ends. All of this for a limited time, a week, two or three... as long as the doctor believes the diet should last.”*

Former lepers confirm Rodica’s stories. Romulus mentioned that he has “other health problems; the nurse, the head physician takes you to medical check-

ups, gives you your treatment and you are bound to obey the doctor; if the doctor says that you cannot do an exercise, you can’t do it.” Medicalization, in its various forms, is a common topic of discussions at the former leper colony. Individuals living in Tichilești become what David Le Breton names “permanent inhabitants of the medical planet” (2008: 317), living in the grey area of lasting indetermination which places the individual in a liminal place, between a capable and incapable human being (Ancet 2013). However, residents of Tichilești adjust this medicalization to their own needs, creating forms of resistance to the yielding of individual autonomy by the institution’s biomedical power (Le Breton 2008). The most common form of resistance is constructed through knowledge, which is shaped around influences from eclectic sources. Biomedicine offers an important model of understanding disease, which is shaped by influences from non-medical descriptions of the disease, daily interactions with others suffering from the same condition or personal symbolic meanings of daily activities limited by hospital regulations.

For many inhabitants of the leprosarium, one form of resistance is adapting the medical treatment plan according to a personalized scheme. It is also a form of individualization of the disease, which is treated according to one’s own needs, symptoms and limitations imposed on the body. Personalizing one’s disease is a recurrent topic, as I will show throughout this text. Personal treatment plans are shaped around biomedical knowledge that is updated through personal representations of the illness. If, in medical terms, after the prescribed period (which can be followed in some cases by other external physical reactions of the body caused by the removal of the dead virus), the treatment should cease, many discussions have revealed that the inhabitants of the leprosarium are still taking the medication frequently. They receive the pills from the hospital,

which orders them from the Ministry of Health. Eva, as a nurse, has also noticed this behavior. She explained it as a need of the former diseased to manage the effects of an illness, whose lifestyle changes required by the treatment are not strictly followed:

*“Yeah, they still take it occasionally, just outside the scheme, but this Dapsone has contraindications, and they have a scheme for a month or for six months; normally it is for six months, but some of the them abuse it; you know how it is, having a good time or maybe somebody brings them something, brings them a drink, and they abuse it and then they feel that they are not well, so they have their symptoms that they have kept in mind and then they ask for the pills; they also ask the doctor for it and they are given a box and they have their stashes. Theoretically, they are not allowed this... you know... that is the placebo effect.”*

Leonard showed me his Dapsone supply; whenever he feels that the disease could reappear, he takes a pill. The pills are collected in the same metal can in which he received the treatment for the first time. When requested, he shares the treatment with others. Leonard believes that the disease, although no longer present in the body, can always reoccur; therefore, he keeps taking the pills. “If, after all these years, you ingest this Promina (the name of the former treatment, before the introduction of MDT), the disease is out and you no longer need to take it, but because the body gets used to it, it is no longer effective and then you have to take a break and then you can take it again.” Anghel did the same thing; he admits taking the pill preventively, although he did not feel ill. Mrs. Miruna, who was born here from diseased parents, also took various forms of treatment during her lifetime, although she was never officially diagnosed with the disease. She was treated for the first time when she was young, at Professor Vulcan’s recommendation, the leprosy specialist from Bucharest who checked all the suspected cases. Although the tests did not

show that Mrs. Miruna was a virus carrier (or perhaps Doctor Vulcan did not want to communicate the news), she has been taking the treatment her whole life, with some discontinuities. Cornel also continues his treatment, even if he does it at a much lower rate than during the period when he was sick: “I take a maintenance treatment. For example, I take 2-3 tablets per week. Because, like I said, it is unpredictable and we should not enable it; especially at an old age, you should not help it. And I’ll soon be 70 years old.”



### **Experiencing Leprosy as Biographical Construction of the Patient**

The struggle over the body is essential in order to understand the behavior of patients who don’t comply with medical regulations. It is a struggle over individual autonomy, in which the patient seeks to regain control over decisions regarding his or her own body. The body is not an object which can be delivered to the institution, but a piece of the self which needs to be re-appropriated. It is through the body that we live, that we experience illness, so it is the body we must control in order to live it. The topic of the lived body appeared in all the discussions I had with the inhabitants of the hospital of Tichilești. The body is the place where disease occurs, but also where its meanings, values and symbols are created. Disease is different from illness. Its perceptions are constructed by means of comparisons with the experiences of the body prior to the illness (Simmel 1967). This bodily subjectivity turns disease into illness, as mentioned by David Le Breton (2010). The disease starts as the first symptoms of body changes appear “and continues with labelling the sufferer by the family or by himself” (Kleinman *et alii* 2006). For him, illness is shaped by cultural factors, assessing discomfort or processes embedded in family, social



and cultural influences through which the disease is perceived, experienced and managed (*ibidem* 141). For Radley, disease imposes important limitations on the body considered to be the place where we live our lives and where we build social relations (1989). Le Breton opposes, in turn, medical symptoms to a subjective perception of the disease. In order to understand the condition of the patient, he proposes giving-up *pain* and replacing it with *suffering* (2010). The French anthropologist argues that the biomedical term lacks relevance. Suffering is the experience of pain; it's not medical, it's social. Concerning leprosy, this distinction is particularly interesting as suffering, as I mentioned above, is related to a body that, to some extent, does not feel pain.

Disease also generates a biographical rupture that occurs as the diagnosis is made (Bury 1982). It restructures daily life and forms of knowledge on which the patient bases his or her values and actions, while also affecting the family and social network (*ibidem*). For those suffering from chronic diseases, biographical rupture is not an instant's product, but a continuous process (Bury 1991). The author says that the experience of disease should be understood within the context of a time interval that provides an overview of each step that builds it. Therefore, disease acquires two kinds of meanings from the patient's perspective: the impact and consequences of transformations embodied in daily life, and the social meanings incorporating all medical conditions (*ibidem* 453). Kleinman also suggests that, considering the diseased individuals, biographies are spaces of the embodiment of the illness, shaping experiences of the concrete life-world (1992). These life-world experiences can shed light on "immediate social existence and practical activity, (...) biographical particularities, decisive events and indecisive strategies" (Jackson 1996). However, Pandora Pound believes that this biographical rupture should be nuanced depending on the

context in which it was produced (Pound *et alii* 1998). Age, social status, gender or any other factor can decrease the impact of the disease on the individual's life (*ibidem*). Differences in perceptions of the disease for the residents of Tichilești are given by the amount of time they were able to spend outside the leprosarium. For people like Cornel, who managed to leave the institution and start a family, to make new relationships or find a suitable job no matter his physical conditions, disease had a smaller impact than for those who, after several years of work, had to return to the hospital permanently. Moreover, in the case of those born in Tichilești, who were diagnosed early on in their lives, a break in the biography caused by disease cannot be accounted for.

Regardless of the moment when the disease was felt for the first time, those affected by it must develop strategies to adapt to the new situation. These strategies are necessary for using the body in the new context, but also in order to manage social interactions through the new ill identity. They arise due to the need to maintain a sense of life stronger than the symptoms or effects of the disease (Williams 2000). These meanings are built on previous experiences through which the patient reconstructs his or her identity. Understanding these identities and behaviors "must take into account the way in which one uses the disease situation as an arena where there are always transactions with others" (Radley 1989). The effects of leprosy are not the result of the disease, but of the social context in which the patient lives and interacts with others. The disease is the way in which sick family members or the extended social network perceive, live with or respond to symptoms and disability (Kleinman 1988), or, as Jean-Luc Nancy has experienced it, is "inscribed in a complex process tied with strangers and strange things" (2000, 21). Doctors, nurses and medical devices or treatments are one of the important *strangers* that become a permanent presence



for the former diseased living in Tichilești. Of course, the biomedical matrix is not the only one shaping the subjective experience of institutionalization. Information exchange with others who share the same experience, inhabitants of neighboring villages, visitors or acquaintances are sources of adaptation of the medical discourse to a more subjective personal background.



### The Sick Body – Subject to the Traces of Leprosy

The individual, subjective disease is constructed in a field of complex interactions between types of knowledge (Martin 1994), but also of perceptions, images and relationships it develops within the body (Janzen 2002). “Knowledge is built on experience and its contextual contingencies” (Adams *et alii* 2014:191), shaping subjective medical constructions of those who have to adopt a new sick identity. Leprosy is a disease with complex effects that requires constant care of the body. “Leprosy is a pretentious dame. This is what I call it. Those who cared, who listened, for example me. An old man said: *“o you see that guy? This is how you’ll end up, unless you listen to what I say, how to act, how to dress when it’s cold or something else, as leprosy loses the senses.* This is the beginning of Margareta’s disease story, a woman of over 80 years old, who moved to Tichilești in 1946. Other people, when asked to describe the disease, quote her. The pretentious dame must be taken care of and continuously monitored. Life orbits around the disease which, in the absence of proper treatment and lifestyle, can take control of the body. *It is very difficult. It is very demanding. So, firstly, you cannot drink, you must eat heartily... so my parents, my aunt, you can see her, when admitted for the first time in the hospital, they followed the treatment and said it was very strong. And they complied,*

*so they followed the treatment and did not have any problems.* Margareta, who went through the same difficulties of managing the disease, reinforces Marița’s perception. Actually, this is common amongst most of my interlocutors. When asked to describe the disease, very few mentioned direct, medical symptoms. They rather focused on telling stories about limitations the treatment imposed on them. It is a different description than the biomedical one, where leprosy is considered just an infectious disease that causes severe skin lesions and breakdown of the nervous system of the arms and legs.

The body should be seen as an agent of subjectivities in order to understand variations of experiences of individuals with a deformed exterior (Staples cited. Csordas 2003:297). The body is experienced from within, not from the outside, as the biomedical paradigm considers (Slatman & Widdershoven 2010, 5). It is a body whose self is connected to its incorporation (Leder 2002) and which *embodies a symbolic value before figuring biology* (Le Breton 2006, 45). For the former leprosy sufferers living in Tichilești, this model of the body provides a framework for understanding the experience of illness. Drew Leder says that, usually, the body disappears on a daily basis, reappearing only when pain or illness is felt (1990). For healthy individuals, *the body is rarely the thematic object of experience* (*ibidem* 3). For my interlocutors, the effects of the illness produced a permanent presence in the body. It is a strange disease that leaves its marks on the body even after it has been cured. Side effects of leprosy are not necessarily experienced from a medical perspective, but from the ways they influence the patient’s life.

Hope ceases to be part of former leprosy sufferer’s future and I have noticed that it is one of the key issues in understanding the social effects of this disease. Loss of hope kills any strategies or any plans for the future. Hope vanishes, leaving behind individuals without any potential future



(Novas 2006). Leprosy-related confinement adds a sense of failure to the general experience of this disease. It is a failure seen through the eyes of others, creating a loss of confidence resulting in marginalization (Le Breton 2013). Furthermore, being ejected from one's group leads to what Collaud calls "a shame of being" (Collaud *apud* Le Breton 2013), a "loss of dignity disconnected from circumstantial reference, a social relation that doesn't tolerate any hesitation between confidence and the confidence conferred by others" (Le Breton 2013). This loss of hope is influenced by restrictions such as being unable to work or to experience a disappeared body which provides individuals with the full autonomy needed for performing regular social roles.

Leonard, the last person admitted to Tichilești, arrived here in 1977 at the age of 13. At 18 years old, as the treatment was effective, and as the disease was not contagious, he managed to leave the leprosarium due to a policy of the communist regime that aimed to reintegrate former leprosy sufferers; their independence would cost the state less money. Thus, after four years of confinement, Leonard was employed at the Sulina shipyard where he trained as a carpenter. This qualification, he says, was the result of chance rather than of will, as he spent time with a worker who taught him how to work the wood. After five years, he got a job in Tulcea, at a lumber mill, which he also left after several years when he returned to Sulina as a carpenter in the construction field. As he mentions, "where and if there was hard work to do, I was there." However, the hard work accelerated the spreading of the disease; *as I felt it reappear, winter was the most dangerous for us. I had to carry lime or cement and I could not do it anymore.* His fingers curled at 67 years old. Gradually, he also lost his senses. *I have told you, you get used to it. Working with logs was something I could handle; you didn't need a fine touch. But when it's about a small nail or something, I could not do it. Something raw, rough work,*

*was OK.* The loss of his senses triggered the impossibility of performing tasks and forced Leonard to return on a full-time basis to the leprosarium where he operated a small workshop for repairing objects belonging to the employees or to other tenants; *I'm not an employee or anything, I do it for myself in order not to forget what I have learned.*

Leonard's story is not unique. Nea Nelu is 69 years old and he first came to Tichilești in 1964; he left after a few years of treatment, only to return in 1986 as his disease reappeared. He left the leprosarium again in 1988, but he returned for good in 1995. Outside, Nea Nelu worked as a tractor operator for several farms in Dobrogea. Same as with Leonard, the discussion quickly turns to the social effects of the disease that leprosy sufferers have to overcome. *There were great heats waves in Constanța and it was even hotter inside the tractor cabin. (...) I was harvesting in July. That literally boiled me. It did not hurt, but I saw something here. I had a blister.* The stubbornness to work in a harmful environment eventually forced Nea Nelu to give up his full-time job. Today, altered senses force him to keep a constant watch over his body. *I have a strong cold in winter, I have a syndrome with the stove: if I touch it, I get a blister full of water that can break, and it takes a month or so to heal, and I need to change my bandage, again and again. That's my illness,* he says, stressing that daily care is imperative. He must be aware of the sun, of cold or touching hot stoves or pots that might cause injuries that, without the senses, could easily infect and cause even greater problems. Cold in itself is a reason for caution. Disease leaves the body less sensitive to cold, which can cause frostbitten limbs, followed by finger amputation.

The story of Mrs. Miruna's mother clearly shows the importance of an increased attention when it comes to a body affected by leprosy. One day, while working in her small garden, the woman stepped on a nail that had been forgotten on the ground. She did not feel it. The nail, found



in the evening, had deepened the wound and caused a strong infection that could not be treated and led to the amputation of her foot. Regarding her parents, Mrs. Miruna says that *they burned, they froze while clearing snow, they worked and stepped on nails or thorns, that's why they got it.*

The lack of senses has also affected Marița, who was born from two diseased parents that got married at the leprosarium. She also developed a social symptomatology; the disease is not only a sum of pains and injuries, but also their effects on the patient's daily life. Right from the first discussion, when I asked her how the disease manifests itself and what its symptoms were, Marița replied that *it's the hand that leaves me first. The left hand... I cannot catch, it doesn't feel safe, I drop plates, glasses, so I don't feel safe with it. So, the nervous system is... the nervous system is attacked and abandons you.* The destruction of the nervous system is especially problematic for those who managed to leave Tichilești. Cornel lived there until he got married. His parents' disease tied his whole childhood to the hospital. At 33, Cornel went to Brăila to live with his wife. Like others, he was able to work in Constanța while young. Thus, he says, he discontinued the treatment earlier than needed. In addition, because of the people he befriended, for several years he led an unhealthy lifestyle that resulted in a paralyzed left leg and problems with his right eye that he can hardly close. He believes that because of this partial paralysis he could not work properly, even if his body was not carrying the disease anymore:

*"This disease socially affected me from an inactivity point of view. I couldn't get a job, find a place to work, make sustained physical effort; for example, the paralysis was very easy to detect from the beginning, even at first glance. As you can see, this is quite striking. And people have questions and confusions, what you were doing, what happened. I answered to some, I haven't to others, but in terms of integration into society, I have never suffered and I haven't considered this*

*disability as a great defeat. I helped my family as much as I could, I worked in places where I could do something. God gave me cars instead of legs, at the time when I needed them, and I was able to use them instead of walking."*

He also personifies the disease as a pretentious lady that requires one's attention in order to take permanent care of her. *Cold and heat give... these temperature differences create, due to the lack of a normal immunity... a leprosy patient has no immunity to the outside world... you know that Romanian saying: neither hot, nor cold. Proper temperature. But leprosy patients know this fact and they pay attention to it. It's uncomfortable.*

Last, but not least, the restrictions leprosy imposes on the diseased body can be observed in the hospital furniture. Daily spaces like toilets or showers require adaptations to make them usable by patients with mobility problems. Eva, a nurse, recounts the case of a patient with an amputated foot who was sent to bathe, even though he experienced problems with balance and stability. *One of them took a bath on the Saturday before Easter; I sent him to the bathroom and he couldn't find another way to get into the tub than to kneel. And by standing on his knees he got a wound. They have special seats that attach to the tub, but he didn't think about them, so he used his knees.*

Fig. 5. The bathing chair





### Subjective Categories of Disease: Individualization of Leprosy

Interactions between the personal explanatory model of former lepers and information received from the medical staff in Tichilești are responsible for filling a void of meaning produced by the failure of success outside the leprosarium. Coming back to an institution that claims control of the body through medical practices and objects also translates into decreased individual autonomy. The body, unable to maintain personal autonomy due to the marks of the disease it exposes, forces former leprosy sufferers into institutionalization. The healthy body, the founding base of individualization according to Le Breton (2004) is opposed to the one carrying the signs of a socially disabling disease, which imposes a confined life on its owner. Thus, the individual seeks to understand the meanings of his body and disease through the medical model of the institution, but also with the help of the social networks developing among the other inhabitants. The way patients conceptualize illness may change deeply within the clinic through interactions with the medical staff and other patients (White 2005). The clinic is the place where the biomedical model meets the strict, subjective patient with no previous access to scientific knowledge (Le Breton 2002). Michel de Certeau talks of the locus within each individual hosting “an incoherent (and often contradictory) plurality of interaction between relational determinations”, defined by the terms constructing them (1988). Such knowledge of the patient is formed in an area of intersection of complex systems, a place where knowledge is created and simultaneously internalized (Martin 1994). These forms of knowledge are reinforced by interactions creating social groupings developed around private and intimate experiences, around what Judith Allsop and her colleagues, referring to Habermas, named “the life-world of ordinary people”

(2004).

Leprosy acquires the individual features of an enemy whom one must fear for life in order to prevent his return which could cause damage. The disease is personified and integrated into a symbolic universe managed by the individual which he is able to handle. I see this as a strategy by which the patient gives meaning to the gap appearing after the diagnosis. Verbs associated with leprosy are eloquent. For Romulus disease “responds” and “attacks”, but can also “stand” when the treatment is effective. For Cornel, leprosy *is the disease that is not a friend, neither cold, nor hot, so it's like some sort of a lady who must be cared for and protected*. For Marița, the disease *is very difficult, very demanding and does not work at once, you know, it works in time*, and for Margareta the *pretentious dame* should be permanently cared for.

The disease is personalized from one individual to another. Discussions revealed an often highly individualized disease, without highly internalized medical categories of disease. Margareta describes her illness: *I had my leprosy. I was not hurt. Do you know how I was aware of it? The senses*. None of the people I talked to provided a thorough medical description of the disease when we discussed its manifestations. Unlike medical categories based on strict, scientific, precise indicators such as the number of bacteria found inside the body, the number of granulomas appearing on the skin of the patient or their size and color, personal experiences are relevant as they include a strong personal side. This is the way the disease was experienced by the patient and the consequences its effects produced on him; as we have seen, experiences are not universal as the disease is strongly anchored in the patient's social world.

To illustrate, I will give the floor to my interviewees, their descriptions being the best tool to evoke this process. For Romulus, the disease is different *for each person as there are several categories. It reacts in many*



ways, not only in one specific way. It's a disease which attacks. It's a disease you don't feel. It's a disease that attacks you and deforms your body. Head, skin, hands, feet, nose, mouth, eyes... all that stuff. Leonard talks about the ways in which the disease affects others. Cornel is, if you look at him better... there are many kinds of leprosy. We close our eyes with our eyelids, but he must roll his eyes. Yes, the nervous system damaged his eyes. He sleeps with his eyes open. Margareta has wrinkles on her face. Tuberculoid leprosy and lepromatous leprosy... leprosy dries you, as people say. It doesn't attack the hands and feet, it attacks the hair, that's another one... there are many... with other wounds that won't heal. Also, Uncle Igor who just died... he had wounds for more than 30 years. He had no tissue left, and he had such strong hands. His eyebrows were gone, his hair fell off, all of that in 30 years. I don't know why he didn't heal. You could see his bones with all those plagues. Knowledge is not medically accurate even when describing their own disease: neither I... I cannot figure out what I have or have not.

However, the side effects are clear: this disease, this leprosy, appears as a sort of gloss. Healthy parts of the body sweat, but where it affects you, you have no sense, you have like a luster and you don't sweat... Here and there it's the same. I sweat, when I work, when I do all kinds of things. I sweated like a pig, but in those areas there was nothing. You must be very careful with the cold; otherwise you don't have a thing. On others' disease? Stan... his mother was sick, he has nothing, he doesn't have leprosy. He has... maybe he's a little gone off his rocker, but as his mother was sick... they hospitalized him too. Romulus, over there, the same. His mother was ill, leprosy, but he's healthy, that's not leprosy. That's nothing. His finger... that was an accident. It's not the disease, it's just an accident.

For Nea Nelu, there are nine kinds of leprosy, some more important than others. For him, Camil doesn't suffer from the disease. He has children's disease... I don't

know if you've heard about it. He starts seizing, and if there's nobody next to him, he could swallow his tongue and die. His mother had leprosy. His mother brought him there. He was not ill, he was just a bus driver. His opinions are even more interesting as Camil is, according to his medical file, the individual with the most visible signs of the disease on his body; he is also being treated for a wound that will not cure as he has also experienced problems due to the lack of senses.

For Miruna, here in Tichilești we had just two types of the disease, unlike Asia, India or China where it could be a lot worst. I know this from Professor Vulcan. So, with this type of disease, the feet, hands, eyes and so on could develop granulomas and you could suffocate. Many have suffocated around here. Cornel also perceives several types of the disease: One has a milder form, another one has a more delicate one, and another has one that leaves most severe sequelae due to lack of treatment. So the problem is the following: it has at least six, seven forms. Some with pain, some without pain, others with malformations caused by the fact that the patient was not treated. However, his disease is also personified, as it can be "mastered" through treatment. The types of disease are constructed through the ways in which they manifest themselves. In a small space, such as the one of Tichilești, those who suffer from leprosy have the opportunity to build their vision of this disease through personal experiences and that of other patients with whom they interact. Moreover, since this is a hospital setting, medicine also has some influence from one case to another.

• • • • •

## Conclusions

Leprosy is an atypical disease. Although, nowadays, it is treatable, and the patient can heal from a medical point of view, leprosy can mark the body for his or her whole life.



Currently, institutions such as Tichilești are no longer used to treat a disease that is not contagious after the first days of treatment. The current treatment plan is administered at home, so the patient can continue to live as she or he did before being diagnosed. However, since this is a long-term treatment (depending on the type of disease, the duration can vary between one to four years) which imposes strict rules on patients' daily activities and practices, many find it difficult to follow it properly; this was true both for those who were treated inside the institution and for those who were treated at home. For these reasons, many of those who have been diagnosed with leprosy bear the effects of the disease on their body, even if they are completely healed. Thus, leprosy ceases to be a medical illness, turning into one that exists at the social level. Signs of the disease continue to oversee the patient's life, which is why many of those who have reached Tichilești had to settle there permanently. Tichilești is a very interesting case of a medical institution caring for medically healthy individuals. It is a medical institution which, in order to hide the bodies of those carrying a burdening disease, tries to control them. In this setting, the leprosarium has also become the only housing option for the diseased as society doesn't provide any other alternative, the hospital accommodating all those for whom regular life is forbidden.

Thus, the hospital becomes a place institutionalizing the loss of hope, as the patients know that once they are confined here, they will not be able to perform current or future social roles. The institution regulates the individual's life and world through medicalization, access to food, clothing or money; it is an institutionally created life-world, which is not entirely adopted by the inhabitants of the hospital. Yet, this institutional, general, life-world is shaped by individuals according to personal backgrounds, constructing a series of local, personalized contexts adapted to big ones. The personalized life-world forms of

resistance to medical models through the domestication of both disease and space have evolved. Leprosy is personalized as it causes subjective experiences. Each individual disease is defined according to unique experiences. It is not a single disease experienced through its objective symptoms, but several illnesses constructed by individual biographies. The *personal* disease, thus, needs to be dealt with in a personal way, via personal treatment plans adapted to individual side-effects of leprosy or knowledge questioning the universal character of medical explanations.

## BIBLIOGRAPHY

- Adams, Vincanne, Nancy Burke and Ian Whitmarsh. 2014. "Medical Anthropology: Cross-Cultural Studies in Health and Illness." *Medical Anthropology* 179-197.
- Allsop, Judith, Kathryn Jones and Rob Baggott. 2004. "Health consumer groups in the UK: a new social movement?" *Sociology of Health & Illness* 737-756.
- Ancet, Pierre. 2013. "Après l'accident: renaître à un autre corps." In *Corps abîmés*, by David Le Breton and Denisa Butnaru, 109-118. Québec: Presses de l'Université Laval.
- Bury, Michael. 1982. "Chronic illness as biographical disruption." *Sociology of Health and Illness* 167-182.
- . 1991. "The sociology of chronic illness: a review of research and prospects." *Sociology of Health & Illness* 451-468.
- de Certeau, Michel and Pierre Mayol. 1988. *The Practice of Everyday Life*. Berkeley and Los Angeles: University of California Press.
- Frank, Arthur. 1997. *The Wounded Storyteller. Body, Illness, and Ethics*. Chicago: The University of Chicago Press.
- Jackson, Michael. 1996. *Things As They Are: New Directions*

- in *Phenomenological Anthropology*. Bloomington: Indiana University Press.
- Janzen, John. 2002. *The Social Fabric of Health: An Introduction to Medical Anthropology*. New-York: McGraw-Hill.
- Kleinman, Arthur. 1992. "Local Worlds of Suffering: An Interpersonal Focus for Ethnographies of Illness Experience." *Qual Health Res* 127-134.
- . 1988. *The Illness Narratives. Suffering, Healing and the Human Condition*. New York: Basic Books.
- Kleinman, Arthur, Leon Eisenberg and Byron Good. 2006. "Culture, Illness and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research." *FOCUS, The Journal of Lifelong Learning in Psychiatry* 140-149.
- Le Breton, David. 2006. *Anthropologie de la Douleur*. Paris: Editions Métailié.
- . 2002. *Antropologia Corpului și Modernitatea*. Timișoara: Amarcord.
- . 2010. *Expériences de la douleur: Entre destruction et renaissance*. Paris:Éditions Métailié.
- . 2008. *La chair à vif : De la leçon d'anatomie aux greffes d'organes*. Paris: Editions Métailié.
- . 2004. *Les passions ordinaires: Anthropologie des émotions*. Paris: Payot.
- . 2013. "Mûrir sa mort: ambivalence et soins palliatifs." *Jalmalv* 43-58.
- Leder, Drew. 1990. *The Absent Body*. Chicago: Chicago University Press.
- . 2002. "Whose Body? What Body? The Metaphysics of Organ Transplantation." *Philosophy and Medicine: Persons and Their Bodies: Rights, Responsibilities, Relationships* 233-264.
- Marin, Claire. 2013. *L'homme sans fièvre*. Paris: Armand Colin.
- Martin, Emily. 1994. *Flexible Bodies: Tracking Immunity in American Culture from the Days of POLIO to the Age of AIDS*. Boston: Beacon Press.
- Nancy, Jean-Luc. 2000. *L'intrus*. Paris: Editions Galilée.
- Novas, Carlos. 2006. "The Political Economy of Hope: Patients' Organizations, Science and Biovalue." *Biosocieties* 289-305.
- Pound, Pandora, Patrick Gompertz and Shah Ebrahim. 1998. "Illness in the context of older age: the case of stroke." *Sociology of Health & Illness* 489-506.
- Radley, Alan. 1989. "Style, discourse and constraint in adjustment to chronic illness." *Sociology of Health & Illness* 231-252.
- Romanescu, Nicolae. 2002. *Ultima leprozerie: din amintirile unui medic*. București: Universal Dalsi.
- Simmel, Marianne. 1967. "The Body Percept in Physical Medicine and Rehabilitation." *Journal of Health and Social Behavior* 60-64.
- Slatman, Jenny and Guy Widdershoven. 2010. "Hand Transplant and Bodily Integrity." *Body and Society* 16 (3): 69-92.
- Staples, James. 2003. "Disguise, Revelation and Copyright: Disassembling the South Indian Leper." *The Journal of the Royal Anthropological Institute* 9 (2): 295-315.
- White, Cassandra. 2005. "Explaining a Complex Disease Process: Talking to Patients about Hansen's Disease (Leprosy) in Brazil." *Medical Anthropology Quarterly*, 19 (3): 310-330.
- Williams, Simon. 2000. "Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept." *Sociology of Health & Illness* 40-67.
- Wokaunn, Mario, Ivan Jurić and Žarko Vrbica. 2006. "Between Stigma and Dawn of Medicine: the Last Leprosarium in Croatia." *Croat Med Journal* 759-766.

