

## Traces and scope of social memory through oral history: post-memory of leprosy – Pará/Ceará

### ARTICLE

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1

### Abstract

This article deals with a social problem that is still present today: the stigma of leprosy. The content is a presentation of a research project developed for our post-doctoral internship. Our discussion highlights transdisciplinarity, cultural history and oral history as methodological options. We look at the imaginary and everyday history in search of the value of social memory about the problem of leprosy in the descendants of those affected by the disease in Ceará and Pará. We hope that the results of this research will provide a better understanding of the social contradictions that affect not only leprosy sufferers, but also their descendants.

**Keywords:** Leprosy. Oral History. Cultural History.

### Rastros e alcance da memória social através da história oral: pós-memória da hanseníase – Pará/Ceará

### Resumo

O presente artigo trata de um problema social, ainda presente atualmente: o estigma da Hanseníase. O conteúdo trata da apresentação de um projeto de pesquisa elaborado para um estágio de pós-doutorado de nossa autoria. Nossa discussão destaca em especial a transdisciplinaridade, a história cultural e a história oral como opções metodológicas. Debruçamo-nos sobre o imaginário e a história cotidiana em busca do valor da memória social acerca da problemática da hanseníase nos descendentes daqueles acometidos por esta doença no Ceará e no Pará. Esperamos como resultados desta pesquisa conseguir formular uma melhor compreensão acerca das contradições sociais que atingem não apenas os hansenianos, como também os seus descendentes.

**Palavras-chave:** Hanseníase. História Oral. História Cultural.

## 1 Introduction

In oral history, as a methodological option, even if a well-justified time frame is indicated, the testimonies given by the people interviewed usually go beyond an indicated period. After all, *individual or collective memory* (Halbwachs, 2006) goes far beyond, breaking down barriers that could dilute the indelible association between yesterday and

today. It is impossible to dissociate a chosen temporality from the *continuum*<sup>1</sup> of history, especially when resorting to the mnemonic revelations of indicated testimonies. Although they are not able to *rescue*<sup>2</sup>, as is often claimed, what seemed to have been lost, they are able to reconstruct a remote or even immediate past in a broader dimension, through the continuous linking of the narrated plot and a reconstructed temporality.

I chose this topic because, during my time at school, a fourth-grade student became my girlfriend and, today, my wife, sharing more than fifty years of marriage. Something that, given the macho tradition, could have seemed trivial, perhaps just one of the possible "flirtations" of a young teacher. However, the lived reality had another projection, with a meaning based on symbolic *representations*, generated in the continuous link between the *imaginary*<sup>3</sup> and the lived reality.

The product of this long experience had already been published by myself and a friend rather than a work colleague (Jucá and Lima, 2016). Our aim was to make public a well-founded narrative about the problems and dilemmas faced by leprosy patients and their descendants, including the testimonies of health professionals working in the former Antônio Diogo Colony, located in the municipality of Redenção, Ceará.

In this first study, the interviewees were leprosy patients, their sons and daughters, a doctor and a special nurse dedicated to them. In this proposal, we decided to focus on the children and possible grandchildren of the "dreaded disease" in order to better understand the educational process aimed at caring for them. In addition, we seek to indicate the contrasts between the proposed objectives and the speeches made, as well as the "disciplinary power" imposed, in comparison to the concrete social results recorded.<sup>4</sup>

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<sup>1</sup> Regarding the dynamics of history versus evolutionism and the dream of progress, it is important to know Walter Benjamin's rejection of the causal genetic method (Benjamin, 2006, p. 1156).

<sup>2</sup> In general, the use of the term rescue has become common in historiographical references, but it should not be forgotten that no past can be rescued, since it has always been and will continue to be reconstructed by the observer from a distant present.

<sup>3</sup> For an understanding of the scope of the term imaginary, and against "the old one-dimensional and totalitarian neopositivisms", I recommend Durand, Gilbert (2012).

<sup>4</sup> For a better understanding of the concept of "Power", see Michel Foucault: fundamental concepts / edited by Dianna Taylor, translated by Fábio Creder. Petrópolis, RJ: Vozes, 2018, p. 21 - 94.

## 2 Towards a transdisciplinary analysis

Given the scale of the subject of the proposed study, leprosy should not be limited to a specific geographical or temporal *space*. In order to better understand the problems arising from a mutilated upbringing, without family support, we resorted to the concept of *space* conceived as symbolic, as defined by Certeau (2016, p. 202), the effect produced by operations that guide, circumstantiate, temporalize and lead it to function as a polyvalent unit of conflictual programs or contractual proximities.

We used oral history as a *methodological option*<sup>5</sup>. Even though we focused on two municipalities, one in Pará and the other in Ceará, the key points of the experiential practices take us back to a broader scenario, involving the continuous link between the past and the present<sup>6</sup>, in the search to understand an undefined tomorrow, but not dissociated from the relationship between *memory and identity*, seeking to understand "the memory of tragedies as an identity resource" (Candeau, 2011, p. 151 – 156).

In the field of the History of Health and Diseases, we can see the sharpness of the problems arising from the imposition of the colonial system, which would be perpetuated over the centuries. The gradual increase in the mortality rate was accompanied by the loss of life of newborns and poorly cared for children.

The scenario of the spread of diseases such as leprosy makes us go beyond the possible limits of time, because in order to understand their social dimension, it is essential to take a retrospective look. Because of this, in the search for a better analysis of the dilemmas that have arisen, we see the interrelationship between macro and micro history (Ginzburg, 2007). Even with the isolationist and repressive character of those affected by the dreaded "Hansen's disease", the meaning of its spread takes us back to a very comprehensive historical process. The dilemma that was revealed in both Pará and Ceará

<sup>5</sup> For more on the subject, vide Amado & Ferreira, 1998, f. VII a XXV.

<sup>6</sup> Temporality should not be recognized as a projection subdivided into past, present and future, but as a continuous association recorded throughout an ongoing historical process.

had no borders, and its defining landmark in relation to the New World was the establishment of the colonial system, based on the slave mode of production.

Treating contagious diseases was only seen as a way of alleviating the dilemma, with a limited proposal for assistance, more focused on defending the interests of the upper social strata, who positioned themselves through a solid defense against the threat of the evils that arose. However, the imaginary symbolism of leprosy, for many understood as a "punishment from heaven", revealed a distorted representation of reality, maintained by the force of traditions in the collective memory.

As we made explicit at the beginning of our research project, the association between *Comparative History and Oral History* is revealed as a path to be followed, not in a straight line, but as paths that intersect, with other routes and sources, such as the postgraduate research already carried out in Pará and Ceará. In order not to leave the central point of our study too open-ended, the central point of our research was to listen to and give a voice to the children and/or grandchildren of leprosy patients. Through their testimonies, we sought to reveal the real meaning not only of the educational practices imposed on them in the course of the educational assistance provided, but also the psychological deprivation generated in them as a result of the irreparable loss of family support.

The studies produced in both Pará and Ceará (Silva, 2009, p. 43), selected as representative spaces for our project, reveal the contrast between the welfare proposals made and the socio-cultural results projected in everyday life. Without wishing to detract from the academic production recorded, concentrated on the interrelationship between Social and Political History, in the field of education, we propose to go a little further, looking at the expression of feelings, behaviors and "values and psychic states" (Lawrence, 2013), characteristics of the analyses produced not only in the exclusive field of psychology, but also, currently, very latent in the field of Cultural History. This indication brings us once again to the meaning of *transdisciplinarity*, which reveals that "the social is not a clear and univocal process". It is always projected not only as a compact reality, but also in the

projection of the imaginary in its multiple representations, which try to simplify what seems complex and difficult to understand.

In relation to the choice of Pará as another field of research, in addition to the traditional link between its history and that of Ceará, resulting from the migratory process generated by the rubber exploitation process, there are also common traits. These traits are visible even today, as a result of social dilemmas without borders, such as the poverty and underemployment rate, resulting from a concentration of income and a lack of resources in welfare and educational bodies. These bodies, although they have defined objectives, are not in a position to meet them. And the more complex the social situation becomes, the more we see a continuous disassociation between schools, families and the state.

Without leaving aside the challenges of everyday life shared by leprosy patients, we decided to focus on the practices and experiences shared by children and grandchildren of leprosy patients, both inside and outside of schools. Despite the gradual expansion of social assistance, the key point of the dilemma remained indelible. There was a continuous contradiction between what could or should be done and the results of an obtuse form of education, deprived of resources and, above all, of a possible way of overcoming the emblematic lack of affection and family attention, which was impossible to overcome. The concrete result of the eternal dilemma of the absence of family warmth was continually revealed in the social relationships shared on a daily basis, always demonstrating the results of the lack of authentic family support that could be conceived spontaneously, without the coercive impositions of rigid social control.

The concentration of income is still an obstacle to overcoming social imbalances. However, the state's assistance has diminished, aggravating the treatment of public health and contagious diseases. Despite the persistence of serious obstacles in the services provided by the SUS, it is still possible to mitigate the worsening of the ongoing deficiency in care. As one health doctor observes:

The Unified Health System (SUS), for example, is more than a symbol of Brazil's re-democratization and the expansion of our population's rights. But despite these

advances, we still face challenges. In many ways, our health system remains fragmented and reactive, with chronic non-communicable diseases dominating the scene (Madeira Neto, 2023, p. 18).

Even in the face of the dilemmas arising from a poor social infrastructure, in the last decade the situation has become less emblematic in Ceará, with the implementation of new measures conducive to greater assistance for children. Ceará's former first lady, Onélia Leite Santana, currently the state's Secretary for Social Protection, has been working on the "Mais Infância Ceará" program, created to develop the national policy for so-called "early childhood", instituted by the Council for Social and Sustainable Economic Development, linked to the Bolsa Família welfare program. Thus, a new source of welfare resources emerged with the institution of the so-called "Early Childhood Benefit", expressed in an additional R\$150.00 for 8,900 children aged zero to six. The strategic axis of the Mais Infância program was the creation of early childhood education centers. The government installs the equipment and maintenance is the responsibility of the municipalities.

The inspiration for this measure came from an experience of positive results put into practice by the government of Ceará. Each extremely poor family received 100 reais a month. In order to assess how parents treat their children, the following question is asked: "Have you kissed your son today?" and the answer is incisive: "No. Man doesn't kiss man ... All I have to do is put my daily bread on the table."

Secretary Onélia Santana's opinion is a precise definition of a promising assistance goal: "*early childhood is the ground we walk on throughout our lives*". From 0 to 5 years and 11 months, which is precisely the period of early childhood, it is the most important period for the human being, where the baby's brain is in full development, and when we acquire our potential (Páginas Azuis, Jornal O Povo, 09 out. 2023, p. 6 e 7).

This comment brings us back to the wit of Françoise Dolto, a French pediatrician and psychoanalyst dedicated to child psychoanalysis, who helps us understand the dimension and meaning of the maternal and filial bond from its roots, from the unfolding of gestation to the blossoming of subjectivity. For her, *everything is language*, which expresses the value of using words as a form of expression, especially in childhood, the

starting point for the psychic delineation of each one of us. The emptiness created inside a lonely child, who needs to communicate from an early age, generates a mutilated *modus vivendi*, marked by the weight of loneliness, clearly expressed in their physiognomy. A lonely child's lack of affection is expressed in his own gaze, which is always sad, as if he can't erase a blurry spot that makes it impossible to see in a multifaceted way. In her analysis:

These [very lonely] children are like sacks that accept any content: they take everything, it's indifferent to them. They live such an imaginary life that they no longer have anything to do with humans, their language escapes human words (Dolto, 2018, p. 12).

Family support is irreplaceable because

Human beings are marked by the real contacts they have had with the conscious and unconscious of the people who lived around them, their mother in the first place, their father, and the first people who played the role of their mother's other. (Dolto, 2018, p. 30).

And what about the sons and daughters of leprosy patients, who from the first day of their lives were cut off from their family, deprived of irreplaceable maternal affection, what state of mind was generated by this affective castration? We shouldn't generalize a state of mind as if it were homogeneous; after all, subjectivity is the indelible mark of each one of us. The way of being and acting is different even in twin brothers, but just as there is a collective memory, the suffering of those who grew up without a family is projected as a loss peculiar to all of them. The desired answers will be given to us by each of the children of leprosy patients.

Even with concrete measures that are worthy of recognition, the problem of assisting underprivileged children is very inadequate. As proof of this, it is enough to look at the IBGE data, which shows a high rate of malnourished children; this is in relation to public health, and in relation to those without family support, the rate is certainly much higher.

Faced with the continuing evidence, we are left with the following question: are the children of leprosy sufferers currently receiving the assistance they need for an adequate

early childhood education? If the lack of paternal and maternal protection is increasingly visible in the daily lives of middle-class families, who fail to participate fully in their children's education, transferring all responsibility to schools, the situation in other social spaces, including public schools, is even more worrying. The gradual loss of real, active support between parents and their children is a collective dilemma. Certainly, due to leprosy treatment in the family, the relationships maintained with the children must be affected by the discovery of a disease that has not ceased to be enigmatic.

The scheduled interviews allowed us to better understand the old question. The biggest problem today is "*The Family in Disorder*" (Roudinesco, 2003), in the most diverse social spaces, which reveals the scope of a dilemma. The transformations that have taken place, more than ever, are undermining the idealized model of the family that has always been united and welcoming, which is no longer projected as the "basic cell" of society.

When we look at recent publications on *The History Of Children*, which represent a step forward in terms of current thematic options, we still see gaps that need to be filled. In the work organized by Del Priore (2021), of the 15 chapters, only three indirectly seem to come close to our study proposal. Two spaces are configured in Aldrin Moura's work: "the domestic universe" and "the world of the street", where "many intersecting forms of sociability" are projected. The third space is for Edson Passetti, in his approach, states that nowadays "[...] many children and young people have experienced *unimaginable cruelties*. Cruelties generated within the family, in schools, factories and offices, in clashes between gangs, *in boarding schools or on the streets*, between drug dealers and the police" (p. 347).

If we associate the themes of these two works with our study, we can see how the daily practices of the children of leprosy sufferers intersect with the experiences narrated by these two authors. After all, the "plural problems" manifested in the most diverse spaces occupied by children are also present in the daily lives of the children of leprosy patients. Whether at home or on the streets, the cruelties are not only visible to the naked eye, but the pain of the family's lack of affection is projected as a manifestation of *unimaginable cruelties*, transfigured into banalities. However, these banalities are configured in a much broader projection: the unconscious of the unassisted. The course of daily and care



practices in relation to leprosy constitutes a long trail of shared experiences, demonstrating the limits and precariousness of public bodies in dealing with the challenges that remain solid, making collective well-being impossible.

As the problem of public health is a concrete reality in the most diverse spaces, whether in the North, Northeast or any other Brazilian region, we cannot underestimate the continuous social assistance provided by official bodies, whether national, regional or state. Even so, the critical situation cannot be overcome. According to a comment by a former state representative from Ceará, out of ten poor children in Ceará, ten are malnourished.

In this symbiosis between the possible and the impossible, the desired and the obtained, the situation of the children of leprosy patients takes the form of an endemic, aggravated by a latent malnutrition, an affective malnutrition that should not be considered only in the sense of material compensation. Even more acute is the absence of family love, without which the reasons for living lose their representative meaning of a model of inner balance desired in the face of everyday reality and its meaning.

In the impulses of shared temporality, the spaces that are offered or imposed on us should not be considered static, categorical, the result of generalizations that can be attributed to them. Even when limited by circumstances or imposed conditions, social spaces do not appear homogeneous, nor are they hermetically sealed, since they allow for the projection of different actions and reactions. Taking positions is decisive in mitigating the impact of everyday challenges. Subjectivity should not be expressed as a passivity capable of easing the burden imposed on us, but should be configured as taking a position, capable of avoiding total submission to the conditions of the time lived.

In light of these considerations, we will try to visualize the children and/or grandchildren of leprosy patients not as victims of a fateful process, but as continuous agents, not so passive, at different stages, yesterday and today. The absence of family care, with a father or mother always distant from their children, even when they are close, is commonplace today. What was left behind in one generation, the next will have to carry, in the continuous relationship between the individual and the collective.

In the paradoxical reception process of the schools for the children of leprosy patients, both in Pará and Ceará, we shouldn't just consider them as victims of a repressive reception that always made them passive. Each one of them, consciously or unconsciously, had and still has the peculiarity of *individuation*<sup>7</sup>, a search for self-knowledge capable of reconfiguring in memory the projection of shared experiences.

### 3 The imaginary and the real at the confluence of literature and history

With the theoretical-methodological renewal of History in recent decades, in the wake of a "New History", with "New Problems", "New Approaches" and "New Objects" (Le Goff and Nora, 1976), traditional barriers have been broken down and a rapprochement between the fields of history and literature has become possible, broadening the horizon of studies in the field of Human Sciences, which are interconnected in a more interactive way. The conceptual support of the new times was sought in Anthropology. The *Imaginary* came to be conceived with new "conditions and [new] methods of approach" and no longer as something random, but projected as a "*plastic category*" (Wunenburger, 2007), subject to multiple interpretative variations, worthy of credit. What had been conceived as the antonym of History came to be recognized as an extension of knowledge, expressed in the revelation of the breadth of an interlocution, well conceived in the use of transdisciplinarity<sup>8</sup>.

After finishing law school, José de Alencar moved to Rio de Janeiro, where he became known as a writer through his publications in the *Correio Mercantil* and *Jornal do Commercio* newspapers. His success as a writer began with his first novel, published in 1856, followed by others that made him famous, such as *O Guarani*, *Iracema* and *Cinco*

<sup>7</sup> For more information see: "Em busca da individuação" in *100 Minutos para entender Jung..* 2.ed. Bauru, SP: Astral Cultural, 2022. (Coleção saberes), p. 45 – 79.

<sup>8</sup> The term interdisciplinarity appears more as a desired goal, but one that is difficult to put into practice in its entirety, without the traditional ties of each area of human knowledge. This is quite different from the meaning of transdisciplinarity, which is capable of breaking down the rigid boundaries imposed on the human sciences. For a better analysis, see PAULA, João Antônio de. (Organizer). *Transdisciplinarity and Contemporary Challenges*. Belo Horizonte: Editora UFMG, 2008.

*Minutos*. In addition to these, Alencar wrote short stories, chronicles, essays, critical articles and plays. In 1846, he entered the Faculty of Law in Rio de Janeiro and, the following year, went to live in Olinda, where he completed his bachelor's degree at the Olinda Faculty of Law. While in Pernambuco, he wrote *A Alma do Lázaro*, one of his first literary works, which was only published twenty-five years later, together with *O Garatujo* and *O Ermitão da Glória*, in the second volume of *Alfarrábios: Crônica dos Tempos Coloniais*.

The book was released by Editora B. L. Garnier in Rio de Janeiro in 1873. *Alfarrábios* was the first step in the production of the author, who was 19 at the time, living in Pernambuco. It was at this time that he was struck down by tuberculosis, which would lead to his death in 1877. A common thread in the plot of these publications is that the main characters in these works were people marked by loneliness and distanced from social life. The reissue of this publication was the initiative of Professor Zilda Maria Menezes Lima, from the History course at the State University of Ceará (UECE), with the support of the Ceará State Department of Culture. It was launched in 2011 as one of the works awarded the Otacílio de Azevedo Prize, sponsor of the Reissue. According to Professor Zilda:

what can be seen is that *A Alma do Lázaro* is a narrative without the stylistic sophistication that generally marks the whole of Alencarina's work. Written in the first person, the plot comes across as puerile if one looks at the strictly literary and/or aesthetic aspects (Lima, 2011, p. 05).

In this *presentation*, she goes on to highlight "the prejudice of the sane" against the dreaded disease, aggravated by the impossibility of a solution, generating a physical and social drama. The setting of the novel is the 18th century, when a student at the Olinda Faculty of Law finds a diary hidden in the Carmo Convent and begins to give voice to the diary's author, marked by the pain, hopelessness and depersonalization of the leper. Supported by the memory and wit of a poor fisherman, Tonico, who accompanied him to the place where the diary was buried, the source found is symbolic and representative. The plot of the diary takes place over a period of three months. It was only in the last decades of the 19th century that the debate that led to the disease being recognized as one of the country's most serious health problems took off in Brazil. "The Evil of Lazarus" led the

politician Alencar to recognize and publicize one of the emblematic social issues of his time. The novel's epilogue sums up the social and psychological significance of the disease:

Assim termina o canhenho do Lázaro. Expulso do Recife, pela plebe irritada com os últimos sucessos refugiou-se na casa abandonadas de Olinda, onde terminou afinal a imensa e cruel agonia de uma existência nunca vivida, mas tão penada (Alencar, 1873, p.106).

The continuous morbidity of leprosy is perpetuated in the trajectory of another character, Edmundo Nonato, better known by the pseudonym "Marcos Rey" (Maranhão, 2004), an inmate who escaped from a school in São Paulo and made a name for himself as a renowned journalist and writer. Escapes such as his were not the majority of cases recorded in the schools, but there is one particularity that deserves to be remembered: because he was not the son of leprosy patients, he always had the support of his family, a very different situation from those infected with the disease in previous centuries.

#### 4 Socialization of everyday practices over time

In a more recent era, that of globalization, marked by multicolored landscapes of messages and advertisements that implode at every moment, the children of leprosy patients no longer find themselves trapped in the old schools, since their parents are free from the old "Chain Colonies" of the Leprosaria. At first glance, paternal and filial relationships are imagined to be more concordant, with possibilities for manifesting affection and cordial sentimentality, in the face of the challenges of the "Age of Emptiness" (Lipovetsky, 2005, p. 31-58) and the projection of a new time, "The Time of Tribes," when "the relativization of values, one for another, leads to *undecidability*" (Maffesoli, 2002, p. 153), the longed-for power of the leprosy patients. 153), the longed-for power of individualized autonomy is being erased by the loss of socialization, projected onto the passivity of the masses in the face of a possible redeemer of the continuous challenges that intertwine (Baudrillard, 1985).

In the theater of everyday life, there are more passive spectators than actors who are aware of their roles; that's why another question arises, referring us to a comparative association, dotted with questions: are the children of leprosy sufferers compensated today with a family life that differs from the forced exile of the schools, or do remnants of the former terror of leprosy still maintain a solid barrier between parents and children? A synthetic and representative definition has just been launched, in a "*strange time*", dotted with dialectical evidence, where "isolation and pornography" increases the number of the "isolated and anxious" with the "trivialization of evil", projecting a world marked by resentment and cruelty (Kehl, 2018, p. 35 – 42 e 43 – 46).

Another question emerges in an associative way: faced with an often distressing reality, in the daily lives of the children of leprosy patients, always marked by the absence of family support, have dreams been completely erased or can the possible memories serve to support the reconfiguration of the emotions projected in the memories that emerge? The symbolic revelations of dreams, submerged in the unconscious, can provide explanations for the amalgam of evidence and incongruities that are projected into memory, through the attempt to recompose what seemed lost.

For Freud, "The dream is the fulfillment of desire". Dreams don't just represent the projection of facts or evidence from the recent past; memories from childhood or even youth are present in dreams, wrapped in images, places and people that seemed lost in time. What seemed unimportant suddenly reappears: insignificant things and fragments of the past are projected into the present through dreams, when childhood impressions that seemed lost resurface (Freud, 2020).

The recognition of the value of dreams was not confined to Freudian thought or the other representatives of psychoanalysis. The dream world of the Yanomani, previously unappreciated by ethnologists, has come to be recognized by the insightful sense of Hanna Limulja, who delves deeply into the meaning of dreams. The relationship between speech and dreams for the Yanomani:

Regardless of what a dream means, this meaning is never given arbitrarily or at the whim of the dreamer. The dream comes into the world through language, by being

told, otherwise it would remain a virtual reality and therefore could not be fully realized. (Shamdasani, 2001, p. 100).

If dreams have a symbolic meaning in different temporalities, in the open-ended interviews with the children of leprosy patients, we intend to resort to their narratives about dreams that may have a revealing representation. For each of the interviewees, the evidence contained in the projected memories, whether with well-structured plots or in the projection of partial memories, sometimes conceived as if they were of no importance, can reveal significant aspects. According to the dialogues held, these representative revelations can provide us with a better understanding of the experiences evoked.

Faced with the revealing dimension of leprosy, in the *spaces and practices* that define the educational system of the schools, there must be something more than a *symbolic hell*, derived from the repressive norms and practices of the education imposed there, as defined by Jung:

Hell is when you know that everything serious you have in mind is also ridiculous, that everything delicate is also crude, everything good is also bad, everything high is also low, that all good works are also bad (Shamdasani, 2001, p. 100).

By turning to this thinker, the concept of the unconscious allows us to better understand experiences that are not always perceptible, whether in a personal unconscious or in a *collective unconscious*. In his words:

We can distinguish a "personal" unconscious, which encompasses all the acquisitions of personal existence, such as what has been forgotten, what has been repressed, what has been perceived subliminally, what has been thought and what has been felt. However, alongside these personal psychic contents, there are other contents, which do not originate from personal acquisitions, but from a possibility of psychic functioning that has been inherited, in other words, from the hereditary structure of the brain. These are mythological relationships, motifs and images which, regardless of tradition or historical migration, can resurface anywhere at any time. These contents I call the "collective unconscious" (Wunenburger, 2007, p. 66-67).

Based on this conceptual dimension, our research hypothesis is the following: if every family has its secrets, the secrets of those "without a family," rooted in "what was repressed" due to the absence of paternal and maternal support, weigh much more heavily

throughout their lives. The history of leprosy has always been shrouded in the power of the imaginary, understood here not as an escape from reality, but "in its double aspect":

The imaginary is the mirror of our emotions, what in our images actually reflects the state of our body, of our neurobiological constitution according to current vocabulary: on the other hand, the imaginary excites in us inner resonances of pleasure and displeasure, because a mental image, just like an external reality, can provoke effects on sensitivity, act on mood, give rise to feelings of sadness or joy. (Wunenburger, 2007, p. 66-67).

Although historians recognize the difference between history and memory, there is a continuous association between these two concepts. Jung's reflection brings us back to the scope of *memory*, according to Halbwachs, in all its projection, be it *individual memory* or *collective memory*. He emphasized that all memory was structured around group identities, highlighting the collective constitution of social consciousness, leaving individual consciousness tied to the strength of the collective. It's as if the collective conscience distanced itself from the concrete way of thinking of each person interviewed. James Fentress and Chris Wickham, who prefer the term "social memory" to "collective memory", make an insightful comment about this restriction:

[...] an important problem facing anyone who wishes to follow Halbwachs [...] is that of elaborating a conception of memory which, while doing full justice to the collective side of each person's conscious life, does not make the individual a kind of automaton, passively obedient to the internalized collective will (Halbwachs, 1990, p. 81 and Fentress & Wickham, n.d., p. 7.).

Faced with these two versions, another question deserves to be asked: which one is more appropriate for our study? In terms of the search for a continuous link between the individual and the social, the experiences of the children and grandchildren of leprosy sufferers, the expression of a collective memory can be demonstrated in the experiences they share. However, faced with the impact of the barriers that were imposed on them during their experiences, which were also marked by competition in search of improvements, the representation of confrontations and clashes is best expressed through a social memory.

Another concept that reveals a broader psychosocial framework, always present in the daily lives of the children or grandchildren of leprosy patients, is *time*, also redefined by various authors, but who share the same observation: despite the different or distant moments, there is a link between yesterday and today, and tomorrow, despite the sudden or unwanted changes. For Nobeit Elias, "time" is a conceptual symbol of a synthesis in the process of being constituted, that is, of a complex operation of relating different evolutionary processes. He adds:

As we've said, the demarcation lines between past, present and future are constantly changing, because the very subjects for whom a given event is past, present or future change or are replaced by others. They change individually, along the path that leads from birth to death, and collectively, through the succession of generations (and in many other ways). (Elias, 1998, p. 41 and 65).

To reinforce our analysis, we turn to Beatriz Sarlo, who coined the term "post-memory" (Sarlo, 2007) to better understand the impact of Argentina's military repression on the families of political prisoners, who lost their newborn children and were sent to couples who wanted to adopt them. In this way, an unbroken distance was delineated between lost parents and parents chosen according to the decisions made by representatives of political and military repression. We decided to use this concept not in the same way as the aforementioned author presents it, but in a different way: in the case of the families of leprosy patients, it was possible for the grandchildren to get to know their grandparents, although in different ways in each family involved. However, as they didn't have a closer relationship with the leprosy patients, their narratives are presented in a peculiar way, depending on the contacts they had or hadn't had, representing a greater distance between them than the sporadic relationship between leprosy patients and their children.

In an attempt to break the ties that lead to the isolation of areas of knowledge in the field of the Human Sciences, starting from the use of Cultural History associated with the History of Comparative Education, we cannot elaborate a revealing analysis through our study without resorting to the traces and links of psychoanalysis. This should not be



understood in a formal sense, but rather through the spontaneous revelations generated in the exchange of experiences.

There are two well-founded academic works on leprosy in Pará, in the past and today (Silva, 2009). They do not make it possible to better understand the contrast between the welfare proposals made and the resulting socio-cultural results, generated by the conditions and contradictions between the speeches made and the realities recorded in everyday life. These analyses allow me to understand how "biopolitics" (Foucault, 1999, p. 291), generated since the 19th century, has been perpetuated throughout the last century, in the intertwining of power, freedom and subjectivity (Taylor, 2018).

## 5 Proposed methodology

The collection of testimonies from children and/or grandchildren of leprosy patients in Ceará and Pará will be based on the use of Oral History as a methodological option. We do not intend to underestimate the use of written sources, as these are indispensable. However, we consider it essential to use *oral history* as a methodological option, as the interviewees will be the main agents of the historical process we are analyzing. The content is transmitted through the interviews, whose agents are sources who speak and dialog in a "*tête-à-tête*" between interviewer and interviewees.

Another point to note is that, in a departure from the tradition of most historians, we will not be concerned with indicating the period studied by means of precise dates for a fixed chronological cut-off; after all, the content extracted from interviews has a much more expressive temporality. Yesterday and today, in search of a tomorrow, cannot be delimited by dates alone, considering the *continuum* of time, as recognized by Nobeit Elias. However, another question arises: this chronology, which is not interspersed with unforeseen events or social impulses, what does it mean?

We don't intend to tie ourselves to dates, but to situate the interviewees in the course of temporality, where the past is projected into the present, in the search for a less oppressive future. According to the survey, the children of leprosy patients are between sixty and seventy years old and the grandchildren are on average between thirty and forty

years old. In this amalgam of yesterday and today, "the rhythm of life" weighs heavily, "from one self to another" where a "[...] collective unconscious is structured around the luminosity of archetypes", in a kind of imposition of a "theory of social relativity", where "[...] the emotional becomes currency" (Maffesoli, 2007, p. 105 – 175). And "symbolic power, subordinate power, is a transformed form [...] of the other forms of power [...]" (Bourdieu, 2001, p. 15) present in social spaces, spaces of differences (Bourdieu, 1995, p. 27).

The trajectories of the children and grandchildren of leprosy patients represent a process of *long duration*, as indicated by the historian Fernand Braudel (1972), who led the Annales School from the post-war period until the early 1970s. From then on, a third phase of this School emerged, the so-called New History, aimed at exploring "new themes" and "new approaches", with previously unrecognized "new agents", eschewing the idea of a long duration (Saviani, 2015, p. 1-9). A "history in crumbs" emerged, following "the thread and the traces" before the "true, false, fictitious", well expressed by Italian microhistory (Ginzburg, 2006). For the French historian François Dosse, this transdisciplinarity uncovered another connection: "History as well as psychoanalysis: an epistemology between science and fiction." (Bosi, 2003, p. 15).

Given these thematic and methodological changes, another question arises: considering the complexity of the subject of *leprosy*, where should we place it: in macro or micro history? In my opinion, the two paths intersect. The dreaded disease has a long course, but a thematic totality does not escape fragments, spaces that are at first glance restricted, everyday, but comprehensive and interconnected through a *continuum*. Memory is multifaceted, shared, with cuts and breaks. There is a mixture of realities and oral tradition, because "oral memory is a precious tool if we want to construct a chronicle of everyday life".

[...] Oral memory, far from the one-sidedness towards which certain institutions tend, makes contradictory points of view intervene, at least different ones, and therein lies its greatest richness. It cannot achieve a theory of history, nor does it pretend to: it illustrates what we now call the History of Mentalities, the History of Sensibilities. (Bosi, 2003, p. 15).

Our aim is to adopt "*Oral History, a plural space*" (Montenegro e Fernandes, 2000) as a methodological option, leaving aside those who consider it a simple complementary technique or even those who recognize it as an autonomous discipline. According to the vision of two pioneers in the use of history among us:

In oral history, there is the generation of documents (interviews) that have a unique characteristic: they are the result of a dialog between interviewer and interviewee, between subject and object of study; this leads the historian to move away from interpretations based on a rigid separation between subject / object of research, and to seek alternative paths of interpretation. (Amado and Ferreira, 1998, P. XIV).

If the use of Oral History breaks the traditional barriers of temporality, going beyond chronological cuts of a given period, the thematic content studied goes much further, taking the researcher into a field very close to psychoanalysis.

When we consider the basic works of Freud's or Jung's thinking, we soon realize this connecting thread between "History and Psychoanalysis". There is a link between "Science and Fiction". (Certeau, 2012). This is why, in our proposed analysis, we seek to understand not only the current problem of the "Family in Disorder" (Roudinesco, 2003), in the "Age of Emptiness (Lipovetsky, 2005)" and the "Hyperconsumption Society", but "the Transdisciplinary Dream" (Japiassu, 2006), present in the testimonies of children and grandchildren of leprosy patients, which allows us to establish an association between the not-so-distant past, the second half of the last century, and the present day, in the search for the reasons and representations of the "Archives of Illness and Resistance" (Birman, 2017) of these "Subjects of Contemporaneity". Thus, the situation of the witnesses of those without families deserves to be narrated in the face of "[...] space, pain and discouragement today" (Birman, 2017), "in the shadow of the silent majorities." (Baudrillard, 1985).

Reality and the imaginary appear as if they were opposite poles, but they are not. They are soul mates. Everyday practices leave indelible marks on each of us. Those shared by the children of leprosy patients, whether adults or elderly people, reflect the origins of their desires and anxieties. Literature is full of stories of childhoods without families, in an allegorical sense, the convicts. And the plot of literary productions is not the fruit of a simple imagination. Today's practices have their roots in yesterday.

At first, two families will be our field of work, after all, it's not the quantitative that defines the validity of a study, but especially the qualitative, according to formal academic language. I prefer to use the concept of *representation*<sup>9</sup> conceived as something more than a simple meaning of a concrete reality, but as a symbolic projection of multiple meanings. After all, "struggles over representations are as important as economic struggles in understanding the mechanisms by which a group imposes or tries to impose its conception of the social world, the values that are its own, and its domination." (Chartier, 2002, p. 17).

In a continuous association between the past and the present, we are faced with two ways of being and acting of our historical agents: the children of leprosy patients, who shared "[...] the multiplicity of situations, experiences, logical and non-logical actions that constitute *sociality*" (Maffesoli, 2002, p. 10).

We still don't consider the route to be followed in our research to be quite ready. Social memory is complex and/or contradictory; in it there is more than a confluence, perhaps a continuous confrontation, revealing the inverse of the desired and the realized. All that remains is to ascertain the direction of the paths, which are not one-way streets. That is our purpose.

## References

ABREU, Martha. Meninas perdidas. in DEL PRIORE, Mary. **História das Crianças no Brasil**. São Paulo: Contexto, p.289 – 316, 2021.

ALBERTI, Verena. **Ouvi Contar**. Textos em História Oral. Rio de Janeiro: Editora FGV, 2004.

AMADO, Janaína e FERREIRA, Marieta de Moraes. Apresentação. In: AMADO, Janaína e FERREIRA, Marieta de Moraes. **Usos & abusos da História Oral**. 2<sup>a</sup>.ed. Rio de Janeiro: Editora da Fundação Getúlio Vargas, 1998.

BAUDRILLARD, Jean. **À obra das maiorias silenciosa**: o fim do social e o surgimento das massas. 2.ed. São Paulo: Editora Brasiliense, 1985.

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<sup>9</sup> "Representations of the social world [...] although they aspire to the universality of a diagnosis based on reason, they are always determined by the interests of the groups that forge them."

BENJAMIN, Walter. **Passagens**. Organização da edição brasileira Willi Bolle et al. Belo Horizonte: Editora UFMG; São Paulo: Imprensa Oficial do estado de São Paulo, 2006.

BORDIEU, Pierre. **O Poder Simbólico**. Tradução Fernando Tomaz. 4ª.ed. Rio de Janeiro: Bertrand Brasil, 2001.

BORDIEU, Pierre. **Razões práticas**. Sobre a Teoria da Ação. 7ª.ed. Tradução Mariza Corrêa. Campinas, SP: Papirus, 1995.

BOSI, Eclea. **O Tempo Vivo da Memória**. Ensaios de Psicologia Social. São Paulo: Ateliê Editorial, 2003.

BRAUDEL, Fernand. **História e Ciências Sociais**. Lisboa: Presença, 1972.

CANDEAU, Jöel. **Memória e identidade**. Tradução Maria Leticia Ferreira. São Paulo: Contexto, 2011.

CERTEAU, Michel. **A invenção do cotidiano**: 1. Artes de fazer. Tradução Ephraim Ferreira Alves. Petrópolis, RJ: Vozes, 1994.

CHARTIER, Roger. **A História Cultural entre Práticas e Representações**. 2. ed. Lisboa: DIFEL, 2002.

DOLTO, François. **Tudo É Linguagem**. 2. ed. São Paulo: Martins Fontes, 2018.

DOSSE, François. **História e Ciências Sociais**. Tradução Fernanda Abreu. Bauru, SP: EDUSC, 2004.

ELIAS, Nibert. **Sobre o Tempo**. Rio de Janeiro: Jorge Zahar Editores, 1998.

FENTRESS, James & WICKHAM, Chris. **Memória Social**: novas perspectivas sobre o passado. Trad. Telma Costa. Lisboa: Editorial Teorema, s.d.

FIGUEIREDO, Aldrian Moura. **Memórias da Infância Na Amazônia**. in DEL PRIORE, Mary. *História das Crianças no Brasil*. São Paulo: Contexto, p. 317 – 346, 2021.

FREUD, Sigmund. **A interpretação dos sonhos**. Porto Alegre L&PM, 2020.

FOUCAULT, Michel. Em defesa da sociedade. Curso no Collège de France (1975 – 1976). São Paulo: Martins Fontes, 1999.

GINZBURG, Carlo. 13. Micro – história: duas ou três coisas que sei a respeito in GINZBURG, Carlo. **O fio e os rastros**: verdadeiro, flas, fictício.; tradução Rosa Freire d’Aguiar e Eduardo Brandão. São Paulo: Companhia das Letras, 2007.

GINZBURG, Carlo. **O fio e os rastros**. Tradução de Rosa Frei d’Aguiar e Eduardo Brandão. São Paulo: Companhia das Letras, 2007.

ESPADA LIMA, Henrique. **A micro-história italiana**: escalas, indícios e singularidades. Rio de Janeiro: Civilização Brasileira, 2006.

HALBWACHS, Maurice. **A memória Coletiva**. São Paulo: São Paulo: Centauro, 2006.  
JUCÁ, Gisafran Nazareno Mota & LIMA, Zilda Maria Menezes. **Memória Social da Hanseníase no Ceará**. Fortaleza: EdUECE, 2016.

KEHL, Maira Rita. **Tempo Esquisito**. 1.ed. São Paulo: Boi Tempo, 2018.

LIMA, Zilda Maria Menezes. Apresentação. In: ALENCAR, José de. **A Alma do Lázaro**. Fortaleza: Expressão Gráfica Editora, 2011.

LAWRENCE, Stone. O retorno da narrativa: reflexões sobre uma nova velha história. In: NOVAIS, Fernando Antônio e SILVA, Rogerio Forastieri da. **Nova História em Perspectiva**. V. 2. São Paulo: Cosac Naify, 2013.

LE GOFF, Jacques e NORA, Pierre. **História**: novos problemas. Rio de Janeiro: F. Alves, 1976.

LIPOVETSKY, Gilles. **A Era do Vazio**: ensaios sobre o individualismo contemporâneo. Tradução Therezinha Monteiro Deutsch. Barueri, SP: Manole, 2005, p. 31 – 58.

MADEIRA NETO, Álvaro. **O futuro da gestão em saúde**. Fortaleza, *Jornal O Povo*, Opinião. 14 out. 2023.

MAFFESOLI, Michel. **O Tempo das Tribos**: o declínio do individualismo nas sociedades de massa. 3ª ed. tradução de Maria de Loyrdes Menezes. Rio de Janeiro: Forense Universitária, 2002.

MAFFESOLI, Michel. **O ritmo da vida**: variações sobre o imaginário pós-moderno. Rio de Janeiro: Record, 2007.

MARANHÃO, Marcos. **Maldição e Glória**. a vida e o mundo de Marcos Rey. São Paulo: Companhia das Letras, 2004.

MONTENEGRO, Antônio Torres e FERNANDES, Tania Maria (Orgs.) **História Oral**: um espaço plural. Recife: Universitária; UFPE, 2000.

Páginas Azuis. Onélia Leite Santana. **Quando A Política Olha Para a Infância**. |Social | Secretária fala do trabalho voltado, principalmente, à primeira infância e comenta o convívio com o marido, Camilo Santana in Fortaleza, *Jornal O Povo*, 09 out. 2023.

PASSETTI, Edson. Crianças Carentes e Políticas Públicas. In: DEL PRIORE, Mary. **História das Crianças no Brasil**. São Paulo: Contexto, p. 347 – 406, 2021.

ROUDINESCO, Elisabeth. **A Família em Desordem**. Tradução André Telles. Rio de Janeiro: Zahar, 2003.

SARLO, Beatriz. **Tempo passado**: cultura da memória e guinda subjetiva. São Paulo: Companhia das Letras, Belo Horizonte: UFMG, 2007.

SAVIANI, Demerval. Da História do Tempo ao Tempo da História. In: SAVIANI, Demerval **História do Tempo e Tempo da História**. Ensaios de Historiografia e história da educação. Campinas, SP: Autores Associados, 2015.

SHAMDASANI, Sonu. **C. G. Jung**. Uma Biografia em Livros. Tradução de Gentil A. Tittomn. Petrópolis: Vozes, 2001.

SILVA, José Bittencourt da. **A Ex – Colônia de Hansenianos de Marituba**. Perspectivas Histórica, Sociológica e Etnográfica. Belém, maio de 2009. 43p

TAYLOR, Dianna. **Michel Foucault**: conceitos fundamentais. Petrópolis, RJ: Vozes, 2018.

WUNENBURGER, Jean – Jacques. **O Imaginário**. Tradução Maria Stela Gonçalves. São Paulo: edições Loyola, 2007.

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24

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