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Dossier
Health/illness, biosocialities and culture

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Articles

- 7 **From exoticism to diversity**
The production of difference in a globalized and fragmented world
Michel Nicolau Netto
- 37 **“I want to marry in Cabo Verde”**
Reflections on homosexual conjugality in contexts
Andréa Lobo, Francisco Miguel

Dossier “Health/illness, biosocialities and culture”

Carlos Guilherme do Valle, Sahra Gibbon

- 67 **Introduction**
Carlos Guilherme do Valle, Sahra Gibbon
- 75 **Time, DNA and documents in family reckonings**
Claudia Fonseca
- 109 **Health and the Value of Inheritance**
The meanings surrounding a rare genetic disease
Waleska de Araújo Aureliano
- 141 **La science de la parenté :**
Adoption, génétique et identité parmi les adoptés au Brésil
Débora Allebrandt
- 167 **From abortion to embryonic stem cell research:**
Biosociality and the constitution of subjects
in the debate over human rights
Naara Luna

- 204 **The multiple meanings of ‘risk’:**
Views on the abortion of non-viable fetuses among
Brazilian medical doctors and magistrates
Juliana Lopes de Macedo
- 231 **La production d’articulations et de mouvements
pour la santé des hommes au Brésil :**
La sexualité comme porte d’entrée
Fabiola Rohden
- 260 **Tracing identities through interconnections:**
The biological body, intersubjective experiences
and narratives of suffering
Telma Camargo da Silva
- 290 **La cosmopolitique de la dépression**
Biosocialité dans une ethnographie multi-espèces
Jean Segata
- 321 **Biolegitimacy, rights and social policies:**
New biopolitical regimes in mental healthcare in Brazil
Sônia Weidner Maluf
- 351 **The construction of citizenship and the field of indigenous health:**
A critical analysis of the relationship between
bio-power and bio-identity
Carla Costa Teixeira, Cristina Dias da Silva

Review

- 385 **Review: Ana Lúcia Pastore Schritzmeyer, Jogo,
ritual e teatro: um estudo antropológico do Tribunal
do Júri. São Paulo: Terceiro Nome, 2012.**
Jerry Dávila
- 387 **Review: WELCH, James R., SANTOS, Ricardo Ventura,
FLOWERS, Nancy M. & COIMBRA Jr. Carlos, E. A. Na Primeira
Margem do Rio: Território e Ecologia do Povo Xavante de
Wedezé. Rio de Janeiro: Museu do Índio/FUNAI, 2013, 248 p.**
Maria Rosário de Carvalho

From exoticism to diversity

The production of difference in a globalized and fragmented world

Michel Nicolau Netto

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Abstract

Difference is a social construction, and as such it needs a discourse to produce meaning and be socially effective. As a discourse is always socially and historically grounded, so it is the meaning of difference. This article proposes that the difference in the contemporary world is dominantly articulated in the discourse of diversity, as the discourse of exoticism was the dominant discourse of difference in the 19th Century. This proposal will be proved as I show that, as diversity becomes the appreciated discourse in the present, the exoticism loses its value. Stating that, I will try to understand the conditions of existence of each discourse. I will argue that the exoticism was founded in the 19th century upon three fundamentals: imperialism, the idea of progress and nation. They provided the condition for a discourse that based the production of difference on the stable separation of an internal and an external space. After examining the fundamentals and their relations with the discourse of exoticism, I will show that the production of difference is no longer based on stable notions of internal and external spaces. Currently, difference is produced on the basis of fragmented and globalized social relations, which requires a discourse flexible enough to cope with these material conditions. The discourse of diversity is this discourse.

Keywords: diversity, exoticism, exotic, difference, nation, globalization.

Resumo

A diferença é uma construção social, e, como tal, necessita de um discurso para produzir sentido e ser efetiva socialmente. Como um discurso é sempre histórico e socialmente fundado, assim o é o sentido da diferença. Este artigo

propõe que a diferença na contemporaneidade é predominantemente articulada no discurso da diversidade, do mesmo modo como o discurso do exótico foi o discurso dominante da diferença no século XIX. Essa proposta será demonstrada ao se notar que, na medida em que a diversidade se torna um discurso apreciado no presente, o exotismo perde seu valor. Ao dizer isso, busco entender as condições de existências de ambos discursos. Eu argumentarei que o exotismo se fundou no século XIX sob três fundamentos: o imperialismo, a ideia do progresso e a nação. Eles proveram a condição para um discurso que baseou a produção da diferença na separação estável entre um espaço interno e um externo. Após examinar os fundamentos e suas relações com o discurso do exótico, demonstrarei que a produção da diferença não é mais baseada em noções estáveis de espaços interno e externo. Atualmente, a diferença é produzida em bases de relações sociais fragmentadas e globalizadas, que requerem um discurso flexível o suficiente para dar conta dessas condições materiais. O discurso da diversidade é esse discurso.

Palavras-chave: diversidade, exótico, exotismo, diferença, nação, globalização

From exoticism to diversity

The production of difference in a globalized and fragmented world

Michel Nicolau Netto

Introduction¹

Diversity is a pervasive discourse in our times. From the consumption of goods to governmental policies, from Argentina to Japan we find diversity branded everywhere. Even nations, historically built under the notion of identity, are now branded under diversity. The Brazilian Ministry of Culture, for instance, promoted the country during the 2006 FIFA World Cup with the slogan “Brazil, the country of diversity” (Paschoal & Odenthal 2006). The Minister of Culture, at that time, Gilberto Gil gave many interviews affirming that the intention of the government was to show the world the “diversity of the [Brazilian] culture” (In Nicolau Netto 2009: 166). In a way or another, under different official offices, many nations do the same, being it Navarre, Slovenia, Hungary², etc. What Walter Benn Michaels once said – “diversity has become virtually a sacred concept in American life today” (Michaels 2006: 12) – may be applied to many parts of the world.

In 2005, diversity received its label of globality, as UNESCO dedicated a Convention to the issue: the *Convention on the Protection and Promotion of the Diversity of Cultural Expressions* (UNESCO 2005). In spite of the many disagreements that surrounded its adoption, the Convention has considerable global acceptance: up to June 2014, 133 countries besides the European Union had consented to be bound to it³, through the “ratification, acceptance or approval and accession, which internationally have the same legal effect”⁴.

1 This paper has been made possible due to the support of FAPESP.

2 See <http://www.turismo.navarra.es/eng/porque-navarra/razones/> (access March 19, 2015) for the Navarre tourist board; <http://www.slovenia.si/visit/> (access March 19, 2015) for the Slovenia tourism board; <http://gotohungary.com/about-hungarian-tourism-ltd/-/article/the-land-of-diversity-and-magic> (access March 19, 2015) for the Hungary tourism board. All of them have diversity as a central term for their branding.

3 <http://www.unesco.org/eri/la/convention.asp?KO=31038&language=E>. Access June 11, 2014.

4 <http://www.unesco.org/new/en/culture/themes/cultural-diversity/diversity-of-cultural-expressions/the-convention/ratification/>. Access June 11, 2014.

In spite of the global and ubiquitous presence of diversity in the contemporary society, it is not right to say that diversity has only been appreciated in our time. In fact, diversity of cultures (more than the term cultural diversity) is an important issue for cultural anthropology, as we can see in the classical work by Ruth Benedict, *Patterns of Culture*, which has a chapter named “Diversity of Cultures” (Benedict 2005 [1934]). It is also present in the context of the foundation of UNESCO, in 1948. A famous text commissioned by UNESCO to Claude Lévi-Strauss also makes use of “diversity of cultures” arguing for the importance of its preservation and stating that historically “men have tended rather to regard diversity as something abnormal or outrageous” (Lévi-Strauss 1952: 11).

But the pervasiveness of diversity is contemporary. In the Constitution of UNESCO, from 1948, “diversity of cultures” appears twice. In the first article, it is meant as a restriction to the power of the nascent Organization: “With a view to preserving the independence, integrity and fruitful diversity of the cultures and educational systems of the States Members of the Organization, the Organization is prohibited from intervening in matters which are essentially within their domestic jurisdiction” (UNESCO 2012: 7). In the fifth article it is a matter of power balance: “In electing Members to the Executive Board, the General Conference shall have regard to the diversity of cultures and a balanced geographical distribution” (UNESCO 2012: 12).

UNESCO was established under the impression that the World War II was caused by cultural misunderstanding and intolerance, and only the comprehension and respect of other cultures could secure peace, as we can read in the first paragraph of the first article of the Constitution (UNESCO 2012: 6). Diversity was therefore a means to achieve a goal, which was to maintain peace. Diversity as a means and not as an end is also to be understood from Lévi-Strauss’ text. For him, what was at stake was the condition of any civilization to prosper, recognizing that “the greater the diversity between the cultures concerned, the more fruitful such a coalition will be” (Lévi-Strauss 1952: 46).

The contemporary account of diversity inherits that preoccupation, but it brings it to a new dimension and a new extension. First, diversity is no longer a means for something, but an end. We fight – or should fight – for diversity because diversity is good, it is a value in itself. Therefore, we should not only be concerned with its protection, but also with its promotion. As value in

itself, diversity was raised within the 2005 UNESCO Convention to the status of a human right. According to the Convention, we should celebrate the document for “the importance of cultural diversity for the full realization of human rights and fundamental freedoms proclaimed in the Universal Declaration of Human Rights and other universally recognized instruments” (UNESCO 2005: 2). Second, it is not only Anthropology or the institutions informed by Anthropology – as it was the case of UNESCO in 1948 – that praise diversity, but, as said before, its appreciation is ubiquitous in the society. Probably an Anthropologist will have more to say about diversity, but there is no need to be one to be aware of its presence and value. In fact, it concerns everyone.

This article enhances an analysis focusing on a comparative perspective. I propose that diversity is a discourse related to the production of difference. In other words, it is the positivity of difference that characterizes, in principle, the discourse of diversity. If difference, however, is a social construction that needs a discourse to make it socially relevant, the discourse of diversity defines the conditions of the production of difference in the contemporary world. Saying that implies that in other time-space realities other discourses have been used for such a definition. If we look back to the 19th Century we will see in the discourse of exoticism the same regularity we see today in the discourse of diversity: the positivity of difference. I want to compare those two discourses relating them to the conditions of their existence.

Before I do that, let me make it clear my notion of difference and of discourse. In the introduction of the book *Ethnic Boundaries*, Frederick Barth (1969) proposes that the superposing of cultures in the same space may not lead to the diminishing of differences but to their augmentation. This is so because, some elements of a culture may become “socially relevant”, as the author says, to maintain the cultural boundaries exactly at the moment when there is a cultural encounter. Therefore, contrary to previous anthropological accounts on the difference, Barth innovates and shows that difference is not to be found in isolated cultures, but in the interaction of cultures. It is so, because there is no *a priori* definition of difference, but only a practical definition of it, since it is in social interaction that some cultural elements will be classified to mark the difference. Therefore, difference cannot be taken for granted and:

one cannot predict from first principles which features will be emphasized and made organizationally relevant by the actors. In other words, ethnic categories provide an organization vessel that may be given varying amounts and forms of content in different socio-cultural systems. They may be of great relevance to behaviour, but they need not be; they may pervade all social life, or they may be relevant only in limited sectors of activity. There is an obvious scope for ethnographic and comparative descriptions of different forms of ethnic organization (Barth 1969: 14).

That is why difference is always a social construction. What may be seen as different for one culture may be imperceptible to others. The idea of Durkheim and Mauss, according to which every classification “is organized according to the model provided by society” (Durkheim & Mauss 2004: 189), may be applied here. It is widely known that the Inuits can see 22 different forms of snow (Hall 1997: 23), far more forms than, for instance, a Brazilian could see. While among the *tewa*, according to an ethnographic research stemming from 1916, “little differences are noticed” among the plants of the regions, “among the whites, a non-trained individual would not be able to distinguish them” (Robbins, Harrington & Freire-Marreco in: Lévi-Strauss 1997: 20). As well as, as John Blacking (1995: 6) made clear, some individuals may not listen to musical intervals that sound clear to the ears of other individuals from different cultures.

This is so because anything to be perceived as different needs to be signified as different. This is a fairly arbitrary process, as anything may be classified as different or as equal to anything, and it will be language that will give it its meaning as one or another. Difference is, therefore, a matter of language as it only exists – it is only signified as such – if there is a discourse that produces it. Skin colors may seem natural to people, but it is only language that will make them meaningfully different from each other, to the extension that it becomes socially relevant to distinguish people. In fact, every society may differentiate skin colors and simply ignore other tonalities that may be meaningful to other societies to categorize people. Racism may be as creative as one can be.

But if I affirm difference is produced by language I do not suppose there is a separation between language and material relations. In other words, there is here no such a thing as the semiotic idea of free play of signs. On the

contrary, what the sign means is conditioned by social relations and forces. Therefore, I follow Foucault's idea (2007) of a discursive analysis looking for the social conditions for the existence of the discourse that produces difference. I want to show that in our time social conditions give existence to the discourse of diversity to produce difference, as much as other conditions gave existence to the discourse of exoticism to produce difference in the 19th century. To say that is to affirm that I see regularity between the two discourses, which is the positivity of difference. In both discourses, difference is positive, in the sense that it is affirmed and produced, instead of denied and excluded. But it is also to say that we do not produce difference today on the same basis it was produced in the 19th century.

The conditions of exoticism

Exoticism is a word that stems from the end of the 16th century (Beyme 2008), not by chance in a moment of European expansionism and colonization. However, it has not been before the 19th century, in the age of imperialism, that it became widely used. In that long century, various modes of exoticism came to be in Europe. Musicians, such as Bizet, Mozart, Liszt, Rameau and Bartók, painters, such as Manet, Klimt, Ingres and Gauguin and writers, such as Lord Byron and Oscar Wilde, praised "alien" cultural elements and brought them to their work. Decorators influenced by Jugendstil or Art Nouveau filled up European houses and public buildings with exoticism, enchanting people dressed after Chinoiserie, Turquerie or Japonisme. In sum, exoticism became omnipresent in the European modernity.

Let me start this analysis pointing to the fundamentals of this discourse. They are three, basically. First, the culture in relation to which the discourse was articulated was seen as the culture of the "Other". It means the discourse presupposes the production of difference. This difference was not denied by any sort of universal discourse, such as progress or reason, which tended to suppress every cultural difference, in benefit of the human nature. On the contrary, under the discourse of exoticism, difference should be appreciated. It is important to notice that such appreciation was to be taken under parameters that had European culture always on top and the exotic culture always as deficient in comparison. Nonetheless, even if exoticism meant the

domestication of an alien culture by the “civilized’ discourse” (Hunter 1998: 54), it was to be affirmed, made present, and not denied or excluded. That is what I mean with the positivity of difference, as mentioned before.

Second, there was a separation between those that discoursed about the exoticism and the cultures and individuals seen as exotic. If the exotic was the Other, the one who spoke about the exotic was the European. The narrator and the narrated were two separated instances. I mean it in two ways. First, I refer to it in the same terms as Edward Said refers to Orientalism (Said 2003), as a discourse produced by Europeans (audience, artists, politicians or intellectuals) and not by those who were referred to as exotic (or oriental to Said). Of course one may not forget the presence of auto-exoticization and must consider *exotic* artists as part of the production of the discourse of exoticism. James Parakilas reminds us, for instance, of the famous Manuel de Falla, who exoticized himself dressing up and playing as a “typical” *Spanish* musician in France, even if he had originally nothing related to that image (Parakilas 1998). Therefore, I am certainly not saying that the narrated is not an agent of the narration, but that he/she mostly reproduces rather than produce a European discourse. The *Revue Nègre*, starred by Josephine Baker in France in the beginning of the 20th century, had its meaning given by reviews as this, found in *Le Figaro* the day after a premiere: “The music seems to have captured the echoes of the jungle and to mingle the moan of the breeze, the patter of rain, the cracking of leaves...” (Baker & Chase 1993: 4). And some of the artists accompanying Baker had to darken their skin, because “some in the audience [were] disappointed that the performers are so fair. Because of the word *négre* in the title, the French are expecting black Africans, not American mulattoes” (Id. *Ibidem*).

The separation of the narrated and the narrator can also be seen in the fact that mainly the European artist could make use of the exotic elements in the most legitimated places for art, in the modern sense of the word. The exotic elements were found in most museums or concert halls, but mainly in paintings and performances executed by European artists. The exotic artists, themselves, were not there, but in places mostly dedicated to entertainment and curiosity, such as Cafés, Cabarets and Vaudevilles (Wicke 2001: 101). The *La Revue Nègre*, once again, was the second part of a show of varieties. “The first half featured vaudeville – Ski Tayama (Japanese acrobats), the Klein

family on trapeze, Saint Granier (a tenor show impersonated Parisian stars), and strongman Louis Vasseur, who twirled on his head a huge merry-go-round bearing six men suspended on trapezes” (Baker & Chase 1993: 115).

The third fundament of the discourse of exoticism is that it referred to cultural practices that took place in the European space⁵. As Théophile Gautier wrote in *Voyage en Espagne*, after being disappointed with a Spanish dance in Spain, “Spanish dance exists only in Paris, just as seashells are found only in curiosity shops, never at the seashore” (in Parakilas 1998: 148). Of course there could be an exotic culture outside Europe, but even there, to be considered as exotic (to have the cultural meaning of exotic) it had to be executed in the spaces assumed as European. Therefore, for the colonial or ex-colonial elites the culture around them could be perceived as exotic, as it was distant from the European reference. In other words, the *habanera* was perceived as exotic both in France and in elite groups in Cuba. Nevertheless, the discourse of exotic, to be meaningfully exotic, had to take place in the European space, being it located in Europe or away. At the same time, that culture assumed as European could logically not be seen as exotic. Liszt could execute an exotic music, but he was not exotic; exotic were the elements he borrowed from another culture. In sum, exoticism was a European discourse that addressed an allegedly culture of the Other present in the space of the Self.

If these are the fundaments of the discourse of exoticism, I propose there are two main structural conditions to it. First, there is the need for a clear, recognizable and stable separation of an external and an internal room, both in temporal and spatial terms. The exotic, as in its own etymology, is something that is exterior, as in the past, or as in another cultural space, to something. However, it is more than that: this exterior must be brought to the internal space, and when it does so it must keep the symbolic aspect of its exteriority, which marks the otherness. This way, the Romany music in the 19th century was a cultural practice defined as exterior to the European space – as essentially different – brought to it (as in Ravel’s *Tzigane*) under the condition of keeping its otherness. What is exterior is brought to what is interior (Europe), but the exteriority is symbolically maintained. A song

5 I should be more precise here. European culture is a too vague term, but I have to keep it here, as I am more concerned with exoticism. Clearly, by European culture I mean an elite culture and a popular culture that have been assumed as a national culture in the 19th century. Both elite and national cultures should be perceived as European, opposed to exoticism.

was still perceived as a Roman song, in spite of the fact it was executed by a European musician.

Second, there was the need for social and historical context that gave the monopoly of the definition of the internal and the external to the European. Jonathan Bellman sees the exoticism (he meant in music, but it can be generalized) as the “borrowing or use of musical materials that evoke distant locales or alien frames of reference” (Bellman 1998: ix). It means that the cultural frames of reference that measured and compared the exotic were European and they were the ones capable of organizing the exotic.

If these are the structural conditions of the discourse of exoticism in the 19th century, we should understand the conditions of their existence. That is, I want to understand the conditions for the separation of the internal and external spaces, in cultural terms, and how the European power undertook such separation. I want to point out that there was an historical context, and two sets of frames of reference that were fundamental for the discourse of exoticism. I do not have the pretension to be exhaustive, but I affirm these are the fundamental social conditions of it. The historical context is the European imperialism, as the sets of frames of reference are the idea of progress and the creation of the modern nation. I will bring nothing new to any of these issues. My originality here, if there is any, is to understand some elements of these issues as the condition for the production of the discourse of exoticism and, more importantly, to show that the changing of these elements in the present partly explains the lack of contemporary legitimacy of that discourse. Bearing that in mind, I start with the social context.

The European imperialism is the context of the discourse of exoticism. It is fundamental for my understanding here for two reasons. First, the imperialism permits an economic and political supremacy of Europe that makes some ideologies (such as progress, an issue to which I will return below) believable. Second, it gave to this discourse its globality. Jack Goody’s critique of the eurocentrism is based on the assumption that the elements that are usually given as the fundamentals of the European supremacy in the 19th Century should have their *europeanness* revisited. Specific forms of commerce, family and reason are usually assumed (by authors such as Max Weber, Goody’s main focus) as the elements that grounded the development of the modernity in Europe. The fact, as the argument goes, that these

elements were only present in Europe is what makes the European case so singular and a parameter that can only be repeated if those elements are imported from Europe. Goody turns the argument inside out by attacking its own ground. The author shows that all these elements are anything but European. In fact, each one of them can be found in many other cultures, especially in those that have developed writing at the same time as Europe. For instance, Goody explains that while “forms of inferential reasoning, logic in the general sense (...), are certainly found in all human societies (though not of course always used)” (Goody 1996: 18), even the formal logic cannot be seen as a Greek exclusivity, but an element present in other cultures of the Antiquity that used the alphabet. The argument goes on for each of the elements that were supposed to be seen as grounds for the European supremacy. According to that, Goody denies that those elements were European, arguing that they, actually, belonged to written cultures. The idea that they were European was, in fact, what the author calls the “theft of History” (Goody 2006). More than that, Goody denies that there is any essentially European element that may explain its achievements, being them related to “rather more immediate, contingent” facts (Goody 1996: 47, 48).

Goody confirms his argument limiting the European achievements to the 19th century, and he shows that, prior to that century, there was no easy way to say that Europe was on the top of the human civilization. “In fact economic activity in Asia in the seventeenth and eighteenth centuries does not seem to have differed greatly in its nature from that in the West” (Goody 1996: 121). Eric Hobsbawm confirms Goody’s assumption stating that a “estimate calculates that between 1750 and 1800 the *per capita* gross national product in what are today known as the ‘developed countries’ was substantially the same as in what is now known as the ‘Third World’” (Hobsbawm 1994: 15).

In the age of imperialism, however, the contingent achievements of Europe were perceived as an essential part of its civilization. The economic, military and political supremacy grounded the belief that Europeans were “almost another order of beings” (Goody 1996: 2), the apex of the Universal History and, as such, able to produce discourses that ordained the production of difference. Moreover, the expansion of European dominions⁶ to the

6 Including states that were directly administered by foreign states, between 1884 and 1914 the “world’s surface controlled by European powers” rose from 67 to 84.4% (Shohat & Stam 2006: 41).

world globalized these discourses, and, from a European belief, the essentialized supremacy of Europe became part of an international belief.

The idea of progress when it meets the idea of evolutionism finds in the context of imperialism the ground to its legitimacy. By no means it is an idea of the 19th century, but as stated by Robert Nisbet (1980): “during the period 1750-1900 the idea of progress reached its zenith in the Western mind in popular as well as scholarly circles”. In this moment two expansions were added to the idea. First, progress became a matter of universal History, a “collective/singular” that enclosed every dimension of History into one. “What [was] not progressive, so said Schelling, [was] not the object of History” (*apud* Rapp 1992: 159). The narration of the progress of things or the progress of a nation in a unilinear fashion has always been common. What was new was the fact that progress could be articulated to narrate the development of mankind itself on an allegedly scientific basis. From Turgot in 1750, with his *A Philosophical Review of the Successive Advances of the Human Mind* (2011), to Hegel’s *Philosophy of History* (2001), originally published in 1837, passing by Condorcet (2013) and his *Sketch for a Historical Picture of the Progress of the Human Mind*, 1795, or Voltaire’s *Essai sur les mœurs et l’esprit des nations*, 1756, the “human race” became part of a universal and linear history that had always pointed to the amelioration of the mankind. Therefore, the present became the moment of the grandeur of mankind, and not of its decadence, as it was typically assumed before the ideology of progress. A frequent view of such idea of progress is given by Turgot, according to whom “commercial and political ties unite all parts of the globe, and the whole human race, through alternate periods of rest and unrest, of weal and woe, goes on advancing, although at a slow pace, toward great perfection” (Turgot 2011: 322).

Such an assumption was made possible because it was believed that in the Age of Enlightenment reason had reached such a stage of development, though still limited to some enlightened persons, which could not be retarded anymore. On the contrary, through the integration of every nation in the world – by commerce or political forces – reason would be spread over, and through it progress would be inexorable. Condorcet’s closing words of his famous book states that clearly:

And how admirably calculated is this view of the human race, emancipated from its chains, released alike from the dominion of chance, as well as from

that of the enemies of its progress, and advancing with a firm and indeviating step in the paths of truth, to console the philosopher lamenting the errors, the flagrant acts of injustice, the crimes with which the earth is still polluted? It is the contemplation of this prospect that rewards him for all his efforts to assist the progress of reason and the establishment of liberty. He dares to regard these efforts as a part of the eternal chain of the destiny of mankind; and in this persuasion he finds the true delight of virtue, the pleasure of having performed a durable service, which no vicissitude will ever destroy in a fatal operation calculated to restore the reign of prejudice and slavery (Condorcet 2013: 218).

Reason was the measure of an ever-evolving mankind and also its condition of explanation. As stated by Condorcet again, his work would show “from reasoning and from facts, that no bounds have been fixed to the improvement of the human faculties” (Condorcet 2013: 20). The idea that reason can be the measure of progress and that it also provides the tools to explain that progress (in fact, a modern idea of History) allows one to measure other peoples and to explain their “moments” in the line of the universal History. That is central to the understanding of the discourse of exoticism.

This idea must be completed with the perception that if progress is a timely oriented discourse, one that unites all mankind in one and single line towards the future, it is also spatially conditioned. Hegel proposes, for instance, four successive stages for the human History: The Oriental World, The Greek World, The Roman World and the Germanic World (Hegel 2001). Condorcet argues that the world had already passed by nine ages and the last (he still points to a tenth age, which is in the future) is the one he finds in the French Republic (Condorcet 2013). Therefore, if History became the History of mankind, its highest development took place not only in the present, but also in Europe. Other peoples, even if part of History, were more likely depicted as the representatives of a past without a History of their own.

Such notions will return when I address evolutionism. Now I want to mention the second modern expansion on the idea of progress: not only it was referred to the whole humankind, but it was applied to every sphere of human activity. In fact, the most visible trace of progress in History, which made it a matter of popular belief and not only of intellectual speculation (Hobsbawm 1994: 338, 339), was to be seen in technology. Technology acquired

7 Translations for Condorcet into English extracted from <http://oll.libertyfund.org/titles/1669>.

an importance never noticed before, and the World Expos were the moments to celebrate it. It was in these mega-events that technological developments were presented, such as the elevator (New York, 1853), the telephone, type-writer and telegraph (Philadelphia, 1876), the phonograph and electric light (Paris, 1889), the electric light bulb and kinoscope (Chicago, 1893), the large screen cinematography (Paris, 1900), the radio tube and flying machines (Saint Louis, 1904) and the mass production of cars (San Francisco, 1915) (Roche 2000: 46; 160).

However, progress was also to be perceived in morality and arts. According to the illuminist notion, “scientific and moral progresses go together” (Hollis 1994: 203), or, as put by Condorcet, “knowledge, power and virtue are bound together with an indissoluble chain” (*apud* Hollis 1994: 204). Art also became progressive. What opposed *les modernes* and *les anciens* in the 17th century was the discussion if art in the present could be considered as of a higher level than the Hellenic one. As Hans Robert Jauss puts it, the moderns “tried to overcome the concept of perfection in the *beaux-arts*, and the concept of perfectibility in the area of science, under the perspective of a continuous and universal progress” (Jauss 1970: 31). If in that century *la querelle* remained unresolved, in the 19th century it was possible and common to see the present European culture as the peak of a progressive History. In fact, it became a common practice in Europe of the 18th and especially of the 19th century the progressive narrative of music in a similar fashion as below, in an example retrieved from the entry “music”, found in a dictionary of music of 1873:

1) Age of Hubald. The 10th century. 2) Age of Guido. The 11th century (...). 11) Age of Monteverdi (1600-1640). The beginning of the dramatical style. Origins of opera. (...). 14) Age of Leo and Durante, for the protestant Church music, especially Bach and Händel (1725-1760). Neapolitan School. Reconfiguration of the aria. Opera buffa. Diversification of the instrumental music through the introduction of wind instruments in the opera. Virtuosi. The theory of the Tonkunst receives an upswing. At first in the teaching of harmony. (...). 15) Age of Gluck (1760-1780). Opera seria (...). 16) Age of Haydn and Mozart (1780-1800). Viennese School. Quartet and great symphony. The German national opera blossoms. 17) Age of Beethoven and Rossini (1800-1830). Highest development of instrumental music and of virtuosity. The German song. The German romantic opera. (...) (Paul 1873: 168, 169).

Within this expanded idea of progress – covering the whole of mankind and all spheres of life – a frame of reference was proposed, one every civilized nation should have as parameter: the European model. This model could be applied to every nation, every person, in order to say in which stage of evolution it was.

In cultural terms, this idea gained scientific validity with Anthropology. Opposing the social, racial (as in Gobineau) and geographic (as in Friedrich Ratzel) determinism for the explanation of the cultural difference of peoples, authors such as Lewis Morgan, Edward B. Tylor and James G. Frazer came up with the cultural evolutionism explanation (Schwarcz 1993). According to this explanation, cultures were different because they were in different stages of evolution. It is supposed, therefore, the existence of a linear and universal evolution of cultures, according to which some cultures are in an early stage (they are primitive) and others are in a later stage (they are advanced). The cultural stages of China, India, America, etc., at the time could be seen, therefore, as an early age of the supposed European evolution. This Anthropological assumption defined the way exotic culture was presented to the Europeans, and the museums were the space for such presentation. In the Chapter “Civilization in the Making” included in a book issued by the British Museum in 1911, about the museum itself, it is stated that the “multifarious objects in the Ethnographical Gallery represent so many starting-points in the world’s civilization” (in Kirshenblatt-Gimblett 1998: 21). In fact,

by the end of the [19th] century evolutionism had come to dominate arrangements of exotic artifacts. (...). The value of exotic objects was their ability to testify to the concrete reality of an earlier stage of human Culture, a common past confirming Europe’s triumphant present (Clifford 1988: 228)

Therefore, the idea of progress, together with the evolutionist explanation united and hierarchized the world. The world had now one single History, always evolving to a higher stage, in which Europe was found. The other cultures, instead, were distributed under it. The idea of progress, therefore, gave a first frame of reference to separate cultures between the internal and the external, something to which imperialism gave legitimacy. Nation, my last issue here, created the institutions that gave the support to such separation.

In a famous formulation, Benedict Anderson defines nation as “an imagined political community – and imagined as both inherently limited and sovereign” (Anderson 1991: 6). I want to stress the idea of limitation. “The nation is imagined as *limited*”, so Anderson continues, “because even the largest of them, encompassing perhaps a billion living human beings, has finite, if elastic, boundaries, beyond which lie other nations” (Anderson 1991: 7). In this sense, the nation is opposed to forms of universal communities (i.e. Islamic or Christian communities) and, as such, it is necessarily a space of production of difference. This difference is based on a process that at the same time defines those that belong to it and those that do not. In other words, the limitation of a nation presupposes that people may imagine themselves as similar to people that share the same nation with them and different from those that do not. In many cases this limitation derives into a clear idea of ethnicity. As put by Ernest Gellner: “nationalism is a theory of political legitimacy, which requires that ethnic boundaries should not cut across political ones” (Gellner 1983: 1). For instance, the Treaty of Versailles “replaced (...) multinational empires with a dozen new states. Apart from Czechoslovakia and Yugoslavia, each was effectively assigned to a dominant ethnicity comprising at least 65 percent of its population. (...). Citizenship was now substantially identified with ethnicity, with minorities in danger of becoming second-class citizens” (Mann 2005: 67).

If the supremacy of ethnicity to define a nation is not the case everywhere some sort of production of identity is necessary to one to imagine him/herself as part of a community. Therefore, nation demands this production, at the same time as it creates the institutions that support and ritualize it: collective memory, national parties, celebration dates, etc. In sum, nation produces and legitimates symbolical references that serve as the separation of the internal and external spaces. These references are of paramount importance to the production of the exotic as something that is external to the national space. Before the formation of the nation-states, exotic was referred both to popular cultures found in European soil and to cultures brought from outside of it. It was common, indeed, to find people stating similarities between the two cultural expressions. For instance, the English writer and public figure Samuel Johnson (1709 – 1784) and his biographer, James Boswell (1740-1795), traveled through the Western Scottish Islands in order to collect

popular culture. Observing the Scots, “Boswell has made an observation to Dr. Johnson that ‘it was about the same to be in an indigenous tribe’, for the villagers ‘were as dark and rustic as any American salvage’” (Burke 2010: 32).

However, there was a change in the exotic idea in the 19th century. The nationalist movement – seen in the Romantic and in the folklorist movements – started the process of collection and appreciation of popular culture as essential symbols of the national cultures (Ortiz 1992). It is the popular culture that will be raised to national culture, along with the culture of the elite. It means that, in the 19th century, popular culture found in the European soil became part of the national identities and, as such, was no longer considered as part of the discourse of exoticism. There was a breach in its discourse, and in the 19th century it reaches stabilization: the discourse of exoticism becomes the one referred to the culture seen as originally from “the rest of the world”, to use a sadly recognizable expression.

Reevaluating the exotic

In the contemporary moment, as diversity is appreciated, the discourse of exoticism is devaluated. It is certainly not true everywhere, as I will admit below, but it may be confidently affirmed that the discourse of exoticism is a disputable way of addressing other cultures today. The most legitimate international institution dedicated to the defense of cultural otherness, UNESCO, actually condemns it as against cultural diversity. In its *World Report: Investing in Cultural Diversity and Intercultural Dialogue*, from 2009, the word “exotic”, or the variants “exoticism”, “exoticization” or “exoticize”, is used only five times, in a document of 402 pages of length, and always in a negative light. In fact, UNESCO must find a “way to counter the exoticization of non-Western forms of expression” (UNESCO 2009: 164), because “the range and impact of such influences inherent in globalizing trends is not without its dangers to cultural diversity” (UNESCO 2009: 164).

Some tourists travel looking for exotic places to visit. At the same time, countries make many efforts to create such places, staging some type of authenticity (MacCannell 1973). For sure exoticism is an important element of every country to attract tourists, even for the former imperial power. In fact, as Ellen Strain (2003: 37) puts it, “touristic pleasure was made possible through the creation of a safety zone within which the exhilaration

of geographical proximity with an exoticized stranger could exist without compromising other, less literal, forms of distance”. However, rarely there is a country that organizes its promotion by reducing it to the discourse of exoticism. In fact, even countries that clearly create and promote “exotic places” for tourism do not affirm their culture simply as exotic and may, in fact, try to deny this notion when defining the country image. In other words, if exoticism may be an important touristic product for every country to promote its tourism, and other products, it cannot be the discourse to organize the production of its identity or culture. I bring one example to elucidate my point.

Due to FIFA World Cup, held in Brazil in 2014, the Brazilian Tourism Board – EMBRATUR – organized a large range of activities addressing the promotion of the country image, or brand, a more contemporary term. These activities were my object of research – some of the results may be found here (Nicolau Netto 2014) – and for that I interviewed in January 2013 the international manager of EMBRATUR during a promotional action organized in Madrid, Spain. At the occasion I asked him what image the instantiation wanted to promote of Brazil. His answer points to the issue stated above:

There are some countries that want a total rupture and the building of a new image. In our case, we do not want a total rupture, because we continue to like soccer, we will keep on enjoying Carnival. But we have more to show. So, this is the direction we follow when we talk about diversity, both natural and cultural, and modernity, modernity in the sense of seeking to take Brazil away from that image that still exists in some markets, that Brazil is an exotic destination such as various countries in Asia. Brazil is not an exotic country. ... The idea is to keep tradition, to keep what is known, but modernized, adding new elements to this image.

Therefore, for national and international agents related to the production of otherness, exoticism has become a degrading discourse. Interestingly, as it must have been noticed above, diversity has become a positive discourse for the same agents.

In order to understand that we must start by stating that the instantiations that clearly separated the internal from the external, in cultural terms, are not operative today as they were before. The end of colonial wars – and

the overall assumption that the colonial era was perverse to the former colonies –, along with the general judgment of the World War II, changed the perspective of Europe in History. Its condition to dictate the universal discourses, according to which the world was organized, is not acceptable anymore as it used to be. In fact, what once has been understood as universalism has become merely eurocentrism (Biebricher 2004: 48; Laclau 1996: 50) and the universal became particular, a matter of “ethnocentrism of the white tribe” (Juliano 2003: 35). In sum, the positivity of the universal discourse, found in the 19th century, became a negative assumption, linked to the European domination (Schulte 1993: 181). It means that the idea of progress loses its legitimacy. Many authors realized that, since the last quarter of the 20th century, we are not sure about progress anymore (Latour 2008: 15, 16; Brunkhorst 2000; Lyotard 2009; Rapp 1992). As a consequence, there is no security to affirm the cultural differences as based upon diverse moments of evolution. Therefore, at least in the public space and in the intellectual field, we can no longer calmly use an expression such as “primitive people”. There is a rupture in a fundamental separation of the Self (the European) and the Other (the primitive). Now, we all live in the same time, each of us addressing it according to our conditions.

And if we live in the same time, we also live in the same space. The last of those aforementioned instantiations that keep exoticism as the discourse to organize the difference is the nation. Globalization destabilizes this condition and, as a consequence, makes us uncertain about what is internal and what is external. For my concerns here, it is important to think about two processes related to globalization. One is the immigration trend of the last fifty years. Currently, 3% of the world population lives far from their nations of origin (Hobsbawm 2007: 89, 90). It is not an impressive number, but still relevant if we notice that from 1970 to 2005 the number of immigrants went up from 82 million to 191 million (United Nations 2006). However, more important than the number *per se* is how it is distributed. Inverting a trend of two centuries, the migration now flows to the European countries. Between 1800 and 1960, 80% of the migration movement flew from Europe to other countries (Habermas 2009: 147), while now it flows to Europe. And not only that, it flows to the global cities, where it becomes a more visible social fact (Sassen 2007). Thus, in metropolitan France (ultramarine departments

and territories are not considered here) immigrants formed 8.4% of the population in 2008; in Paris immigrants were 17% of the population in 2010 (INSEE 2014). In Germany, the immigrants were 8% of the population in 2009 (Statisches Bundesamt Deutschland 2011); in Berlin they were 13.3% (Gebiet und Bevölkerung 2010); in Frankfurt 24.3% (Frankfurt 2011). In England, persons born away from the United Kingdom formed 11% of its population in 2009; London had one third of its population under this circumstance (Office for National Statistics 2009). Immigration to the United States, on the contrary, is not new and between 1820 and 2003 the country received 69 million immigrants. However, the recent flow is as exceptionally intense as to the European countries, and out of this total 16.5 million persons (23%) immigrated between 1981 and 2000. Such a trend can only be compared, in American History, to the first decade of the 20th century (Office of Immigration Statistics 2004). In 2009, the immigrants formed 11.8% of the American population (U.S. Census Bureau 2010); foreign-born persons formed 37% of the population of New York in 2013 (Department of City Planning - City of New York 2013).

As important as the amount of immigration, and its concentration in the global cities, it is the qualitative aspect of it. It is remarkable that this enormous contingent of immigrants living in the global cities come mostly from countries away from the European space. The same sources used above show that the largest contingent of immigrants in Paris come from Algeria and Morocco; in London, they come from India, Pakistan and Poland; in Berlin and Frankfurt, from Turkey; in New York, from Asia and Central America.

Immigration is important to my analysis because it questions the separation of the internal and the external, as the “Self” and the “Other” came to live in the same space. Therefore, it is no longer possible to consider exotic the culture of the “Other” based upon the assumption that the “Other” is external to the “Self”. This way, the difference must be produced upon other bases. The edges imposed by the nation-state, in terms of cultural affiliation, are also questioned by the flow of information. Cultural expressions now circulate the globe in ways and in speeds never imaged in the 19th century, creating what Arjun Appadurai called *ethnoscapes* that cannot be determined by the nation-state alone (Appadurai 1996). Moreover, with the Internet this circulation even suspends the national borders, and now who has access to

a cultural expression does not know for sure where it is executed, if not in the Internet itself. Therefore, cultural expressions become indigenous to territories from where they were alienated in the 19th century. As the so-called Western cultures now inhabit the East, non-Western cultures are part of the identity of Western countries (Veer 1997)⁸.

The culture of the Other is no longer external to something. We do not have any stable instantiation to assure these boundaries, as there was in the 19th century. It is, as if, as put by Renato Ortiz, the whole world had been internalized (Ortiz 2003); as what was said in a Congress about the interculturality held in Berlin, in 1988, “Wir sind alle Ausländer” (We are all foreigners) (Barkowski & Hoff 1991), which would be the same as saying no one is a foreigner anymore. Once again, this is not to say that the boundaries have fallen or that we all have the same national condition to operate in the world, but to say that the stable boundaries that separate the internal and external are questioned, while other boundaries are getting into place. Nevertheless, currently “home and abroad”, “self and other”, “savage and civilized” are not clearly opposed terms (Clifford 1988, p. 14).

There is one last issue that highlights the devaluation of the discourse of exoticism in the present. I mentioned above that this discourse was based on the fundamental difference of the narrated and the narrator. It happens now, when the cultural flow floods globally, that the narrated has a great amount of interest in the narration about itself. I refer here to the commodification of identity that turns it into a value in the international market of symbols. As John L. and Jean Comaroff (2009) show, ethnicity has become a very profitable business nowadays, both for corporations that try to benefit from it, but also for the ethnic groups themselves that try to work with their identity as a brand⁹ and, as such, to attract tourism and business. In the research studies I carried out in the music and in the tourist markets¹⁰ investigating the articu-

8 Clearly, identity is always an arena of conflicts, and certainly cultural expressions seen as non-Western do not have the same condition in Western countries as the expressions seen as traditionally national. That is why we still keep on using the word exotic to address many cultural expressions. I extensively addressed this unbalanced process in two works (Nicolau Netto 2009; 2014b). However, what I want to point out here is the structural aspect that produces difference, and for this matter it is meaningful the possibility of a non-Western cultural expression to be part of a European national identity. Certainly, no country can currently affirm its cultural identity without bringing together cultural elements traditionally seen as “alien”.

9 See Melissa Aronczyk (2013) for the issue on place branding.

10 The main results of my research studies on music markets are found in two books (2009, 2014b). My research on tourism market is not yet concluded but some previous result may be found at Nicolau Netto (2014).

lation of identity in the global space I could confirm the assumption herein. In fact, the trade fairs related to these businesses are mainly organized in national pavilions¹¹ where national and local offices enhance branding efforts in order to build a positive image of their nation, state, ethnic groups, etc., in the market. It means that these offices want to assume the protagonism of the representation of a culture in the global space, basing this claim on a contemporary tendency that sees the self-representation as the legitimate form of representation (Kirshenblatt-Gimblett 1998). In other words, the difference between the narrator and the narrated is not so clearly given anymore, as the narrated has the interest, and acquires legitimacy to, of narrating itself.

Therefore, exoticism is still present among us. It may be a useful description for small ethnic groups or local regions to promote themselves, as it is the case of Sarawak, a province in Malaysia, that aims to attract tourists looking for “a place for History, mystery, romance and exotic adventures”¹². It may also be articulated to promote touristic products within a nation, being it an “exotic” or a European nation. In the present exoticism may signify something related to not only India or Turkey (as in the 19th century), but also to a European country or the United States. Thus, currently, it is not difficult to book a tour through “exotic” Paris, “exotic” New York or “exotic” London.

However, and here comes my argument, exoticism can hardly be a useful discourse to produce (or self-produce) broader cultures and identities. In the case of nations – as shown above – exoticism may even become a cursed word. It is so, first because exoticism brings back the past described above, in which the culture of the Other means archaism, primitivism. In the global capitalism, primitivism may become a commodity of high value, but it cannot limit the definition of broader cultures or nations interested in entering in the world of modern businesses.

More important to my argument is that there is no institution in the present that may regulate the production of difference in any broader cultural sphere. As stated by Nancy Fraser (2003:55), today

no single master institution [such as the nation] supplies a template of cultural

11 Some trade fairs I have visited, due to my studies, that are organized mainly by national pavilions: a) Music market: Midem (Cannes, France, www.midem.com), Womex (various places in Europe, www.womex.com); b) Tourism market: Fitur (Madrid, Spain, http://www.ifema.es/fitur_06/); Fit (Buenos Aires, Argentina, www.fit.org.ar); World Travel Market (São Paulo, Brasil, <http://www.wtmlatinamerica.com>).

12 <http://www.malaysiasite.nl/sarawakeng.htm>. Access in February 23rd, 2015.

value that effectively governs all social interaction. Rather, a multiplicity of institutions regulates a multiplicity of action arenas according to different patterns of cultural value, at least some of which are mutually incompatible.

Take the national identity as a case. As stated, nations now make use of their identity in the international market and this fact alone already pluralizes the instantiations related to the production of difference, as at least each nation becomes an agent in the process. However, even within nations identities are not produced by a single master institution, but by disperse instantiations, both located within the nations or abroad. As Tim Edensor (2002: 30) states, “national identity is now situated within an ever-shifting matrix, a multidimensional, dynamic of networks. (...) Within such a matrix, national identity is being continually *redistributed*”. A concrete example of this *redistribution* of national identity may be taken from the music market, once again. Since the beginning of the 2000s the government of the state of Pernambuco, in Brazil, sponsors a project called Music from Pernambuco. Government representatives and music producers travel to music trade fairs around the world distributing compilations in order to promote the music of that state abroad. It is of interest for my argument to notice that the idea behind the project is to affirm Pernambuco as part of the Brazilian identity, widening the most traditional account of it. This assumption is confirmed in the first compilation released by the project. We can read in it that what inspired the production of the compilation and its promotion abroad, “is the fact that most international agents, bookers and music promoters have never visited Pernambuco and their knowledge of Brazil is restricted to Rio de Janeiro and Salvador. So, when you hear this compilation, you might have an idea of the richness and diversity of the music produced in Pernambuco” (in: Nicolau Netto 2009). The fact that national identities are now commonly defined as diversity, as aforementioned, lies exactly in productions as this.

Therefore, the production of difference in the present must be carried out with a discourse that is flexible enough to be articulated by various agents, with different cultural elements and interests. The exoticism must fit in in this discourse, but its restrictiveness prevents it from being the one to organize the production of difference. Diversity, because of its flexibility, can be that discourse.

Conclusion

Armand Mattelart says that “the appeal to cultural diversity is a generic interpellation, a trap that includes contradictory realities and positions, open to every contextual commitment” (2005: 13) and concludes that cultural diversity is an “amorphous concept” (2005: 128). Mattelart is worried about the political implications of using cultural diversity instead of other political concepts, such as cultural exception. What interests me about Mattelart’s assumption is that diversity is an open discourse, flexible enough to produce difference in a moment of reflexive modernity (Beck, Giddens, Lash: 1994), in which social practices, such as the formation of identity, are no longer assumed as “given” by instantiation, but the result of a negotiation between agents and multiple instantiations. Therefore, currently, difference has become diverse, which means it is never stable and can be continuously produced and resignified.

It means that, in the 21st century, difference becomes the result of daily struggles that never come to an end. Most importantly, all the agents in dispute will strive to produce the difference according to their interests and under certain conditions. These conditions are no longer given by an overarching instantiation, but by multiple ones, such as social movements, market, politics, academia, media, etc., which are operative not only in nations, but in the global space. It does not mean difference is now freely produced. On the contrary, if the discourse of diversity opens up the production of difference, social agents will put their forces into action in order to determine the difference according to their interests. Social movements of human rights and global media corporations, for instance, are both producing difference in the global space, undoubtedly, but certainly they do it in an unequal and unbalanced way and it is fair to say that the images globally produced of, for example, the Islamic culture, is much more a production of those corporations than of the movements. Therefore, it is important for any social analysis to question the forces in power producing difference nowadays. However, to question that is to realize that the difference is ceaseless produced in the discourse of diversity.

That is why difference may be used for discrimination and for politics of recognition, as a meaning of protection and threat for individuals, for oppression and emancipation. And, thus, it is constantly produced, as

the production of a difference is always open to new meanings, but never resumed in the stable internal/external relation. The legitimacy of the discourse of diversity is based on its flexibility to address the difference in the contemporary moment.

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“I want to marry in Cabo Verde”

Reflections on homosexual conjugality in contexts

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Resumo

Este artigo pretende explorar o universo das relações afetivas em Cabo Verde que envolve aspectos relativos à conjugalidade e à sexualidade. Nosso interesse tem início nas demandas por casamento veiculadas pela Associação Gay Cabo-verdiana, bem como nos dados etnográficos em que o tema do casamento gay é debate entre militantes homossexuais na cidade de Mindelo (Ilha de São Vicente). Tais fatos serão analisados em contexto, ou seja, pretendemos refletir sobre as demandas da Associação situando-a no universo de conjugalidade e sexualidade heterossexual no país. Argumentamos que analisar o debate sobre o casamento gay ampliando a discussão para o entendimento de como as relações afetivas são vividas entre homens e mulheres no arquipélago é fundamental para refletirmos não somente sobre as dinâmicas das afetividades locais, mas especialmente sobre a circulação de discursos e valores no âmbito dos movimentos sociais globais e suas relações com as dinâmicas locais.

Palavras-chave: Cabo Verde, homossexualidade, conjugalidade, globalização, antropologia

Abstract

This article explores the universe of affective relations in Cabo Verde, especially those aspects related to conjugality and sexuality. Our interest begins with the demands for same-sex marriage made by a gay Cabo Verdean

association and the ethnographic data on the gay marriage issue when it was debated by homosexual militants in Mindelo (São Vicente Island). These facts will be analyzed in the context of conjugal arrangements and heterosexual sexuality in the country. We argue that analyzing the debate on gay marriage and broadening the discussion to understand how affective relationships are lived between men and women in the archipelago, it is necessary to reflect not only on the dynamics of local affections, but especially how the circulation of discourses and values within global social movements impinges on the situation in Cabo Verde.

Keywords: Cabo Verde, homosexuality, conjugality, globalization, anthropology

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Introduction

In 2013, in the first gay parade of Cabo Verde, a *traveste*¹ protestor sports in the streets of Mindelo a rainbow flag – symbol of the international gay movement – and a poster that reads:



“I want to marry in Cabo Verde”

Source: Julliette Brinckmann/AGC/Facebook/Promotion

¹ It is difficult to stabilize in writing sexual identities that are ethnographically fluid. Thus, in Cabo Verde, the boundary that separates gays and *travestes* (Cabo Verdean term for ‘transvestite’) is very thin and porous. The *traveste*’s identity concerns not only the ratings by intensity of masculinization/feminization of bodies, but also reverberates class positions. Overall, however, *travestes* are those born with male genitals to poorer strata of society, and who want to be *women*, and for this purpose, keep their bodies as feminized as possible, advocating, at times, this identity for themselves. The distinct spelling intends not only to mark a phonetic distinction of the word in the Creole language (*traveste*) in relation to the word in Portuguese (*travesti*), but also distinguish the *traveste*’s identity as being culturally different from the Brazilian transvestites’, for never having their bodies transformed by silicone implants and hormone treatments, technologies which are not always desirable, not locally available, and unviable from an economic point of view for them.

This demand is easily recognizable, if understood within the context of contemporary struggles in some countries for legal recognition of the right to same-sex civil union and marriage. However, it gains specific contours in Cabo Verde, since in this country, as we shall see, amorous relationships in general are not marked, necessarily, by their formalization before the state, nor the cohabitation of the spouses.

This article aims to explore the universe of amorous relations in Cabo Verde involving aspects related to conjugality and sexuality. Our interest begins in the demands for marriage made by the Cabo Verdean Gay Association (AGC), as well as in ethnographic data gathered during the debate on gay marriage among homosexual militants in the city of Mindelo (São Vicente). These facts will be discussed here in context of the universe of heterosexual conjugality and sexuality in Cabo Verde.

We also reflect not only on the dynamics of local amorous relationships, but especially on the circulation of discourses and values within the global social movements and their relation with the local situation. We utilize the concept of global assemblage by Ong & Collier (2005), who see this type of phenomenon as a global fact, proposing to comprehend the ways in which the values resulting from a global logic are incorporated into local realities.

The text is divided into three parts. We will first seek to describe amorous relationships between men and women, marriage in ideal and practice, the significance of children, and the strategies, especially of women, to deal with the constraints of this model. Then, we will explore how the demand for same-sex marriage is configured by looking at the debates that have arisen among homosexuals of one of the islands of the archipelago of Cabo Verde, São Vicente. In the second part, we will analyze the various facets of the aforementioned demand in the local contexts and how they are reconfigured. Finally, we will reflect on the global agendas of the gay movement and how they strengthen notions of cosmopolitanism in Cabo Verdean society, so that we can then go back to the concept of global assemblage.

The paper results from a dialogue between two researchers of Cabo Verdean society. Andréa Lobo has concentrated on understanding family dynamics and contexts of migration, values, discourses, and objects for the last 15 years. Her studies reflect on how family relationships are configured in a society marked by movement as a cultural value, from a perspective that seeks to reveal the historical depth of family values. Francisco Miguel, on the

other hand, presents his data on male homosexuality and homosociability and the recent LGBT movement in Mindelo, on the island of São Vicente².

Marriage as a process

The Cabo Verdean family has been the focus of debate both among social scientists and local politicians. Associated with issues of domestic violence, problems concerning juvenile offenders, and the high proportion of female-headed households, the family appears both as a birthplace of social problems as well as a lifeline to society, that is, it is both the source of troubles as well as the solution for them. Local notions of disruption and disorganization appear as adjectives for family arrangements that follow their own logic, a dynamic that can only be understood as a deviation if compared to something held as a standard, as a model. In this case, an idea held of what the nuclear family is or should be.

There are many aspects to explore in this debate, however, we will focus on describing and analyzing conjugality, on the basis of ethnographic data gathered during research conducted on one of the islands of Boa Vista.³ The theme, therefore, is marriage. What we will seek to demonstrate is that the notion of marriage must be understood within context, that is, as a native category, for if it is used as an analytical term it leads to dangers already widely discussed in the realm of kinship anthropology (Schneider 1972; Leach 1974; Peletz 1995).

Between men and rivals

Romantic relationships between men and women are not easily noticeable in everyday public life. Couples walking holding hands, embracing or exchanging caresses are not part of the daily scenario, even in bars or nightclubs. Knowing who *tem com* (has with) requires entering local networks of sociability, meeting people, and being privy to rumors, comments, and

² This research resulted in a Master's Dissertation at the University of Brasília (Miguel, 2014).

³ Boa Vista is one of the ten islands that form the archipelago of Cabo Verde. It is the third largest in area, with the main town being Vila de Sal-Rei, which hosts more than half of the total population of the island. Boa Vista was one of the first islands to be discovered, but was only inhabited later on. Within the national context Boa Vista is historically marked by modest settlement, a fact that has been reversed over the last ten years thanks to the growth of tourism investments.

confidences about one's own or another's love life. *Ter com* is the local expression that may be considered equivalent to dating, or even having a more lasting relationship with children, regardless of whether the couple live together or not.⁴ When there are children the terms *father-of-child* or *mother-of-child* are used to refer to the partner with whom one shares the child, and such expressions are used referentially even if the amorous relationship between them has already dissolved. The term marriage is only used when it is legally sanctioned, that is, *no papel* (on paper).

From a woman's perspective, relationships, from the start, are marked by the real threat that the companion might also be seeing another woman, or other women, concurrently. As we will see, this expectation is a source of tension and conflict, experienced with anxiety by a number of women. Having more than one *pequena*⁵ is perceived as a masculine characteristic, something inherent to *being a man*, a symbol of masculinity shared by both men and women.⁶ Therefore, it is something to be expected but not necessarily accepted by women, who use various strategies to ward off the *rival* and have their partner all to themselves.

To a certain extent, these relationships quickly become public through comments, which range from approval to reproach. It all depends on how the *betrayal*⁷ takes place. This becomes very clear in the account of Sónia⁸, who has lived for over 15 years with her *father-of-child*. In one of our conversations about the behavior of men, she claimed to distinguish herself from other women saying that she never underwent the situation of actually seeing her man with another *pequena*. She states never having allowed this lack of respect: of having the man pass in front of her or walk down the street with

4 It is difficult to find a translation equivalent to the Creole expression "to have with so and so" given its plurality of meanings, which can go from dating, to having an affair with, or even be applied to a long-lasting relationship, with children and cohabitation. We opted, therefore, to keep the expression in Creole in order to avoid translations that carry a moral burden, fatally inadequate to the case at hand here.

5 Local term for girlfriend or lover.

6 Other behaviors are described in the literature as important symbols of masculine identity in Cabo Verde, especially a public performance marked by violence and machismo. On this subject see Vasconcelos, 2012; Bordonaro 2012; Miranda 2013.

7 This is a local category, often used by women when referring to the relationships their partners have with others. The notion of betrayal, from an analytical standpoint, seems to translate exactly this dimension of the dilemma experienced by the women, of something that is expected, but not accepted. Since it is a category used locally, it will be used here in italics.

8 It was agreed with our interlocutors that their real names would be replaced in the publications resulting from the research in order to keep their experiences and stories in relative anonymity.

another woman. “He does his own because every man does, but does it well done, well hidden, because to this day I’ve never caught him red-handed. I’ve heard stories, but to see with my own eyes, I’ve never seen. As long as it is so, it is all good, all within respect.”

Sónia was not the only one making this kind of statement, which is more common when more mature women compare ancient times with the present day. “In the old days” refers to the time when men had other *pequenas* and even families, but it was all *within respect*, that is, they did not “rub the other woman in the face of their families”. According to them, nowadays things have changed a lot and no one has respect anymore, “today they are with one, and tomorrow they already show up with another strolling through the square, for all to comment”. It is interesting to note the major concern with the rumors that *betrayal* can cause, rather than with the fact itself. As Sónia says, “every man cheats, but the important thing is for it to be done with respect”.

In fact, *betrayals* and conflicts between rivals are preferred subjects in conversation between women and men. There are numerous reports of fights, men caught in the act, and cases of aggression between rivals, including situations that ended up involving the police. Reports vary with regards to the nature of the relations: sporadic affairs, seduction games, and even dual residence. Women send messages and threats to those who *invade* their relationship with their partner. If the warning does not result in the end of the rumors, they come to blows. Information about the alleged *affair* circulate through *faladeirezas* (gossip) and the rivalry takes on greater proportions as these rumors gain wide circulation, which thus seems to augment their credibility. In cases of suspicion, women, relatives, and friends begin a process of investigation that can last a long period of time.

Every effort boils down to driving rivals away from their companion, in an attempt to curtail the relationship, and especially to avoid the birth of children. There is an explicit fear that she be *exchanged* for the other, and maybe this is why there is a preference for the other relationship to be kept hidden, because it is a sign that the man does not intend to take on the other *pequena*. On the other hand, when the relationship becomes public, the woman is pressured to take action, either confronting the rival (physically if

necessary) or ending the relationship with the *father-of-child*.⁹ In most cases, men who maintain relations with many women say they would never accept the same behavior from their partner and would never fight over a woman.¹⁰

In this universe, what are the strategies used by women in order to maintain a minimum of control over their conjugal relationships? It is common to find in Cabo Verdean literature on conjugality the interpretation that the man's ability to provide for the home and the children is an important factor in maintaining a conjugal relationship. However, the stories of women maintaining a relationship with men who do not support them emotionally and economically are common. When asked why they stay in a situation of conflict and defined by their own selves as humiliating, women always replied in the same way: "the woman is weak, she has a weak spirit."

Being weak does not mean she is dominated or without power in all aspects of life. Being weak means she is the frail part of the relationship between the sexes. As with polygynous masculinity, female frailty is constructed and perceived as something inherent and inevitable to the universe of women. Female sexuality predisposes women to be unfit/unable to resist male seduction. In addition, there is the notion that men are all the same and that a good companion is hard to find. The way out is one of two choices: not staying with anyone, at least steadily, or remaining with the same person, since it is *no use changing*.

The notion of a "good companion" seems to oppose that of a "Cabo Verdean man". Ideally the good companion is a man "like the European", who helps at home, gets involved with the care of the children, is affectionate, romantic, and does not go around with other women. At the opposite end is the Cabo Verdean man, "who is no good", is never home, provides no attention or emotional and financial support for the children and *mother-of-child*, has other women, and is a brute, not romantic. Despite being defined with these negative characteristics, these would be considered the best partners

9 This rarely happens in actuality, the most that was witnessed during the research were threats or temporary separations. Generally, the dispute occurs between the two women, with the man only being the pivot of the conflict. However, in the few accounts we have of women who took a stand, they became a reference of how a woman should act with a man who disrespects her.

10 This affirmation does not mean that women do not have other relationships, either through life or concurrently. The sexual and emotional behavior of some of them is also called into question, being the target of gossip and possible mistrust. However, for women this is not a typical way of living sexuality, being more the exception rather than the rule, and subject to heavier moral sanctions.

as far as sex is concerned. Such a combination of factors results in the female perspective of *weakness* and in the feeling that it is *no use changing*.

Exploring women's strategies, the birth of a child is, sometimes, a way of ensuring a man's support. It is common for a woman to get pregnant in an attempt to create a stronger sense of duty in the man. This often does not work and she ends up having several *fathers-of-child* throughout life, having to support her children without a man's constant support.

Hercules and I *have already had with each other* for 20 years, we've never lived together in the same house because he *already had with Lina* when I arrived (in the relationship). We got pregnant at about the same time, because there is a six-month difference between their first daughter and my son. But his family put pressure for they were neighbors and there were some relatives involved. Soon she came to be pregnant again, went on to live in his family's house, and they live so up to this day. I am not one to make trouble, so I never *meddled in*, for me it is alright the way it is. It wasn't because she came before me, because we did arrive together, but it was because she used cunning and ended up getting three children from him, so there was no way of him getting away, and he ended up living with her. But I never went without a man; he was always there for me when I needed him, although he never gave much to the child. However, I do not let any other women who want to intrude do it, I really fight back, because they already found me here and I will not give up what is mine that easily, it's been 20 years together, and it's not any *pixinguinha* (prostitute) who will come and take over just like that.

The advantage of being the first *mother-of-child*, the argument that she was *already there* when the other women arrived is important. These two factors give her a "right" over the man that is expressed concretely in the fact that she may fight for him. On the other hand, it warrants her the respect of the other women, who also recognize her prerogative to *fight* for the maintenance of her relationship. It is clear that this tacit agreement does not guarantee the stability of the union, for the man may, at any time, abandon the *mother-of-child* and establish a *fixed* relationship with another woman. It is also clear that, as seen in the passage above, *firstness* is a target of dispute between rivals, and the factors time and children can act in favor of both.

To have with another is, therefore, a constant source of quarrels between the rival women, often generating conflicts between the couple, and it may

reach the point where the woman threatens to leave her companion, even though this hardly ever takes place. On the one hand, the most common is the feeling that too much time has already been invested in the relationship, and therefore, one has the right to want to keep it. On the other hand, there is the feeling of impotence or weakness is common among women. They feel they can not break off a relationship that has already lasted a considerable period of time, has already generated children, and they justify this by saying that if they leave the *father-of-child*, they will find another man who will do the same or worse, so they stay where they are and avoid having a child from each father. Another reason used in order to explain why the relationship is kept lies in the fact that while the man goes around with other women, he always returns.

It is worth drawing attention to the dilemma experienced by these women: to remain or not to remain in relationships that they themselves classify as being problematic or a source of suffering. One possible analytical answer would be to invoke the competition of models operating in the Creole society of Cabo Verde (Trajano Filho 2003; Lobo 2014). In the family context these standards in competition inform the dynamics of life of women, men, and children through the notions of family structure and dysfunction. Breaking with family behaviors considered destabilizing becomes imponderable for young women who find themselves in constant conflict between discourses and practices in competition.

“Marriage is for life”

As it must have become clear by now, the fact that a couple has a child does not mean they share a new home. Usually the mother, along with the child, continues to live with her mother or family in which she was raised, while the father remains in his home. But when the couple reaches a more mature age, the transitory nature of relationships tends to be less frequent. Couples live a conjugal relationship not formalized by marriage, but living together, or, even if in separate homes they visit each other on a daily basis. Usually the woman goes to sleep with the *father-of-child* or companion, but spends the day and affirms living in what she calls *nha casa* (our home), with her immediate relatives.

The older they get, the more common it is for men to claim being in search of conjugal tranquility and stability. They say they want a peaceful life

by their *mother-of-child*. In spite of this, it is rare to find adult couples living in a situation formalized by legal marriage; the most common form of conjugality is union itself, and legal marriage is more an exception than the rule.

The postponement of the formal wedding is generally linked to the perception that it is an expensive and unimportant ceremony. However, in practice, it is envisioned as a possibility or project, especially for women. They hope to get married and the moment upon which the desire will become reality ultimately depends on the men. Directly or indirectly, the power of decision is male. In conversations with women on the island of Boa Vista, it was common to hear them say they were waiting for the man to settle down in order to formalize the union, because marriage is a serious business and it is for life. This moment arrives when they are older, when the children have been raised and grandchildren already tread their grandparents' house (Lobo 2010).

A document on the analysis of weddings in Cabo Verde for the period between 2000 and 2011 presents interesting data (INE 2013). The crude marriage rate per year is considered low, less than five weddings per one thousand inhabitants, and the age at which marriages occur is considered high, of almost 40 years for men. This data is in accordance with our field experience, in which we were able to interview, observe, and talk to dozens of women and men on this topic, finding that the overall voice is that marriage is seen as a *serious step*, one that requires responsibility, and which is *forever*.

A formal wedding is an important symbol of prestige, especially when the ceremony is held in a church. We see, then, the Christian model, so valued in this society, as a reference of an ideal way of life, being, finally, fulfilled through the formalizing of a conjugal relationship that has already lasted for years in a situation of "informality". The statistical rarity of formal weddings does not mean a detachment from the Christian model of marriage. On the contrary, it indicates full adherence to it. People marry formally only when they truly feel able to follow the model to the letter, keeping the marriage forever. This data suggests that it is more worthwhile not to marry rather than to do it and subsequently break such an important bond.

A man marries when he is willing to take on formal responsibility for the family, even if he is already doing so in practice. With the wedding, which implies cohabitation, the woman feels safe. This is the phase in which the man has already *settled down* and is more present in the domestic sphere;

usually, it is during this period that religious weddings take place. Organized by the children and grandchildren these ceremonies tend to celebrate the couple's long years of union. It was so in the case of Nha Raimunda and Nho Justino. When they completed 25 years of living together, the children organized the wedding ceremony in the church to celebrate and formalize the union. Nha Raimunda confided that she had always wanted to marry, for she is religious, but they had never had economic conditions to do so, and also because Nho Justino used to drink a lot and was a *man of his parody* (party). He had now grown tired of this *evil life of going out stag with his fellows* and was more *settled down*, that is why he decided to get married and have the celebration his children wanted.

The case of Boa Vista is no different from other Cabo Verdean islands and other ethnographic scenarios. For example, Edith Clarke, in her study on Jamaica (1979), states that instability is the central feature of conjugal relations in Creole societies, noting that, within these social contexts, relations of extra-residential, non-domiciliary, or visitation nature, and with various alternatives to the conjugal standard are institutionalized. Another central feature is that the ideal age for marriage is high, with it being typical for marriage to be preceded by several years of cohabitation. It is normal for father and mother to marry after the children are already grown and even when they are already grandparents. The author also points out that few are the men who only have one conjugal union. Most are involved in two or more, aside from engaging in a series of chance encounters.¹¹

However, when analyzing the phases through which conjugal relationships go through, a question remains: instead of accepting the idea of instability, we could ask ourselves whether the postponed wedding would not represent a strategy within another scale of priorities¹². Wouldn't the wedding in Cabo Verde, as in some African cases, have a processual character?

In order to clarify this point, we propose going back to the analysis of the Tallensi marriage made by Fortes (1969), in which he demonstrates that

11 In the extreme of this model, there is the ethnography of Cai Hua on the Na, from China (2001). The author provides an interesting analysis of a kinship system in which there is no formal marriage, or cohabitation, nor are there the terms in the language for "husband" and "father". Social reproduction takes place through nightly sexual visits. Who takes care of the children is the mother's brother.

12 Woortmann (1987) in his book "The Family of Women" does not gratuitously buy into the notion of stability and instability to define families of poorer strata of society in Salvador either. Such notions, according to the author, are not easily determined.

marriages are unstable in the early stages. A young man rarely remains permanently with his first bride and the young women themselves see their first marriage as an experiment, except in the cases in which the husband is older or the marriage is the result of a negotiation. Mature men claim not to remember all the women they had. Although the idea of marriage is not one of an eternal bond for the Tallensi, many couples stay together for life. In his effort to understand African marriage, Radcliffe-Brown (1978) states we should not think of it as an event or condition, but rather as a process in development.

Given these examples, we risk suggesting that conjugal relations in Cabo Verde may be less unstable than they appear to be in the speech of the interlocutors. Instability as a negative factor arises, then, as a clash between local practices and a Western model, which, according to Pina Cabral (2003), merges affiliation, conjugality, and residence in family formation. Against an ideal model that values a Western Christian perspective, the local universe appears as dysfunctional. As in other ethnographic contexts, marriage here can be understood as progressive, the result of a process of long negotiations and that develops in stages. Unlike the case described by Clarke, what we have here is not instability, but process.

In the local explanation, marriage and other forms of union can not be seen as alternative forms of conjugal association in which the individual is free to choose. While union in fact is a type of arrangement that does not involve a secure conjugal bond or a well-defined relationship of kinship, legal marriage is seen as a serious step which requires responsibility from both parties. Marriage takes place, then, as the last stage of an association that before took other forms: first, of chance affairs (with or without children), then, actual unions, and finally, marriage. The last being an indication that the economic and social conditions for such have been met. Marriage is the sign that the contracting parties have approved of each other to the point of submitting themselves to the risk of changing *status* and the responsibility this entails. This type of union marks the end of a free association that can, theoretically, be dissolved at any time. In the conception of women, one should only marry after the man *stopswandering* and *sits his head* at home, because marriage is *for life*.

It is within this particular context of conjugal relations that lies the main issue that concerns us in this article: how to understand the demand

for gay marriage in Cabo Verde, if in this archipelago the nuclear conjugal model held as hegemonic and presupposed in the international LGBT agenda (Epprecht 2013)¹³ might not take place?

Male (homo)sexuality and gay marriage in Cabo Verde

Before proceeding, it is necessary to understand how male (homo)sexuality is experienced in this country.¹⁴ In order to do so, we open this section with the account of Bela, a *traveste* from Mindelo:

We in Cabo Verde, we are gays, we are *travestes*, but we never get involved with gays. We like to get involved with men. Men who do not like to take it in the ass. Men. We like men; we do not like gays, unlike foreigners. Abroad, gays like gays. But not us, we are different.

In this account, the *traveste* Bela discusses in local terms the hegemonic system of male sexuality in Cabo Verde, which separates *men* and *gays*¹⁵. Such a system is analogous to the one described by anthropologist Peter Fry for the poorer strata of society in the outskirts of Belém, in Brazil, studied in the 1970s. In Brazil, the author finds a system that separates “men” and “fairies”. In his own words:

13 Marc Epprecht notes that: “The ‘gay international’ has been instrumental in developing such responses, in helping African associations to network and professionalize, and in funding research to support rights claims. Global solidarity associations such as Human Rights Watch, ILGA, and the International Lesbian and Gay Human Rights Commission (IGLHRC) have also played a significant role, lobbying donor governments to be alert to the issues.” (Epprecht 2013:159) For some examples of pro-gay marriage campaigns promoted by international civil society movements, see: http://www.ilga-europe.org/home/issues/families/campaigns_and_events

14 We take this opportunity to briefly justify our decision of dealing solely with male homosexuality. From Brazil, the little material that arrived from the Cabo Verdean LGBT movement made male homosexuality much more visible than female homosexuality. Upon arriving in Cabo Verde, our closest interlocutors were all men, aged between 15 and 40 years old. Within this group of friends, there was only one girl who identified herself as being “30% homosexual” and who *had with* another female friend from the group. Thus, female (homo)sexuality will not be approached in this work, because, aside from being made more socially invisible, our relations in the field led us primarily to male homosociability. An exemplary case in the field of this invisibility brokered by the lesbian women themselves, was when, upon being invited to participate in the first TV program in Cabo Verde that would discuss “homosexuality”, they promptly refused.

15 Being *gay* or *homosexual* within the hegemonic model of Cabo Verde – and these are categories triggered as synonyms locally – has to do not only with an attitude of publicly taking on one’s own homosexuality (and this is done not only verbally, but also with the people one hangs around with, garments, body performance, etc.) but also with the local classification on sexual performances, which couples male passivity to *homosexuality*. Being *gay* on those islands is also bearing on one’s own male body signs of femaleness; it is to resemble a woman, in some way or in some aspect.

The category *bicha* (fairy) is defined with regards to the category “man” in terms of social and sexual behavior. While the “man” should behave in a “masculine” manner, the “fairy” tends to reproduce behaviors generally associated with the female gender role. In the sexual act, the “man” penetrates, while the “fairy” is penetrated [...] the act of penetrating and the act of being penetrated acquire within this cultural area, through the concepts of “activity” and “passivity”, the sense of domination and submission. Thus, the “man” ideally dominates the “fairy”. In addition, the relationship between “men” and “fairies” is analogous to the one established between “men” and “women” within the same social context, where the male and female gender roles are highly segregated and hierarchized (Fry 1982:90, free translated).

This system, which Peter Fry denominates “system A” is the hegemonic model found in the fieldwork in the city of Mindelo, in present-day Cabo Verde. In this city, ideally, the male and female genders are equally segregated and hierarchized. There, the sexual behaviors of *men* and *gays* are also, ideally and respectively, “active” and “passive”. Finally, in Cabo Verde, men are also presumed to act in an extremely masculine way, while *gays* and *travesties* would articulate many of the feminine signs found in their culture. Obviously, there are creative displacements and recitations of these signs of masculinity/femininity in the bodies of the subjects, and sexual performances are not always so Cartesian either. In other words, this model never transpires perfectly, but operates as a standard and it is in this sense that such models of sexuality proposed by Fry help us here.

Nevertheless, there as here, there is more than one male sexuality system coexisting and competing (Fry 1982:91). Thus, a second model formulated by Fry, also applicable to Cabo Verde, would be the symmetric model of the “knowledgeable men”, or system B.¹⁶ This model B of male sexuality, in which the division lies between men and “knowledgeable men”, or “heterosexual” and “homosexual”, also operates in Cabo Verde, however, with less resonance.

16 In system B, “the male world is no longer divided between masculine men and effeminate men as in the first system, and is divided between ‘heterosexuals’ and ‘homosexuals’, between ‘men’ and ‘knowledgeable men’ (Fry 1982:93-4, my emphasis). The author points out that: “the ‘man’ is not the same as in the previous system, for in that one, the ‘man’ could perform homosexual behaviors if he restricts himself to being ‘active’. In this new system, the male who engages sexually with another male, even if ‘actively’, ceases to be a ‘real man’ and becomes ‘knowledgeable’ or ‘homosexual’. Thus, in this new system the acceptable sexual relations are different from the ones in system ‘A’. Now, men must only relate with women, and ‘knowledgeable men’ with ‘knowledgeable men’ (Fry 1982:94).

Bringing forth the hegemonic Cabo Verdean system (“System A” or “hierarchical”, in the terms of Fry) is key to understanding the relationship.

With the “non-gay” category, we intend to encompass all men who do not identify themselves with a non-heterosexual identity, yet that relate erotically with people of the same sex. This criterion is not simply an arbitrariness of the anthropologists, but rather a classification of gay interlocutors themselves who always tended to categorize these “straight with quotation marks” or “non-gay” men within the same class. The prefix “non” is not by chance: it is used here because, even if they relate sexually with people of the same sex, it is precisely in the coincidence of the negative responses of these young men, when asked if they are “gay”, that there is a possibility of classifying them within a same group.

With this understood, homosexuality among Cabo Verdean men is mostly experienced non-conjugally, and, above all, is hardly experienced romantically¹⁷, whether in the lower or middle classes. Unlike the cases presented by Rodrigues (2010) within the upper classes of the capital¹⁸ male homosexuality in Mindelo is experienced, especially through isolated sexual encounters, even though many participants suffer enormously due to this lack of romanticism.

In this regard, in one of our long conversations through the nights in the city of Mindelo, Didi, a young non-heterosexual actor, sarcastically asked his friend Elzo, gay activist and defender of same-sex marriage as a priority in the agenda of the local LGBT movement: “Ok! If they institute [same-sex] marriage here, who will marry whom? You will convince the young lad over there to marry?” Didi was referring to the non-gay young men who eventually *have with* them. And goes on, “I will marry Lunga? Tchinda?” What Didi meant is that since homosexuals do not date homosexuals, here could be no reason of having marriage if there were no people who intended to marry. Didi also argued that it *would take decades to change the minds of Cabo Verdean men*, so that they would want to get married.

17 By conjugality, we mean a relationship marked by the ideal of cohabitation and an emotional, sexual, and financial commitment taken on between the parties, in most cases on monogamous terms. This is an “ideal”, since the non-occurrence of one or more of these characteristics in people’s real everyday lives would not necessarily disrupt the notion of conjugality.

18 The Cabo Verdean sociologist Claudia Rodrigues inaugurates the field of homosexuality studies in her country. Her master’s dissertation, defended in 2010, covers various aspects on gender, sexuality, and class among some *homoaffective* couples of the elite of the capital Praia.

As we saw in the previous section, conjugality is a broader issue that also affects the universes of heterosexual affection in Cabo Verde. It is a way of experiencing conjugal relations, which have in the categories *mother-of-child* and *father-of-child* its greatest expressions. In Mindelo, and not only on the island of Santiago, as diagnosed by Miranda (2013), masculinity is constructed, overall, through the public display of virility (Miranda 2013:77). Thus, masculinity is exercised through dramatized actions, simulations, much public display, quarrels, and the depreciation of femininity (Miranda, 2013:81). The ways in which a Cabo Verdean man's masculinity is constructed, however, has its burden and bonus both for women and for the self-identified *homosexuals*, with whom these men also tend to get involved. Thus, gay subjects value virility, the "grip" of other non-gay men, the manly way in which they approach, however, even though they sometimes complain about the lack of romanticism, the lack of a fixed relationship and "affection". There is anguish among some of our gay interlocutors who share the romantic values of monogamy and conjugality. As we have already seen, it is not only gays who complain of this lack of affection from Cabo Verdean men, women do the same.¹⁹

Perhaps as a further indication of the so-called "liquid love" (Bauman 2004) in contemporary times, in which dyadic relations are transformed, becoming progressively more fluid, these almost exclusively sexual and fleeting relations between gay subjects and Cabo Verdean young men are treated with less and less enthusiasm by the former. This maxim, hovering over the Creole spirit, of a masculinity that is impenetrable (Sáez & Carrascosa 2011) by romanticism, and in which it is unbecoming for the man, understood as the masculine subject, to display affection, impacts the subjectivities of Cabo Verdean gays.

Although most gay subjects say they experience casual relationships with young men, at least three interlocutors in Mindelo claimed having *fixed* conjugal relationships, even if these deviate significantly from the more hegemonic romantic model they hold as a reference. The first was the *traveste* Barbie, who, nonetheless, never told us anything about her "husband". The second was Pedro, a 29-year-old physical education teacher, who claimed having experienced a conjugal homosexual relationship with cohabitation

¹⁹ This is, in fact, one of the reasons cited by the young university student from Mindelo, Mônica, of why she relates affectionately and sexually with other girls.

in the island of Santo Antão, but now lived what appeared to be a non-monogamous long-distance marriage, because his companion lived in Spain. The third was the hairdresser and makeup artist Cesar, age 40, who between comings and goings with former partners, ended up reconciling with an “ex-husband”, whom we never met. Allegedly, it was a young man with whom he *had* shortly before his long season in Europe. The young man, persuaded by family and neighbors to forget Cesar, became involved with a local girl for three years, until the moment Cesar returned to Cabo Verde.

One day, they had an argument, when the boy provoked Cesar by deciding to show him photos of his girlfriend so that he would be aware of *the level of woman he was able to attract*. When we asked Cesar why he had made up with this “ex-husband” (since he was getting on with another young man he said he liked), he replied the “ex-husband” forced him to. When asked if the boy had that kind of power over him the answer was positive, echoing the same characteristic of *weakness* highlighted by women. Gays and women live different experiences of affection, but as representatives of a feminine *ethos*, they would be the weak link in these relationships.

Elzo once joked about both Cesar’s and Pedro’s claim of having “husbands”, because for Elzo it seemed very strange for someone to have a husband and not to live with him, or worse, spending long periods of time without seeing him, as in the case of Pedro. These stories show that a current complaint among gay subjects is that the relationships they establish with non-gay men are almost always “casual”. Unlike the accusation of the *homo-affectionate* of the elite from Praia described by Rodrigues,²⁰ this has nothing to do with a sort of “ignorance” typical of gays of lower classes, but is mainly due to the refusal of non-gay men to “assume” a properly “gay” identity, as it becomes clear in this interview with Lunga:

20 The moralizing view of this elite, which the author calls “homo-affectionate”, for considering that this term extracted from the Brazilian context would best describe her interlocutors (Rodrigues, C. 2010:3), is narrated as follows: “In their view [of the *homo-affectionate* of the elite], gays of lower classes reproduce the homo-affectionate model that comes down to sexual intercourse, with clear distinction between the ‘masculine’ man and the gay man, denoting the power relationship between two men. He who practices oral sex on another, or has an affectionate attitude, is seen as an equal, or, in the voice of my interlocutor, as a ‘fairy’, and the lower-class gays want to have relations with men who they see as straight and not as ‘fairies’” (Rodrigues 2010:81). The colonizing perspective of the *homo-affectionate* elite of Praia, mostly inserted into a “symmetric model” of homosexuality, seems to propagate a modernizing ideal that conceives the becoming of such relations between individuals of the same sex as egalitarian and democratic. However, as we have shown previously (Miguel 2014:87-88), for various reasons, this elite does not display the same subversive character of the lower classes, with regards to the LGBT political agenda.

How is the relationship between same-sex partners here in Mindelo? Is it always casual? Is there dating?

No, it's casual! I think 99% is all casual. That's if there is such a thing as 1% (laughs), it's all casual. It may be a casual that lasts a few months, it can last for years, but it's all casual.

Why? What is it then to be casual?

Because, like... here... it is very complicated. Because here, I don't know whether it's because it's a small place, people... Yeah... Homosexuality here in Cabo Verde is very complicated. Take me for example, I'm openly gay, or Elzo who is also out... We are gay, we say we are gay and we like men and I don't know... The young men who relate with us, they are not... They can relate with you for years on end, but for them, they are not gay. They are boys who like to be with gays, but they do not identify themselves as being gay. So, then, I think there is this difficulty of having a relationship. Because they may even like you and want to be with you, but they do not want to face society, they do not want to come out publicly. For example, he can tell Elzo, for example, "Oh, I want to be with you" and there may even be a relationship, but it's all hidden. He will not go out with you out there... I'm not talking about walking down the streets holding hands, because I don't want that either. But they will not... For example, say "oh, I date him", "I'm going steady with him" but to meet you and come to your home or... It's all very discreet, because... they do not want to face it, they do not want to say on the streets "Oh, I live with a boy" or... So the relationship is a bit complicated. I think it's more because of this that relationships only remain within the realm of casualness, right? It's all...

I understand. And these guys date girls too?

In most cases, yes. In 99% of cases (laughs).

The "casualness" pointed out by gay subjects, also understood as a lack of commitment on the part of young men towards them, is something that is diagnosed as early as the courting ritual, in *sending mouths*²¹, in the "aggressive" or "brutish" performance, going through a contempt for them in everyday life, until the final refusal of continuing the relationship. From what

21 *Sending mouths* (*mandar bocas*) is an idiomatic expression of Cabo Verdean Creole which allows for a more or less broad set of meanings. It can, therefore, refer to both the exchanging of banter with friends, regarded as innocent, as well as operate as jeers, insults, and humiliation. The *mouths* can be directed to typical targets of *mockery* (jokes) and teasing, such as fat people, the very thin, country people, the toothless, the effeminate, the very stupid, and any others identified as "deviants" (Miguel 2014)

we have seen so far, it is already possible to speculate that the behavior of non-gay young men, if analyzed within the context of heterosexual relationships, may be less a problem of embarrassed sexuality and more of a broader Cabo Verdean masculine *ethos*, which tends to escape the model of romantic conjugality. As suggested by the anthropologist Peter Fry at a given point, *in this case it may have more to do with gender rather than with sexuality*.

In this sense, and without disregarding the importance of the dimension of sexuality, from the field we were interested in knowing, for example, how young men acted when gay subjects with whom they had some kind of amorous or sexual bond, greeted them on the streets.

And for example, one of these boys who do not, do not assume their homosexuality, and suddenly you meet one of them on the street, can you greet him in front of his friends, if he is together with friends?

There are some you can't, and others who you can. And ... It is always a middle term here. There is always an intermediate. There are those with whom you shouldn't even, even, even show your face.

What happens? What would happen?

No, they would get completely flustered. (laughs) They get totally flustered. Especially if they have, like, a girlfriend, or any other girl with them. They get that... that distraught look, as if we are going to do something: we're going to shoot him...

And how do you feel in one of these situations, occasionally, having one of these more steady partners and for whom you have some affection, and, publicly, you can't even... even greet him, in the street, like... How is that? Is it ok for you?

[At one] point it [was] not easy. Nowadays it's ok. Again I repeat: "I become blonde"²². Of talent. Back in the day, I used to get super upset.

If Leandro places "getting super upset" in the past, it was not exactly what his eyes and his expression conveyed. In our conversations the hurt resulting from the impossibility of achieving a specific model of a romantic relationship was a constant, very much in the present. The warnings from the boys "you don't know me and I don't know you" immediately after a fleeting sexual act in the streets; or the aggressive *mouths* such as "*paneles*"; the

22 Here, the expression "I become blonde" means that he pretends that something is not happening.

disappearance of the boys when gay subjects went after them; the hesitation about the kiss on the mouth during sex; the denial about the relationship by the boys when they are with friends in a public place; all this creates a feeling of anguish among the homosexuals of Mindelo.

It was with sadness in their eyes and tone of voice that some young gay subjects such as Romeo, Leandro, or Didi, as many others, spoke of their amorous experiences with boys:

And how are these relationships? Do they last a while? Do you stay together?

So far in my situation they did not last long. Only one stayed a while, but he soon left.

And is it usually so?

It has usually been so. I don't know if someday I'll find someone and we can be together like this, I don't know.

Would you want to date?

Absolutely! It's my greatest wish.

And you can't because these men do not take on, do not want these relationships...

Yeah...

And then... Well, the sexual intercourse happens, but is there any complicity, is there any emotional relationship, jealousy, longing...

Um... no. If there is, I think it's immediately annihilated by the boys themselves, because the pressure is so high. They, I don't know, it is very confusing... It's really impossible, it's impossible. I would say there is no affection at all, none... There isn't. If something begins to emerge, as I said, it is annulled immediately. There's nothing. It's really impossible. With me, and others as well. Of course there are other cases of some who can get something out of it, I don't know what... But because they invest their time and insist and insist and suffer, suffer, suffer, suffer, suffer... But not me! I usually say that I really like myself very, very much.

But have you dated? Have you been married?

No. "Dating" in quotes, around here, around here one should not even use this word.

Oh yeah? Why?

Dating here is... has... it's like a scale: there's a plate facing up and another one facing down. It's hard to keep your balance. Because the partner is never, never fully surrendered to you. There's always a conjuncture or another. Another engaging side to it. It's something, like... A salad.

And you're talking about male partners specifically?

Specifically.

The dialogues above point to several interesting issues. Firstly, they are the accounts of students, artists, or activists, relatively mature young men, aged between 25 and 30 years old who gradually realize the mismatch between the values of their culture and the romantic values they project onto their lives. Aside from this, it is interesting to note that they do not draw, in their speech, a parallel with the forms of relationship between men and women. Although their speech is very close to women's – who negatively perceive the expressions of local masculinity materialized by the fortuitous relationships, a sense of instability, the lack of romanticism, and the non-realization of a relationship within the idealized “Western” standards – our interlocutors did not observe that the hegemonic standard does not occur in the heterosexual world either.

What seems to permeate such contrastive discourse – between what they experience in reality and what they would like to experience – is a set of external values, possibly introjected by their emigration experiences in the American and European continents; by Brazilian soap operas that have been showing for some years now homosexual couples on local prime-time television;²³ and by the agenda of the LGBT movement in many countries for the legalization of homo-affective unions²⁴ (Vale de Almeida 2010), even with the support of important scientific associations (American Anthropological Association 2004).

Although non-gay young men maintain sexual relations with gays, they simply do not conceive the possibility of conjugality in these relationships. Marrying or even dating, most of the time is not part of the relationship

23 Some examples of Brazilian soap operas which had homosexual couples in their plot and were broadcast during prime time in Cabo Verde are: “*América*”, “*Paraíso Tropical*”, “*Avenida Brasil*”, “*Senhora do Destino*”, among others.

24 Extracted from the Brazilian legal world, we will use the term “homo-affective” here to refer always to sexual and amorous relationships, more or less stable, between people of the same sex, which do not cease with fleeting sexual encounters.

grammar of these young men. Even younger individuals, who already establish some kind of change upon identifying themselves as “bisexual” (and, therefore, differently from others, take on a non-heterosexual identity), do not escape traditional amatory and erotic games. Therefore, the boy Tiago, age 16, and self-proclaimed “bisexual”, when asked about his dreams, projects a future in accordance with the possibilities provided by Cabo Verdean tradition:

Yes... I want to get married, as always. To a nice person, I want to be a doctor, let me see what else... Leave, get to see new places...

And when you say married, is it to a man or a woman? Or it doesn't matter?

Oh, that I do not know. I don't know if I'll marry a woman and cheat on her.

As with the women, we asked, after all, why they get involved with these non-gay young men and get frustrated, if it is set culturally that the language of relationships is permeated by these signs understood as “crudeness”, “insolence”, “rudeness”, etc.

Yeah... There's that, too, because we... I speak for myself, but I can also speak for others. And... We have fetishes for difficulty, almost as if it attracts us. Instead of being here in the gay scene, some people more associated with one another... Instead of being here, peaceful, experiencing our conversation. No! We do not live like that! We go on to look for a really... thorny and knotty problem.

Which are these boys...

Exactly.

And why? What is attractive in them?

I don't know (laughs). To this day I am searching for the explanation. I don't know, I don't know... I like them. I think I like them. Because only a person to like.

But is there some physical attribute, a behavior, what is it that attracts?

Certainly! A lot attracts. The physical matter is indifferent. But, sometimes even by, by the character too. Sometimes we see some little thing that, like a... a speck that attracts. But in the end, no, it is not set. There is always something...

Leandro's account reveals that the amorous and erotic game between two people demands from them a shared semantics, in which both need to create convergent expectations, match meanings, and communicate with each other. In other words, it is clear that both gay subjects as well as women, although they negatively evaluate the treatment received, somehow share and corroborate the social norms of gender and sexuality that keep the system operating. Among the gay subjects, for example, it is evident how they demand from the young men a hyper masculine posture, corroborated in tradition. And which if not performed by the boys – as when they reveal they prefer to be passive in the sexual act – is denounced and ridiculed by the gays themselves. On the other hand, women often blame their *fathers-of-child* for failing to support their offspring, as if this were the primary social role of a man, reaffirming or reviving traditional gender roles.

It is worth going back to the dialogue at the beginning of this section, to the clever way in which Didi provokes Elzo: “Ok! If they institute [same-sex] marriage here, who will marry whom? You will convince the young lad over there to marry?” This question seems to touch deeply on the argument raised here – would the demand for gay marriage have any echo in this society? Our response can follow two routes. The first one would be to analyze the local political-sexual environment, or the universe of discrimination as approached by Miguel upon reflecting about the native category of *hypocrisy* (Miguel 2014). But our choice was to put into dialogue the local conceptions on affection and conjugality and the ways in which gays and their demands are inserted in such a context.

Upon comparing the characteristics and expectations of women and gays with regards to the universe of affection and sexuality with men similarities and differences emerge. There are interesting parallels in the construction of the image associated with the masculine and in the expectations generated from it. Women and gays associate with the Cabo Verdean man's behavior when it comes to fortuitous relationships, the lack of romanticism, the impossibility of a monogamous relationship, and, by contrast, present a self-image of fragility and dependence. Both construct a scenario for which there seems to be no way out, since *men are all the same*. However, the parallels seem to end there. While within the homosexual environment contacts do not usually go beyond the sphere of the erotic, of fortuitous moments (albeit with some continuity in some cases) left to anonymity, women have

in their favor a set of strategies explored here, and, above all, the expectation of building a path together which results in the formalization of the relationship, that is, *marriage on paper*.

Once acknowledged that marriage must be understood as a process, which, in order to become effective, needs to go through several phases in which it is up to the woman to wait while the man enjoys the possibility of fully experiencing his masculinity, which can also involve having children; and also once understood that homosexual relations are experienced between gays and non-gays and that the latter perceive such practices as an exercise of their masculinity rather than as a reason to put it into question (Miguel 2014); the demand for romance and marriage in the universe of homosexuals seems to sound out of context. Why, then, raise this banner?

Various flows in Cabo Verde

Cabo Verdean society is markedly known in the field of social sciences for its migratory profile. Emigration in the islands is central to an understanding of local social dynamics, national identity, and the country's integration in the global scenario, both in the past and in the present. Local historians, writers, and poets have also spent much ink upon mentioning the 10 tiny grains of sand scattered in the middle of the Atlantic, which were not forgotten by God there thanks to the character of its people, who see in the sea their source of pain and isolation, but also of hope, adventure, and the possibility of a better life. These perceptions go beyond the pages of academic and writers and are reflected in everyday practices, in a cosmopolitan atmosphere that Cabo Verdeans update in the relation with foreigners, in the incorporation of external signs, in the fluidity with which they overcome linguistic and cultural barriers.²⁵

This openness to the other takes on important contours in the insertion of the Cabo Verdean nation state on a global scenario. Ever since independence, in the 1970s, the political and economic relations with European states and international organizations, through their international cooperation actions with countries classified as poor or third-world, are of fundamental

25 On these themes see Trajano Filho 2009; Lobo 2014b; Braz Dias 2014; Miguel 2014; Braz Dias and Lobo 2012; Carling 2001.

importance to Cabo Verde on several fronts, exemplified in the actions in the field of the Struggle Against Poverty, of health, and education.

Within civil society the same trend is observed. Various non-governmental organizations and associations update in Cabo Verde the leading discourses, values, and demands of social movements around the globe. Gender, violence, environment, and other issues of the global agenda are banners of numerous associations who find fertile ground on Cabo Verdean soil. This is the context within which the Cabo Verdean Gay Association (AGC) is inserted. Composed of militants from different social backgrounds and founded in 2010 by a *traveste* who had recently returned from Italy, the AGC was the first local gay association to have been legally registered. It has always counted on the human and financial support of international organizations, such as the Spanish Triangle Foundation, which fights for gay rights in Latin America and Africa.

The demand for gay marriage within a hegemonic model of marriage, which, as we have been demonstrating, does not find immediate assent in Cabo Verde, does even so have resonance, since cosmopolitanism is also a feature of Cape-Verdean culture and society. (Vasconcelos, 2007; Correia & Silva 2000; Nascimento 2008) In addition, for Cabo Verdean activists the gay marriage banner has the effect of marking a historic diacritic with the Africa continent, supposedly “uncivilized”, and which now *murders gays* (Miguel, 2014). Thus, the demand for gay marriage is related to various internal and external dynamics that go beyond, by far, a simple desire to formalize new types of conjugality.²⁶

The reflections of Aihwa Ong²⁷ on globalization studies, and her proposal to focus on understanding the ways in which the values resulting from an adjustment of global capitalism to local realities are incorporated, and to map who the relevant actors and protagonists in the distribution of power and

26 By focusing on the dimension of cosmopolitanism, we do not intend to deny that there are other reasons for the demand for gay marriage in Cabo Verde, as well as for the gay movement itself. Among these demands we could even include a social appeal for male subjectivities in the country to be domesticated by romanticism, in line with the Western model. Therefore, we suggest that this demand might result from the anguish of those gay subjects, who are more enthusiastic about the Western romantic models, of not being able to fulfill their individual cosmopolitan gay projects in a culture such as theirs. Finally, in order to explain the existence of the local gay association, the less noble, but equally human, reasons could be mentioned, such as the vanity of the leaders of this association, their need to take part in functions of social prestige, and the need to raise international funds for the survival of these very activists, who most of the time are formally unemployed.

27 See Ong (1999) and Ong & Collier (2005).

knowledge of a so-called global citizenship (2009) are, can help us understand how AGC's demands for gay marriage interact with local concepts and practices on conjugality. This is because her notion of global assemblage allows us to look at the universe of strategic interactions inherent to global and local flows and actions; her emphasis falls on the interactivity of the flows in social practice and the consequent reconfiguration of power relations.

By proposing to discuss the demands for gay marriage within context, that is, viewing them within the local dynamics of conjugality, our focus falls on the universe of interactions between the global and the local. Therefore, we turn our attention to how the structural dimensions of social life – family, community, nation – condition, shape, and transform the subjects and their practices producing political-moral dilemmas. The dilemma experienced by gays we have presented, masterfully expressed in the dialogue between Didi and Elzo, in our view, serves to stress the fact that the fluidity with which global demands and values circulate are limited by the local social order.

Globally hegemonic views on how to live conjugality (hetero or homosexual) appear in dispute whenever they interact with local contexts. However, as Ong (1999) reminds us, this is a field of power relations where what is at stake is the implementation of processes of intervention in “living arrangements” (Collier & Lakoff 2005), dictating political, social, and economic conditions that raise the question of “how one should live”. “I want to marry in Cabo Verde” is, therefore, a demand to be problematized, for it encapsulates values and relations that seek to remake lives and social practices within contexts of dispute for power and hegemony.

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Introduction

Dossier

HEALTH/ILLNESS, BIOSOCIALITIES AND CULTURE

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In this dossier, we present 10 articles exploring the theme of “Health/ Illness, Biosocialities and Culture”. Addressed to a larger non-Portuguese speaking audience, our aim is to promote the research that has been developed by Brazilian Anthropologists from different generations, academic disciplines and university institutions on a variety of topics associated with this central theme. The articles presented here highlight the diverse ways that medical knowledge and technologies are being constituted by and constitutive of culture, politics, ethics and identity in Brazil. In doing so they extend and bring to bear novel theoretical perspectives in approaching questions of biosocialities, health and illness.

All the articles in this dossier consider the social impact of biomedicine, biotechnologies and public health policies and their role in the definition of new “pathologies”, novel meanings of risk, contemporary social practices and cultural conceptions of ‘life’. A range of ethnographic contexts inform these discussions including clinical or medical settings, non-governmental organizations (NGOs) and patient groups, thereby illuminating the diverse arenas of social practice through which contemporary cultural configurations are being co-produced. Moreover this Vibrant issue presents empirical material that shows not only that there are continuities with global social processes

but also how historical, political and cultural specificities of the Brazilian context inform these developments in unique ways.

In the wake of developments in genetics in the late 1990s, linked to high profile initiatives such as the Human Genome Project, North-American anthropologist Paul Rabinow, extending and transforming the theoretical paths initiated by Michel Foucault on biopower, observed the emergence of a historical context of “post-disciplinary rationality” he termed biosociality (1992; 1996; 1999; and also 2008). Different from either the anatomo-disciplinary practices of the body or the modern regulations of governmentality related to populations, which were mainly privileged by Foucault, the focus on the body and population in the context of biosociality would potentially be a novel configuration. For Rabinow, the questions and problems engendered by contemporary science and biomedicine, exemplified by research on the human genome in the late 1990s, held out the potential for greater transformation of identity and social life because of the capacity to transform and intervene on the biological. Thus in contrast to sociobiology where ‘culture is constructed on the basis of a metaphor of nature’ in biosociality ‘nature will be modeled on culture understood as practice,...known and remade through technique (1996: 99). As a heuristic category, biosociality was therefore primarily conceived to highlight the new hybrid relationship between biology and culture. In this sense, as Rabinow subsequently suggested (2008), it might be thought of as an experimental tool for examining the interface between recent developments in the life sciences, social practices and individual and collective subjectivities. Of particular interest for many social scientists has been the focus on the transformations brought about by developments in genomics and identity (Rose and Novas 2005). Subsequent anthropological research in transnational and comparative arenas has illuminated the variable and diverse manifestations of biosocialities (Gibbon and Novas 2008; Gibbon et al. 2010). This work has highlighted both the limits and scope of transformations in identity, drawing attention to the way that continuities co-exist with novelty and posing new questions about the applicability of a notion of biosociality in particular disease fields and within specific national and transnational contexts (see Lock 2008; Weiner 2010; Raman and Tutton 2010 and Bharadwaj 2008).

The articles in this dossier extend and inform these comparative studies. All the articles compiled here show how in Brazil the practices, social forms and subjectivities that emerge in association with seemingly novel “practices of life” are co-produced at the interface with particular socio-cultural dynamics as much as they are informed by political, ethical and historical specificities. Of particular interest in the discussions outlined in this dossier are the way many of the empirical studies presented highlight the ongoing importance of social vulnerability and inequalities in examining how novel developments in the life and medical sciences inform social and cultural practices. While contemporary so called neo-liberal transformations in subjectivity and citizenship (Rose and Novas 2005) are acknowledged as relevant in many of the articles the impossibility of excluding an ongoing biopolitics of health is also brought to the fore. There is reference to a range of other social science and anthropological work that extends the boundaries of biosociality as defined by Rabinow. This includes differently constituted notions of biological citizenship as outlined in the work of Petryna in her work in post-communist Ukraine (2002) as well as Fassin’s discussion of ‘bio-legitimacy’ (2009). For many contributors questions of political legitimacy and health care inequities directly inform the scope and limits of how the biological and social are being co-configured in the context of developments in the life and medical sciences within Brazil.

In addition the papers presented here illuminate how in Brazil specific historical processes of social differentiation associated with gender, sexuality, race/ethnicity and class play a role in constituting various biosocialities. Of particular note are recent anthropological studies examining the fraught and complex relationship between developments in population and medical genetics and issues of race and ethnicity in Brazil (Santos & Maio 2004). These studies show how the transnational configuration of genetic ancestry and molecularized categories of population difference are dynamically informed by Brazilian histories of racial classification and discrimination, national and nationalizing discourses celebrating race mixture, as well as contemporary attention to multiculturalism in the realm of health and education (Kent et al. 2014). The articles in this dossier focus on diverse categories of social difference, most prominently gender and sexuality (see Rohden), yet show equal attention to historical and cultural specificity.

Similarly in examining how biomedicine and biomedical technologies are central to the ‘making up’ of groups and individual as well as collective identities, these articles highlight the on-going relevance of long standing political controversies and disputes related to abortion in Brazil (Macedo and Luna), the politics of mental health (Maluf), the relevance of Brazilian health policy towards indigenous peoples (Teixeira & Dias da Silva) as well as the particular modes through which health activism has unfolded in Brazil (Fonseca, Aureliano, and Camargo da Silva).

While genomics and developments in genetic medicine have provided the impetus for many anthropologists examining the dynamic relationship between subjectivities and novel biomedical knowledge and technologies, a much wider range of health arenas and interventions are encompassed under this shifting socio-cultural terrain, as testified by this collection. The paper for instance by Rohden illustrates how recent non-genetic health technologies, namely pharmaceuticals and diagnostic testing, inform and are dynamically informed by gendered cultures of activism and identity. Nevertheless a number of genetic technologies are examined in this special edition of *Vibrant* illuminating aspects that reflect particular socio-cultural issues of relevance in Brazil. While the use of DNA to articulate biogenetic relatedness has been widely explored in diverse cultural arenas beyond Brazil (Rabinow 1999; Finkler 2000) in the articles presented we see how this is both reproduced and questioned by Brazilian adoptees (Allebrandt) and also used in the pursuit of legal repatriation of human rights violations in the historical context of the clinical management of Hansen’s Disease also known as Leprosy (Fonseca). In both cases DNA and genetic testing constitute what Fonseca calls a ‘fragile’ truth subject always to social and cultural mediations within and between kin, health practitioners or scientific researchers or activist organizations and legal processes. The paper by Aureliano sheds further light on how medical genetics is unfolding in the context of ‘rare’ disease in Brazil in an arena where rights to health (and medications) are being increasingly politicized and where moral obligations between kin unfold in ways that are described by Aureliano as constituting a ‘familiarization’ of genetics. DNA, genetic information and technologies far from being totalizing or asocial in their impact are therefore shown in the articles presented here as imbricated with moral and affective meanings, as well as being co-configured within institutionalized settings of the clinic or the judiciary.

The dynamic arena of reproductive technologies has, like genetic medicine and technology, been of intense interest to many anthropologists examining technological interventions on the reproduction of life and the processes of naturalization and de-naturalisation that these practices seem to constitute and bring forth (Franklin 2003, Thompson 2005) While novel techniques such as Human Embryonic Stem Cell research, which now depends upon and should be 'is productive of reproductive interventions such as IVF, would seem to illustrate the extent of being 'after nature' (Strathern, 1992) the instability of the biological and its ongoing ability to signify in both deterministic and non-deterministic ways suggest complex configurations of the natural and the social in these contexts. This is reflected in Luna's study of how questions of human rights have played out in debates about the use of embryonic stem cell research in Brazil. She shows how the fiercely contested question of abortion informs how sociality and personhood of the embryos are brought to bear on ethical and legal decisions relating to the use of and research with stem cells. The novelty of not necessarily being 'after nature' but potentially post-human is explored in the article by Segata. Examining animal-human biosocialities in the context of a diagnosis of depression among pet dogs in Southern Brazil, he shows how a biomedical model of human health is made relevant in relation to animals, including the popular use of psychiatric drugs.

Reflecting the need to account for and attend to the biopolitics *and* biosocialities of health and illness many authors discuss the implications brought about by changing public health policies in Brazil, particularly in a context where the judicialization of health has become a growing and widespread phenomenon (Biehl and Petryna 2011 and 2013). Here the concrete properties and scope of an emerging politics of recognition have come to the fore where the demands of specific rights, especially rights and justice related to health and illness, are playing out in diverse social, public and personal spheres. A critical perspective on issues of citizenship and rights are explored in many of the articles in this special edition, including the works of Fonseca, Maluf, Aureliano, Teixeira/Dias, and Camargo da Silva.

It is important to recognize how political issues are central to understanding a wide field of research in Brazilian Anthropology. As a specific academic tradition, it has a complex relationship with research exploring

questions and processes of nation-building and citizenship precisely because it is a process that anthropology has been central to facilitating as well as researching (Peirano 1991, 1998, 2005). Many Brazilian anthropologists have historically positioned themselves in the public sphere, dealing with many different issues related to the rights of traditional communities (indians; *quilombolas* - black rural communities; peasants, fishing communities) to the rights of women, LGBT communities, but also social demands of health movements and activism; all areas where the Brazilian Anthropological Association has been politically visible and active also. The articles presented here continue therefore a long tradition showing how anthropologists mediate morally polemic topics such as abortion (Naara Luna) or participate in discussions on governmental policy in relation to indigenous peoples and health (Teixeira & Dias da Silva).

To conclude, our aim in bringing to fruition this dossier is that the articles published here will contribute to strengthen the dialogue and the engagement between different anthropologies within and beyond Brazil and facilitate critical discussion and engagement with the continuities and transformations in health, illness, identity and culture.

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Time, DNA and documents in family reckonings

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Abstract

In this paper, drawing on literature from both STS and the anthropology of kinship, we describe a political movement aimed at legal reparation for human rights violations perpetrated by the Brazilian government against children of the compulsorily institutionalized patients of Hansen's disease. We conduct our investigation by exploring the action of intertwining technologies – narrated recollections, written documents, and the DNA test – employed by major actors to “reckon” the family connections at the core of this drama. The notion of technologies helps underline not only the materiality of certain processes, but also the complex temporalities at play. Responding to a challenge proposed by Janet Carsten, our ultimate aim is to show how political events as well as collective institutionalized structures – operating through the mediation of these diverse technologies – produce a particular kind of sociality, interwoven with perceptions of family and community.

Keywords: kinship, temporality, human rights, DNA, Hansen's disease

Resumo

Neste artigo, com inspiração tanto nos estudos da ciência quanto na antropologia do parentesco, descrevemos um movimento político que exige do governo brasileiro reparação legal pela violação dos direitos humanos dos filhos de pessoas compulsoriamente internadas por causa da Hanseníase. Realizamos essa investigação através do exame de três tecnologias interconectadas – narrativas orais, documentos escritos e o teste de DNA – usadas pelos atores principais para “calcular” as conexões familiares no cerne desse

drama. A noção de tecnologias permite destacar não só a materialidade de certos processos, mas também as temporalidades complexas em jogo. Ao responder a um desafio lançado por Janet Carsten, nosso objetivo último é demonstrar como eventos políticos assim como estruturas institucionalizadas coletivas – mediadas por essas diversas tecnologias – produzem um tipo particular de socialidade, enredada em percepções novas de família e comunidade.

Palavras-chave: parentesco, temporalidade, direitos humanos, DNA, Hanseníase

Time, DNA and documents in family reckonings¹

Claudia Fonseca

December, 2012. Around 60 people have made their way in the late afternoon dusk to the neighborhood association of Marituba, a satellite city of Belem de Pará. In this part of Brazil, at the mouth of the Amazon river, the heat is intense. A few women set up a table with refreshments at the back of the room while newcomers mingle, waiting for the meeting to begin. Many people come from nearby, arriving on foot with their children in tow. Others have driven all night to be here, responding to telephone and internet convocations. Their common aim: to hear more about possible reparations for the state's violation of their human rights.

Thanks to tireless political campaigning by the social movement MORHAN (*Movimento pela Reintegração de Atingidos de Hanseníase*²), the older members of the audience – those who were forcibly confined in Brazil's last-century lepers' colonies – have received official apologies from the government as well as financial reparation in the form of a lifetime pension. Since then, efforts have been channeled toward the cause of the patients' sons and daughters – those “orphans of living parents” whose destinies, it is argued, have been permanently stunted by the traumatic experience of forced separation from their mother and/or father. A bill designed to concede financial compensation to this second generation of victims is rumored to be arriving in congress any day now. There is thus an air of anticipation at the meeting, as people seek ammunition to achieve the recognition and benefits they hope the federal government will grant in the very near future.

Today's guest of honor is a geneticist from the Federal University of Rio Grande do Sul. Her supervisor has volunteered the team's services free-of-charge to help prove the genealogical connections necessary for the

¹ Aside from the many colleagues (most of whom are cited in this article) who have somehow contributed to this article, I would like to thank my anonymous reviewers for their invaluable provocations.

² Movement for the Reintegration of those affected by Hansen's disease.

“separated children” to press their claims. The young woman explains in clear detail the test’s basic genetic logic, how the material will be collected (through saliva samples) and who exactly will need it. Those with national ID cards that show the proper names of both mother and father can dispense of her services. Their kinship tie has already been legally established. It is others – those who have no ID, or those who were falsely registered as the biological offspring of their adoptive parents – who will need a test, provided they find a living parent or sibling with whom to match their DNA.

After a few seconds of low murmurs from the audience, a fiftyish gentleman, visibly frustrated, stands up to pose his question: “My father was a patient in the colony for years. My ID shows I’m his son. You mean I won’t get a test?” The geneticist explains with great patience that there is no need. His identity has already been legally confirmed: “No one can take that [identity] away from you”. The man’s consternation appears to mirror that of others in the audience who were also expecting to spit into the plastic vials readied for tests. Spurred on by the intent gaze of those around him, he persists: “My sister and I have driven hours to be here. We know this test is important. How can we be sure that, in a couple of years, documents will be worth anything? I’m thinking that in the future the only valid proof of identification will be the DNA test.”

This scene, as others evoked in this article, are based largely on field research conducted between 2012 and 2014, consisting in the perusal of documental archives, brief ethnographic incursions in two ex-colonies, and interviews with ex-internees and their sons and daughters in the states of Pará and Rio Grande do Sul³. In this initial phase of research, I have worked hand in hand with a team of geneticists from Rio Grande do Sul as well as the social movement, MORHAN, both described in greater detail below.

My original research aim was to explore the “agency” of the DNA test as a prominent actor in a network that links political aims for the reparation of human rights violations with personal subjectivities and family relations. However, inspired by concerns such as those voiced by the man cited above, I found it necessary to make a few adjustments to my plan. The man’s anxiety underlined the fact that things change. Granted, the production

³ Glauca Maricato, a student of postgraduate studies in Anthropology at the Federal University of Rio Grande do Sul (see Maricato 2013, 2014), has been a close collaborator in all phases of this work.

of knowledge about the past affects people's present and future. However, what one considers "proof" of past events may well be reframed by new (and future) technologies. Hence, yet another element was introduced into my analysis: temporality.

The link between politics, time, and family relations has been a theme of anthropologists ever since Evans-Pritchard put the highly malleable Nuer genealogies on our map. Yet, although our Britannic forefather saw kinship as inseparable from political structures, J. Carsten (2007) comments how, in recent times, research has tended to follow two divergent paths. Anthropological analysis of kinship, focused largely on the lived experience of relatedness, has consistently sidestepped the political dimension of these processes. On the other hand, analysts interested in political issues may well focus on memory (for example, of the Argentine dictatorship or the Holocaust), while side-lining the question of kinship and family relations. Searching for a point of convergence between these two approaches, Carsten proposes a sort of analysis that would focus on the way personal and family memories interact with large-scale political events as well as collective institutionalized structures to produce kinship as "a particular kind of sociality in which certain forms of temporality and memory-making, and certain dispositions toward the past, present, and future are made possible" (*Ibid* 2007: 5). I propose to embrace this approach, however, with one minor reservation.

The notion of memory, notwithstanding its recent comeback among anthropologists is an unwieldy analytical tool. As Berliner (2005: 201) reminds us, many scholarly articles use "memory" to stand in for cultural continuity, society's ability to reproduce itself, a "past" transmitted and stored (like in a computer without meaning remembering)". I would identify, rather, with another strand of scholarship focused on the phenomenological dynamics of lived recollections involving the eminently intersubjective processes of registering, retaining and revisiting experiences of the past. The inspiring articles in Carsten's *Ghosts of Memory* (2007) contribute greatly to the sort of de-objectivation of memory (as well as kinship) that interests us. Yet, although the ethnographies are full of rich description of mnemonic devices (photos, tapestries) as well as institutional presences that encourage or inhibit the transmission of knowledge, remembrance still appears as an "internal" process centered in the subject (whether an individual, a personage or a psychological self).

The question voiced by the man at the meeting urges us to follow a slightly different approach. His concern underlines the fact that personal identity is tied up with institutional forms of recognition: “valid proof” emerges as part of a system of concrete technologies that mediate (measure and calculate) what people know and feel. In this sense, people’s recollections, momentarily fixed through photos, letters or oral narratives, are one technological device, alongside others – written records, legal documents, and the DNA exam – that co-produce ways of reckoning personal identity and family ties. Here, neither memory nor the subject can be taken as an a-priori given, remembrance is seen as an action that is constantly “overtaken” by various agencies, de-centering the possibility of any one actor (Jasanoff 2004, Latour 2005). It is with these concerns in mind that, in this article, I speak of reckoning instead of memory.

“Reckoning”, a term found in anthropological analyses on time, ethnic identity, and family belonging, has proven to be highly useful for operationalizing my research concerns. As a gerund, it draws attention to an ongoing, eternally-incomplete process. As a substantive, it is easily pluralized, underlining multiple and heterogeneous modes characterized by possible power asymmetries (Gingrich, Ochs, and Swedlund 2002). What makes the term particularly interesting, however, is the way, through multiple and often ambiguous meanings (calculation, accounting, retribution), it combines instrumental with moral connotations.

On the one hand, we learn how calculations are seldom void of political and moral implications. Strong and Van Winkle (1996), for example, show how efforts to “reckon” an individual’s quantum of Indian blood in the context of late twentieth century North America involve the tense interplay between government policies, tribal bids for collective rights and individual strategies. On the other hand, in scholarly papers on the atrocities of war and dictatorships (Stern 2010, Atencio 2014), we are reminded how “reckoning” also evokes a sort of collective coming to terms with facts people are not anxious to remember⁴. Diane Nelson (2010) explores the various facets of “reckoning” in her provocative analysis on the aftermath of war in Guatemala. Her description of how the dead are counted weaves into a depiction of how

4 It is used, for example, to criticize Amnesty Laws that decree what is deemed by many a premature closure to debates on state-perpetrated atrocities.

compensations are calculated, showing the ironies of the diverse forms of reckoning that converge toward the production of a sort of final judgment on the morally ambiguous events of the past. “Reckoning”, in this case, is pregnant with the promise of a biblical sort of “Day of Reckoning” – truth uniting with virtue to guarantee a just retribution for all.

As we shall see in the case of the Brazilians affected by Hansen’s disease on whom we focus, it is this combination of rough materiality with subtle morality that makes the term “reckoning” soanalytically rich.

Politics and family in the social studies of science

Curiously, I found in science studiesa divide somewhat similar to that described by Carsten – between the political uses of DNA and the consequences of this technology for personal subjetivities and family relations. On the one hand, there has been no little academic discussion on the use of DNA as a technology of government for the legal identification of individuals in paternity suits (Machado and Silva 2012, Rothstein et al. 2005, Fonseca 2014) or criminal investigations (Machado and Moniz 2014, Fonseca 2012). Furthermore, a modest number of studies exist on the uses of DNA in collective or human rights claims. Hopeful speculation around musteringproof of genetic ancestry to validate various minority rights claims (affirmative action in the areas of education, employment, and territorial rights) may have had, as yet, little relevance in the courts (Kent 2011). [In Brazil, it has served more often than not to argue against such claims(Santos and Maio 2005)]. Nonetheless, working with the victims of mass killings, forensic anthropologists have gained considerable reputation in the fight for recognition of human rights violations in Chile, Colombia, and Guatemala, among other sites (see Penchaszadeh 2012). In these various studies, although the political implications of DNA technologies are made quite clear, there has been little effort to investigate how these technologies may have reconfigured notions of time, personal identity and family relations among the people concerned. (The outstanding exception to this rule – the use of DNA tests to “restitute the stolen identity” of children kidnapped during the military dictatorship – will be addressed further on.)

On the other hand, medical anthropologists have done a brilliant job of analyzing the repercussions of genetic medicine for personal and family

identity while touching only lightly on political elements. Finkler (2005), for example, in her study on North Americans concerned with a form of hereditary colon cancer in their families, speaks of “the ideology of genetic inheritance”. According to this author, the development of information on gene-connected disease has led many people not only to delve more carefully into their genealogical past (asking “where did I get this gene?”), but also to reconfigure their perception of significant others (“who else has it?”). At the same time, the fear of passing on mortal ailments to future generations has made people think hard about screening techniques and procreative choices (“what legacy do I wish to leave?”). Finkler thus argues convincingly that DNA technology implies a sort of time-space compression that may “stand in for the past and forecast the future”, serving as “proxy for memory”, and leading to new forms of sociability:

Ironically, when confronted by affliction the solitary, independent, and autonomous individual of the 21st century is becoming unified with people with whom he or she may only share a social and amoral DNA. The individual can enjoy kinship and family relations, and develop new curiosities about past ancestors and unknown relatives with only limited obligation, responsibility or sociability (Finkler 2005: 1069)

Most critical observers in the field of STS would today agree that there are no “amoral” technologies. As S. Jasanoff (2004) so aptly insists, scientific and technological artifacts alter our way of looking at the world, producing effects that are at the same time moral, metaphysical, political and symbolic. Sahra Gibbon (2013), in her discussion of genetic markers for possible breast cancer in southern Brazil, comments how, in certain scientific publications, the new technology appears to exert a “telescoping effect” on perceptions of past and future. Tuned into a global agenda sensitive to issues of race and genomic studies, researchers present the results of their clinical studies amidst speculations on the “European ancestry” and likelihood of “Caucasian haplotypes” among certain present-day populations. Gibbon, however, goes on to demonstrate through interviews with medical researchers and patients that such perceptions are neither linear nor homogeneous. In her analysis, it is the mediating influences of particular regimes of living that help explain what, in practice, prove to be highly “mutable” and “plastic” ways of interpreting the genetic information provided by globalized technologies.

A recent article on “Indigenous DNA” (Kowal et al. 2013), discussing the cryopreservation of body tissues – the freezing and thawing of blood samples used in scientific research–, carries still further the analysis of mediating influences that affect the impact of genetic knowledge. Far from treating DNA as some sort of a temporal entity, the authors argue that the meaning of this “co-produced” artifact mutates over time. In their proposal to demonstrate a “temporalized form of interrogating dynamic negotiations between technical and social orders” (p.471), they evoke the various temporalities involved in the biovalue of blood samples held in the scientist’s laboratory. Over the decades, the political attitudes of the indigenous groups engaged in guarding or releasing these samples have changed. Furthermore, many of the scientists who established the original accords concerning the gathering and use of blood samples, having grown old, have left or are about to leave the research scene. What happens when a new generation of researchers takes control of the biobanks? Finally, the potential uses of the material have been multiplied by recent technological developments. The “biosocial mutation” implied in the conjugation of these different temporalities, the authors suggest, decries simplified dichotomies of modern/pre (or post)modern, pro-science/anti-science, North/South or us/them.

The reflections of Kowal et al. are, of course, directed toward a purpose different from ours. Theirs is a reflexive effort to bring the ethics of science and scientists under the analytical microscope. Nonetheless, transpositions to our theme are tempting. Evoking the temporality of DNA, the authors sweep aside presumptions of “hardrock” scientific fact. Placing the emphasis on various forms of “scientific sorcery”– ie., the network necessary to assure a blood sample’s scientific usefulness –, they jostle DNA off its pedestal, putting it alongside other technologies (in our case, technologies of identification). In the process, they have prodded us to examine the “mutations” involved in these other technologies– for example – written legal documents. Where as Kowal et al., speak of “imperial compulsions” that tend to colonize “subjugated knowledges”, we will be targeting legal state bureaucracy that competes with lived memories. In lieu of biologists, given to “technocratic optimism” and the belief in a clearly defined past, we will be thinking of state and legal operators who rely wholeheartedly on written documentation. Instead of cryopreserved DNA, thawed and mined for new

purposes, we consider written artifacts from the past – sometimes lost, often altered – that are reenacted on the contemporary human rights scene.

Carrying forward this sort of feedback from STS into the analysis of other thematic domains, we reconsider in this article certain of Finkler’s assertions on DNA and kinship. To allege that genetics may promote an “asocial” reckoning of kin with time-space compression is to presume that previous technologies (documents? memory?) were eminently “social” and with clear lineal temporalities. When put to the test of a comparative analysis, does such an opposition hold? With heightened awareness of the dynamic and interdependent nature of the various technologies of identification, we hope to raise new ways of looking at the reconfigurations caused by genetic tests geared to verify family belonging.

The timely construction of a human rights cause

The high point of the meeting in Maritubawas to be the announcement of DNA test results that would confirm or deny the sibling relation between two women in the community. Their story – similar to that of many others undergoing tests in Acre, Amazonia, Minas Gerais, São Paulo, and throughout Brazil – demonstrates the combined effort of a number of important actors: patient activists, politicians, academic researchers and geneticists. To understand the role of each, let us first look more closely at the two women being tested in Marituba.

The younger sister, Iara⁵, was born in the Colony of Marituba where both parents were in treatment. Not more than a few hours old, she was duly registered by attending nurses in the name of her genitors and sent to live in a *preventório* – a specialized orphanage where she would grow up with the sons and daughters of other patients interned in the colony⁶. Neusa, the older sister, had been born years before Hansen’s disease affected her mother’s life. Fruit of a brief romance between two adolescents, her birth had taken place in the modest, rural abode of her maternal grandparents and she was “given away” soon afterwards to be raised by her mother’s aunt and uncle. Although

5 I have used pseudonyms in this article in the paragraphs relating to ethnographic observation.

6 In a 1944 report, Brazilian philanthropist, Eunice Weaver, proudly announces the existence of 22 of these “modern homes” for the healthy children of victims of leprosy, spread through 18 states and housing at the time nearly 2,500 youngsters (Weaver 1943).

Neusa had never been legally adopted, all her identity papers, from the birth certificate on, registered this aunt and uncle as her biological parents.

Both sisters had lived intermittently in other towns, and even other states... But, tied in through a similar network of kin, both were once again settled in the close-knit neighborhood of Marituba at the time of the DNA test. Now, as they prepared for the anticipated benefits to be allotted the “separated children”, the first-born, hoping to legally prove a biological connection with her mother – long since deceased –, needed her younger sibling’s cooperation. Since Iara had documents attesting to her status as daughter of a compulsorily interned patient of Hansen’s disease, they reasoned, it would suffice for Neusa to prove, through DNA testing, that she was indeed the younger woman’s sibling.

Notwithstanding the homey, almost humdrum, aspect of the scene, the ritual devolution of the DNA test results was fruit of several decades of political activity and the coalescing of several important allies. The key group of people responsible for the scene we witnessed in Marituba consists of activists and volunteers from the social movement, MORHAN. Since its founding in the 80s, MORHAN has shown great ability in the navigation of choppy political seas in direction of the movement’s goals. Initiated by ex-patients of Hansen’s disease who had spent the better part of their lives in leper colonies, the movement began during the “democratic reopening” of the early 1980s. Its leaders quickly forged affinities with other of the decade’s many grass-roots associations, establishing national headquarters in São Bernardo dos Campos – heart of the modern labor union movement – where they would conquer a life-long ally in the person of Luis Ignácio da Silva (the nation’s future president, known as Lula). Weathering a number of challenges – from the death of key figures and change in leadership to a more conservative political climate during the 90s, and, recently, the professionalization of NGOs – the movement has managed to survive and prosper while maintaining its roots solidly in the overwhelmingly working-class population of those whose lives have been “affected” by leprosy. Elected president of Brazil in 2002, Lula put human rights and reparation for past violations high on his administration’s agenda. Reflecting a timely international trend of humanitarianism particularly sensitive to images of suffering, the new mood brought diverse sorts of “victims” into the limelight (Fassin 2012, Gatti 2011). Here, alongside a wide array of categories with a legitimate cause

– *quilombolas*⁷, indigenous groups, people with disabilities, battered women, etc. – MORHAN quickly found a leading role.

Run almost entirely by unremunerated volunteers, the movement today occupies an important place in national and international forums on health issues, promoting measures to combat the still alarmingly high incidence of Hansen’s disease in Brazil⁸. Evidence of the public health campaigns MORHAN wages for the eradication of Hansen’s disease and the combat against all forms of discrimination can be found on the movement’s internet site and blogs. At the same time, the movement, working through regional and local chapters throughout the country, aims at promoting the quality of life for patients and ex-patients of Hansen’s disease. At the moment, efforts are concentrated on the *filhos* – the “separated children” who were deprived of their parents because of state policies. In periodic meetings held in the neighborhood of former colonies, people summoned through social networks by phone and internet gather to hear reports on the progress of their cause, to fill out preliminary forms, and to perform other varied tasks deemed necessary to lay claim to hoped-for benefits. With powerful allies such as Chief Minister Gilberto Carvalho and President Dilma Rouseff who have publicly manifested their support, the *filhos*’ optimism is understandable.

Not least among its allies, MORHAN has inspired or collaborated with a good number of academic scholars such as myself (e.g., Maciel et al. 2003, Mendonça 2009, Monteiro 2003, Serres 2009). Together with journalists who have produced in recent years a formidable array of videos and articles for mass consumption, these researchers have played an important role in reconfiguring the image of the colonies – from a model Utopia to a nightmarish Holocaust –, and that of the colonies’ interns – from lucky recipients of the government’s humanitarian benevolence to victims of state terrorism⁹.

As the by now well-established narrative goes, it is in these hospital-colonies, built for the most part in isolated rural areas that, starting in the early 1940s and continuing on for nearly half a century, the Brazilian hygienic services confined people diagnosed with leprosy. In the early years, the “sick”

7 Descendants of Afro-Brazilian slaves.

8 With over 30.000 new cases diagnosed every year, Brazil appears in epidemiological statistics behind only India in number and proportion of cases.

9 We have been inspired here in the analyses of Alexander (2002) and Gatti (2011) on the reconfiguration of the massacre of Jewish people during World War II – from “war atrocity” to “crime against humanity”.

of all ages and classes would be brought in whether they wanted such treatment or not. There are many poignant stories about mothers torn from their children by the “sanitary police”, about youngsters “abducted” at school and carried off to the colonies (Maranhão 2005). As time went on, internment policies became more flexible, but those who remained in the institution – sometimes for decades – were submitted to draconian restrictions.

On paper, the project was ideal. There was to be a semblance of ordinary life in these little cities. Designed to be self-sufficient, they housed from one to three thousand people. Patients would be put to work on the premises – the women doing laundry, cleaning or working in the kitchen, the men producing rice, beans and other staple products in the surrounding fields, or building and repairing the colony’s many pavilions. The more specialized patients might help out at the hospital; others would take on administrative responsibilities or man the community radio. Some might receive a small salary, paid with special coins minted exclusively for institutional life.

In fact, financial and administrative support was never steady. Ex-patients consistently describe periods in which food grew scarce and medical care all but nonexistent, likening their experience to that of prisoners or war confined in a concentration camp. And, although patients eventually conquered the right to establish marital unions, they were denied any possibility of a standard family life. In the name of the child’s welfare, infants were taken from their mothers within hours of birth and carried off to the closest *preventório*. The tearful stories describing these forced separations of mothers from their new-born infants are legion. According to institutional policies, communication between parents and children was kept to a minimum, restricted at best to a monthly visit during which no physical contact would be tolerated.

Not all the *filhos* grew up in an orphanage. Many, especially those born before their mother or father’s internment (as in Neusa’s case) were dispersed in the homes of distant relatives or family friends. Some passed only briefly through the orphanage before being given in legal adoption, with or without their parents’ consent. Many of the institutionalized youngsters ended up being reintegrated into their original families when their parents – either pronounced cured or abruptly expelled by a change in health administration policies – were released from the colony. But the youngsters continued to

bear the psychic and physical scars of years of institutionalization in far-from-ideal circumstances.

Compounding an already grievous situation, some youngsters have lost trace of their original identity. Because of fraud, incompetence or sheer bureaucratic indifference, they have no legal proof of what they have lived through. And that is where yet a third group of allies of fundamental importance for the Marituba meeting comes into the picture: the geneticists who offered the possibility of a DNA test.

The coordinator of INAGEMP (the National Institute of Science and Technology in Medical Population Genetics) at the Federal University of Rio Grande do Sul has long been a volunteer collaborator of MORHAN's. She played a key role in articulating a previous project on the history of leprosy colonies in Brazil (Schüler-Faccini 2004). In 2011, as the *filhos* movement gained steam, she and her team proposed a new sort of partnership with MORHAN through the Project *Reencontro* (Reencounter). This time, with research funds provided by the Brazilian Ministry of Science and Technology (CNPq), the idea is to use DNA in the service of human rights, validating the identity of those *filhos* who, because of faulty or missing documentation, have been unable to demonstrate their family links. Organizers estimate that some 1000 of the 30,000 *filhos* will need this sort of validation.

There can be no doubt that the use of DNA analyses in the Reencounter Project draws inspiration from the experience of the Argentine *Abuelas de la Plaza de Mayo* (Abuelas 2008, Regueiro 2010). Just as DNA was used to reconstitute the "suppressed identity" of children whose parents were murdered by the military dictatorship, so it is now being used to reaffirm the biological identity of Brazilians whose parents, sufferers of Hansen's disease, were sequestered by the state sanitary police. The link between the two movements is made explicit by the project coordinator in public talks to lay audiences as well as in academic articles (Penchaszadeh and Schüler-Faccini 2014). Yet, contrary to the Argentine case, the MORHAN project is not geared to press criminal charges against any particular individual. The "accused" here is the state itself, summoned to make reparation for the violence it has perpetrated in the past. All parties being tested have come forth voluntarily. There is no legal injunction obliging them to submit to the process. Here, the test is intended to help people press legal claim as victims of a crime against their basic human rights.

The somewhat blurred “paper trails” that document the past

The use of DNA entered tardily into this movement. The first generation had relied entirely on documentary evidence to qualify for benefits as victims of compulsory segregation. Between the passing of the 2007 law and January of 2014, nearly 12,000 dossiers had arrived in Brasilia where a special Interministerial Commission of specialists (including researchers, medical doctors, state-appointed administrators, and a representative of MORHAN), organized by the Special Secretary of Human Rights (SSHR), would pore over documents to decide which of the candidates was legally entitled to receive the lifetime pension.

Theoretically, the process should have been simple. A candidate had but to prove that he or she had been committed to institutionalization in a certain place (one of the leprosy colonies), and at a certain time (during the years of compulsory segregation). In fact, it took a lot of work to clarify who had lived through what experience. Policies varied from state to state. In some regions, compulsory internment appears to have loosened up early on – in the fifties – soon after specialists from the World Leprosy Conferences declared that, as a measure to combat epidemics of leprosy, segregation was useless. In other regions, confinement was considered to have continued into the 1980s, long after the 1976 law decreeing its demise. Also, there was some discussion about the type of leprosy each patient was registered to have had, since not all types had called for compulsory segregation (Maricato 2014).

At any rate, written documents to prove the where and when of experiences forty years old were not necessarily easy to come by, much less decipher¹⁰. The federal *General Law of Archives*, making administrations responsible for the records they keep, is a recent element on the scene – passed in 1991. Most colonies had neither the staff nor the know-how to care for archives. If, by some miracle, the patient’s file had survived decades of administrative indifference, the printed forms were often incomplete, and full of ambiguities. In some dossiers, ex-patients were able to produce nothing more than a signed statement from a present-day administrator responsible for the region’s out-patient clinic stating that the petitioner had been interned in the local colony at a certain date.

10 See Scott et al. (2002), Herzfeld (1992, 2005) and Peirano (2009) for some of the vast discussions about written documentation as part of the technologies of governance.

Another sort of problem the Commission had to face concerned the identity of the petitioner – if he or she was indeed the person referred to in the historical information provided by the colony administrators. There exists a national identity card in Brazil, containing a person’s thumbprint, photo, and date of birth, as well as the name of both parents. But, the RG, as it is known, is generally established on the basis of a person’s birth certificate that includes neither photo nor fingerprints. Especially in the middle decades of the last century, birth certificates were often not established until years after the child’s birth, making it nearly impossible for the registrar’s office to demand any corroborating evidence aside from the declarant’s say-so. Furthermore, the system of national ID documents issued by the different states lacks federal articulation. Hence, a person may have many different IDs. It is therefore not surprising that, in the screening of demands, experts called in from the office of Federal Social Security were able to pick up a number of apparently deliberate frauds: the same person who, under different identities, had submitted plural demands for financial reparation; people who had assumed the identity of a deceased internee, etc. However, it was much more common to encounter what appeared to be administrative errors – names that were slightly altered from one document to the next; parentage or dates of birth that were different in hospital records from those on the ID card, etc. In such cases, the historians and ex-administrators of the colonies who worked on the Commission were sorely needed to interpret the spotty data provided in the dossiers.

Already challenging for the first generation of activists (the colonies’ internees), documental complications are compounded for the generation of *filhos*. In ideal cases, the parents are still alive and have already gone through procedures proving they were institutionalized for Hansen’s disease during the critical period of repression. The children, having been declared at birth as their parents’ biological offspring, and able to prove this filiation by showing a correct ID, are told they will have no problem in laying claim to benefits. But in most cases the parents died before the 2007 law was passed, and the children will have to do their own detective work, going after the dusty documents they hope have been kept somewhere in the colony’s files. With luck, they may find their parent’s admittance form, albeit with possibly disturbing information. Although most these forms registered the new patients in reasonable or good mental and physical condition, their

“intellectual level” is frequently marked “null” (“knows how to read and write” is yet another item on the form), and the category “indigent?” is more often marked yes than no. Written by hand on the lines for miscellaneous commentaries, there may be a mention of how many children the patient had, but seldom anything else – no mention of age or sex, much less name of the offspring. To prove filiation, the *filho separado* must therefore show up with a proper birth certificate – a feat easier said than done when referring to the mid-1900s, a time when Brazil was largely rural, most children were born at home and many registered only years later.

Child circulation between the homes of parents, grandparents, god-parents, neighbors, and acquaintances – already a common child-rearing practice in Brazil’s working class populations (Fonseca 1995) – was accentuated in the case of *filhos*. Here, disease only added to a long list of difficulties (poverty, migrations, death and conjugal instability) that urged toward a pooling of resources. Most of the foster parents, if not illiterate, lacked familiarity with the state bureaucracy, and so – when called upon (at a school or hospital) to produce the child’s documents – they would simply follow the most expedient path, taking out the child’s birth certificate as though they were the genitors. This practice, although technically illegal, was extremely common and, in most cases, appeared satisfactory for all concerned. Nonetheless, as time passed – the child matured or the circumstances changed – the “false” filiation could present problems.

Neusa’s is a case in point. The woman admits that when she was a child circulating among the households of different relatives, her faulty birth certificate seemed to be of little importance. Practically all she knew about her birthmother was that the woman had been confined in a colony because of Hansen’s disease. But, with the pending law of reparation for “separated children”, suddenly the accuracy of her birth register took on new importance. The problem now was: having been born at home, how was she to prove her “true” identity? Witnesses of her birth, even if she could locate them, would not carry sufficient weight to alter her legally established birth certificate. A quick DNA test, such as those commonly used today in court services to settle paternity disputes, was excluded since both parents were deceased. Neusa’s luck was to have a living sister who had been correctly registered in the name of a mother whose confinement in the colony had been legally demonstrated. Without Iara’s proper documentary records, proof of their

sisterhood would have been useless. Here, DNA is not a substitute but rather a complement to documentation.

There are instances in which *filhos* consider they may altogether dispense with worries about identifying their parents. For, example, Edmundo – leader of one regional chapter of MORHAN – explains that, although he has both parents’ names on his identity card, this fact does not necessarily help him. Since his parents died before the 2007 law, they never put in for benefits and he can’t be sure they’d have found the documental proof to qualify. Nonetheless, he has no doubt about legal proof of his rights, “My birth certificate states that I was born in the maternity hospital of the colony during the years of compulsory segregation. And that’s enough.” Ironically, it is those *filhos* born in the colony’s maternity ward who have the best chance of proving their parental heritage as, in most cases, administrative staff would take care to assure proper birth registration either at the hospital or at the closest office of registry.

Since the *preventórios* were reserved exclusively for the children of the colonies’ internees, a *filho* might also prove his or her right to reparation by demonstrating residence during some time in childhood at such an orphanage. However, if medical archives from the colonies are far from ideal, written documentation from these orphanages is even more problematic. Many of these institutions changed hands over the years, alternating between different religious orders of the Catholic church. By the early 1980s, with the end of compulsory segregation, the institutions were being channeled toward other populations: the homeless, the elderly, etc. During the following decade, with the anti-manicomial movement going strong¹¹, and the general condemnation of large-scale orphanages written into the 1990 Children’s Code, most buildings that had housed the *filhos* were demolished. Hence, people trying to chase down the “paper trail” to prove their status commonly report that they have not been able to find any trace of the institution’s records, much less an administrator legally responsible for such archives. Some searchers, their suspicions peaked by media reports on scandals relating to Catholic orphanages of the past, and projecting the church’s fear of financial liability, will mutter that the “loss” of documents

¹¹ We refer here to the movement that spread from Europe and North America toward other parts of the world during the 60s and 70s, to de-institutionalize mental patients and other patients living in asylums.

is deliberate: “They say there was a fire, but, as far as I’m concerned, the fire didn’t start by accident.”

We see then that documents – easily scattered or destroyed – may be hard to come by, fragile, and even perishable. And when they materialize, they may be subject to suspicion of fraud. In fact, outside the technological network necessary for the standardization, preservation and classification of accessible documents, written registers are of little worth. Nonetheless, once considered “in order” – with certificates properly rubber-stamped – they take on the air of long-lasting legitimacy. The geneticist quoted at the Marituba meeting appears firm in her assurance that once a person’s identity (and filiation) has been legally established, “No one can take that identity from you”.

And yet, throughout the Western world, DNA technology has recently provoked the “mutation” of a number of legal statuses previously considered irrevocable. Dolgin (2009), for example, speaks of ways in which, in U.S. courts, genetics have “unhinged tradition” by dethroning the “marital presumption” in paternity cases¹². In France, “irrevocable” adoptions have likewise been reverted in the name of a biological father’s right to lay claim to a child given up by its birthmother (Fonseca 2009). Paraphrasing Kowal et al., we would suggest that these cases provide examples of how the legal order reworks the past and future in non lineal ways in keeping with politically charged presents (2013: 472).

There remains, however, the question: Just how much do these changes in identification technology speak of (or mirror) actual social relationships? By drawing closer, in the next item, to the subjects in question, we hope to outline some points that might provide an answer.

Recollections: the importance of support technologies

As 50-year-old Tamara guides me through her neighborhood streets, waving to people on their front stoops, she comments, “We’re all family around here”. In fact, it would seem that the vast majority of the *filhos* from any one region know each other well. For example, the meeting described above took place in an area that previously belonged to the “Colônia de Marituba”. Nearly all those who live in the surrounding avenues belong to

¹² See Fonseca (in press) for changes in a similar direction in Brazilian law and jurisprudence.

one or another of the extended kin groups descended from the colony's previous patients. Most of them also have relatives still living in the *Colônia do Prata*, an even older institution, founded in an isolated rural area around 100 Km away. Although some have managed to find jobs in local commerce or working as mechanics or cleaning ladies in Belem, many earn their living by helping out at the single institutional remnant of the old colony – a residential home and out-patient clinic dedicated to people who suffer the sequels of Hansen's disease. In the small, semi-attached apartments inhabited almost entirely by elderly ex-interns, a younger generation is employed to care for their "aunts" and "uncles" – people who carry remembrances of certain genealogical connections.

For people still in the neighborhood, it is narrated recollections – especially those of the community's older members – that are the most reliable sources of information on the past. Through the retelling of their own lived experiences, midwives, hospital employees or simply neighbors and relatives of the older generation are key to filling in the blanks left by faulty birth certificates, unknown paternity or informal adoption. Even those who no longer live in the area may find the recollections of a particular bureaucrat more helpful than official records. Alba, a young woman adopted in infancy by a middle-class family in Belém had never thought to search for her birth family. But, upon checking her birth records in order to replace a lost ID card, she was taken by surprise when the public clerk, working in a town just outside the colony in which she was born, exclaimed, "My! So you're the daughter of X and Y. I'm the one who married your parents." And thus, soon after, Alba's reencounter with her birth family – welcome although not sought after – took place.

Alba's story speaks of one sort of "support technology" that can activate narratives and produce or change feelings of family belonging – tidbits of knowledge provided by eye witnesses. But in many cases, death and geographical distance creates obstacles to the mining of this sort of information. In the following case, we see how it took years – and the proliferation of modern communication technologies (transportation, phones, etc.) for vague memories to actually take effect.

Marília, a young mother-of-three living in Belém, is one of the "separated children" who, despite never having suffered personally from Hansen's, has incorporated the disease as integral part of her family saga. As she tells the

story, her mother was only nine years old, living in a rural area of Macapá, when the family was told she had leprosy. At first, they built a separate hut where she was to live well removed from the others, but her big brother – feeling sorry for her – decided to take her to the city where she might hope for treatment. Thus, he placed her in domestic service in the city of Belém, without mentioning to the employers anything about his sister’s affliction. Five years later, the disease could no longer be hidden, and when the employers found out, they took the 15-year-old girl straight away to the Colony of Prata. Soon after, the girl’s mother, having learned of her whereabouts, traveled to the colony to try and take her daughter home, “but the doctors explained that they mustn’t live together – because of the contagion”. And so, the little girl matured, married, had children, grew old and died – all in the colony – without ever again seeing anyone from her original family.

Last summer, Marília goes on to say, she had taken her kids to spend a couple of days at her (paternal) uncle’s house in the rural village built around the remains of “Prata”;

...and, out there in front of the church, I saw this couple I didn’t recognize – odd, because everyone around here knows one another. They were taking pictures. I thought it was one of you [reporters and researchers who come through]. The fellow was asking everyone about a Dona Sebastiana, but no one could figure out who he was talking about. Finally someone remembered – “Do you mean Dona Babá? It seems her name was Sebastiana. Maybe you should talk to Marília”. So he came over and talked to me. I said, “Yeah. Sebastiana – that was my mother’s name”. And, still sort of puzzled, I answered his questions: yes, she had family in Amapá and, yes, she had three daughters’. That’s when he started to cry. He took out his cell phone and I heard him say, “Ma. I’ve found them. I’ve found Auntie’s family”.

For the narrator of this tale, it is absolutely logical that her cousin’s mother had been trying for years to find something out about a beloved little sister sent away decades before. The importance of blood relations has been brought home to Marília by growing up around her paternal relatives – a veritable clan. Fourteen of her father’s sixteen siblings had had “this disease”, and most either lived in or were somehow connected to the colony. Some of her uncles were able to hold regular jobs at the city docks, others stayed in the colony, occupying influential slots reserved to interns – such as sheriff.

Having spent much of her childhood with a foster mother who lived close by and brought her on regular visits to see her parents, Marília maintained a strong sense of family. Today, she keeps in touch with this vast web of kin through facebook where, among snapshots of herself and her daughters, she publishes the visual registers of family events crowded with cousins on her paternal side. And yet, as the young woman reminds me, she had always been curious about her mother's relatives. Her opinion that "I don't look like anyone in my father's family" left interrogation marks that would only be voiced (and answered) after she had reunited with her maternal kin.

Marília's mother, interned during the sixties, obviously did not have the benefit of the internet. For that matter, she probably didn't have any of the other material supports of identification. As we said above, many if not most people did not have a birth certificate – principle identity document at the time – until far into their adult years. Photos were practically non-existent. Occasionally, I would see, hanging on a living-room wall, the faded black-and-white posed portrait of forbearers – for example, a couple on their wedding day, their simple garb and unsmiling faces portraying the solemn esthetic of the time. But even in the unlikely event that Marília's mother had managed to find and keep treasures such as a photo – or even her parents' proper names – it would probably not have been much help. The woman had no means (money or maps) to travel, phones were practically inexistent, and, in the case of this largely illiterate population, addresses irrelevant.

I heard of only one instance in which contact with a long lost relative was reestablished by letter – a contact initiated by the relative who had been legally adopted in Germany. After having tracked down her birth mother through legal records at the court house, the adoptee wrote her a long letter, addressed to and duly delivered by the local social services. However, as the adoptee's sister tells me, no one in the family remembers much about that – whether the letter came in German or Portuguese, what the German sister's address was, etc. Their mother has long since died, and the letter appears to have been lost when the family moved house. The failure of the German adoptee to reactivate ties with her Brazilian relatives suggests that a blood relation is not enough to "belong" to a family. It would appear that, here, for "family reckonings" to be of consequence, they must include more than the memory and recognition of biological ties.

Reckoning kinship, narrating the past

Recollections, as we see in Marília's story, help to fill in the dots, placing individuals within what they perceive as the given structure of their blood kin. They also rekindle notions of "practical" or "performative" kin – i.e., family relations created through shared experience. Here, once again we invoke Carsten's work which – building on the insights of David Schneider, perspectives in feminist anthropology, and practice theory – underlines the creativity of non-procreative experiences of relatedness constructed through everyday acts such as co-residence, commensality, cultivating the same fields, etc. These practices of participation, revealed through ethnographic particularities in specific contexts, are innumerable. However, they have in common the idea that relatedness is under constant construction. It is the cumulative result of the hard work involved in making and maintaining relations (Carsten 2000: 26).

Lambek (2007), exploring the mutuality of memory and kinship, points to the notion of "care" as a way to understand the "deep temporality" of this hard work: "Caring is the form of remembering generally characteristic of the ethos and practice of kinship everywhere" (p. 220). Indeed, in our ethnographic explorations, caring about and caring for one another proved to be crucial for determining who counted as an intimate relation. However, we insist: acts and experiences of care become relevant through explicit narrative references. Narrations of the past are, in this sense, reckonings of kinship. The feeling of family is nurtured by tales told and retold (Van Vleet 2008).

As I chatted with a group of *filhos*, seated around a kitchen table in the Colony of Prata, I was amazed at the endless number of stories they could weave collectively together. The sentiment of relatedness seemed to be fueled not only by the shared experience of people from a close-knit community, but also by mutual recognition of how they had suffered under the harsh conditions of institutionalization. Some of the *filhos* are reputed to bear the mark of the orphanage in their very bodies, in the shape of their "pot-cover" (*tampa de panela*) heads. (Supposedly, to facilitate care, babies were doped and left sleeping on their bellies for so long that their heads took on the flatness of the bedding.) However, relatedness is most evident in remembrance of specific acts of caring for one another.

Although most of the “separated children” had siblings in the same institution, their recollections appear to concern other children – those who were closest in age, worked in the fields together, or suffered at the hands of the same caretakers. During our chats, they would summon one another to confirm their stories: “Remember how mad the nuns got, how they punished us, when we jumped the wall to pick tangerines?”, “Remember how I took care of you that time you broke your arm?”, etc. Closeness to those of the same age group appears to be heightened by the feeling many *filhos* share of having been abandoned by their parents.

There were patients in the colonies who fought hard to maintain contact with their institutionalized offspring – defying restrictions and freighting their own collective transportation in order to visit “every second Sunday of the month”. Marília recalls how she managed to “escape” the orphanage when she was five or six years old thanks to this collective effort. “It was the father of another girl who saw what was happening, but when it came visiting day, there, *everyone was father and mother.*” The visiting father reported to Marília’s parents that she appeared doped – and that they should get her out before she became feeble-minded like so many of the other institutionalized children. And so the six-year-old left the orphanage to live with a friend of her parents.

However, many of the youngsters went years without any contact with their mother or father. Some say that, of the patients interned in the colony, only those without skin lesions were allowed to visit “so as not to frighten the children”. Others claim that parents had to “prove negative” – i.e., be pronounced cured – before they were allowed near the orphanage. One way or the other, the adults were normally forbidden to touch their children – explaining the repeated reference in people’s narratives to the low brick wall (or, depending on the colony, glass pane) that kept the two generations physically separate during visits. It is not surprising that, together with sickness and penury, the frustrating circumstances of visiting day caused many parents to desist from the effort.

And so, when years later, children were summarily reintegrated into their families (either because they had grown to majority or – as in the case of the younger *filhos* – the orphanage had shut down), many parents as well as children had the impression they were being condemned to live with complete strangers. The many bizarre coming-home stories reflect yet another

experience that the “separated children” have in common. To illustrate, let us come back to Edmundo. During one of our interviews in his comfortable brick house, I expressed admiration of his home. “Built by my dad”, he told me, “but we never lived here together”:

Mom gave her first child away. We know nothing about him. Then the three of us (two brothers and a sister) were born while my parents were in the colony. I was sent away from the maternity when I was only hours old – carried away in a basket with two others. I was eight when the administration decided to de-institutionalize. The orphanage people told my mother that they’d be returning the kids to their families. My father was working in Santarem at the time. When she called to tell him their children would be coming home, his answer was: “What children? The government took them, let the government raise them”. And he threatened he would beat her within an inch of her life if she took us back.

We see here how certain experiences deactivate what others might consider natural kinship relations. Not only Edmundo’s father no longer considered himself tied to his children, Edmundo also finds a way to minimize connections to his father. We saw earlier how he insists he has no need to demonstrate a filial tie with his parents in order to accede to the benefits of a *filho separado*. (It is enough for him to prove he was born in the colony hospital because, at the time, all patients were internees and all children were sent to the orphanage.) We may deduce that – just as people with a family history of genetic disease have a way of re-interpreting their genealogies in terms of local contingencies – so our interlocutor signifies his documental identity in terms of his own life experience: minimizing the importance of genealogical connections and underlining individualizing information such as place of birth.

There are, on the other hand, experiences that activate unexpected forms of kinship. Edmundo goes on to explain that, upon release from the orphanage, he and his brothers and sister went to live with his sister’s “adoptive” parents for about six months. By then their mother had died from complications of Hansen’s disease and Edmundo began “rolling” between the houses of different people – ex-internees of the colony as well as the nuns who assisted the neighborhood.

As mentioned above, this manner of socializing child-raising responsibilities was not uncommon in Brazilian’s working-class populations. Many

of the *filhos* have older brothers and sisters who – just as Neusa – had been placed as infants in another family (usually relatives or neighbors) before their birthparents were sent to the colony. Others, such as Marília, born during their mother’s internment, were brought up either in the orphanage or in a foster home of their parents’ choosing. Still others, such as Edmundo, extended their network of significant others after they left the orphanage. Some youngsters, given away as infants, may never find out they were adopted. In most cases people grow up well aware of the difference between one set of “parents” and another. Yet, indifferent to distinctions concerning blood relations or legal status, they will continue to name these various foster parents (whether referred to as “mother” and “father”, or “aunt” and “uncle”) when asked to elaborate on their family history.

There is no firm rule in these situations. This sort of family belonging is not a fact, but rather a process reactivated and deactivated by remembrances as well as by present-day social interactions. Understandably, it is precisely this sort of “performed” kinship that is largely ignored by legal institutions. When summoned to be of service to the formal justice system, DNA’s contribution appears to lean in other directions.

In wait of a day of reckoning

Much of the technological rigor used in the case of the *filhos* is similar to that used in Argentina to locate the children of political prisoners and *desaparecidos* kidnapped during the military dictatorship. There, a “grandparentage index” was developed in the mid-1980s so that the genetic relationship between alternate generations could be verified, even in the absence of parents. The criteria used today in Project Reencounter to verify siblinghood is a logical extension. Yet, technology has become at the same time more sophisticated and simpler than when the *Abuelas* began their activities. Today, both projects use the Applied Biosystems test kits involving a high number (in Brazil, 23) short tandem repeats loci. With the analyzed material having changed from blood to saliva, samples are gathered with relative ease in different geographic locations and the vials transported in light room-temperature bags to the accredited university lab where analysis takes place. With MORHAN activists preparing the necessary documentation – including a photocopy of the individual’s identity card and proof of address –, it takes

no more than two technicians to gather up to a hundred samples in a day. As of early 2014, some 196 tests had been run. A sibling relationship was confirmed in 158 cases. In the other tests, with less than 80% coincidence of STRs, results were considered inconclusive, suggesting the relationship of half-brothers or of more distant relations (Penchaszadeh and Schüler-Faccini 2014). There have been, up to now, only two outright “exclusions” of consanguineal relations.

For the *filhos*’ legal purposes, however, the DNA results are still in the preliminary phase of a “hard legal fact”. The law has not yet passed that will require proof of family belonging, and, when it does, it remains to be seen exactly what importance will be given to genetic tests. For the moment the tests, although under rigorous control, from collection of saliva samples to the ultimate signing of the lab report, do not have the official status of a court-ordered test. Only time will tell, if and when the new law is enacted, whether or not the courts will validate these tests or if they will require others.

But the genetic tests seem to exert other important effects, independent of their legal validity. MORHAN’s coordinators, referring to DNA’s tremendous popular appeal, describe how the test increases coverage in the media as well as guaranteeing a sizable audience at the organization’s meetings. It is thus an active ingredient in the collectively constructed version of past events (Fonseca and Maricato 2013). It serves further as an aggregating force, literally bringing people together. Brothers and sisters who have been estranged for years are put in touch because one of them needs to legally document their family tie. In many situations, the years of separation nurtured resentment against what was perceived as abandonment. For some of my interlocutors, to be “forgotten” by a brother or sister seems almost as reprehensible as to be “abandoned” by a parent. Activists are convinced that an understanding of the exceptional circumstances that caused the family’s separation helps heal these wounds, “increase auto-esteem”, and promote more congenial relations among kin. As we see, the test appears to be feeding into prevailing genetic mystique (Nelkin and Lindee 1995).

Perhaps the most striking effect brought on by the introduction of DNA deals with a form of sociability that spans life and death, extending into the future. Having discovered the potential of DNA testing, the Argentine *abuelas* reacted with enthusiasm donating their genetic samples to the “bank”

in the hope that, even long after their demise, victims of suppressed identity might still discover the truth of their origins. So too in the case of the *filhos*, there now exists a databank composed of the genetic samples taken from living individuals in the hope that some as yet unknown relative will eventually show up.

Hope is all the more poignant in the case of relatives supposed long dead. During the years of internment, it was not uncommon for parents to receive news that their child sent to the orphanage had died. And yet, as people tell me, they were shown no tangible proof of the youngster's death – no death certificate or little graves to visit. My interlocutors have learned through stories in the press how, at the time, orphanages might conduct covert operations, furnishing adopted children in exchange for large sums of money. And they wonder if the orphanage's report of the child's death was not simply a cover-up for this sort of illicit operation.

Just as in the Argentine case, here also, there's a certain urgency in collecting genetic material from the parent generation. Most of the original patients forcibly interned in the leper colonies have died, but some are still living. Since, the team from INAGEMP does not contemplate doing exhumations, the genetic samples from these survivors may prove crucial in the identification of "lost" *filhos*. Nonetheless, many of the samples connected with the 60 odd entries in the bank were donated by people in search of a lost brother or sister – a strong indicator of the importance of sibling ship in this context.

In fact, the reopening of seemingly settled facts shows to what extent the notion of "family" extrapolates dyadic parent-child relations, affecting a wide array of relatives in successive generations. During the public events organized by MORHAN, one might encounter a cluster of middle-aged adults – all somehow related and some with their own teenage children in tow – come to investigate the story of their lost brother, cousin or aunt. Before the movement that literally created the *filhos* as a recognized and self-recognizing collectivity, infant deaths had been all but forgotten, assimilated into vague memories with no clear implications. The DNA banks have, to a certain extent, brought these deceased members of the family back to life. Circumstances of birth, probable age, and other defining elements, gleaned from the recollections of the older generation, suddenly become solid facts in the family's history. And the inexistence of any documentary proof (of the

death, and sometimes even life, of the child) only heightens the mystery that the DNA samples, it is hoped, will one day solve.

In this case, the DNA test operates a sort of moral coupling between, on the one hand, recognition of the “facts” of the *filhos*’ connections and, on the other, recognition of the state’s violation of their fundamental rights. The culmination of this process is projected into the future – a sort of day of reckoning – when the purportedly dead will come back to life, families will be reunited, and the *filhos* will finally receive their just compensation. It is interesting to observe how, in this expectation of moral retribution, “reckoning” – previously defined as an ever-incomplete process – narrows to something resembling an absolute truth. Just as DNA reveals the ineluctable truth of family connections, so the law of reparation will finally bring out into the open the “history that Brazil wanted to ignore”. Science and morality unite in ultimate triumph, relegating to backstage the fragile connections that made all this possible: the genetic calculations produced through scrupulously observed laboratory techniques, as well as the hard political investments involving decades of activism.

* * * *

We have described in this paper a political movement aimed at legal reparation for human rights violations perpetrated by the Brazilian government against children of the compulsorily institutionalized patients of Hansen’s disease. We have chosen to conduct our investigation by exploring the action of intertwining technologies – narrated recollections, written documents, and the DNA test – employed by major actors to “reckon” the family connections at the core of this drama. Resort to the notion of technologies has permitted us to underline not only the materiality of certain processes, but also the complex temporalities at play. Written records are created, falsified and destroyed according to new situations, demanding an organized bureaucratic structure that guarantees preservation, validation, and access before any document can take on legal value. Personal narrations rework facts and relationships in function of possibilities afforded by new social, political and technological circumstances. From the recruitment of test subjects by activists, to the collection and examination of samples by scientists and the (hoped-for) validation of tests by jurists, DNA tests entail a

still more elaborate network in order to produce “solid facts”. In other words, not one of these modes of reckoning appears intrinsically more consistent or long-lasting than the others. The usefulness of these different technologies depends very much on the various mediations that give them life.

Altogether, the particular way these technologies interact and evolve in the reckoning of family ties depends very much on yet another temporality – that of the political context. In mid-2014, as I finish this paper, the political movement, orchestrated through enthusiastic local chapters of MORHAN, has gathered the *filhos*, reopening long-forgotten episodes from each individual’s past, as well helping to consolidate a feeling of community. It is this political movement that has brought DNA tests into people’s lives, established a wide audience for personal narratives, and made legal documentation of the past and present a vital issue.

Harkening back to Carsten’s thesis, it appears clear in this instance how political events as well as collective institutionalized structures – operating through the mediation of these diverse technologies – have produced a particular kind of sociality, interwoven with new perceptions of family and community. Political forces have been crucial in bringing about a realignment of the different modes of reckoning that reach into the past and project onto the future elements that constitute the way people situate themselves in the world. In the process, facts are rearranged and relationships are consolidated or, eventually, undone. But throughout all, one finds a steadily growing idea of moral entitlement furnishing the hope of a common goal – a goal that evokes and refashions notions of family belonging as well as ideals of social justice.

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Health and the Value of Inheritance

The meanings surrounding a rare genetic disease

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Abstract

In this article I explore the meanings acquired by the notion of ‘genetic inheritance’ for families in Rio de Janeiro affected by a rare hereditary disorder, Machado-Joseph disease. My analysis examines three points: 1) how experience of the disease was thematized in the family prior to knowledge of its genetic and hereditary origin; 2) how knowledge of genetics affected the family’s perception of their health and reproduction through the notion of risk contained in medical explanations; 3) finally, I problematize the meanings of ‘hope,’ a sentiment frequently cited by people with the disease and their descendants. Notably, despite the high value attributed to science and ‘medical progress,’ the use of certain biotechnologies is not always seen as positive or capable of enabling choices and actions in response to a rare disease. Notions of risk, responsibility and hope thus acquire singular contours for managing life and the continuity of the family.

Keywords: Rare Genetic Disease; Machado-Joseph Disease; Genetic Inheritance; Family and Kinship; Hope.

Resumo

Neste artigo analiso os significados que a noção de “herança genética” adquire para famílias cariocas afetadas por uma enfermidade rara e hereditária, a Doença de Machado Joseph. Considero na análise três pontos: 1) como a experiência da doença foi tematizada na família antes de se saber sua origem genética e hereditária; 2) como o conhecimento em genética afetou a percepção da família sobre sua saúde e reprodução a partir da noção de risco

apresentada pelas explicações médicas; 3) por fim, problematizo os significados da “esperança”, sentimento frequentemente mencionado nas narrativas dos sujeitos afetados e seus descendentes. Percebe-se que, apesar da valorização da ciência e dos “avanços da medicina”, o uso de certas biotecnologias nem sempre é encarado como positivo ou capaz de permitir escolhas e ações diante de uma doença rara. Assim, noções de risco, responsabilidade e esperança adquirem contornos particulares para gestão da vida e a continuidade da família.

Palavras-chave: Doença Genética Rara; Doença de Machado-Joseph; Herança Genética; Família e Parentesco; Esperança.

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Introduction

In November 2013, the Inclusion Program on Brazil's TV Senado channel was dedicated to the subject of rare diseases.¹ The program showed a family with various generations affected by a serious form of ataxia.² An older man with a mild manifestation of the disease's symptoms accompanied his 24-year old daughter. She had already become blind due to the complications caused by the ataxia and used a walking frame to move about. Her own eight-year old daughter had also inherited the genetic mutation and presented the worst symptoms among all the family members: she was blind and in a vegetative state, breathing and being fed via medical equipment. The family had filed a lawsuit for the state to provide a mini-ICU and nursing care in their home. The child's grandmother, who was responsible for looking after her, along with the nurse, recognized that the disease had no cure, was nonetheless hopeful that some kind of treatment would be discovered soon.

The same television program showed the day-to-day care for Fernanda, a 15-year old adolescent diagnosed with cystic fibrosis (CF).³ Though the disease is genetic and serious, Fernanda declared that she wanted to raise her own family, since "if my child are born with CF, I shall know how to treat the disease. And I'm hopeful that in the near future they will be a cure for the disease, because some mutations already have a cure, though not mine yet."

¹ TV Senado is a public television channel broadcasting events and activities promoted by Brazil's Federal Senate.

² Ataxia is the name given to a series of degenerative neurological diseases that mainly affect movement and speech. Though various acquired forms of the disease exist, the majority are genetic and hereditary in origin.

³ CF, also known as mucoviscidosis, causes breathing difficulties, digestive tract problems, infertility and frequent respiratory infections. People with the disorder have a life expectancy of around 40 years: cause of death is generally respiratory failure.

Despite winning a court decision that obliged the State to pay for a series of medications needed to treat his daughter, Fernanda's father claimed that he spent around R\$ 8,000 a month (equivalent to U\$ 3,400 at the time) on other medications not covered by the legal ruling.

The two cases raise a number of the questions surrounding the experiences of Brazilian families affected by rare genetic and hereditary disorders currently without cure or treatment. One of them is the perceived limitations of the medical knowledge available concerning these diseases and the care provided in both the public and private health systems. This situation has led to a rise in healthcare-related lawsuits in Brazil and prompted discussions on the advances made in universalizing Brazil's public health system and its limitations (Biehl & Petryna 2011, Biehl et al. 2009, Diniz 2009).

A second issue to emerge from the TV program is the families' varying perception of two notions central to studies of genetic and hereditary diseases in both the biomedical sciences and the social sciences: the ideas of genetic risk and self-responsibility (Rose 2013, Finkler 2003). Contrary to what some studies predict (Finkler 2001), knowledge of genetics does not necessarily alter significantly people's perception of risk when it comes to family reproduction and the construction of kinship.

Moreover, the forms of self-care that emerge in the Brazilian context appear more closely bound to a conception of 'fighting' to ensure that good health care is mandatorily provided by the State, rather than being necessarily related to the idea of autonomy or choice, as observed by researchers studying Euro-American contexts (Rose 2013). Hence "taking responsibility for your own health" may mean anything from everyday care for a body debilitated by disease to the demand for public health care policies, which may be collective or individual, as in the case of the lawsuits for the State to provide specific medications.

Finally, in practically all the interviews recorded for the TV program, hope figured as a feeling that needs to be nurtured if one is to continue living in the face of incurable diseases. This hope is an element necessary both for the construction of the present and for imagining future possibilities involving the sick person and his or her family. It rests on the 'scientific prospects' for a cure, though this does not always signify the kind of political engagement with the field of science identified in other analyses (Rose 2013,

Novas 2006, Epstein 1996). Rather, this hope seems to be directed towards an everyday practice and a moral project capable of making life possible in the present, even though the future remains uncertain (Mattingly 2010). In this process, science emerges as an agent capable of ‘producing hope.’

Setting out from this set of questions, in this article I shall examine the ideas surrounding the notion of ‘genetic inheritance’ for families in Rio de Janeiro affected by a rare and hereditary disorder, Machado-Joseph disease (MJD), exploring the different meanings attached to genetic technologies. This aim in mind, I consider three points: 1) how experience of the disease was thematized in the family prior to knowledge of its genetic and hereditary origin; 2) how knowledge of genetics affected the family’s perception of their health and reproduction through the notion of risk contained in medical explanations; 3) finally, I problematize the meanings of ‘hope,’ a sentiment frequently mentioned in the narratives of people with the disease and their descendants.

The data analysed here results from on-going research with families with a history of MJD living in the city of Rio de Janeiro.⁴ Contact with these families was established in December 2012 with the creation of an association for people from Rio de Janeiro state living with acquired and hereditary ataxias and their families.

MJD is one of the inherited forms of ataxia and was first identified in the medical literature in the 1970s, though it was only in the 1990s that it was identified genetically. In Brazil it is the most frequent form of hereditary ataxia (Jardim et al. 2001, Lopes-Cendes et al. 1997).⁵ There is no treatment or control for MJD. Therapeutic interventions like physiotherapy and speech therapy aim to minimize the effects of the disease, which eventually leads to bodily paralysis. Generally speaking MJD manifests in adult life around the age of 40.⁶ People affected can live for decades while the disease evolves before dying not from the disease itself but from secondary complications.

4 I thank CNPq for the postdoctoral award that enabled this research to be carried out at the Museu Nacional/ Federal University of Rio de Janeiro (2012-2014).

5 The principal symptoms of MJD are loss of balance, muscular paralysis, speech problems, difficulty swallowing and double vision.

6 In some cases the disease may begin at the end of adolescence, and very rarely during childhood. The age when the disease manifests may be connected to the severity of the genetic mutation, aggravated by the higher number of repetitions of the CAG code on the ATXN₃ gene, located on chromosome 14 (<http://www.ncbi.nlm.nih.gov/books/NBK1196/>, accessed on 07/10/2013).

As far as I know, there is just one work in anthropology that tackles the subject of MJD in Brazil, namely the book by João Biehl (2005). His analysis focuses on the story of a woman abandoned in a 'geriatric house' in the south of the country, labelled mad by doctors and her family alike. Exploring what he calls "social zones of abandonment," Biehl takes the life history of this woman as the basis for analysing the complex network formed between the family, medicine, the State and the economy, which culminated in her complete social exclusion following a psychiatric diagnosis for someone who, in fact, suffered from a rare hereditary disease. However, the author does not analyse how the technologies and medical discourses involving genetics have been received in Brazil, nor their impact on the construction of kinship, which are my objectives here.

The article divides into four parts. In the first I describe the current scenario of rare diseases in Brazil and the policies being developed for sufferers. Next I explore some of the ideas that emerged in anthropology at the end of the twentieth century and the beginning of the twenty-first to explore the knowledge generated by the field of genetics. My survey of this topic is not intended as a theoretical review: it merely serves to introduce a number of concepts important to studying the possibilities and limitations of their utilization in the diverse cultural contexts into which genetics has penetrated. Lastly in the final two parts of the text I turn to my ethnographic data to analyse how my interlocutors manage notions of risk, responsibility and hope as part of their experience of a rare disease in the family.

Rare Diseases in Brazil

The World Health Organisation classifies a disease as rare when it affects 65 in every 100,000 people. Despite the lack of consensus on the exact figure, estimates suggest that between 6,000 and 8,000 rare diseases exist in the world, 80% of them genetic in origin, affecting 8% of the world's population. Data from Brazil's Ministry of Health suggests that between 13 and 15 million of the country's inhabitants have some kind of rare disease.

Most of these diseases are incurable and untreatable, provoke severe states of morbidity and disability, and, in some cases, lead to early death. This reality, allied with the fact that many of these diseases have only recently

been identified by the medical literature, can have profound impacts on how the individuals involved continue to pursue their life projects, relationships and reproductive choices, marked by the idea of ‘genetic inheritance.’

Families with a history of rare diseases, each with its own emphases and forms of action, have joined forces politically at global level in search of treatments and health care. In this process, they have built relationships with biomedical, scientific and legal systems and civil society organisations through associations of sufferers of rare diseases and their families (Rose 2013, Akrich et al. 2013, Rabeharisoa et al. 2013, Rabeharisoa et al. 2012, Novas 2006, Rabinow 1999).

In Brazil, the joint action of government, scientists, physicians and associations led to the development of the **National Policy for Comprehensive Care of People with Rare Diseases (PNAIPDR)**, instituted through Directive 199, published in January 2014.⁷ In 2012 a workgroup was set up by the Ministry of Health to draft this policy. In April 2013, a public consultation was held to hear from other associations not present in the official workgroup. PNAIPDR envisages the creation of medical referral services equipped to provide specialized care to people with rare diseases.

One of the main complaints of families concerns the delays in obtaining a precise diagnosis, the outcome, they argue, of the lack of knowledge among physicians themselves concerning these diseases. The planned referral services would improve this situation by offering more precise and quicker diagnoses. This, in turn, would allow more effective treatments to begin sooner, offering a better quality of life to patients, albeit often only in palliative form since treatment does not always imply control of these diseases.

To achieve these goals, various actions and procedures will need to be created within the National Health System (SUS), including expansion of the list of medications offered, DNA testing and genetic counselling. The challenge now, the associations say, will be to make sure the policy “leaves the drawing board.” Since the public health system in Brazil is hierarchized and decentralized, responsibility for introducing the referral services will fall to the states and municipalities, using their existing structure, but receiving a financial input from the federal government.

7 http://bvsmms.saude.gov.br/bvs/saudelegis/gm/2014/prto199_30_01_2014.html (accessed on 20/04/2014).

In this scenario, specialists in medical genetics will be needed to compose the referral service teams and a new question arises: the scarcity of professionals trained in this area in Brazil. The directive initially envisaged that only physicians trained in this speciality would be able to provide genetic counselling. This decision prompted criticisms from non-medical geneticists who claimed that there were insufficient professionals to meet demand.⁸ According to data from the Brazilian Society of Medical Genetics (SBGM), the speciality was recognized in Brazil in 1983. However as recently as 2011 the Federal Council of Medicine (CFM/CREMESP 2011) reported that just 156 medical geneticists are found in Brazil, 85% of them working in the south and southeast regions of the country.

In Brazil, the majority of the genetic testing and counselling services are located in university hospitals, public hospitals located in large urban centres and blood donation referral centres (Diniz & Guedes 2005). A portion of the services offered in public centres for genetic medicine are intended for investigating genetic traits potentially responsible for chronic and degenerative diseases that can be transmitted to a couple's descendants, looking to provide advice towards their reproductive decisions.⁹

According to a report in a national publication,¹⁰ around two thousand people undergo genetic testing each year in Brazil. At the time of this report (November 2009), the price of the tests in private clinics varied between R\$ 600 and R\$ 15,000, making them accessible to only a small section of the country's population. In 2008, the National Supplementary Health Agency (ANS) included genetic testing and counselling in the list of procedures to be covered by private health plans. According to the SBGM,¹¹ these initiatives are expanding the Brazilian population's democratic access to biotechnologies

8 For criticisms from non-medical geneticists on the guidelines of Directive 199, see: <http://www.ib.usp.br/mais-noticias/725-portaria-exclui-geneticistas.html> (accessed on 25/03/2014). According to the president of one patient association that played an active role in constructing PNAIPDR, this ruling had been revoked and non-medical geneticists would be able to provide genetic counselling following appropriate training.

9 This is the case, for example, of the Department of Medical Genetics at the Fernandes Figueira Institute, run by the Oswaldo Cruz Foundation (FIOCRUZ), which has a genetic testing and counselling program aimed at couples and expectant mothers with histories of genetic disease in their families or who have had children with congenital diseases (source: <http://www.fiocruz.br/portalliff/cgi/cgilua.exe/sys/start.htm?inoid=166&sid=75>, accessed on 25/02/2012).

10 <http://veja.abril.com.br/251109/testamento-dentro-cada-um-p-104.shtml> (accessed on 08/03/2012).

11 <http://www.sbgm.org.br> (accessed on 25/02/2012).

developed in the genetics area. In December 2013, ANS extended the list to include tests for 29 genetic diseases and set guidelines for the procedures already approved since 2008 but that had yet to be covered by the private health plans.¹² Nevertheless, hundreds of rare diseases still remain uncovered by these initiatives.

What we can observe in the Brazilian context is that interventions requiring specialized knowledge in medical genetics depend on a coordination of the public and private sectors, similar to what already occurs with other diseases. People face difficulties in accessing diagnostic tests: at present, while PNAIPDR is still waiting to be implemented, these are very often obtained through networks of collaboration between professionals and researchers based in public universities. The Porto Alegre Polyclinic Hospital, for example, conducts tests for patients of university hospitals in a number of Brazilian states, employing resources and professional staff linked to a research project run by the Federal University of Rio Grande do Sul (UFRGS). Financed by the Rio Grande do Sul Research Support Foundation (FAPERGS), the project's main objective is to make the molecular investigation of neurogenetic conditions available for individuals from diverse parts of Brazil, forming a national research network on such diseases. Today eleven hospitals are linked to this network.¹³

In Rio de Janeiro, patients with MJD receiving care at one of the city's university hospitals have successfully obtained genetic tests via this network, which depends on public funding for scientific research in order to be able to continue testing. According to one Rio medical geneticist:

We obtained the tests through the network, it's an exchange, they need research material, we need to assist patients who have spent years searching for this diagnosis. But if funding for the research ends, the tests end too. It's not SUS that conducts the tests.

In this case, groups of patients are invited to visit hospital on the same day in order for a blood sample to be taken and sent to Rio Grande do Sul.

12 <http://g1.globo.com/bemestar/noticia/2013/12/planos-de-saude-terao-de-cobrir-exames-para-29-doencas-geneticas.html> (accessed on 15/12/2013).

13 For more information on the UFRGS Neurogenetic Network, see <http://www.ufrgs.br/redeneurogenetica/> (accessed on 09/12/2014).

The hospital lacks the funds to dispatch this material so the patients themselves share the freight costs. It may take several months before the results are ready. However this is how some Rio patients have managed to confirm the diagnosis of a rare and degenerative disease and, furnished with this information, take life-changing decisions such as requesting retirement with a disability pension.

The publication of PNAIPDR aims to transform the present scenario by creating permanent channels for the diagnosis and treatment of rare diseases. It remains to be seen just how and when the policy will be finally introduced into the public health system and the extent of its coverage. It seems likely that due to the variability in the diseases (some of which affect just a few dozen people) and the shortage of trained professionals (such as medical geneticists) just some Brazilian states and municipalities will manage to institute referral centres.

One alternative for care has been to link the initiatives for people suffering from rare diseases to those already formally established for people with physical disabilities, which are more widely disseminated in the country (such as special pensions, free access to public transport, specialized care in the public health system). Unlike someone who is blind, deaf or paraplegic, however, a person suffering from a rare disease does not always find it easy to obtain formal recognition of their disability, especially in the case of diseases that evolve gradually. Hence the situation for people in Brazil living with a rare disease is complex: they face limitations ranging from diagnosis to the lack of treatments or social recognition of their specific problems and needs.

Exploring Concepts and their Possibilities

In investigating rare diseases we can quickly perceive the interconnections between some of anthropology's canonical themes, such as studies of family and kinship, combined with recent theoretical explorations that emerged at the end of the twentieth century surrounding the new biogenetic technologies, including Rabinow's concept of biosociality (1999) and Lippman's concept of geneticization (1992). Both were developed in the 1990s during a period preceding the first public release of the Human Genome Project results. Despite the particularity of each author's approach, Lippman

and Rabinow pointed to a series of transformations in social relations and the construction of new individual and collective identities, which would later be spurred on by the new genetics.¹⁴

Other researchers have analysed the development of gene-based biotechnologies and their effects on the construction of family and kinship. Finkler (2000, 2001), for example, argues that these categories have been medicalized following the advent of genomics. In her view, genetic medicine attributes a cultural meaning to genetic transmission that reflects American perceptions of kinship as a biological fact, as studied earlier by Schneider (1980), reinforcing the traditional pattern of the western family.

Finkler conducted her US-based research with healthy people from families with a history of diseases like cancer and with adopted people. Among both groups she observed the adoption of care practices motivated by the idea of 'genetic risk' by people who were otherwise completely healthy: these practices range from the regular use of medical tests to the search for biological parents in order to compile a family clinical history to be presented at medical meetings.

On the other hand, authors like Rose (2013) and Novas (2006) regard the new scenario opened up by genetics as a source of potential revitalization for the social and human sciences. They point to what they interpret as new forms of exercising biopower and creating biopolitics that no longer operate 'top-down' but through feedback loops, connecting patients, associations, scientists, the market, the media and the State.

In Rose's view, our present historical moment has moved away from an earlier period of euphoria over genetics, epitomized by the eugenicist projects of twentieth-century totalitarian states. Contemporary biopolitics necessarily involves the dynamics of choice, autonomy and self-responsibility, and, at the same time, bioeconomic interests aimed not at eliminating individuals or groups but at improving bodies and generating profits. Focusing on advanced liberal societies, Rose claims that we are living in an 'economy of vitality' based on the 'molecular' knowledge of life and its possibilities for

14 Castiel et al. (2006) argue that the terms 'new genetics' and 'genomics' were created to dissociate the recent research in genetics from the eugenicist projects developed under totalitarian regimes. For the authors, "while the old eugenics operated repressively via state authority, modern genomics acts primarily through market mechanisms and uses the language of individual empowerment and the consumer's freedom to choose" (2006: 194).

exploration, which acquire different meanings for different actors (industry, governments, patients and markets).

Novas (2006), for his part, analyses how patient activism in search of cures or treatments for certain diseases has reconfigured the Foucauldian perspective of biopolitics. Specialists and States are no longer the only agents to define the mechanisms for controlling life. Subjects themselves, sick or otherwise, also conceive of themselves as biological entities and demand adjustments to social policies for promoting the life and well-being of individuals and collectivities.

Novas analysed two cases in the United States where patient associations played a central role in collecting funds and, principally, biological material for the development of research on rare diseases. In this process the human body and its parts were turned into 'bargaining chips' in the patient-scientist relation, forming a *biovalue*.¹⁵ Uniting the interests of both is hope, a sentiment evoked to mobilize attempts to discover a cure, necessary to save the lives of some and produce wealth for others.

The discussions opened up by these authors raised some stimulating topics for anthropology, traversing theoretical fields spanning from family and kinship studies and the anthropology of health and medicine to social studies of science and technology, economics and politics. However we also need to pose a question: just how influential is the new genetics in sociocultural and economic contexts where biotechnologies are still largely inaccessible? How does this area of science influence decisions over health, bodily care, reproduction and relationships? Is knowledge of their own genetic condition really becoming a widespread demand among individuals with a family history of serious disease? How are notions like choice, risk, responsibility, 'genetic prudence' and autonomy imagined in contexts distinct to those where the above authors conducted their research – and indeed within these contexts too?

Recent studies have shown that there are limits to the generalized use of concepts such as 'geneticization' and 'biosociality,' even in advanced liberal societies. Gibbon (2004), for example, questions the passivity attributed to

¹⁵ The term *biovalue* was introduced by Waldby (2002) to describe how certain biological materials (blood, tissue, DNA and so on) are transformed into values due to their potential to augment human health and, at the same time, generate economic wealth.

patients in analyses that overestimate the impact of new genetic technologies on the formation of clinical identities, ignoring the negotiations that inevitably unfold in patient-doctor discussions on the hereditary nature of breast cancer. Lock (2008), in turn, observed that the genetic testing used to assess the risk of developing Alzheimer's disease (AD) is not a major factor for family members with the disease. Family life is perceived to be more important than testing, which is ambiguous and uncertain in terms of establishing risk, meaning that trying to produce a sociability founded on genetic inheritance makes no sense to many people. Lock also observed that the associations between these families centred much more on providing and obtaining guidance on everyday care for people with AD than on determining the genetic causes of the disease. We need to ask, therefore, whether the new genetics really has transformed family relations, medicalizing kinship – or has it merely facilitated the shifts between the already existing physical, moral and affective dimensions of constructing the family?

To explore these questions in more depth, I shall present the ethnographic material collected by myself over an almost two-year period with families affected by Machado-Joseph disease living in Rio de Janeiro. This group represents just one tiny sample from a vast and diverse population with rare diseases. I approach my analysis, therefore, as a case study that cannot be generalized but which is useful to the development of new questions capable of shedding some light on the complex multiplicity formed by the universe of people living with rare diseases.

Other Logics for Comprehending Risk and Responsibility

I begin with the narratives of people with and without symptoms of MJD from two different families, who I shall call the Silva family and the Santos family. Both families originally came from the Rio de Janeiro suburbs, with some members still residing in this region, but with relatives also living in the north and west zones of the city. Though from a working-class background, today the economic conditions of family members would place them among Brazil's urban middle class. The second generation, now aged between 48 and 73 years old, with whom I have had the most contact, and most of whom present symptoms of the disease, were formally employed

in the public sector (civil or military). Among their own children, the third generation aged between 16 and 43, many have completed higher education, with one of the women being a university professor.

Most members of the two families access health services through a combined use of the public and private systems. Those with health insurance plans and/or who visit private doctors also turn to the SUS for health care. Some use the Rio de Janeiro unit of the Sarah Kubitschek Network, popularly known as 'Rede Sarah,' a complex of hospitals run by the federal government that specializes in neurorehabilitation, offering treatments like physiotherapy and speech therapy to people with ataxia.¹⁶ However individuals can remain patients of this referral centre for only a set time and, after being discharged, must continue their treatment by themselves, paying specialized professionals.

In both families, ataxia began to be recognized through the condition of the father of those today presenting the same symptoms. The recollection of the father who had slurred speech, walked unsteadily and ended up in a wheelchair emerges as the strongest early memory of the disease, subsequently observable in other members of the paternal family. Both families refer to the suffering of the father (or the grandfather for those in the third generation) being compounded by his condition going undiagnosed.

For two cousins from the Silva family, married for more than 40 years, who I shall call Ana and Otto, the earliest memory of the disease relates to their fathers, albeit in different ways: Ana, symptomless, recognizes that her father had MJD, though no precise diagnosis was obtained before his death. Otto, who has manifested evolving symptoms of the disease for 20 years, initially repeated his father's explanation that his paralysis had been caused by an accident.

Both also evoke the image of the paternal grandmother who 'died paralytic,' but the association with the same disease as their fathers was not immediately made at the time. Temporal and spatial distance seem to be a key element influencing the lack of connection made between the disease of their two fathers, witnessed first-hand, and the illness of their grandmother, who lived in another city and 'died an old woman' when they were still children. According to Ana:

¹⁶ See <http://www.sarah.br/>

The people there from the Northeast said grandma so-an-so died paralytic, but we had no idea what it was, what that was, that it came from the family. Because this disease came from this grandma of mine.

In the absence of any conclusive diagnosis and given the advanced age at which the disease manifested and worsened in the grandmother and both fathers, associations ‘age-related diseases’ were not discarded. Other explanations were also cogitated, such as an accident in the case of Otto’s father, or even a ‘weakness’ in the case of Ana’s father who for a long time, according to one of her sisters, was assumed to be a heavy drinker when the symptoms first manifested, not only by neighbours, but by his own family.¹⁷

The Silva family discovered that the disease was genetic and hereditary after one of Ana’s sisters, manifesting symptoms around the age of 40, decided to take a DNA test. Since the test in question was not performed in Brazil at the time, her sample was sent to the United States. The identification of her disease paved the way for another two siblings from the Silva family to seek out the tests when they too began to show symptoms, primarily to explain their problems at work and retire with a disability pension. The first test was conducted in a private laboratory in Minas Gerais and the result proved negative. This provided leeway for their work colleagues to claim that the siblings were ‘somatizing’ their sister’s disease and their problem was ‘just psychological.’ However their symptoms worsened and they sought out a second test, this time at a laboratory of the University of São Paulo. The result was positive and today they are suing the laboratory in Minas Gerais.

In the Santos family too, it is the father of those manifesting symptoms today who is mentioned first. The proximity with the aunts and uncles, siblings and cousins – almost all of them living in the same city, unlike the Silva’s who have close relatives living in other states – made it clear, though, that the disease was some kind of ‘family problem.’ But until members of the second generation were diagnosed, nobody knew for certain what it was. Describing his father, Miguel, an MJD sufferer, said:

At the time the disease wasn’t known, my father was being treated by Doctor X here in Rio, and the latter told him: ‘Look, you have an incurable degenerative disease,’ but he didn’t mention its name and my father just couldn’t accept it,

¹⁷ The staggering and slurred speech mean that many of those suffering from MJD are mistakenly taken to be drunk.

the fact he didn't know what it was, he couldn't accept it. He just felt himself fading away.

For his niece, who I shall call Sofia, who had no symptoms of the disease, the image of the grandfather is present, but so too the image of a great aunt who in fact raised her mother, since the latter was left an orphan at the age of 2 (her mother is Miguel's half-sister and also shows symptoms of the disease). Describing her great aunt, she said:

She hauled herself about. Of all those I saw, she was the worst. She couldn't walk, she dragged her feet until one day she fell in the bathroom, she spent the whole day in the shower.

Miguel and Sofia both refer to the reluctance of the father (grandfather) and aunt to use a wheelchair: this would have been the social concretization of the disability caused by the disease. According to Miguel, his father died when he was 73: "But because he let himself go [...]. He didn't do any physical exercise, he wouldn't agree to using a walking stick, he refused to use a wheelchair, he didn't accept anything."

The disease was first identified among the Santos family when a cousin living in Germany began to present symptoms around the age of 50 and took a genetic test in 2003. On the advice of her doctors, she compiled a dossier on MJD and sent it to all her relatives in Brazil. The family's response was to ignore the document. Miguel, then without any symptoms of the disease, told me:

I didn't pay any notice, I didn't want to know, who kept it was my sister [Sofia's mother], I didn't want to know, I don't want to know about any disease.

Sofia meanwhile said that:

In 2003 I was beginning my master's course, starting to teach classes, it was tumultuous time, there were so many things in my head, I didn't take time to read the dossier. My cousin deluged us with this topic, she wanted us to study it, she wanted me to investigate more deeply, but nobody did, nobody would listen to her.

However the diagnosis sent by the cousin did at least put a name to the disease, even if the family made no attempt to learn more. Those who developed symptoms after this dossier knew what disease they had and were able

to tell the doctors. Members of the third generation, still without symptoms, did not seek out predictive tests or genetic counselling.

The situation experienced in the Santos family invites comparison with Konrad's analysis (2003) of diagnostic revelations, the construction of prognoses for genetic diseases and their repercussions on the family. Konrad worked with people 'at risk' of having inherited the gene for Huntington's disease (HD)¹⁸ and explored the moral obligation that surfaces in the management of genetic information: who to tell and who not to tell? This produces an intense moral dilemma involving the disclosure or secrecy about the genetic condition, which permeates from the medical sphere into the domain of the family. The situation elicits an important discussion on ethics, personal rights, duty of care to the other, and how family relations are impacted by genetic information.

On the other hand, revealing a personal diagnosis to other family members morally compels them to learn more about their own genetic condition, something not always welcomed, especially among kin without any symptoms, who, like Sofia and her uncle, "don't want to know about disease."

Sofia, for example, once told me that she has no wish to take the predictive test to discover if she carries the MJD gene because she thinks that "the mind constructs everything in us." In her view, being diagnosed while still young could mentally accelerate the physical manifestations of the disease.¹⁹ Her biggest concern is the wish to have a child. Though she recognizes the health problem in the family, its hereditary nature and its complications, Sofia says that she has never thought about not having a child. However this does not mean that she did not make precise plans for her life, taking into account the risk of genetic inheritance in her family. For example, she waited until she had passed a public sector recruitment exam before trying to become pregnant:

18 A rare genetic disease that affects the central nervous system and whose typical neurological manifestations are involuntary movements, intellectual deterioration and a variety of psychiatric disturbances.

19 This concern with the mind-body relation, and the capacity of the former to affect the latter, is relatively common among people affected by rare diseases that attack the neurological system. Indeed it appears among health professionals too, as illustrated by a remark made by one psychologist in a book intended for people with MJD. There she claims that "it should be stressed that the gradual physical incapacities present in Machado-Joseph disease and/or in other types of ataxia generate and/or is generated automatically by negative emotional responses" (Abrantes 2009: 134). The author adds that failure to give new meaning to everyday life and relations after onset of the disease may trigger depressive and anxious mental disorders and thereby "aggravate the symptoms and quicken the disease's evolution" (ibid: 135).

I always thought that I had to have a job first, a good job, that would allow me to live, and if the disease appeared, one that would enable me to pay for a health plan.

Ana and Otto, who are first-degree cousins, always joke that had they known about MJD earlier they would never have been ‘mad enough’ to get married: since both of them may have the disease, they recognize that the chance of having sick children will be higher. When I asked them about their children, two adult men now in their forties, each with a daughter of his own, and whether they have displayed any concern about having inherited the MJD gene, Ana replied that all her family are opposed to “this testing thing.” They argue that having a genetic disease “is like an electronic device that comes out of the factory with a defect and is irreparable.” For them, while there is no cure or treatment for MJD, there is no point learning about your genetic condition in advance.²⁰

The transmission of genes to grandchildren is not an issue among either family. The daughters-in-law of Ana and Otto know about the genetic condition in the family, they say, just like Sofia’s husband who has seen the evolution of the disease in his mother-in-law and other relatives. The opinion among both families is that if the children are already born and out in the world, they should live their lives as fully as possible, including having children and raising their own families. Ana, for instance, remarked:

That’s how we think. I think that if the Lord [God] has not yet given us a problem with them, if one day he does so, we’ve already reaped the reward: they were born, they’ve already started their own family, they’ve already made their own way in life, both of them. I think it would be much worse to have a [sick] child who hasn’t even began living.

Miguel, father of three daughters, says there is no point spending time worrying about the disease and discourages his daughters from doing so:

²⁰ This view is frequently encountered among descendants of people with rare hereditary diseases without prospect of cure or treatment. Guedes & Diniz (2009) cite research showing that between 80% and 85% of individuals at risk of developing Huntington’s disease decide not to submit to predictive genetic testing. However, the reasons behind this refusal are diverse, ranging from the fear of receiving a positive diagnosis and not knowing how to respond, to encountering future problems with health insurance companies should this information ever reach them.

If they're already born, they're already here, there's nothing to be done, they just have to live their lives and not think about disease.

“Living their lives” includes starting their own family, embarking on a professional career and obtaining financial independence, all factors whose attainment is seen to justify downplaying the genetic issue present in the family.

Rather than analysing the percentages, statistics, genograms or long-term physical consequences, my interlocutors thus far seem keener to evaluate the kind of life still possible with the disease. The close relationship with parents, aunts, uncles and cousins who have developed MJD but previously had a professional career or still work today, who can drive even though they become unsteady on their feet, who use computers when they can longer hold a pen, who had time to raise children before they became ill – all of this is taken into account when evaluating predictive genetic testing and the desire to have children or not.

In this sense, the age at which the disease first manifests has an important role in the way in which it is perceived by the members of the two families. Its late evolution and the gradual limitations that do not completely impede some activities from being performed, such as driving or small household tasks, though taken as undesirable may also be comprehended as a tolerable addition to the ('natural') process of aging. Becoming paralytic at the age of 70, after having raised children or had a career, seems less serious than having a career interrupted while still young or being unable to have children and raise them, as becomes clear in Ana's remarks.

However this does not mean that my interlocutors, whether with or without MJD, see aging as a stage of inevitable dependency, decrepitude or disability. On the contrary, even those of the senior generation with physical symptoms of the disease and the limitations it imposes do not live with their children. Ana and Otto, for example, aged 64 and 73 respectively, live alone in an apartment. Their children visit regularly, but the couple insist on maintaining their independence, travelling by subway or taxi to association meetings or medical consultations.

Sofia's mother also lives alone with her husband. In 2012 he had a stroke that left him paralysed on one side of his body. Using a walking frame to move about, Sofia receives help from a nurse during the day, but says that

after 5p.m. “it’s all up to me.” In her case too, her children are in frequent contact, but she says “each of them has their own life.”

This perceived independence, even in the face of the disease and old age, is something Sofia highlights too as a reason for not fearing her genetic inheritance. As well as her own parents, she mentions her parents-in-law, both aged over 80, who have had other serious illnesses like cancer and yet still live alone. In contrast, as her uncle Miguel recalls, her father died sooner because he “let himself go,” failing to do any physical exercise, something he himself practices regularly to minimize the disease’s symptoms and remain independent for longer.

In both these families, therefore, age emerges as an important factor in how they evaluate the meaning of the disease over the course of life. Its manifestation almost always around the age of 40 is perceived to allow the family to reproduce or the person to plan their professional career.

This helps explain why Sofia waited to establish herself professionally by passing a public sector recruitment exam before attempting to become pregnant. She was well aware that, were she to have inherited the MJD gene, her financial independence would be hugely important, especially in terms of possessing the material conditions to care for herself and her family. Her refusal to take the predictive test does not imply a complete disregard for the possibility that she or her descendants may have the disease: it just means that other values shape her choices and her projects.

Taking tests to confirm the disease becomes important for members of the two families when they begin to display symptoms and need a definitive diagnosis in order to retire, justify their work problems and forced absences, and avoid negative comments, such as the suspicion that they are alcoholic or that they are ‘somatizing’ a relative’s disease.

Miguel, for example, was in the armed forces. During the first years of manifestation of MJD he tried to hide the symptoms and developed strategies to avoid job-related events that would make people suspect he was unwell, or in the best case scenario, that he was drunk, an impression admitted by some colleagues after he left. Only once he had the test results in his hands, five years after the first symptoms appeared, did he finally speak about the problem to his colleagues and immediately retired from work:

Had I said before [the test when the symptoms were milder] they would have said I was shirking, because I didn't look like I had any kind of disease [...] Had I gone about telling everyone I had the disease, I would have been labelled a shirker.

In these two families at least, therefore, we can observe that the demand for genetic testing is informed by different factors: for those who have symptoms, the test confirmation can resolve various sociorelational issues, such as the need to prove their genetic condition to other people and legitimize their leave from work, removing the stigma of being seen as a drunk or a 'shirker' from their job. For those not presenting any symptoms, the test is seen as merely a way of anticipating the suffering and anguish of a positive result, and even quickening the disease's development by making the person spend "the rest of their life thinking about this," rather than a way of planning life or enabling reproductive choices.

MJD's symptoms are expressed in various degrees of severity. Several of my interlocutors, with different ages and different periods of manifestations, still drive cars and perform other activities that prevent them from being classed as disabled. Unlike other degenerative and hereditary neurological diseases, MJD does not affect cognition. These factors are taken into account when people refuse to take the predictive tests or reject the idea that they cannot or should not have children. As we saw in Ana's remarks, people argue that by the time the disease manifests, the person may have already lived a full life, a cycle deemed complete when they raise their own family and obtain financial stability.

This does not mean that the families are unconcerned with the risk and seriousness of the disease and its effects, or that they fail to realize there is a risk. They simply conceive this risk in another form, taking other variables into account, such as the potential degree of independence the person can achieve and the fact that the disease manifests later on in life, demonstrating that the perception of this risk is mediated by each person's experience of the disease and operates through affective, moral and relational logics, not only the logic of health.

Obviously there are contrary cases of people highly concerned with the fate of their potential offspring and thus severely question whether they should have children. For these people, *in vitro* fertilization with a pre-implantation genetic diagnosis (IVF-PGD) has been offered as an alternative

possibility for those already diagnosed with the disease, and those who do not want to know their genetic condition, to have children free of the disease. In this technique various embryos are created through IVF, a cell is removed from each to test whether or not it is free of genetic mutation and, therefore, suitable for implantation.²¹ However this biotechnology-based choice runs up against various obstacles. One is the high cost of this procedure, unavailable through Brazil's public health system, meaning that it can only be obtained via private clinics. In addition, as in every IVF process, the rate of successful pregnancies per attempt is still low, around 30%.

At an event I attended in 2012, in Rio de Janeiro, which brought together people with movement disorders, including people with ataxia, IVF-PGD was mentioned as an option by women with MJD or who were daughters of sufferers. None of them took part in the association formed later the same year. They wanted to know from the physicians present at the meeting whether the technique could be requested through the courts, given that it is not offered by the National Health System (SUS). In a document sent by the Union of Relatives and Friends of Sufferers of Huntington's Disease to the president of Brazil's Federal Supreme Court in 2009, IVF-PGD was listed as a necessity for families affected by with this disease and that it should be offered by the SUS.

At one of the association meetings, the son of a man with MJD – a young man in his early twenties who I shall call Pedro – announced that he wanted to take the predictive test to discover whether he has inherited the genetic mutation for the disease from his father. If so, Pedro said that he will try to have children while he is still young, before the first symptoms of the disease appear. He argued that:

If I wait to have children when I'm 35 and start to manifest the disease at 40, like my dad, when my child is 15 years old I won't even be able to drive him to a party any longer.

I asked him whether he knew about the IVF-PGD technique and he replied yes, but he did not intend to use the procedure because of the considerable expensive and the uncertain outcome. Knowing whether he could develop the disease would not help him decide whether to have children or not but when to have them.

21 For an ethnographic analysis of pre-implant genetic testing, see Franklin & Roberts (2006).

Depending on the person's religious views, this ability to choose may also be problematized. As one of my interlocutors, a spiritist, asked: "Who am I to choose who will be born or not? I don't know if I would choose like that." Religious values heavily influence how this technique is comprehended and explain why it was removed from the list of procedures set to be introduced into the SUS by PNAIPDR. As the president of an association involved in drafting the latter policy told me at one event, many members of the Ministry of Health workgroup considered IVF-PGD a viable form of containing the course of the disease in vulnerable families. However the technique was not included under the argument that it would undoubtedly be targeted by conservative religious groups, hindering or delaying approval of the policy.

More in-depth analyses of families with rare and hereditary diseases are needed in order to observe in what way some social markers of difference, such as religion, gender and age, may be related to perceptions of the family and reproduction, and to biomedical technologies and their uses. My intention at this point is to highlight this variability in perceptions, though aware that a broader study with more families is needed to evaluate the significance and impact of these social markers of difference on the apprehension of genetic knowledge and its uses in Brazil. In so doing I wish to avoid reducing this complexity to a purely economic or structural question of a lack of access to such technologies.

The economic dimension is undoubtedly important and itself a social marker to be analysed, but moral and practical questions also form part of the perceptions and actions of individuals at risk of developing a rare disease. Sofia, for example, after learning about IVF-PGD, went to a clinic specialized in human reproduction and the last time we spoke was waiting for the results of some exams before talking to the specialist again. Meanwhile she continued her attempt to become pregnant "via the traditional method." In other words, she did not discount using IVF-PGD, but she did not want to limit her possibilities to a technique that possesses a high degree of uncertainty in terms of achieving a pregnancy.

The data obtained from these families and from the testimonies of people with other forms of rare and hereditary diseases on the internet and in books leads me to question, in part, Finkler's claim (2001) that biogenetics is reshaping kinship relations previously based on honour and the sharing of beliefs, values and ways of being through the gene's substantiality. What

I have observed, along with other ethnographic studies (Lock 2008, Weiner 2011, Chilibeck et al. 2011), is that although genetics is indeed extremely important, it has not become a determinant factor in the construction of projects related to the family and its reproduction. Values associated with individual and professional autonomy, the perception of different ages and their phases over the course of life, as well as the affective relations between kin with and without the disease, all have a significant impact on how MJD is perceived and responded to by asymptomatic people.

I concur with Chilibeck et al. (2011) when they argue that genetic knowledge and the use of various biotechnologies has not led to a universal 'geneticization' of individual or family identities. On the contrary, the experience of disease in the family may actually produce a 'familiarization of genetics' (ibid: 1771). Genes are reinterpreted in light of family history, rather than family history being radically modified through genetics.

To repeat my earlier point: this does not imply ignorance of the risk, limitations and consequences of a rare disease, but the attribution of other meanings to these elements as part of the process of making decisions and building life projects. In this process, hope emerges as a moral feeling capable of opening up possibilities in response to the uncertainties of the future and, simultaneously, continuing life in the present.

Hope in the Era of Genomics

Good et al. (1990) produced one of the first analyses on hope in the health field. The authors focused on how this feeling evolves from the revelation of a diagnosis to the adherence to treatment plans, including as a source of motivation for physicians working with people with incurable or untreatable diseases. How do people engender care and sustain the willingness of others and themselves to continue in a scenario offering few resources to alleviate suffering?

This perspective in mind, hope can be interpreted as a moral project capable of engendering life in the present in situations involving extreme pain and suffering, as Mattingly (2010) explores in her study of Afro-American families with children suffering from serious and disabling diseases. The author focuses on hope as a critical dimension of the clinical encounter, negotiated between the families and their sick children and the

physicians who are also confused about how to provide care to patients with no prospect of cure in a health system as unequal as America's. Consequently, she argues that hope is not linear: it is constructed in direct opposition to the fear and despair that pervade these people's lives and affect their relations. Being hopeful thus amounts to both a practice and a process:

Hope most centrally involves the practice of creating, or trying to create, lives worth living even in the midst of suffering, even with no happy ending in sight. It also involves the struggle to forge new communities of care that span clinical and familial worlds. This is why I have chosen to speak of hope as a practice, rather than simply an emotion or a cultural attitude (2010: 6).

To analyse hope as practice, in her study Mattingly selected a demographic cross-section that included differences in class, race and power. Here she shows how the cultivation of the feeling of hope assumes different proportions depending on whether people have access to an apparatus (medical, social and financial) capable of 'facilitating' the construction of hope – if not for a cure, then at least for a better quality of life. Poor black Americans have to construct this hope through other meanings and within a specific range of possibilities.

With the advent of the new genetics, hope has been analysed as an element in the political organization of people with serious diseases and their families, including their relationships with medical doctors, researchers and the pharmaceutical industry in what Novas (2006) has called a "political economy of hope."²² He argues that patients and scientists construct a joint field of action impelled by the hope of finding a cure or treatment for rare diseases, bringing relief to the suffering of the sick and profits for the medical-scientific corporations and the drugs industry. The biological material needed to make these hopes concrete is therefore simultaneously a vector of health and wealth.

Less optimistic, Brekke and Sirnes (2011) criticize the literature promoting the concepts of biocitizenship and biosociality for, in their view, trying to rid the new genomic medicine of the ideas of eugenics by using the argument of hope. The authors suggest that this literature presents a unilateral

22 The expression was originally used in the text by Good et. al. (1990), but with a meaning distinct from the one employed by Novas.

and narrow reading of the discourses involving hope, a feeling whose directional force is not always guided by the possibilities of the future, they say, but by the despair experienced in the present. For Brekke and Sirnes, the contemporary logic of hope annuls the distinction between research and medical treatment. Moreover, the urgency with which certain demands are made by patients is bending the limits of ethics, jeopardizing the principles of bioethics.

Despite the conservative tone permeating the text when it argues for a separation between politics and science (something highly unlikely to exist), one interesting point in Brekke and Sirnes's analysis is their highlighting of the association between hope and despair: specifically, how the possibility of the former depends on emphasizing the latter, a movement that demands the production of specific moralities. This dynamic is observed in the processes of judicialization of health care, just as it was central to the activism surrounding HIV/AIDS (Epstein 1996).

In a recent analysis of the medicalization of hope in the case of terminally ill patients, Menezes (2013) analyses how this feeling has shifted in the modern West from the sphere of Christian suffering to a hedonism centred on physicality. This process transplanted hope from the religious field to the space of science, attributed the capacity to develop infinitely, all the while enhancing the human body and life. Assisted reproductive technology, transplants, new medications and stem cell research all constitute "technologies of hope" (Leibing & Tournay 2010 apud Menezes 2013) capable of mobilizing people and groups to act in the present in the expectation of a different future.

The feeling of hope is, then, related to an active process, rather than a passive process as might first be thought. It involves a relation between present and future, and, for people with serious diseases, science appears as a horizon through which other futures can be constructed (Novas 2006).

My interlocutors recognize the uncertainty of the future, but this uncertainty can also imply a set of possibilities – and this is where sciences looms large. Although the hope mobilizing these people very stems comes from a religious faith, it is directed towards the achievement of a scientific discovery rather than a miracle. Here it is worth noting how biotechnologies can be legitimized and delegitimized simultaneously in the construction of contemporary ideas of hereditary genetic diseases: while the predictive tests are regarded with distrust due to the present therapeutic limitations of genetic

medicine, the development of these technologies is valorized as ‘advances’ toward better knowledge of rare diseases and the discovery of potential treatments or cures in the future.²³

One of the Silva family with MJD says that she does not believe in a cure for herself, but for her children, should they have the disease:

Today for them, if they have it [MJD], the path is easier, a diagnosis already exists, because just imagine not knowing what condition you’ve got? Today that’s changed: if it happens you already have a path to take and I believe, I’m hopeful, that something will be found in the future, a new drug or something. At USP [the university where she took her genetic test] I became very hopeful, I saw all those heads together studying, I think that something will emerge from there.

The same feeling drives on Sofia, who is also a researcher and academic. She says that, though more or less convinced she has inherited the gene from her mother, she does not want to take the test to know if she has MJD:

I’ve already decided that if I get the symptoms, I’ll manage to find a treatment, that’s what I think: by then someone will have discovered something, someone will discover something.

Given the dilemmas permeating the notion of risk, the lack of effective treatment and the difficulties in accessing and using genetic technologies in Brazil, hope functions as a moral value for the construction of everyday life and the projects involving the family.

At the same time, hope is also evoked as a stimulus to collective action, the construction of associations uniting these families²⁴ and involving various degrees of engagement and participation. It should be stressed that there is no homogenous disposition among actors to participate in associations in the context under analysis. While for some of my interlocutors the patients association signifies a space to campaign for rights and knowledge relating to their disease, for others it is somewhere to meet their peers, a way of not feeling alone with their disease and of constructing shared forms of confronting it.

23 A similar conception can be found in Lock’s work (2008) on families with Alzheimer’s.

24 The slogan of one leading Brazilian association for people with Huntington’s disease is: “Huntington – it will never degenerate our hope” (http://www.abh.org.br/index.php?option=com_content&view=article&id=83&Itemid=53, accessed on 05/09/2012).

Hence “investing hope in science” does not always involve patients interacting directly with scientists, as Novas describes, although relations may indeed be formed between them. This can be observed in Brazilian associations for patients with rare diseases, which often include collaborators from medical areas and researchers, some having been founded by them or at their suggestion.

In Brazil, though, these patient associations have played a more important role in mediations with the State, campaigning for public health policies that offer care to those suffering from rare diseases, rather than focusing much attention on pushing for more research towards cures (Grudzinski 2013). Here, certainly, the national context and the way in which relations between patients, scientists and the State unfold all play an important role in the way that activism has developed in the country.

For people living with rare and disabling diseases, therefore, hope is not always imbued with the same meanings, neither does it result in the same kinds of action. Its meanings depend on local scenarios and the relations established between diverse actors, the observation of a field of possibilities that favours certain actions rather than others, whether these are individual, everyday actions that need to be managed for life to continue, or those that involve personal or collective projects for the future.

Although evoking a mutual understanding, ‘having hope’ may represent many things given the uncertainty caused by being diagnosed with a rare hereditary disease. For my interlocutors, these distinct dispositions share the desire to project a future capable of dealing with the issues of the present so that the latter is not paralysed before its time.

Concluding Remarks

Concepts such as biosociality (Rabinow 1999), biological citizenship (Rose 2013, Petryna 2002), the medicalization of the family and kinship (Finkler 2001, 2000) and geneticization (Lippman 1992) have all been evoked to comprehend, from particular angles, the social processes engendered by the knowledge produced in genetics, usually indicating significant ruptures in the way that subjects conceive themselves individually and collectively. As Rose underlines (2013), these studies have mostly been conducted in countries with advanced liberal economies and health care systems based on

a logic of choice (Mol 2008), historically recognized forms of social engagement in campaigns for health care (Epstein 1996, Brown et al. 2004) and a strong market conception linked to the development of scientific research (Dumit 2012, Petryna 2011).

These are important factors when we turn to analyse how knowledge in genetics affects and is affected by the social fabric, becoming part (or not) of the conceptions of the body, health and sickness of particular groups in these societies. Hence it is important to note how even in these Euro-American centres such categories prove dynamic, revealing the multiplicity of understandings through which they have always been understood and that have not been reduced to genes as some have feared (see Chilibeck et al. 2011, Weiner 2011, Lock 2008, Gibbon 2004).

Given the expansion of biotechnologies and their migration to other national contexts, each with its own particular logic and practices related to health, illness, family, kinship, medical care and scientific research, we need to explore both the possibilities and limitations to using this conceptual framework. Ethnographic research into health in different contexts has shown us that the subjectivities related to disease and the body are neither stable nor homogenous, just as conceptions and uses of medical technologies vary. In this sense, the concepts of biosociality or 'technologies of hope' may be more productive if they remain adaptable to the results of ethnographic observation, which has presented us with distinct nuances for exploring what previously seemed evident, like the definition of genes. This is precisely what I have looked to emphasize in this article by showing how notions of risk, responsibility and hope are constructed and managed by families living with rare hereditary diseases.

These concepts acquire particular meanings, always open to transformation, which may or may not share the meanings produced by the new genetics, allowing shifts capable of responding to everyday life and continuity of the family in a scenario of ever more 'technological advances' that, nonetheless, have yet to pass beyond a horizon of uncertainties.

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La science de la parenté :

Adoption, génétique et identité parmi les adoptés au Brésil

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Résumé

Cet article discute la part de la science et des notions d'héritage et de génétique dans la quête des origines menées par des personnes adoptées au Brésil. Il examine comment les nouvelles technologies et découvertes de la science sont intervenues dans les domaines de la parenté et explore la façon dont leur importance grandissante pourrait expliquer la fascination pour la découverte des origines biogénétiques. Il considère donc comme essentiel de discuter de quelle manière la science est devenue un objet d'étude des sciences humaines. Cela est primordial pour comprendre l'influence des connaissances scientifiques, et particulièrement celles touchant à l'hérédité, sur nos décisions concernant la parenté et la famille. À partir des récits d'interlocuteurs, ce texte problématise les cheminements de la quête des origines au Brésil et soulève des questions sur le poids de l'argument génétique, surtout en lien à la santé, pour justifier la quête des origines.

Mots-clés: quête des origines ; parenté; génétique ; adoption

Resumo

Este artigo tem por objetivo discutir como ciência e noções de herança e transmissão fazem parte da busca das origens de pessoas adotadas no Brasil. Para além de examinarmos como as novas tecnologias e descobertas da ciência influenciam os domínios do parentesco, buscaremos explorar como sua importância crescente poderia explicar a fascinação pelas origens biogénéticas. Acreditamos excepcional discutir de que forma conhecimentos científicos, sobretudo aqueles que versam sobre hereditariedade, influenciam nossas decisões sobre parentesco e família. A partir das narrativas de nossos interlocutores, problematizamos os caminhos da busca das origens no Brasil

e buscamos questionar a influência do argumento genético, ligado à saúde, para justificar a busca das origens.

Palavras-chave: busca das origens; parentesco; genética; adoção.

La science de la parenté :

Adoption, génétique et identité parmi les adoptés au Brésil¹

Débora Allebrandt

Depuis que Schneider (1968) a mis l'accent sur la relation entre la parenté et les avancées scientifiques beaucoup de choses ont changé tant dans les configurations familiales que dans la place que la science y occupe. Ainsi, quand la technologie a permis de marquer les gènes et de réaliser les célèbres examens d'ADN, la preuve sociale de la paternité n'a soudainement plus suffi. La densité du sang aurait-elle changé?² De fait, il semblerait être devenu plus épais, lourd de nouveaux éléments – l'ADN, le gène, le génome, notre histoire, notre héritage, nos racines, notre identité et nos origines dans le sens le plus large. Cette série de développements dans le domaine moléculaire de la science, dont l'examen d'ADN, a transformé les enquêtes juridiques de paternité (Allebrandt 2007a; Fonseca 2002, 2004a; Cabral 1990). De l'investigation sociale à l'analyse de la preuve génétique, la relation entre loi et science n'avait jamais été aussi étroite. Cependant, d'autres usages de l'examen d'ADN s'éloignent du domaine juridique pour trouver de nouvelles fonctions, sur l'Internet par exemple. Les sites d'aide à la construction d'arbres généalogiques sont populaires sur la toile depuis une dizaine d'années. Ils profitent de l'avancée de la technologie utilisant des tests d'ADN pour retrouver des maillons manquant dans la recherche généalogique (Wade 2009; Legrand 2007, 2009). La scientificité de ces recherches peut certes être contestée, mais la décision individuelle de poursuivre la quête n'est pas critiquable en soi. Il faut se demander comment l'enquête servant à reconstruire l'arbre généalogique se différencie de celle faite par des adoptés et de personnes issues d'un

1 Cet article se base sur une recherche de terrain développée pour ma thèse de doctorat, financée par l'agence CAPES (*Coordenação de Aperfeiçoamento de Pessoal de Nível Superior*) que je remercie.

2 Abreu Filho a beaucoup exploré les dimensions et signification du sang pour la parenté au Brésil. Pour plus de détails voir : Abreu Filho, 1981 et 1982.

don de gamètes.³ Cela démontre combien la recherche des origines préoccupe notre société et que, aujourd'hui, cette quête passe plus par le laboratoire que par les archives.

L'application de la science aux domaines de la parenté est claire : elle devient l'outil pour connaître la « vraie » paternité et aide à avoir un enfant « vraiment » à soi. Cependant, on ne peut pas faire comme si la science était simplement un outil ou un moyen. Symboliquement, la science, soit comme preuve d'une relation génétique, soit comme rhétorique parlant de ce qui est vrai ou de ce qui appartient à la nature, fait partie d'un discours transcendant plusieurs domaines de notre société. Elle est intimement liée avec notre façon de comprendre le monde où nous vivons.

En plus d'examiner comment les nouvelles technologies et découvertes de la science sont intervenues dans les domaines de la parenté, je veux explorer en quoi leur importance grandissante pourrait expliquer la fascination pour la découverte des origines biogénétiques. Il me semble donc essentiel de discuter de quelle manière la science, et surtout ses laboratoires, est devenue un objet d'étude des sciences humaines. Je me concentrerai plus particulièrement sur les cas d'adoptés ayant décidé de retracer leurs origines pour y étudier l'influence des connaissances scientifiques, particulièrement celles touchant à l'hérédité, sur nos décisions concernant la parenté et la famille.⁴

La science décryptée : le génome au cœur des études de laboratoire

Le laboratoire, vu à travers le filtre des sciences humaines, peut, et l'a effectivement fait, inspirer plusieurs études. Cette approche rompt avec la vision lointaine d'une science dure car elle l'expose à la vérité de ses propres faiblesses. Comme Bruno Latour l'a relevé, la science est le lieu de constantes disputes particulièrement dans le domaine de la nature. Or, c'est justement dans ce domaine que le projet du séquençage du génome humain (HUGO), connu populairement comme « projet génome », a inspiré des études

3 Cette comparaison a été développée dans d'autres travaux, notamment Allebrandt, 2013.

4 La recherche de terrain ayant permis d'établir la base de données exploitée ici a été menée entre 2010 et 2011. Cet article fait partie de ma recherche doctorale qui comparait la quête des origines des adoptés et de personnes issues d'un don de gamètes. J'ai interviewé vingt adoptés ou parents ayant des enfants issus d'un don de gamètes sur la quête des origines, dix au Brésil et dix au Québec. Un panorama des méthodes de recherche et des défis affrontés est disponible in Allebrandt 2013.

remarquables : Bamford et Leach (2009) nous rappellent que ce projet visait à comprendre qui nous sommes en tant qu'espèce et, même, qui nous sommes « vraiment ». Cette idée que notre vérité absolue réside au plus profond de notre nature fait écho à l'argument de Viveiros de Castro qui croit que « *perhaps biology is what we get when we start believing too much in our own ways of speaking* » (Viveiros de Castro 2009: 242) Autrement dit, on sait depuis longtemps que le rôle des métaphores de la science ne peut être négligé dans notre société (Keller 2003).

Après la découverte de la double hélice d'ADN,⁵ les avancées de la science nous ont conduits à envisager la vie et la nature de façon de plus en plus « moléculaire ». Comme carte qui nous conduirait aux réponses sur l'origine de la vie ou à la dangereuse possibilité de forger une clé pour ouvrir la boîte de Pandore, ce projet a reçu une énorme publicité et ses résultats suscitent encore bon nombre d'espoirs, de peurs et, surtout, de pouvoirs.

Foucault (1976) a énoncé en quelques pages l'un des concepts les plus influents de notre époque : le biopouvoir. Pour lui, le pouvoir souverain de laisser vivre et faire mourir s'actualise dans la modernité : le biopouvoir représente la gestion calculatrice de la vie et de l'administration des corps.

« La vieille puissance de la mort où se symbolisait le pouvoir souverain est maintenant recouverte soigneusement par l'administration des corps et la gestion calculatrice de la vie. Développement rapide au cours de l'âge classique des disciplines diverses – écoles, collèges, casernes, ateliers ; apparition aussi, dans le champ des pratiques politiques et des observations économiques, des problèmes de natalité, de longévité, de santé publique, d'habitat, de migration; explosion, donc, de techniques diverses et nombreuses pour obtenir l'assujettissement des corps et le contrôle des populations. S'ouvre ainsi l'ère d'un « biopouvoir » (Foucault 1976: 172).

Cet auteur affirme que la gestion calculatrice de la vie établit des enjeux transformant la vie en objet politique. Des disputes et des revendications sur le contrôle de la vie, du corps, de la santé et de la sexualité, entre autres,

5 La discussion de la découverte/adaptation de l'ADN à sa représentation en tant que double hélice peut être lue dans le livre « La science en action » de Latour(2005) Pour une lecture anthropologique de l'histoire de la génétique, voir Bibeau(2004) et pour le rôle de la génétique dans la santé, voir Baird (1994).

voient le jour. Le biopouvoir est ainsi directement impliqué dans la gestion de l'existence humaine.

Bien que ce concept se retrouve dans plusieurs autres aspects de sa théorie, Foucault a laissé plusieurs questions sans réponse dans la relation entre biopouvoir et biopolitique. Aujourd'hui, des théories affirmant que le biopouvoir est né lorsque la vie biologique en est venu à intégrer la politique, donnent du crédit à Foucault. Pour Agamben (1997),⁶ par exemple, le pouvoir sur la vie, ou biopouvoir, est aujourd'hui exercé par le juriste, le médecin, le scientifique, et même le prêtre. Autrement dit, il est aux mains d'alliés du souverain.

Pour sa part, Rabinow(1996) souligne l'importance de la biopolitique dans l'étude de grandes entreprises comme « Celera », l'un des principaux acteurs dans la course au séquençage du génome, dont le but principal était d'établir « le gène responsable » de plusieurs maladies. Cet auteur a ainsi introduit un nouveau concept conjuguant socialité et biologie : la biosocialité (biosociality)⁷.

Il croit que, à l'avenir, avec la nouvelle génétique, le biologique ne sera plus une métaphore du vrai et du « naturel », mais un producteur d'identités. Ainsi, la biosocialité est un nouveau mode de production, résultat du changement de représentation de la nature et de la culture. Pour lui, « *Nature will be known and remade through technique and will finally become artificial, just as culture becomes natural.* » (Rabinow 1996: 99)

Un autre chercheur, Gilles Bibeau (2004), démontre également la liaison entre l'État et la science. Dans *Le Québec Transgénique*, il révèle que, lors du séquençage du génome humain, les compagnies pharmaceutiques et l'État ont uni leurs efforts pour développer un projet « nationaliste » prenant en compte les spécificités québécoises. Il examine la question de l'humanisme au sein des études génomiques en précisant que le but du décryptage du génome est, en fin de compte, d'en connaître davantage sur la condition humaine. Selon lui,

« [...] d'une part, l'humanité devra assumer, au cœur d'une civilisation devenue de plus en plus biotechnique, un rapport critique envers son savoir et ses

6 Il caractérise l'état précédent comme la « vie nue », c'est-à-dire une vie sans contraintes légales.

7 Un livre dirigé par Gibbon et Novas (2008) discute la répercussion et l'utilisation de ce concept dans les études dialoguant avec la santé et la génétique.

pouvoirs sur la vie ; d'autre part, elle devra formuler un nouvel humanisme organisé autour de la notion même de vie plutôt que de celle de matière, un humanisme ancré dans les sciences de la vie, plus, ou tout autant, que dans celles de la matière, un humanisme qui devra se diffuser dans l'ensemble de la société, chez les scientifiques et chez les spécialistes des sciences dites humaines » (Bibeau 2010: 110).

Il s'agit d'un nouveau langage de délibération cherchant à analyser et mettre en relief les valeurs humaines au détriment du marché, de la loi ou des faits de science. Selon Jasanoff (2005), les règlements et lois visant à établir ce qui est correct et juste en termes bioéthiques sont vus par les citoyens comme responsabilité de l'État. Cependant, elle se demande « *How, for example, could the law speak persuasively of human dignity or of protecting nature when the meanings of "human" and "nature" were themselves under siege ?* » (Jasanoff 2005: 171)

Culture et science

Quand on pense à la science, il n'y a pas de place pour le sens commun. C'est pour cette raison que Latour affirme que si « les ethnosciences peuvent se rattacher pour une partie à la société et au discours, la science ne le peut pas » (Latour 1991: 16). C'est ce qui a conduit Malinowski (1963), à l'avant-garde de son époque, à dire que les peuples primitifs étaient capables d'utiliser la logique rationnelle, de la même façon qu'il y avait une place dans la société occidentale pour la pensée magique. Cependant, comme l'observe l'anthropologue Laura Nader (1996), Malinowski n'est pas arrivé à la conclusion logique de son argument : la rationalité scientifique est aussi un produit culturel. Mais, ne faisons pas de Malinowski un bouc émissaire. L'histoire nous a montré que la science était bien protégée derrière les murs de la citadelle (Haraway 1991).

Selon Nader (1996), la relation entre science et culture n'est pas nouvelle. Elle définit donc la science comme un corpus de connaissances incorporant savoirs, empirisme et curiosité. Toutefois, en Occident, la science évoque des configurations institutionnelles établies sur des règles d'ordre et de rationalité, aussi bien que sur des personnes unies par des compétences communes.

Pour Nader, il faut remarquer que beaucoup d'assertions construites sur la science sont prises comme « vérité ». En effet, ces formulations viennent

du contraste entre science et superstitions ou pratiques occultes. Par son homogénéité et son autonomie par rapport à la nature, la science prend donc la relève des pratiques païennes. Pour autant qu'elle s'éloigne de la vie quotidienne, remarque Nader, elle peut être définie de différentes manières, la définition académique n'en étant qu'une parmi d'autres.

Or, c'est justement la définition/démarcation des domaines de la science qui est au cœur de ce travail. Nader affirme que si la science est faite à partir de contrastes, ceux-ci, en dernière instance, produiront des hiérarchies pouvant privilégier une forme de connaissance au détriment des autres. Ainsi, les frontières déterminant la science sont aujourd'hui « fréquemment » arbitraires, « rarement » neutres et « toujours » des enjeux de pouvoir (Nader 1996). Nader cherche donc à s'éloigner des idées évolutionnistes plaçant une certaine version de la science au-dessus du bien et du mal, du vrai et du faux.

À partir d'inquiétudes semblables, Jasanoff utilise le concept d'« épistémologies civiques » pour « *move away from a priori assumptions about what publics should know or understand of science* » (Jasanoff 2005: 250). Aussi, dans un chapitre dédié à la compréhension des épistémologies civiques mises en pratique, cette auteure décide de sortir de l'aspect de la gouvernance et du biopouvoir pour examiner le rôle du public dans le développement de la science et de la démocratie.⁸ Pour ce faire, elle commence par énoncer la distinction entre épistémologies civiques et « *public understanding of science* » (PUS). À travers cette notion, la science est vue comme « *unproblematic, universal, and invariant, equally understandable in all places and at all times.* » (Jasanoff 2005: 249)

Du long parcours des études de la science vers une compréhension épistémologique des outils de connaissance, l'anthropologie a hérité d'un riche champ d'études. J'ai souligné dans cette brève révision l'importance de ces études pour mettre en tension la relation entre nature et culture et pour prendre la science elle-même comme objet d'étude. Ainsi les paradigmes de la science aussi bien que ses priorités d'étude et formes d'assertion sont-ils influencés par le contexte culturel dans lequel ils sont produits. Voyons

8 Jasanoff (2005) affirme que, comme au théâtre, la politique qui fait usage de la science ne pourrait exister sans le public. Ainsi, de grands projets scientifiques comme le séquençage du génome ne pourraient pas exister sans support populaire.

maintenant comment la demande d'accès aux informations permettant d'identifier les parents biologiques des adoptés brésiliens s'est configurée en droit reconnu avec la rédaction de la nouvelle loi de protection de l'enfance en 2009.

Chercher ses origines au Brésil : découvrir et enquêter

L'intérêt pour la biologie, l'ADN et le génome comme moyen de comprendre l'homme dans la complexité et la complétude de son héritage génétique est partagé autant par les scientifiques que par les personnes en quête de leurs origines. Si la recherche de notre « vraie nature » a conduit les scientifiques au cœur du génome humain, la quête des origines biologiques des adoptés et des personnes issues d'un don de gamètes semble emprunter le même chemin (Rabinow 1996).

Au Brésil, le Statut de l'enfant et de l'adolescent (ECA) régleme depuis les années 1990 l'adoption et tout ce qui s'y rapporte. Les changements produits par ce nouveau code ont été exhaustivement analysés par les anthropologues brésiliens. Fonseca affirme que la réponse sociale à la nouvelle législation peut être vue comme un indice de la manière particulière dont plusieurs personnes voient dans l'approbation des lois la solution à des problèmes comme la pauvreté et l'inégalité sociale. Ainsi, en garantissant le droit à la vie, à la santé, à l'éducation, à la culture, au loisir, à la liberté et à la vie de famille, entre autres, cette loi devrait changer le destin des enfants brésiliens (Fonseca 2004a). L'ECA institue l'attribution aux enfants du statut de sujets de droit, lequel marque la transition d'une politique de contrôle des enfants à une politique visant à les protéger, voire à garantir leurs droits. Malgré son engouement pour cette initiative brésilienne, Fonseca se penche sur les limites de son adéquation à la réalité brésilienne et sur la spécificité de l'enfance comme sujet d'une loi (Fonseca 2004b).

Les amendements apportés à l'ECA en 2009 comportent d'importants changements. Pour les personnes adoptées, cette réécriture garantit la préservation de leur dossier et la possibilité de le consulter après l'âge de 18 ans.

« Art 48. L'adopté a le droit de connaître son origine biologique et d'avoir un accès illimité au procès ayant conduit à cette mesure dès qu'il aura 18 (dix-huit) ans.

Paragraphe unique.

L'accès à la procédure d'adoption peut également être accordé à l'enfant adopté de moins de 18 (dix-huit) ans, à sa demande, s'il est l'objet de conseils et d'une assistance juridique et psychologique. » (ECA, 2010)

Il s'agit d'une grande conquête pour les adoptés désirant entreprendre une recherche sur leurs origines. Pourtant, une fois de plus, la loi brésilienne méconnaît la réalité locale, qui inclut la pratique d'adoption irrégulière connue comme « adoption à la brésilienne » consistant à élever et déclarer l'enfant de quelqu'un d'autre comme sien. Même si cette procédure, qui efface complètement l'existence d'autres parents, a beaucoup diminué avec l'augmentation du nombre de naissances en milieu hospitalier, ces dernières décennies, les personnes adoptées irrégulièrement ont beaucoup de mal à faire valoir leurs droits. En choisissant de ne pas évoquer ces cas, la loi brésilienne néglige une grande partie des adoptés et considère les enfants de « l'adoption à la brésilienne » comme des « non adoptés ». Ce qui pose problème surtout quand l'adopté décide de faire une enquête.

Mes entrevues au Brésil se sont centrées sur la recherche des origines. Ceux qui ont réussi leurs retrouvailles en parlent comme d'une période d'efforts intenses accompagnés de nombreux échecs avant d'arriver à un résultat. Un des grands défis pour les adoptés ayant décidé de rechercher leurs origines est de convaincre les personnes et institutions ayant participé à l'adoption à les renseigner. Cependant, une condition importante est nécessaire avant la quête : savoir que l'on a été adopté.

Les données de ma recherche font croire que, au Brésil, il y a encore une forte tendance à garder le secret sur l'adoption. Dans leurs récits, les adoptés ayant répondu à l'enquête parlent de la découverte de l'adoption comme d'un événement marquant. Même si parfois l'expérience de cette découverte a été vécue comme très négative, ils disent comprendre les raisons pour lesquelles les parents adoptifs ont caché l'adoption et parlent de leur gratitude de ne pas avoir été abandonnés.

Parmi les répondants, trois personnes ont découvert qu'elles avaient été adoptées après leur vingtaine. Soulignons que cette tranche ne concerne pas les personnes nées après 1990 qui, en majorité, l'ont su dès leur petite enfance. Les données de l'enquête révèlent un lent changement de philosophie et même l'influence des théories psychologiques sur la question des

origines. Cela peut être aussi le fait de l'amendement de la loi qui, dans les années 1980, a institué l'égalité entre enfants adoptés et biologiques au Brésil. Toutes ces transformations démontrent le passage graduel de la compréhension de l'adoption en tant que moyen de construire une famille « comme si », reposant sur le secret, à celle d'une famille « comme les autres », garantie par l'égalité de statut des enfants naturels et adoptés.

Ne savoir que l'on a été adopté que plus tard, ou encore à l'âge adulte, peut provoquer beaucoup d'angoisse. Cependant, dans ma recherche, ceux qui ne l'ont su qu'à plus de vingt ans ne semblent pas avoir plus de difficultés que ceux qui l'ont appris pendant leur petite enfance. Silvana, une pédagogue de 45 ans l'a découvert à 20 ans. Elle comprend qu'à l'époque le secret était de rigueur.

« Quand ma mère adoptive a décidé de me raconter, j'ai ressenti une grande douleur et, en même temps, de la gratitude pour mes parents adoptifs. Tout au début, je ne voulais rien savoir de mes parents biologiques... c'est venu 10 ans après... »⁹ (Silvana).

Silvana raconte être passée par plusieurs émotions : la douleur d'être la dernière à savoir, la gratitude pour ses parents adoptifs, quand elle évoque des récits d'abandon, le déni de curiosité pour ses origines et, dix ans après, la volonté de faire ses retrouvailles.

Dans une autre tranche d'âge, Ieda, 34 ans, a découvert à 24 ans qu'elle avait été adoptée. Elle affirme que, bien qu'elle ne l'ait découvert que très tard, rien n'a changé dans sa vie. Elle n'était d'ailleurs pas surprise. Non pas qu'elle ait traitée différemment dans sa famille, mais, intuitivement, elle le sentait. Aujourd'hui, elle a décidé de rechercher, sans hâte, ses parents biologiques avec l'aide de ses parents adoptifs.

En l'absence de données au niveau national, pour contextualiser ma recherche, il me faut ajouter aux éléments obtenus dans mon enquête des informations publiées par l'Association des enfants adoptés du Brésil (AFAB)¹⁰ et d'autres études, pour tenter de dresser un état de la recherche des origines dans ce pays. Le site Internet de l'AFAB affirme disposer d'une

9 Toutes les traductions du portugais ont été faites par l'auteure.

10 Au Brésil, l'AFAB a été la première organisation d'adoptés à la recherche de leurs origines. Elle a été créée en 2007. Voir : <http://www.filhosadotivosdobrasil.com/index.php/historia/missao-de-resgatar-identidades>

liste de 3 000 personnes recherchant leurs origines et avoir aidé presque 500 personnes à faire leurs retrouvailles, depuis 2007.

Dans l'histoire de l'adoption, la recherche des origines a parfois été interprétée comme le résultat d'une adoption manquée. Ceux qui décidaient de retracer leurs origines étaient vus comme des instables et des ingrats envers leurs parents adoptifs. Ils devaient affronter nombre de préjugés¹¹ qui font de plus en plus partie du passé. Néanmoins, le fait de rechercher son origine peut encore heurter les sentiments des parents adoptifs, voire provoquer leur jalousie, ce qui a donc toujours une influence sur la prise de décision. Retarder les retrouvailles ou le faire en secret est une stratégie mise en œuvre pour ménager les parents adoptifs.

« J'ai peut-être attendu si longtemps (28 ans) pour éviter que ma mère adoptive ne souffre de quelque manière que ce soit. Généralement les personnes n'ont pas le choix par rapport à leur famille. Je sais que j'ai été choisi par mes parents et j'ai donc une responsabilité beaucoup plus grande. Et ce même dans une famille formidable comme la mienne... je vois qu'il existe toutes sortes d'épreuves, de doutes et de regrets même concernant le sentiment le plus important qu'est l'amour » (Felipe).

Le récit de Felipe laisse à penser que l'épreuve la plus importante est peut-être de décider de faire ses retrouvailles. Silvana, qui n'a su qu'elle avait été adoptée que quand elle avait 20 ans, dit que, pour sa part, la peur de blesser son père, qui était très angoissé par l'idée de ces retrouvailles, était une raison suffisante pour ne pas y penser. Toutefois, sa mère abordait souvent le sujet et insistait même sur la possibilité des retrouvailles. Ce que Silvana a appris, en écoutant sa mère, explique la résistance de son père : sa mère biologique était en effet la sœur de ce dernier, sa tante paternelle.

Dans ce cas, les résistances s'expliquaient par le fait que les retrouvailles impliqueraient de reparler d'un sujet très délicat de l'histoire familiale : la grossesse hors mariage de la petite sœur de son père. À l'époque, être mère célibataire était une honte pour la famille. Pour le père de Silvana, aborder ce sujet, c'était déterrer quelque chose de très délicat que l'on préférerait passer

11 Le sujet des retrouvailles est fort bien travaillé par Modell(1994) et Carp(2004) dans le contexte d'adoption aux États-Unis. Pour plus de détails, voir leurs travaux.

sous silence. L'adoption intrafamiliale de Silvana s'appuie sur des décisions basées sur la morale de l'époque. Le secret, en accord avec les mœurs et coutumes, préservait les apparences.

La transmission de gènes et le besoin de compenser des manques par rapport à l'idée même de famille sont des arguments qui reviennent dans les récits de mes interlocuteurs. Pour Juliana, la volonté de connaître ses origines a commencé quand elle est tombée enceinte.

« En effet, ce qui me pousse à connaître mes parents biologiques c'est le fait que je sois enceinte. J'aimerais connaître mes origines, les faits physiques et ce qui passera à mon fils. J'ai toujours évité de toucher ce sujet pour ne pas blesser ma mère... en fait, jusqu'à aujourd'hui, je ne me sentais pas vraiment incitée à les connaître... » (Juliana).

Il est important de noter que, pour elle, connaître ses origines est une façon de savoir ce qu'elle pourrait *transmettre* génétiquement à son fils. La transmission de cet héritage biogénétique est souvent appelée « côté/facteur médical ». Pour Valérie, c'est le déclencheur.

« Mon élément déclencheur, je dirais, pour aller de l'avant, c'était mes enfants. Quand j'ai eu mes enfants, et quand ils étaient vus par un médecin, il me demandait, bon, les antécédents dans la famille. Je ne pouvais pas y répondre. Je pouvais répondre du côté du père des enfants, mais de mon côté je disais, je suis adoptée, puis je ne sais pas. Pour moi, ce n'était pas grave, mais là, je me disais, j'ai une partie du sang de mes enfants aussi. Pis ça a été vraiment mon élément déclencheur, bon, j'ai besoin de savoir mon côté médical. Qu'est-ce que moi, Valérie [dit son nom complet] je transmets à mes enfants? Qu'est-ce qu'ils vont transmettre à leurs enfants? Ça, c'était vraiment mon élément. Le côté médical. Pas parce que les enfants étaient malades, mais pas du tout. J'ai eu des enfants en bonne santé et tout, mais ça a été ça l'élément » (Valérie).

Les antécédents médicaux prennent une toute autre dimension quand ils deviennent part de l'histoire des enfants. Comme le souligne Valérie, le fait que les siens étaient en bonne santé ne changeait rien à son besoin de savoir. Invoquer le « côté médical » n'est pas tant rechercher une carte génétique ou un bilan de santé, que connaître l'histoire de ceux qui nous ont engendrés, mettre une image sur le mythe, avoir un nom et une adresse.

Au Brésil, le grand nombre d'« adoptions à la brésilienne » pousse les adoptés à suivre d'autres pistes pour obtenir des informations. Cette recherche témoigne de la diversité d'approches. Comme je l'ai souligné, le caractère « irrégulier » des « adoptions à la brésilienne » est source de défis particuliers. Cependant, en ce qui concerne l'accès à l'information, les adoptions régulières ne sont pas beaucoup mieux loties.

Pour ceux qui ont été « adoptés à la brésilienne », les parents et membres de la famille restent la source première de renseignements. Ils préfèrent généralement rechercher des informations auprès d'un autre membre de la famille ou même de voisins à affronter leurs parents. Ceux qui le font rencontrent souvent des résistances, obtiennent peu d'information et produisent des récits flous (Fonseca 2009a). Ils peuvent aussi chercher dans les registres, les hôpitaux et sur les forums Internet. La recherche dans les registres civils est cependant une alternative coûteuse.

Parmi tous les témoignages que j'ai recueillis dans mon enquête, seule une seule personne ayant des informations incomplètes (un prénom à peine ou une date de naissance inexacte) s'est rendue à l'hôpital de sa naissance et raconte son parcours. Les hôpitaux prétendent souvent que les archives ont été détruites dans un incendie. Quoi qu'il en soit, même quand l'information existe, l'adopté aura besoin d'un ordre judiciaire pour que les archives lui soient ouvertes.

Comme le souligne Fonseca, qui a interviewé des professionnels du système juridique, l'ordre autorisant l'ouverture des dossiers dans les hôpitaux n'est pas garanti de fait. De plus, son application dépend de la bonne volonté de l'établissement qui devra chercher et fournir les informations (Fonseca 2009a). Il faut cependant noter que, des années 1960 aux années 1980, les hôpitaux étaient les intermédiaires des adoptions tant légales qu'illégales. À l'époque, ce genre de médiation était parfaitement normal. Dans les récits qu'elle a recueillis, Fonseca constate que seule une personne a souligné que son adoption était irrégulière. Ce manque de différenciation indique que l'« adoption à la brésilienne » n'était autre qu'une tentative de simplifier le processus bureaucratique lié à l'adoption par les voies officielles. Si l'adoption produisait un nouveau registre civil, « comme si » l'enfant avait été engendré par le couple, l'« adoption à la brésilienne » avait les mêmes effets dans la pratique. Jusqu'à récemment, avec le changement de la loi sur

l'adoption, en 2009, qui permet l'accès sans restriction des adoptés à leur acte de naissance, j'oserais dire que l'« adoption à la brésilienne » offrait plus de pistes sur l'origine que l'adoption officielle. Autrement dit, dans un pays de la taille du Brésil, avoir le nom des parents naturels et le lieu de naissance ne suffisait pas pour effectivement réussir ses retrouvailles. Pour les personnes interviewées, la plus grande difficulté était de briser la barrière du silence.

Pour cette raison, la plupart de mes interlocuteurs ayant réussi leurs retrouvailles au Brésil attribuent cela au destin ou à des coïncidences. Ce serait donc le hasard et la chance qui décideraient du succès des retrouvailles. Malgré les particularités de chaque cas, la prise de décision, la motivation et les retrouvailles ont été vécues de manière très semblable par mes interlocuteurs : on obtient des réponses, on perd ses illusions, mais finalement on se sent comblé.

Anthropologie de la science : un récit des origines

Comprendre l'origine de l'homme reflète l'espoir et le succès de nos avancées techniques. Cependant, l'argument biogénétique de la quête des origines des adoptés peut être perçu comme une arme à double tranchant. Les avancées scientifiques permettant, au travers des antécédents familiaux, d'identifier d'éventuels risques pour la santé sont un argument d'importance dans la quête des origines. Mais trop insister sur cet argument oblige la personne en quête à valoriser à l'excès l'aspect biologique dans la construction de sa famille. Toutefois, ne pas mentionner le « côté médical » et argumenter que la quête des origines n'est qu'une question identitaire est tout autant empreint de préjugés, puisque ces personnes sont considérées comme ingrates envers leurs familles adoptives.

Tous mes interlocuteurs font mention de l'importance de connaître les antécédents médicaux de leurs parents, ce qui est d'ailleurs souvent le déclencheur de la quête des origines. Curieusement, il ne s'agit que d'une « mention » puisque l'histoire de santé n'est ni analysée ni problématisée. Pourtant, le côté médical figure parmi les faits que l'on ne saurait ignorer (Fonseca 2009b; Strathern 1995). Un seul de mes interlocuteurs rapporte une expérience où avoir mieux connaître ses antécédents familiaux aurait pu « changer » son avenir. Philippe, un avocat de 53 ans, raconte qu'il était en

pleine santé quand, à 46 ans, il a fait un infarctus.¹² À l'époque, bien qu'ayant fait des démarches pour obtenir un résumé de ses antécédents sociobiologiques, il ne pensait pas avoir de prédispositions à un accident cardiovasculaire.

Il a su très tôt qu'il avait été adopté et, pour lui, c'était plutôt réaliser sa chance.

« [J'ai su que j'étais adopté] très tôt. Mes souvenirs sont très lointains... je me rappelle que je devais avoir cinq, six ans. Et ma mère m'avait dit qu'elle ne pouvait pas elle-même avoir d'enfants, et que mon père adoptif et elle voulait vraiment avoir des enfants pis ils sont allés voir un organisme pis justement, ils ont pris un enfant qui était mis en adoption... C'était comme si c'était la chose la plus naturelle au monde. Moi, en apprenant ça, je n'ai pas eu de problème. Au contraire, comme ça m'a été présenté, dans le fond je me suis dit que j'étais chanceux »

Comme il s'est heurté à une clause de confidentialité qui l'a poussé à chercher des voies alternatives, sa perception est diamétralement opposée. Mais aucune n'a répondu à ses attentes. Il évalue les informations qui lui ont été fournies.

« [Dans mon dossier] il y avait quelques informations sur la personnalité de mes parents naturels... Je me rappelle que mon père était un commis de bureau et ma mère naturelle, elle était la fille d'un cultivateur, donc ils se sont rencontrés jeunes, ils m'ont eu et pis... ils m'ont confié en adoption. Ce qui est assez, quand même, étonnant au niveau du père, au niveau de sa personnalité, de ses intérêts ça ne ressemble à rien. Par contre au niveau de la mère, il disait que c'était une personne qui était très, très sociale, qui aimait les gens, qui aimait aller à la rencontre de gens, qui aimait beaucoup la musique, et je suis pareil... » (Philippe).

La notion d'identification est toujours présente. L'absence de certaines informations fait ainsi ressortir l'importance de combler ces lacunes.

« Mais ça ce n'est vraiment pas satisfaisant... Quand je suis né, j'ai fait une jaunisse à peu près tout ce qui a là dedans, et je n'ai même pas le type sanguin

12 Comme Philippe est québécois, son cheminement ne fait pas partie des adoptés au Brésil. Son histoire unique nous aide toutefois à situer l'importance de la génétique dans la recherche des origines.

de mes parents... je n'ai rien... sur le plan médical j'trouve ça aberrant... moi-même, à 46 ans j'ai fait un infarctus et pourtant j'étais bien en forme, je faisais attention à mon alimentation, je fais du sport, et comment ça? Probablement j'avais une prédisposition à faire ça. Heureusement, je suis resté sans séquelle, comme j'étais en forme, pis du fait que j'ai récupéré visiblement sans dégât, ils m'ont fait une angioplastie... mais avoir été au courant en fait que mon père naturel lui, l'avoir su peut-être j'aurais pu rencontrer un médecin et pis j'aurais été suivi sur ça... là, encore là, c'est aberrant de ne pas savoir ça... mes parents sont plus vieux que ça, ils m'ont eu très jeunes, mes parents naturels m'ont eu très jeunes... encore là ma mère elle avait 18 ans, elle n'a même pas 78... Mon père il a peut-être une couple d'années de plus, pis il doit avoir... quand on regarde ça, c'est de l'information qui pourrait avoir de l'influence, qui me permettrait d'éviter des actions un peu plus, je pourrais peut-être être un peu en santé, et ça, ça c'est en partie frustrant... »

Philippe poursuit ses arguments en revenant sur la génétique. Pour lui, au-delà des problèmes de santé qui pourraient être expliqués par son héritage génétique, la personnalité elle-même peut être clairement reliée aux gènes. Il l'a compris grâce aux « petites notes sur ma mère naturelle, qui aimait danser, qui aimait la musique, qui était sociable... ». Il affirme :

« En tout cas c'est ça... la connexion était amputée par le fait que tout le bagage des parents naturels, comme je suis, une grosse partie de ce bagage-là, ce qu'on a vécu, j'ai aucune idée et que je n'ai pas accès à ça, honnêtement, ça m'a manqué. [...] et pis, moi cette carence là, je l'ai eu mais par rapport au fait que je n'ai pas pu bénéficier de tout le bagage de mes parents naturels. »

Philippe voulait faire ses retrouvailles, mais il s'est heurté à une clause de confidentialité. Il pense que les informations qui figuraient dans son dossier étaient incomplètes. Cependant, celles qu'il souhaitait obtenir ne sont pas identifiables sur une carte génétique.

Cependant, il existe tout un marché destiné à offrir ces « cartes génétiques ». Caroline Legrand s'est intéressée au marché des généalogies. Selon elle, « [...] l'acte généalogique invite l'anthropologue à penser les choix électifs et autres sélections à l'œuvre dans le processus d'appareillage » (Legrand 2009: 133). Sa recherche concernait les Irlandais, « quêteurs de parenté » et elle a étudié la commercialisation du savoir de parenté et la possibilité de redéfinition du réseau d'appartenance.

Elle montre que, pour les experts en biologie moléculaire effectuant des analyses ADN, l'idée de preuve est d'« attester » les liens de parenté non seulement parmi les faits de la nature, mais aussi parmi les données vérifiables scientifiquement. Par conséquent, ils valident la technologie et produisent un faisceau de croyances plus qu'ils n'identifient. Legrand souligne que cette croyance en la généalogie comme preuve ultime est tellement importante qu'une remarque dans les brochures avertit que « les testeurs doivent être conscients que certaines certitudes peuvent être invalidées par nos services. » (Legrand 2009: 142)

Finkler affirme que la notion d'« héritage génétique » utilisée aujourd'hui est en vogue depuis quatre décennies et devient plus populaire avec les avancées de la biologie moléculaire. C'est justement la manière dont ces notions sont de plus en plus employées pour expliquer le comportement humain de façon plus générale qui inspire le travail de cette auteure (Finkler 2001). Pour elle, l'accent de la biomédecine sur la génétique comme base de la famille va à l'encontre des changements majeurs que représente la famille de choix. Autrement dit, si, socialement, nous sommes en train d'élargir et de privilégier la famille basée sur des relations d'affinité, la biomédecine veut en comprendre les liens et agencements sur la base du sang et de la génétique.

Finkler examine comment les connaissances génétiques sont appliquées dans le domaine de la biomédecine. Cette relation, qu'elle appelle la médicalisation de la parenté, privilégie une forme de parenté biologique. L'auteure est particulièrement critique par rapport à la relation entre santé et génétique, d'autant que même les notions de causalité et de risque en viennent à être expliquées par la génétique. Elle donne ainsi l'exemple de quelques interlocuteurs ayant une histoire familiale de cancer pour qui la question n'était plus de se demander « si » ils allaient avoir un cancer, mais « quand ».¹³ Ce genre de « certitude », issu de la connaissance généalogique, place l'ADN comme dépositaire de notre histoire et en fait une mémoire implacable

Un autre volet de sa recherche mettant en relief la quête des origines des adoptés révèle que la médicalisation de la parenté incite les adoptés à chercher leurs origines biogénétiques même si plusieurs de ses interlocuteurs se sentaient en conflit par solidarité envers leur famille adoptive. Pourtant,

13 Dialogue avec le travail de Finkler les études de Gibbon (2009; 2002) sur le rôle de la génétique sur la santé et la parenté.

Finkler souligne comment la médicalisation de la parenté s'est développée au début du XXI^e siècle.

« [...] the fact that American kinship builds on a biogenetic template facilitates the wide popular acceptance of the belief in genetic inheritance and also explains, along with the powerful authority that science possesses in contemporary society, the lack of resistance to and even ready acceptance of the medicalization of family and kinship. Folk notions of family as a biogenetic entity allow for an effortless embrace of the scientific and biomedical notion of genetic determinism precisely because it mimics cultural conceptualizations of the biogenetic foundations of kinship » (Finkler 2001: 247).

Pour elle, l'acceptation de la médicalisation de la parenté s'explique par le fait que la génétique base ses « inventions »¹⁴ sur les mêmes principes de transmission et d'hérédité que les configurations culturelles. Autrement dit, le déterminisme génétique serait en réalité en mimétisme avec les conceptions culturelles et les fondements de la parenté. Toutefois, elle affirme qu'un des résultats de cette médicalisation de la parenté est de fragmenter la vie en deux mondes dont les relations se basent sur le sang, pour l'un, et sur le partage des relations affectives, pour l'autre.

Cependant, cette vision assez catastrophique de la relation entre parenté, santé et génétique affirmée par Finkler ne trouve pas de correspondances dans les récits de mes interlocuteurs, ce qui ne signifie pas que leurs préoccupations pour leur santé et l'importance de connaître leur héritage génétique soit volatile. Au contraire, obtenir ces informations leur permet de reformuler toute une identité, ce qui peut produire de nouvelles identifications sans que cela ne produise nécessairement une fragmentation, car les retrouvailles révèlent une addition sur une voie de continuité.

Un autre usage de la connaissance généalogique est souligné par Turney qui travaille sur les tests d'ADN pour obtenir l'identité du donneur de gamètes,¹⁵ dans le contexte de la politique d'accès aux origines de personnes issues d'un don de gamètes à Victoria (Australie). Ce test est utilisé comme preuve dans plusieurs contextes.

14 Finkler s'appuie sur Bowler(1989) pour affirmer que les découvertes scientifiques ne sont pas seulement forgées socialement, historiquement et culturellement mais avant tout un produit de notre création. Elle affirme donc que les théories sont inventées et non découvertes.

15 Le sujet de l'anonymat du don de gamètes au Brésil a été bien exploité dans les travaux d'Allebrandt(2007b) et Salem (1995).

« *Biological paternity is now fixed and certain and provides definitive knowledge about paternal status that has raised new issues for regulatory bodies around the world who deal with issues of parentage or family connectedness (such as child support, immigration, repatriation and new reproductive technologies [NRTs])* » (Turney 2010: 401).

Turney affirme que la différence entre les pères biologique, le géniteur, et socio-affectif, le *pater*, n'a été jamais aussi marquée, développée et, en même temps, validée. Elle trouve dans l'historique du changement de la loi permettant aux issus d'un don de gamètes de connaître l'identité du donneur quelques pistes pour saisir les changements dans la compréhension de la paternité.

Cet amendement de la loi a inquiété l'*Infertility Treatment Authority (ITA)* – Victoria, Australie – pour ce qui est des couples entrant dans la catégorie « *subfertilité* », dont le *pater* pouvait aussi être le géniteur. Comme la fidélité des femmes était mise en doute, des tests ADN ont également été prévus. Cela, affirme l'auteure, a provoqué un changement dans la dynamique des retrouvailles. « *However, the imperative to confirm paternity in this way itself created new ethical complexities, not the least of which would be that the first contact between the genitor and donor conceived person would, by default, be a request for a paternity test* » (Turney 2010: 403). Ces modifications ont redéfini l'identité et, plus largement, la nouvelle place que la biologie et la biogénétique occupent désormais dans notre vie:

« *With the democratisation of genomic knowledge through the print and electronic media, particularly the Internet, genes have become central to 'real' or legitimate identity and important determinants of health and behaviour. Genetic medicine and the promise of finding, curing and eradicating disease and its causes have placed a pervasive new emphasis on biological relationships.* » (Turney 2010: 403)

L'auteure en conclut que, dans ce contexte, connaître ses origines devient un impératif, puisque dans cette interprétation de la génétique, la transmission de ce que nous sommes « vraiment » passe par l'ADN. Dans ce nouveau contexte, garder le secret ne pourrait que frustrer les attentes et serait préjudiciable à la relation parents-enfants. En accord avec cette perspective, le gouvernement a créé une campagne pour inciter les parents à évoquer l'existence d'un tiers donneur dans l'engendrement de l'enfant. En dépit de cette emphase sur le rôle de la génétique, les données de Turney montrent

que, dans la pratique, le géniteur ne modifie pas le rôle du *pater*. Ainsi, dans ce contexte où la paternité génétique semblait avoir besoin d'être confirmée l'auteure recommande que le statut de *pater*, indépendant du lien biologique, soit validé et respecté.¹⁶ Les débats sur la parenté se polarisent aujourd'hui entre un biologisme extrême et une survalorisation des liens socio-affectifs.

Enfants de la science ? Parenté, droit et science

La signification et l'importance que la connaissance des antécédents biogénétiques prend aujourd'hui doivent être comprises comme un reflet de la négociation entre trois catégories : parenté, droit et science. La quête des origines implique ces trois domaines. Dès le début de cet article, je me suis demandé si cette quête des origines mettait l'accent sur l'aspect biologique de la parenté. Le poids de la science sur la parenté a-t-il produit une nouvelle forme de filiation ?

La génétique liée à la famille et à la santé, surtout dans le contexte des adoptés, peut susciter des positions opposées. Je reconnais que, dans ce débat, il est important de souligner le rôle exceptionnel que la science, en tant que source de « vérités », peut aujourd'hui jouer dans la connaissance de notre arbre généalogique et de nos origines. La force de l'argument génétique saurait être ignorée. De même, on ne peut pas fermer les yeux sur la place de plus en plus importante que la génétique et ses métaphores prennent dans notre culture. Autrement dit, même si la quête des origines est, en dernière instance, une décision individuelle, il s'agit d'une expérience qui doit être précisée au sein de la famille. Avoir un espace de dialogue pour partager la décision et les retrouvailles semble un élément indispensable de cette équation. Pour mes interlocuteurs, découvrir précocement le fait d'avoir été adopté était aussi important que de pouvoir parler avec leurs parents adoptifs d'une possible quête de leurs origines biologiques.

Au Brésil, l'ECA a été modifié en 2009 pour répondre plus efficacement aux placements d'enfants. Il a dès lors garanti aux adoptés un accès à leur

¹⁶ Fonseca, qui a analysé l'utilisation de tests d'ADN dans le contexte juridique brésilien pour l'investigation de la paternité, avoue craindre que cela puisse transformer les relations sociales de paternité et même entraîner une vague de contestation de paternité. (Fonseca 2002, 2004). Son étude, entre d'autres, a montré que, finalement, la preuve ADN est utilisée pour réaffirmer le fait social et peut être ignorée au bénéfice de la paternité affective (Allebrandt 2007a).

dossier d'adoption. Je partage l'avis de Fonseca quand elle affirme que, malgré l'avant-gardisme de cette loi, rien n'assure son application, car plusieurs aspects sont laissés à l'interprétation et à la discrétion du juge. En outre, après lecture de la loi, quelques questions subsistent : cette mesure est-elle rétroactive ? Les adoptés et parents d'origine bénéficieront-ils d'une assistance ? Dans un pays de la taille du Brésil, avoir un dossier en main ne signifie pas nécessairement avoir accès aux informations, voire établir un contact avec la personne concernée.

Si l'on ne peut nier l'importance de ces changements, qui affirment le droit aux origines dans la loi, mes données permettent d'affirmer que l'accès au dossier d'adoption ne bénéficiera qu'une partie des adoptés. De fait, les adoptés « à la brésilienne » n'auront toujours pas d'informations sur leurs origines et ne pourront donc pas en apprendre plus sur leur histoire.

L'identité est un concept qui a été approché de diverses manières. La place de l'identité et de l'appartenance dans les récits des adoptés et issus d'un don mettent en relief l'identité civile, le sentiment de soi, et les identités collectives. La ressemblance est un point qui revient toujours dans leurs histoires. Le manque de ressemblance avec leurs parents adoptifs, leur recherche incessante sur le visage d'étrangers qu'ils croisent et l'identification dans la rencontre avec les parents naturels sont autant d'exemples traduisant l'importance de cette problématique. Le fait de chercher des ressemblances peut exister dans n'importe quelle famille, mais ces dernières peuvent être forgées sans le besoin d'un lien biogénétique (Marre & Howell 2009). Cette pratique chez les adoptés et les issus d'un don de gamète met en évidence, dans une famille, le « *significant same* » (Finkler 2001). Cependant, la popularisation des recherches généalogiques fait ressortir l'importance d'une identité génétique comme source de mémoire et de descendance. La fascination pour ces liens perdus et le besoin toujours plus légitimé par la biomédecine de connaître nos origines génétiques soulèvent des questions comme celles d'Edwards et Strathern(2000), qui se demandent pourquoi les connexions sont toujours vues comme positives. Je ne peux pas donner de réponse définitive à cette question. Ce que je veux mettre en relief, en reprenant la question de ces auteures, c'est que nous valorisons vraiment les connexions. Je crois que les raisons incitant les personnes à rechercher ou non leurs origines pourraient donner des pistes pour expliquer ce processus.

L'identité civile, l'identité personnelle et l'identité collective sont des « informations constitutives », donc capables de redéfinir les règles du jeu (Strathern 1999 p. 75). En ce sens, les informations sur les parents d'origine dans l'adoption font partie de l'identité des sujets. La quête des origines dépasse les domaines locaux, familiaux, politiques, et même les frontières nationales, car elle touche, sans doute plus profondément, à l'identité personnelle et collective. Elle révèle surtout le désir de comprendre les liaisons et différentes formes de connexion.

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From abortion to embryonic stem cell research:

Biosociality and the constitution of subjects
in the debate over human rights

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Resumo

O artigo analisa a presença do discurso dos direitos humanos nos debates sobre o aborto e sobre a pesquisa com células-tronco embrionárias como integrante do processo de biossocialidade. Tais questões emergem no campo da saúde reprodutiva e chegam à esfera do Direito em vista de problemas éticos. O discurso para constituir fetos e embriões em sujeitos de direitos será examinado em eventos do Supremo Tribunal Federal: a ADI 3510 contra o artigo 5 da Lei de Biossegurança que autorizou o uso de embriões excedentes de reprodução assistida para obter células-tronco, e a ADPF 54 que propõe incluir a antecipação de parto de anencéfalo na interpretação dos permissivos para o aborto legal.

Palavras-chave: direitos humanos, biossocialidade, aborto de anencéfalo, células-tronco embrionárias, ADI 3510, ADPF 54.

Abstract

The article analyzes human rights discourses in debates regarding abortion and human embryonic stem cell research as a part of the process of biosociality. These questions arise in the health and reproductive field and move into the realm of the law because of ethical issues. The text examines discourses regarding the transformation of embryos and fetuses into subjects of rights in the context of the Supreme Court: the legal move for unconstitutionality against Biossecurity Law that authorized stem cell extraction from supernumerary embryos created through assisted reproduction (ADI 3510), and the

legal case that proposes to include in legal abortion anticipated parturition of anencephalous fetuses (ADPF 54).

Keywords: human rights, biosociality, abortion of anencephalous, human embryonic stem cells, ADI 3510, ADPF 54.

From abortion to embryonic stem cell research:

Biosociality and the constitution of subjects
in the debate over human rights¹

Naara Luna

The present article analyzes how human rights discourse is inserted in legal struggles in Brazil in the context of the debate regarding research utilizing stem cells extracted from human embryos created during the *in vitro* fertilization process (IVF). We take as our principal material for analysis two cases in front of the Brazilian Federal Supreme Court. These questions emerge from the field of reproductive health and end up in the legal realm due to the ethical problems that arise in several distinct contexts.

The article follows Rabinow's strategy for research, concentrating life practices as the most potent space for the development of new powers and forms of knowledge (1999, p. 137), widening the scope of this strategy to take in juridical structures. Rabinow believes that, in the future, the new genetics will cease to be a biological metaphor for modern society, becoming instead a network in which identity terms and restricted spaces circulate and through which a new form of self-production – biosociality – will emerge. (Rabinow, 1999: 143). With biosociality, nature will be molded around culture, understood and reworked through practical techniques. Nature will become artificial exactly as culture has become natural. With regards to the topic of the present article, biosociality will see human rights discourse appropriating beings who were earlier strictly defined by biology. New subjects will be constructed along this interface between biology and the law.

¹ This article was constructed based on the presentation, “Do aborto à pesquisa com células-tronco embrionárias: o estatuto de embriões e de fetos e o debate sobre direitos humanos” given at the 8th Meeting of MERCOSUL Anthropology, workgroup #20, “Implementação de Direitos e Gestão da Vida” (The Creation of Life and the Implementation of Rights). It is part of the “Do aborto à pesquisa com células-tronco embrionárias: o estatuto de embriões e fetos e o debate sobre direitos humanos no Brasil” Project (From Abortion to Research with Embryonic Stem Cells: the status of fetuses and the debate over human rights in Brazil), which has received APQ1 funding from FAPERJ.

Associated with the concept of biosociality is that of biological citizenship, a term invented by Petryna (2004), which means “a demand for, but limited access to, a form of social welfare based on medical, scientific, and legal criteria that recognize injury and compensate for it” (Petryna, 2004, p. 261). The concept was created based upon the situation following the Chernobyl disaster, when people who had been affected by the reactor’s radioactive fallout demanded that the Ukrainian government provide them with social assistance and compensation based on medical, scientific and legal criteria. Rose and Novas (2005) argue that a new kind of biological citizenship is taking form in this era of rapid biological and genomic discoveries and biotechnological fabrication and biomedicine. New subjectivities, new policies and new ethical standards are forming the biological citizens of today. Rose and Novas claim that biological citizenship has both individualizing and collectivizing trends. It is individualizing to the degree that individuals reform their relationship with themselves in terms of understanding their somatic individuality. It becomes collective when the new forms of biosociality and ethical technologies are grouped around categories of bodily vulnerability, somatic suffering and genetic risk and susceptibility (Rose and Novas, 2005). Fassin believes that biolegitimacy creates the foundation of biocitizenship. Biolegitimacy is the “power of life as such” and is linked to the sense and worth given to life or to concrete lives, referring in this sense to the sacred character of life. The concept of biolegitimacy reflects upon how contemporary societies treat their members, to the value attributed to life in general and the worth attributed to lives in particular. Connecting the three concepts, the circulation of identity markers that is characteristic of biosociality is related to the revindications that emerge from a biological citizenship that is, in turn, founded upon biolegitimacy. These processes can be perceived throughout material analyzed below.

The present article thus seeks to debate the formation of new subjects and identities, looking in particular at those moments when new modes of recognition and legitimacy emerge from biomedical technologies as they are understood and absorbed by juridical technologies, particularly those technologies dealing with embryo production, anencephalic fetuses and stem cells and which recreate these beings in public spaces. In Rabinow’s concept of biosociality, nature is recreated as culture. This is the very problem exposed by the public debates regarding research with stem cells

extracted from human embryos and the abortion of anencephalic fetuses. By discussing the recognition of these new beings, these fetuses and embryos, juridical thought must ask itself if they are subjects of rights (Dworkin, 2003) to whom the law owes protection. Biological characteristics are emphasized in order to deny or attribute to these beings the status of personhood. This process illustrates the individualizing aspects of biocitizenship, but here we can plainly see that the constitution of subjects through biosociality is not restricted to biomedical discourse, but is also dependent upon juridical technologies. Boltanski's concept of the technofetus can help clarify our thoughts on these matters (2004). The technofetus emerges from the new medical technologies of conception (*in vitro* fertilization) and imaging (fetal visualization) and from the juridical technologies that regulate these beings. The technofetus has a central place in both the abortion debates and in the discussions regarding anencephalic fetuses, touched upon below. It also is central to the debates regarding the status of extra-corporal embryos, which in turn involves assisted reproduction and research with embryo stem cells.

The background to these controversies is the individualist configuration of values that is characteristic of modern Western cosmology and which, for the purposes of this article, we understand according to the works of Dumont. In modern individualist societies, the human being is the atomic, indivisible element, represented as a biological, thinking subject. Each human being is incarnate and humanity as a whole is the measure of all things. Society is the means and each individual life is the ends. Equality and liberty are central ideas to modern life and presuppose, in principle, the existence of the human individual. Each individual carries the essence of humanity. The individual is almost sacred and his/her rights are limited by the identical rights of other individuals (Dumont, 1997). The individual is a moral being, independent and autonomous. Essentially asocial, he is the vessel and vehicle of the supreme values (equality and liberty) and occupies pride of place in the modern ideology of humanity and society (Dumont, 1992). One cannot speak of biological citizenship or in biosexuality if there is no prior concept of the modern subject as an individual.

In the controversies regarding abortion or research with extracorporal embryos, the inherent rights of subjects are juxtaposed. On the one hand, we have women's prerogative to control their own body; on the other, rights attributed to fetuses and embryos, independent of the context in which they

are found. Fetuses and embryos become represented as autonomous subjects, as if they could dispense with a uterus and continue developing and existing.

Discourses situating fetuses and embryos in a lab as autonomous, rights-bearing subjects appear in the Federal Supreme Court Cases we will analyze below. The first of these is *Ação de Inconstitucionalidade* (Movement to Declare as Unconstitutional, ADI)² 3510 against Article 5 of Brazil's *Lei de Biossegurança* (Biosecurity Law), which authorizes the use of left-over embryos from assisted reproduction therapy for the production of embryonic stem cells. The second case analyzed here is *Arguição de Descumprimento de Preceito Fundamental* 54 (Accusation of Non-Compliance with a Fundamental Precept ADPF 54),³ which proposes to include the premature birth of anencephalic fetuses as a legal form of abortion.

In the first case, the rights of patients who are the potential beneficiaries of stem cell research are set against the rights of the frozen embryos. Here, we will examine the petition for and judgment of ADI 3510 and the public hearings regarding these processes. In defense of the right to life, we find such actors as the Catholic Church and other religious segments, pro-life movements, associated scientists and jurists. Questioning this right, we find feminist movements, liberal jurists, scientists in favor of embryonic stem cell research and (in the religious field) the non-governmental organization (NGO) Catholics for Choice. After presenting all the stages of the ADI 3510 debate, the article will then analyze the public hearings surrounding ADPF 54. We will then compare and contrast both lines of argumentation in our

2 According to the Federal Supreme Court's juridical glossary, an *Ação Direta de Inconstitucionalidade* (ADI) is an "act that has as its goal the declaration that a law or part of a law is unconstitutional; in other words, against the Federal Constitution. The ADI is one of those instruments jurists call 'a concentrated control of the constitutionality of the laws'. In other words, in theory, it is the direct contestation of legal norms". The entities and people who can propose this act include: the President of the Republic, the Chair of the Federal Senate, the Chair of the Chamber of Deputies. The chair of a legislative assembly or of the Federal District's legislative chamber, any state governor or the governor of the federal district, the Attorney General of the Republic, the federal council of the Brazilian Bar Association (Ordem dos Advogados do Brasil), any political party with representatives in the National Congress, any national-level labor organization. Available at: <http://www.stf.jus.br/portal/glossario/verVerbete.asp?letra=A&id=481> Accessed on 12/29/2014.

3 According to the Federal Supreme Court's juridical glossary, an *Arguição de Descumprimento de Preceito Fundamental* (ADPF) is "a type of action, exclusively judged by the Federal Supreme Court, which has as its goal the avoidance or repair of damage to a fundamental precept, resulting from the act of some public power. In this case, it is said that the ADPF is an autonomous action. However, this type of action can also be equivalent in nature to the ADIs, given that it can question the constitutionality of a norm using the Federal Constitution (in this case the pre-1988 constitution). ADPFs are regulated by Federal Law #9.882/99. The same powers that might enact an ADI can enact an ADPF. Available at: <http://www.stf.jus.br/portal/glossario/verVerbete.asp?letra=A&id=481> . Accessed on 12/29/2014.

conclusion. Values regarding autonomy, human dignity, and the right to life are central to this debate.

1. ADI 3510

Article 5 of Brazil's biosecurity law authorizes the extraction of stem cells from human embryos created for assisted reproduction, which are not viable, or which had been frozen for three or more years at the time the law was passed, with the "genitors" (sic) permission. Congress passed the law in March 2005 and then-President Luiz Ignácio "Lula" da Silva⁴ signed it into effect in October of that year. Before this, however, in May 2005, then Attorney General of the Republic, Cláudio Fonteles, authorized a Move to Declare as Unconstitutional (ADI). ADI 3510 questioned the constitutionality of Article 5 of the biosecurity law, arguing that this negatively affected the right to life and human dignity, the foundation stones of democratic rule of law. The press accused Fonteles of Catholic religious motivations. The Catholic Church entered into the case as an interested party, from the beginning.

1.1 *The Initial Petition*

Fonteles' petition questioned Article 5 based on constitutional arguments. The petition's central thesis affirms that "human life begins upon fertilization" (p.2). This affirmation was based upon testimony, scientific articles and a book published by the Brazilian National Bishops' Conference (CNBB), *Life: The first right of citizenship (Vida: o primeiro direito da cidadania)*, in which scientists defend the thesis that life begins at fertilization. The petition emphasizes the advances of research undertaken with adult stem cells and the laws protecting embryos in other countries. After arguing against the constitutionality of Article 5, the petition proposes that public hearings be conducted in the Federal Supreme Court and suggests as speakers nine scientists, six of whom were cited in the petition.

The petition concludes:

⁴ Luiz Inácio Lula da Silva, Brazilian President for the Workers' Party (PT), during two mandates, from 2003 to 2010.

- human life begins at fertilization: the zygote is generated by the meeting of 23 masculine and 23 feminine chromosomes;
- it begins at fertilization, and because human life is continuous, it develops;
- it continues to develop because the zygote, made up of a single cell, immediately produces human proteins and enzymes and is totipotent, meaning that it gives the embryonic human being the ability to form all of the human body's tissues, which differentiate and renew themselves, becoming a unique and unrepeatable human being.
- beginning with fertilization, the mother takes in the zygote and, from that point on, provides the environment for its development, an environment which is, in its final stage, the uterus. It is not, however, the uterus which becomes pregnant but the entire woman, at the moment of fertilization. (p. 10-11)

These arguments are employed to establish that an embryo is a human being and that Article 5 of the biosecurity law thus violates the right to life and breaks the foundation upon which the democratic rule of law resides: the preservation of human dignity.

The petition and its justification are grounded in biological data in order to demonstrate the status of the human embryo as a person and as a human life. This is the “individual” described by Dumont (1992) as an asocial and autonomous being, the atomic reference of value in modern western culture. Uniqueness and autonomy characterize this zygote as an individual.

The hearing with the scientists

Attending to the petition's proposal, the case's relator in front of the Federal Supreme Court, Justice Carlos Ayres Britto, convoked the first public hearing for the benefit of the Court on the 20th of April, 2007. 22 invited specialists attended, almost all professionals, researchers and professors in the biomedical sphere, the sole exception being an anthropologist with a post-doctoral degree in bioethics. The testimony was divided into two blocks: one including those chosen to testify by the Attorney General of the Republic and the CNBB and the other suggested by those “accused by the Movement to Declare as Unconstitutional”: “the National Congress, the President of the Republic and friends of the Court”. According to the case's sponsor, the hearing's goal was to seek “a jurisdictional concept for the word ‘life’” and for the expression “human dignity”.

Examining the trajectories of both groups of specialists, we can see that the greater part of those against the use of embryonic stem cells in research were involved with the institutions of the Catholic Church. This is not surprising, given that the CNBB helped to choose the invited specialists who were to testify.⁵

The synthesis presented below focuses on the arguments regarding the condition of the embryo in the laboratory, principally with regards to questions about whether or not it is a life or a person. Here, we will pay special attention to the underlying ideologies informing these arguments.⁶ The discourses allow us to understand how these bioentities or somatic identities actually emerge.⁷ The values of modern Western individualist ideology could be identified in both groups of expert speakers. The life of an embryo was understood to be sacred as are the rights of individuals in Western ideology (cf. Dumont, 1997). The block opposed to the use of embryos in research surrounded itself with biological arguments and refuted other biology-based arguments offered up by the block that favored research. Both groups understood nature to be the foundation stone of reality (Laqueur, 1992)⁸. The group that questioned the biosecurity law made great use of bioethical discourses. Those in favor of it adopted a relativistic discourse, preoccupied with the dynamics and consequences of research while their opponents' strongest argument had to do with the sacredness of life and the rejection of relativism in the face of sacred realities. However, this group also based their definition of the statute on biological markers.

5 We analyzed the Lattes CV (the official CV all Brazilian scientists maintain with the Federal Government) of all the people invited to give testimony. Where this CV did not exist, we searched for similar data via the internet. With regards to scientific production and participation in research with stem cells, it was discovered that the group in favor of research using embryonic stem cells was composed (except for the anthropologist) of researchers engaged in stem cell studies, many with quite impressive scientific credentials. In the group that was against the researchers, there were few who had participated in stem cell research. The arguments of these individuals thus centered on the positive results obtained with therapies conducted using adult stem cells – research in large part undertaken by members of the first group. The scientific production of the second group was much less in comparison with that of the first group and many of the second group's members were engaged in issues of bioethics.

6 This hearing is described in Luna (2010b).

7 Bioentities are somatic entities constituted through emphasizing procedures involving bodily, medical, aesthetic and hygienic care (Ortega, 2003).

8 Laqueur identifies the emergence of a new episteme in illuminism whereby nature is understood as the bedrock foundation of reality. "Biology – the stable, ahistoric and sexed body – is understood to be the epistemological foundation of prescriptions for social order" (1992, p. 6).

The group which opposed the research attempted to fuse the concepts of life and personhood, creating a base for their arguments. They considered the human embryo to be a living being in an initial stage of life, based on the fact that certain vital biological processes. These were understood to represent true human existence and thus establish the embryo as a human person with all due legal rights. The concept of life itself is taken from biography (cf. Waldby, 2002)⁹ and is sacralized. The anti-research group wanted to establish fertilization as the natural beginning of human life, in contrast to other biological referents which might be used but which were accused of being arbitrary.

Some of the specialists of the group that favored the use of embryos in research got around the definition of life by considering its conceptualization to be a “false problem” or an unanswerable question. A smaller number of specialists proposed the establishment of the nervous system as the beginning of life, looking to the already established medical definition of “brain death”. The embryo’s viability was also contextualized as life inside the mother. Some considered this relationship to be the beginning of human life. The non-viability of the embryos used in research was also repeatedly touched upon, and it was pointed out that this would eliminate their human character as established by the opposing group. The tiny size of the embryos was also employed as a rhetorical tactic to negate their status as people. Three distinct representations of the embryos could be found in the pro-research group. The first emphasized continued vital processes instead of individual biography or, in the words of Waldby, a “raw biological vitality” (Waldby, 2002)¹⁰. The second focused on the embryo’s relationship with the environment that allowed it to continue to exist (Fyfe, 1991)¹¹ : in other words, its relationship to the mother, which guaranteed its condition as a person

9 Those who opposed embryonic stem cell research understood an embryo’s life as biographical: the beginning point of a human narrative which should be allowed to follow its social course (Waldby, 2002, p. 313)

10 For those who defended research with embryos, the embryo’s life was a form of raw biological vitality. The embryo is not killed in this view of things. Rather, its vitality is re-channeled and reorganized (Waldby, 2002, p. 313).

11 In his analysis of abortion legislation in England between 1803 and 1967, Fyfe reveals a gradual separation of the fetus from its mother and the emergence of the concept of fetal viability (i.e. its capacity to be born alive). During this period, then, the fetus was redefined in the terms of medical knowledge as a limiting point for the classification of crimes.

(Salem, 1997)¹². The third representation focused upon the emergence of the nervous system, both as the parameter for brain death (and thus, presumably, for birth) and as the first sign of rationality (Luna, 2010b) or sensibility (Salem, 1997).

The anti-research group based their testimony on the principle arguments to come out of the bioethical field regarding the status of embryos. Claudia Batista and Dalton Ramos repeated the formula used in Church documents regarding the embryo: “coordinated, continuous and gradual development” (Pontifícia Academia para a Vida, 2000). The emphasis here is on the beginning of individual human life. In the group who supported the bio-security law, anthropologist Débora Diniz shifted the discussion towards ethics in research. In this group, there were three positions. The first situated life as a continuous generative process, without answering the question of when it began. The second took into account the embryo’s context, pointing out that it can only live if it is implanted in maternal womb (this might be labeled the relational perspective). The final position drew an analogy with brain death in order to invoke the establishment of the nervous system as the beginning of life. The pro-research group’s principal strategy was to avoid the question of life and to concentrate on the origins of the embryos and their fate. To attribute dignity to this fate in the possibility of saving lives was also a way of appealing to religious values.

The anti-research group wanted to make the juridical, political and biological definitions of an embryo coincide with the concept of personhood, with this status being conceded to the embryo from the moment of fertilization. On the other side of the debate, Debora Diniz claimed that it was incorrect to believe that a biological phenomenon – in this case, fertilization – could be sufficient to decide moral questions such as how embryos are to be handled. Appeals to nature were present on both sides of the debate and I will explore these in more depth below. Right now, I want to argue that the use of biological references in order to define what is a person is related to the circulation of the identity terms that Rabinow (1999) explores, as well as the

12 Salem observes that an *in vitro* embryo does not have this relationship, which permits it to be considered on its own terms. In this view of things, implantation in a uterus would be the only criterion which creates the necessary relationship for life (1997, p. 85, 88). Also according to this author, embryos feel nothing before they generate a nervous system.

notion of biological citizenship: the sacredness of human life is emphasized at all times (Dworkin, 2003; Fassin, 2009). Subjects emerge through juridical and biomedical technological apparatuses in the cases studies here, exactly as these authors point out.

Judgment and the justiceial vote

The Federal Supreme Court began its first session on the 5th of March, 2008, when Justice Carlos Ayres Britto (the relator), Justice Ellen Gracie (then president of the court) and Justice Carlos Menezes Direito took to the bench. Justice Carlos Menezes Direito asked to examine the process. Judgment was forestalled and the case was taken up again in two sessions on the 28th and 29th of March, 2008. Six Justices voted in favor of the law's constitutionality and five partially questioned it. Of these five, three claimed that the use of embryos in research attacked the right to life. The other two restricted themselves to suggesting that organs should be created to oversee and supervise this research. The synthesis that we provide below shows what the voters thought with regards to the moment when life begins.

Rejection of the debate about when life begins

Four justices considered the debate regarding when human life begins to be of marginal interest. According to Justice Ellen Gracie, "There is no constitutional definition regarding when human life begins and it is not the role of the Supreme Court to establish concepts that are not specifically covered by the Federal Constitution. We are not an Academy of Science" (p. 2).¹³ Gracie also dismissed the idea that the law violated the right to life.

Justice Carmen Lucia considered a juridical ruling on when life begins to be unnecessary in order to guarantee rights to embryos or fetuses (p.6). The principle of human dignity extends beyond the person and attaches to the entire species: all those who are a part of humanity – including embryos and the dead, who are not considered persons under the law – are contemplated by this value and are protected by the right to it (p.37).

¹³ All of the votes were collected as isolated documents and for this reason an independent pagination is used to reference the quotations.

Justice Joaquim Barbosa rejected the attempt to define the point at which life begins. A biological definition of this sort wouldn't solve the issue at hand (p.1). This original affirmation was an attempt to remove the debate from a purely biological sphere and, instead, shift it towards a verification of the legitimacy of creating an exception to the law's protection of the right to life (p.1). The right to life and the legal safeguards over it are two aspects of one single right which is not absolute (p.2). Barbosa claimed that there are different degrees of legal controls over human life during different phases of the life cycle: fertilization, gestation, birth, development and death (p.2). He contrasted the rights of an embryo and the right to life of people who had incurable diseases (p.4).

Justice Gilmar Mendes thought it unnecessary to discuss the points where human life begins and ends for the purposes of legal protection (p.5). These points were not yet clear and there was no consensus about them in scientific, religious, philosophical, or vulgar thought. He concluded that in the debates regarding euthanasia, abortion and research with embryos, there were no morally correct, universally acceptable answers (p.6). Mendes also observed that it is not necessary for one to be a subject of rights in order for one's life to be protected by the law (p.6).

Relativization of the debate about when life begins

In the opinion of the relator, Justice Carlos Britto, the beginning of human life coincides with the instant of fertilization (p.35). However, this justice also observed that "the beginning of life is a reality that is set apart from those things that constitute a physical or natural person... at least according to the Brazilian Juridical Code" (p.36). Britto cited the Brazilian Civil Code, which states that civil personhood begins at birth, but the justice also pointed out that the law protects the rights of the unborn from conception on (p.22). Personhood, in this view, is predicated on "who a person is in their biographical dimension and is thus more than simple biology" (p.22). Britto employed constitutionalist Richard Dworkin's concept of proportional juridical tutelage: "The law protects in different ways each step of the biological development of the human being" (p.28). Opposing the argument presented in the petition and by the scientists at the hearing, Britto

affirmed that embryos, fetuses and human people are distinct and separate realities. For this reason “an embryonic human person” doesn’t exist, “but only embryos of human people” (p.34). The human person is understood here to be the result of this metamorphosis: she/he does not exist before it occurs (p.34). This concept of metamorphosis sets Carlos Britto’s concept of humanity apart from the notion of “potentiality” implicit in the “life begins at fertilization” argument, which sees the realities of later stages of life as implicit or contained in the seed. Britto also differentiated between the use of embryos in a lab and the interruption of pregnancy: in the first case, there is no gestation underway and thus the laws criminalizing abortion do not apply. The embryo conceived in a laboratory and confined *in vitro* is not subject to reproductive progression (p.40). Britto likewise emphasized the importance of gestation to the continued life of a fetus (p.54) and he traces a parallel between the criteria for establishing brain death and the embryos referred to by the bio-security law: in the embryo’s case, it does not have a nervous system, unlike a brain in gestation. Finally, this justice concluded that without a brain, there can be no human person, even potentially. In the context of the bio-security law, then, an embryo is “a vegetative life that comes before the development of the brain” (p.62s).

Justice Marco Aurelio also took a relativistic perspective with regards to the question of when life begins by suggesting that there is no escaping an opinionated perspective with regards to this question. He listed the various ways of marking this beginning: conception; implantation of the fetus in the uterus; formation of individual characteristics; quickening, or mother’s first perception of the fetus’ movements; viability; birth (p.4-5). His examples were all based on physical markers of development that are characteristic of the constitution of the person in modern western cosmology (cf. Conklin and Morgan, 1996).¹⁴ Marco Aurelio also distinguished between stem cell research using embryos and abortion (p.6-7). Article 5 of the bio-security law specifies that viability is not an issue, because the embryos in question would never be implanted in a uterus and the only ones to be used will be those which have

14 Both sides of the abortion debate tend to seek fixed markers and structures in order to define when personhood begins. The irreversible nature of these criteria makes the question of whether or not a fetus is a person an “all or nothing” affair. If the fetus is even in the slightest considered to be a person, it has rights. The condition of personhood in this debate is, in any case, always established by recourse to biology (Conklin and Morgan, 1996, p. 660, 665)

been frozen for three years or are otherwise not viable (p.8). In this view of things, the beginning of life presumes not only fertilization, but viability, which does not exist without pregnancy (p.9). According to this justice, “it is controversial to claim that the constitution protects life in general, or even *in utero* life in any phase of existence” (p.9) and he brought up the example of abortions permitted to save the mother’s life (p.9) or to end pregnancies that result from rape (p.10) as an example of this, as well as the case of *in vitro* embryos that do not necessarily end up implanted in a womb, let alone in births. The juridical person who has rights is thus dependent upon live birth (p.10). In *in vitro* fertilization, the people who furnish the eggs and sperm are not obliged to bring all resulting embryos to term (p.10), something which would turn women into mere “incubators”, negating the family planning stipulations of the Brazilian constitution (p.11).

Justice Celso de Mello proposed judging this controversy from the perspective of human rights. He didn’t question the “sacredness and inviolability of the right to life” (p.3) and emphasized “the postulate of the dignity of the human person” as the “true source of value” of the constitutional order (p.4). He defended the State’s secular nature against the religious perspective with another principle of constitutional order (p.5). This justice did not see “an ontological parity, in the normative sphere, between an embryo... and a born person” (p.30). He affirmed that the right to life “can possibly be pondered by the State, in the face of situations that threaten this basic right”. These circumstances, however, conflict (p.34) with the interests of people afflicted with incurable diseases who might gain relief from the fruits of research with embryonic stem cells (p. 35). Mello also reminded the court that the right to life from conception onward has not been established by the Brazilian constitution (p.35).

Justice Cezar Peluso took an different position from the others by defending the thesis that life does not exist in frozen human embryos. In his deposition, he defines as “theoretical subjects of the right to life” the following categories: frozen embryos, implanted embryos and the fetus and adult humans or human children who carry those attributes understood by the constitutional order to signify the quality of personhood (p.9). Peluso looked at whether there different degrees of constitutional protection for “people actually given life in all its plenitude” and embryos (p.9) and concluded that

the frozen embryo only participates to a very basic degree in the protections given to the human dignity of human adults (p.9). The object of the court's tutelary power with regards to life is only the life of a human person. The justice criticized the argument of the anti-research faction that life can be defined as the continuous development of the life cycle from the embryonic stage on: this did not apply to frozen embryos (p.27). According to Peluso, the life cycle perspective "does not consider or depreciates the biological function and the corresponding juridical-normative condition... of the female uterus" (p.25) which, to the justice's mind, was reduced by the petitioners to the status of "an adequate environment" and "source of necessary nutrients" for fetal development. "Intra-uterine life also has constitutional value" (p.26). The implantation of the fertilized egg in the uterus is a condition of its development and constitutes the criterion for the definition of the beginning of life.

The beginning of life at fertilization, understood as a fact

Three justices argued that life begins at fertilization and affirmed that life and personhood began at the same time. The three defended the thesis that obtaining stem cells by destroying embryos violated the right to life and attacked human dignity. Aside from questions regarding research regulation (which would affect assisted reproduction), these three justices would only allow proven non-viable embryos (those which had stopped dividing on their own for over 24 hours) to be destroyed for stem cell harvesting. With regards to frozen embryos, these justices would only allow techniques which would extract a cell without damaging the embryo, with further stem cells being cultivated from this cell.

Justice Menezes Direito wrote a technical opinion which referenced scientific literature regarding assisted reproduction and embryo cultivation. His particular original contribution was his analysis of the thesis defended by the group which favored embryo use in research: the philosophical discourse regarding the intermediate status of the embryo, which was supported by analogies referencing death (p.58). In this discourse, the embryo was understood as non-human life and the law cannot protect the right to life in this case because there was simply no person involved (although the protection of dignity could still be recognized). This intermediate status of the embryo

was associated with its incapacity for moral or rational thought. The justice insisted that the Supreme Court explain its position regarding the beginning of life. He criticized the metamorphosis model adopted by Carlos Britto and defended the concept of potentiality (p.47). Menezes Direito claimed that the embryo was already a potential being and would only not develop if prevented from doing so by outside circumstances (p.50). He also affirmed that life regulated the protection the embryo deserved and opposed the notion that life without personality was not human life. Personality was an attribute of life: not the other way around (p.59). Finally, Menezes Direito claimed that embryos were living based upon the characteristics of autonomous development, genetic patrimony and diversity (p.59).

Justice Ricardo Lewandowski's arguments were in many ways similar to those of Menezes Direito. With regards to human embryo stem cells, he believed that there were controversies because harvesting the material "required destroying a living organism that resulted from the fertilization of human gametes" (p.5), which some didn't consider to be "persons in the moral or juridical sense". This research represented a threat to the human species (p.6) and Lewandowski denounced what he considered to be the evil consequences of this scientific activity. He proposed ethical and juridical limits for science in order to avoid the transformation of people into things or objects (p.11). The justice also argued that, in the juridical sphere, life begins at conception according to the American Convention on Human Rights (or the Costa Rican Pact) of 1969, signed by Brazil in 2002.

Eros Grau wrote a synthesis opinion, claiming that the Brazilian Civil Code as stipulating that the civil person begins at live birth, "but the law protects the rights of the unborn from conception on" (p.4). Given this, the unborn are rights-bearing subjects under law and that they should logically thus be considered as people. Human dignity was understood by Grau to exist before birth (p.4) and "all beings capable of acquiring rights are people". The capacity to exercise the rights of legal personhood depends upon birth (p.5), but the unborn are indeed part of humanity. The constitution thus guarantees them protection of their dignity and the right to life (p.6).

The Supreme Court's ruling in the ADI 3510 case made the debate about the origins of life even clearer. Individual biography (identified as human life) as opposed to the simple biological process of cellular multiplication

were the two views of embryos present during the hearings and judgment of this case. By focusing on the circulation of terms of identity that is present in processes of biosociality, we will see in the discussions I present below that the focus on anencephalic fetuses during the ADPF 54 hearings moved in a very different direction from that seen regarding embryos in ADI 3510. The characteristics attributed to anencephalic fetuses in order to concede or deny them personhood were rooted in biology, but pointed to different aspects of humanity.

ADPF 54

In June 2004, the National Confederation of Health Workers (Confederação Nacional de Trabalhadores da Saúde) proposed ADPF 54 to the Federal Supreme Court in order to ensure that pregnant women carrying anencephalic fetuses would have the right to therapeutic early delivery and to ensure the right of doctors to perform this procedure, once this anomaly was detected, without requiring judicial authorization (Fernandes, 2007).

Anencephalic fetuses are known as brainless babies. Anencephaly is a congenital deformation characterized by total or partial absence of the brain and the skullcap (FEBRASGO, 2007). It originates in a failure during neural tube closure in embryonic development. The fetus does not develop brain hemispheres and its cephalic matter is exposed without bones or skin covering. An anencephalic fetus or baby is blind, deaf, unconscious and unable to feel pain. If not stillborn, the prognosis is death within hours or days after birth (National Institute of Neurological Disorders and Stroke, 2010). It is the most common lethal central nervous system abnormality. More than half of anencephalic fetuses are born dead (Fernández et al., 2005). A document published by FEBRASGO (the Brazilian Federation of Gynecology and Obstetrics Associations – Federação Brasileira das Associações de Ginecologia e Obstetrícia) claims that anencephaly is 100% lethal (2007). This biomedical discourse constructs anencephaly as incompatible with human life, but certain segments of the Brazilian public have questioned this definition.

During the four sessions of public hearings regarding ADPF 54, there was a clear-cut opposition between speakers who took the pro-choice line of reasoning adopted by ADPF 54 and those speakers who were pro-life. Both

sides made use of human rights discourse. As was the case with stem cell production using human embryos, the two groups organized around distinct identities in order to put forth their claims with regards to human right, in a process that neatly illustrates the dynamics of biosociality.

The ADPF 54 public hearings¹⁵

ADPF 54's relator, Justice Marco Aurelio Mello, granted a preliminary injunction recognizing the right of pregnant women carrying anencephalic fetuses to therapeutic anticipation of birth on July 1st, 2004. This injunction was repealed by a Supreme Court plenary October 20th of the same year (Fernandes, 2007)¹⁶. The relator's delay in convoking public hearings was understood to be due to his desire to wait for the final decision of the Supreme Court regarding ADI 3510.

The hearing's four sessions were conducted on the 26th and 28th of August and on the 4th and 16th of September 2008. 27 speakers were heard, of which eleven were pro-life and sixteen pro-choice. Of the eleven pro-life speakers, three came as experts and the others represented for six entities and associations. Two religious organizations were present on the pro-life side: the CNBB, whose two representatives (the national adviser of the CNBB's Episcopal Commission for Life and Family – Comissão Episcopal para a Vida e a Família – and the president of the Union of Catholic Jurists of the Archdiocese of Rio de Janeiro – União de Juristas Católicos) shared their time and two representatives of the Brazilian Medical Spiritist Association (Associação Médico-Espírita do Brasil). Also speaking were representatives of the Pro-Life and Pro-Family Association (Associação Pró-Vida e Pró-Família), the National Citizens' Movement in Defense of Life: Brazil Without Abortion (Movimento Nacional da Cidadania em Defesa da Vida – Brasil Sem Aborto), the Association for the Development of the Family (Associação para o Desenvolvimento da Família) and a federal deputy who was then president of the Parliamentary Front for the Defense of Life (Frente Parlamentar em

¹⁵ I would like to thank Debora Diniz and the NGO Anis (Bioethics, Human Rights and Gender Institute) for facilitating my access to the hearing transcripts.

¹⁶ This hearing took place in April 2012, but will not be dealt with in the present article. We believe that looking at the groups present during the public hearings will contribute more to the debates regarding biosocialities and the constitution of social subjects through discourses regarding health and illness.

Defesa da Vida). Three experts were pro-life speakers: two in gynecology and obstetrics and a pediatrician who specialized in neurology.

Among the sixteen pro-choice speakers, two were public officials: Health justice Jose Gomes, and the justice of the Special Secretariat for Women's Policies and president of the National Council of Women's Rights (Conselho Nacional de Direitos da Mulher – CNDM), Nilcéa Freire, as well as a federal deputy who appeared as a specialist in gynecology and obstetrics. Also on the pro-choice side were five representatives from NGOs: Anis (Bioethics, Human Rights and Gender Institute – Instituto de Bioética, Direitos Humanos e Gênero), the People School: Communication Inclusion (Escola de Gente - Comunicação em Inclusão), the Feminist Health Network (Rede Feminista de Saúde), Citizenship, Study, Research, Information, Action (Cidadania, Estudo, Pesquisa, Informação, Ação – CEPIA), and Conectas Human Rights and the Human Rights Center (Conectas Direitos Humanos and the Centro de Direitos Humanos: one representative spoke for both NGOs). Representatives of scientific and professional associations councils also testified for the pro-choice side: Federal Council of Medicine (Conselho Federal de Medicina – CFM), the Brazilian Federation of Gynecology and Obstetrics (Federação Brasileira das Associações de Ginecologia e Obstetrícia – FEBRASGO), the Brazilian Society for Fetal Medicine (Sociedade Brasileira de Medicina Fetal), the Brazilian Society of Genetic Medicine (Sociedade Brasileira de Genética Médica), the Brazilian Society for the Progress of Science (Sociedade Brasileira para o Progresso da Ciência – SBPC) and the Brazilian Association of Psychiatry (Associação Brasileira de Psiquiatria). Finally, two religious groups participated on the pro-life side: a bishop from the Universal Church of the Kingdom of God (Igreja Universal do Reino de Deus) and the president of the NGO Catholics for Choice (Católicas pelo Direito de Decidir).

Medical doctors dominated in terms of profession, with 16 among the 27 speakers. The composition of the speakers contrasted with that of ADI 3510, which called in 22 experts (11 on each side), but no members of NGOs, social movements, or representatives of scientific or professional associations (Luna 2010b).

Below, I will outline core themes from the exhibitions. These reveal their origins in a common configuration of values, although their arguments are presented in symmetrical fashion. These themes are: life; the relationship between life, anencephaly and brain death; the human condition; dignity;

autonomy/choice; disability, eugenics, and degrees of anencephaly; technical descriptions of anencephaly; the right to life; the right of mothers/families; other rights; the contrast between abortion and therapeutic anticipation of delivery; maternal risk and suffering; the secular state. In general, questions revolved around whether or not anencephalic fetuses could be considered to be living human beings and whether they were thus due rights or not.

Luis Roberto Barroso, a lawyer who represented the National Confederation of Health Workers, presented seven theses in order to synthesize the case at the end of the hearings. Using these, one can identify the main axes that directed the debate:

1. The 100% certainty of the diagnosis of anencephaly and its irreversibility.
2. Anencephaly's 100% mortality rate. Barroso refrains from commenting on the case of "Marcela" considering it to be exceptional¹⁷.
3. Gestation of anencephalic fetus is a risk to women's physical and mental health.
4. The absence in Brazil of any record of anencephalic fetuses organs being used in transplants. Such transplants are not feasible because the other organs of the fetus may carry defects.
5. Barroso proposes to treat the interruption of anencephalic pregnancy as the therapeutic anticipation of delivery and not as abortion, given that the fetuses are brain dead and the criterion for death under Brazilian law is brain death. Given that anencephalic fetuses are not really alive, they cannot be aborted and their removal is a therapeutic procedure.
6. The difference between anencephaly and physical deficiency, given that there are no anencephalic children or adults, and the lack of relationship with other humans in the case of anencephaly. Barroso classifies arguments relating to eugenics in this context "empty rhetoric"
7. In view of the testimony of the women who opted for therapeutic anticipation of delivery and of others refused, and given that both groups

¹⁷ This is the case of Marcela de Jesus, a girl diagnosed with anencephaly who survived for one year and eight months. Her mother decided to carry her pregnancy to term and is seen as an example by the Catholic Church, receiving support from this institution. Pro-life experts used this example to argue that there are degrees of anencephaly, corresponding to different prognoses for life and that these degrees are impossible to detect with ultrasound. Therefore, pregnancies involving anencephalic fetuses should not be terminated. Some pro-choice experts believed that Marcela was not anencephalic, however, but suffered from merocrania, a more rare anomaly which allows for longer survival and which is subject to intrauterine identification. This distinction was discussed by several speakers during the hearings.

claim to be satisfied with their decisions, Barroso asks that Supreme Court to ensure these women's right to live in accordance with their choices, values and beliefs. "Each one should suffer as she wishes and not as the State imposes" (16th september, p. 38-39).¹⁸

Those who supported ADPF 54 sought to prove the absence of human life in anencephalic fetuses. If there was no life in these fetuses, early delivery or the termination of pregnancy would not be abortion. There are two cases in which abortion is exempt from punishment in the Brazilian Penal Code (both date from 1940): when the mother's life is at risk and in pregnancies resulting from rape. If the Supreme Court determined that anencephalic fetuses were not alive, then pregnant women and their doctors could decide to terminate these pregnancies without judicial authorization and without need for changing Brazil's laws (the prerogative of the legislative branch).

In defence of life

Those speakers opposed to early delivery of anencephalic fetuses argued that these possessed human **life** and that they thus needed to be defended and preserved. According to Father Luiz Antônio Bento, one of the CNBB representatives, individual life is "an unalienable personal good" but also "a social good that belongs to all". As such, it's society's obligation to "defend and promote these rights of the human person, of the fetus that has this anomaly" (26th of august, p. 4). Dr. Marlene Nobre from the Brazilian Medical Spiritist Association also defended the idea of life as a granted good. After describing scientific research that demonstrated that cells were designed by a higher intelligence¹⁹, she then affirmed that "Life... is a granted good.... It is not religion that says this, but science" (26th of august, p.30). The view of life as a juridical good or blessing appears in law (cf. Fernandes, 2007), but the argumentation of the representative of the Brazilian Medical Spiritist Association is original in that it invokes the authority of science, and not that

¹⁸ The four sessions were transcribed as separate documents and, for this reason, I present the page numbers with the date of the session.

¹⁹ She cites the book *Darwin's Black Box*, which argues for intelligent planning (also known as intelligent design), according to which cellular structure and functions follow an efficient plan. The book seeks to demonstrate that Darwin's theory of natural selection does not explain the origins of these structures and that the way in which these structures are arranged could only be part of a planned act (see a critical review of this book in Martins, 2001): this would be the superior intelligence that Doctor Marlene Nobre refers to.

of religion, in order to show that life is a blessing. Religious views consider life to be a gift from God (cf. Franklin, 1995):²⁰ Dr. Nobre's view mix science and religion. The anti-choice group wanted to show that fetuses are alive by moving away from the comparison with brain death. Cintia Macedo Specian, a pediatrician specializing in neurology, cited an article that showed that anencephalic babies can live for more than seven days while showing signs of cerebral activity. She concluded, based on this, that one cannot diagnose brain death from cerebral electric activity (4th of september). A member of the public at the hearings pointed to the presence of life and the human condition of the anencephalic fetus: "Can we consider this child to be stillborn even if it is crying and moving and giving all signs of life?" (Dóris Hipólito Pires of the National Association of Women for Life – Associação Nacional Mulheres pela Vida, on 16th of september, p. 36).

Many of the pro-life speakers justified their position based on the human condition of the anencephalic fetus. According to Luiz Antônio Bento of the CNBB: "the fetus carries the human genome, all of the genetic data is present in the life of this individual" (on 26th of august, p. 6). Genetic essentialism is the basis of this declaration (cf. Salem, 1995).²¹ Others alleged that the anencephalic fetus is still conscious on some physical level. Doctor and adjunct professor Rodolfo Acatauassú Nunes (National Pro-Life and Pro-Family Association – Associação Nacional Pró-Vida e Pró-Família) believed that there is "a certain degree of primitive consciousness" and "the possibility that this nucleus of primitive consciousness is distributed between the diencephalic, mesencephalic and encephalic trunk". Such structures are present in anencephalic fetuses and, for this reason, their consciousness, demonstrated on the physical plane, indicates that they partake in the human condition. Doctor Irvênia Luiza de Santos Prada (Brazilian Medical Spiritist Association) also made a similar statement: "anencephalic fetuses have a neural substrate which carries out their vital functions and serves as a form of consciousness. For this reason, the abortion of these fetuses

20 Notions of life or vital force are frequently connected to belief in the supernatural, the divine and the sacred and these understandings are made more explicit in relation to death. These attributes characterize both the Judeo-Christian and classical understanding of life. According to the first of these traditions, life is interpreted and valued as a gift from God (Franklin, 1995, p. 1346).

21 According to Salem: "it is the gens which, substituting 'blood' or the biological, now appear embodying a reality that came before human designs, or an essential truth that imposes itself upon the superficial appearances of culture" (1995, p. 66).

is counter-indicated, as well as their use for organ transplants” (em 26th of august, p. 29). The physical presence of characteristics that were earlier understood to be part of the spirit or the mind, such as consciousness, refers to the concept of physicalism: “the belief that corporeality in itself is a self-explaining dimension of human being” (Duarte, 1999, p. 25). In these examples, consciousness demonstrated on the physical plane is a sign of humanity. The human identity of the anencephalic fetus is demonstrated through the biological substrate which proves the presence of human consciousness. Here we find a series of meanings that link immanent values to the presence of a rational human consciousness: rationality is understood as having a physical basis, recognized through biomedical techniques of fetal diagnosis.

More abstract dimensions of these values referencing the human condition are also invoked. Father Luiz Antonio Bento mentioned the value of human dignity with respect to the anencephalic fetus: this would be inherent as it is inherent to all individuals of the human species. (26th of august). The value of autonomy was also brought up by Father Bento: “a fetus with anencephaly is not relative to anything or anyone and does not depend on another or others for its dignity” (26th of august, p. 4). This autonomy granted to anencephalic fetuses was denied to pregnant women, however, by Doctor Ieda Therezinha do Nascimento Verreschi (Association for the Development of the Family – Associação para o Desenvolvimento da Família): “the fetal-placental unit – which is unique and has a sick component – must be respected” (4th of september, p. 26). The woman who is pregnant with an anencephalic fetus is thus understood to be part of a “fetal-placental unit”, but it is the sick component of this unit – the fetus – which truly matters here. The right to life of an anencephalic fetus is here opposed to the mother’s rights: “the life of an anencephalic fetus overrides any right of already formed people – in this case, the mother. Life is a fundamental good. Life is a blessing granted. It is science itself that tells us this” (Marlene Noble, Brazilian Medical Spiritist Association, 26/08, p. 31). Once again, scientific authority is here invoked in order to support transcendent truths. The rights of a pregnant woman are encompassed by the rights of the being she contains. Elizabeth Kipman Cerqueira, a specialist in Obstetrics and Gynecology, questions the liberation of anencephalic abortions: “Who is more important:

the fetus or the woman? The fetus – of this we are certain” (16th of september, p.1). From the pro-life group’s perspective, a pregnant woman’s presumed suffering does not justify the “sacrifice of her son’s life,” in the words of Father Bento (CNBB). Congressman Luiz Bassuma (of the Workers’ Party – PT – at the time of the hearings), president of the Parliamentary Front for the Defense of Life and Against Abortion, was one of many who invoked the **inviolability of the right to life** as established by the Brazilian Constitution (28th of august). Several other speakers compared the condition of anencephalic fetus to that of the **physically disabled**: “the anencephalic fetus is deficient; he is not undead” said biologist Lenise Aparecida Martins Garcia (National Citizenship Movement in Defense of Life: Brazil Without Abortions, 28th of august, p. 49), arguing that anencephaly was a variable condition that allows for different lengths of survival after birth. To support her argument, she mobilized statistical data and the case of Marcela de Jesus. Garcia also remarked upon the inability to determine, with certainty, the degree of anencephaly in intrauterine examinations. Gynecology and obstetrics specialist Dernival da Silva Brandão rejected the euphemism “therapeutic anticipation of birth”, claiming that the technical term, used in health care, was abortion: “the withdrawal of the child before it is viable” (4th of september, p.52).

The protection of the anencephalic fetuses supposedly demand on account of their biological characteristics illustrates the concept of biocitizenship (Petryna, 2004 Rose and Novas, 2005). The attribution of rights here occurs through legal devices that create a technofetus (Boltanski, 2004) and which are integrated into networks of circulation of identity in terms of biosociality.

Pro-choice

The same themes were repeated among the speakers in favor of ADPF 54, although with opposite approaches. The concept of **life** was symmetrically associated with **brain death**, the defining mark of death in Brazilian law. José Aristodemo Pinotti, a professor of obstetrics and gynecology and a federal Congressman (Democrats – Democratas; DEM) said: “An anencephalic fetus has no brain, no potential for life “ (28th of august, p.42). Similarly, Rafael

Thomaz Gollop (SBPC, gynecologist and obstetrician) noted that: “The anencephalic fetus is a brain dead but has a heartbeat and is breathing.... It has no cortical activity... [and] has is only in a state of vegetative survival” (28th of august, pp.54s). The representation of the anencephalic fetus is that of an ambiguous figure: a dead body that is nevertheless breathing and demonstrating a heartbeat.²² According to Lia Zanotta Machado (Feminist Health Network – Rede Feminista de Saúde – and senior anthropology professor), there would not “even be any **legal interests** to consider” because the expected child will not legally appear (4th september). Gollop quotes the CFM resolution on brain death, applying it to anencephalic fetuses: “Infraspinal signs of reactivity – ie., breathing and heartbeat – do not prevent a diagnosis of brain death” (28th of august, p. 54). Signs of vegetative life are not enough to avoid a diagnosis of brain death: the identity of a living human being depends upon the verification of cortical activity, thus invoking another sign produced by the biological body in support of a position regarding the status of anencephalic fetuses.

The **human condition** of this fetus is questioned: “this baby will not think and it will not be a human person the law protects” says Luiz Roberto D’Avila of the CFM (28th of august, p.4). In the words of Gollop (SBPC), “it has no skull or brain. Therefore, it cannot have any kind of feeling, because there is no station to process this” (28th of august, p. 56). The lack of the possibility of creating human relationships, represented by feeling and thinking, shifts the anencephalic fetus away from human personhood as protected by law. Claudia Werneck, representative of the School for People: Communication and Inclusion (an NGO that works towards the social inclusion of people with disabilities) established the crucial point for the defense of terminating anencephalic pregnancies. After stating that “humanity” is a “not subject to gradations” (4th of september, p.14), she rejected the classification of anencephalic fetuses as **disabled people**, citing the UN Convention on the Rights of Persons with Disabilities, which “assumes.... the presence of life even in the form of expected life” (p. 15). Lack of extra-uterine life expectancy excludes anencephaly from the category of disability. **Life** expectancy or **viability**,

22 In order to deal with this ambiguity Penna avoids using the term “biologically active organism” in an article that questions the criminalization of abortion of anencephalic fetuses. Penna compares the anomaly to brain death and thus avoids the contradiction between dead person / living organism (2005).

associated with the presence of **rationality** or **consciousness**, characterizes the **human person**. The overall lethality of anencephaly was affirmed in order to refute the claims that terminating these pregnancies was a denial of the right to life and discrimination due to disability. Rabinow points to the circulation of terms of identity and sites of restriction in the constitution of biosociality (1999, p. 143). In the case of anencephaly, we can see the restriction in terms of the denying anencephalic fetuses identity as living human beings due to their not being expected to live (not being viable) and also due to their lack of awareness and rationality. The pro-choice position questioned the biogitimacy of anencephalic fetuses: if there is no viability, there is no value to life, nor could one speak of biological citizenship.

The absence of the potential for life justifies the avoidance of the use of the term “abortion”: there would be no interruption of pregnancy if the fetus was already dead. Since the fetus was “stillborn” the procedure to remove it would be properly known as the “therapeutic anticipation of delivery in order to save the mother’s life”, or so concludes Talvane Marins de Moraes of the Brazilian Psychiatric Association (16th of september, p. 33). According to anthropologist Debora Diniz (professor of bioethics, Anis NGO), the therapeutic anticipation of delivery is an “anthropological portrait” of the experience of these women, who talk of anticipating the birth of a fetus which would not survive (28th of august). Speakers who presented a technical description of anencephaly emphasized the mortality of the syndrome, the confidence of diagnosing it in the first trimester of pregnancy via ultrasound (an exam available in the Brazilian public health system) and its high frequency of occurrence (one birth in a thousand: the main cause of congenital malformation in the first three months of pregnancy). These speakers also questioned the diagnosis of anencephaly in Marcela de Jesus, as did the representative of the Brazilian Society for Fetal Medicine, Heverton Neves Pettersen (28th of august). Contesting the view that folic acid was a means of preventing anencephaly, Salmo Raskin of the Brazilian Society of Genetic Medicine stated that adding it to pregnant women’s diet would reduce the cases of anencephaly between 10 and 40%. This would not extinguish the problem, due to a number of factors. Raskin also noted that, depending on the percentage of defects (20-40%), anencephalic fetuses should not be used for organ donation purposes (28th of august).

The suffering of pregnant woman and their families was mentioned by the pro-life speakers, but the risks of anencephalic pregnancy were omitted or minimized, a point emphasized by pro-choice speakers when they talked about the medical perspectives and the women. Representatives of scientific and professional associations and councils Luiz Roberto D'Avila (CFM), Jorge Neto Andalaft (FEBRASGO) and Gollop (SBPC), as well as Federal Deputy Pinotti (a specialist on gynecology and obstetrics), talked about the increases in morbidity and risk during anencephalic pregnancies and childbirth. They pointed to complications such as polyhydramnios (excess amniotic fluid), toxemia, hypertension and diabetes, placental dislocation, fetal positions that make delivery difficult, premature birth, prolonged gestation, no uterine contraction (requiring hysterectomy), and emotional impacts. Talvane Marins de Moraes of the Brazilian Psychiatric Association likened compared forcing a woman to carry out an anencephalic pregnancy to torture and remarked that this could trigger a serious psychiatric condition (16th of september). The researchers presenting the point of view of the women emphasized the emotional impact, which they felt was analogous to the “experience of torture”. They said torture would not so much be in the anencephalic pregnancy itself, “but in the duty to maintain the pregnancy solely in order to bury the child after birth” (Debora Diniz , 28th of august, p. 61).

Mentioned was made of the value of the pregnant women’s **human dignity**, a “constitutional democratic principle” that would not be observed in those cases where women opted to end anencephalic pregnancies under the current law (Maria José Rosado Nunes Fontelas of the NGO Catholics for Choice 26th of august). **Autonomy** was the main value that guided this group, expressed as a choice., and this them was emphasized by many of the pro-choice speakers. Bishop Carlos Macedo de Oliveira of the Universal Church of the Kingdom of God founded the **right to choose** in theology: “God gives every human free will. We argue that in these cases, the will of the woman undergoing these circumstances should prevail” (26th of august, p. 12)²³. Those speakers focusing on autonomy referred to the woman or the doctor who was caring for her, given that authorization to end an

23 Gomes (2009) describes the relationship between the pursuit of “life in abundance”, as defended by the IURD, to family planning. This creates a more flexible position with regards to abortion, which is seen as being necessary under certain circumstances. On the other hand, the disposition of this churches’ representative centered upon the autonomy of women, whose rights and health were under threat.

anencephalic pregnancy depended on a judicial decision made by an external body. Jacqueline Pitanguy (CNDM, CEPIA, Citizenship and Reproduction Committee) claimed that the **right to choose** was private ethical matter: it was not the State's right or responsibility to interfere in intimate decisions about risks to individual health. The State's proper role was to respect diversity and guarantee the fundamental principles of the Constitution (4th of september). To not give the right to choose to terminate a pregnancy of this kind would be to treat women as things, said Maria José Rosado Nunes Fontelas (26/08). Health justice Jose Gomes questioned whether the lack of the right to terminate an anencephalic pregnancy didn't constitute the "political control of women's bodies" (4th of september). Salmo Raskin of the Brazilian Society of Genetic Medicine said that the "couple" should undergo genetic counseling after verification of the anomaly, in order that they might make an informed decision (28th of august). Luiz Roberto D'Avila of the CFM commented on the current impossibility of properly orientating couples due to doctors' dependence of the judiciary: "we are absolutely hostages of judicial decisions" (p. 4). He emphasized the need for greater respect for autonomy (28th of august, p. 5). Eleonora Menicucci de Oliveira of the NGO Conectas Human Rights and the Human Rights Center denounced the "humiliating and embarrassing process... through which women decide to terminate pregnancies of anencephalic fetuses in Brazil." Such women need to ask permission from a public power (the judiciary) in order to have a "reproductive right" that should be "private in nature" – private for the couple and, ultimately, for the woman herself, given that it is in her body that pregnancies are generated and born to term (16th of september, p. 17). Lia Zanotta Machado pointed out that certain judges and prosecutors refuse to authorize the procedure (4th of september). Talvane Marins de Moraes put forward the position of the Brazilian Psychiatric Association: "in the name of women's mental health" he defended "the mother's right to choose therapeutic early delivery in cases of pregnancy with anencephalic fetuses" (16th of september, p. 33). Nilcéa Freire, justice of the Special Secretariat for Women's Policies, presented the view of the National Council of Women's Rights that women need to have the right to make an informed and untrammled choice in order that "women be seen as subjects of rights" (16th of september).

Dumont's analysis (1997) of the individualistic configuration that is characteristic of the values of modern Western culture can be very fruitfully

applied to discussion of **rights**.²⁴ Women are individual subjects of rights, and the rights of a higher social power such as the State or a religion cannot compromise these rights, given that this would damage autonomy/freedom, which is understood to be a supreme value in the modern West. On the other hand, this configuration values can also create conflict between the rights of two individuals. An example of this can be seen in Jacqueline Pitanguy (CNDM, CEPIA, CCR) charges that a woman's lack of legal permission to terminate pregnancy in the case of an anencephalic fetus is "serious disrespect of her rights". "Here we see a *conceptus*, an act of conception that precludes any possibility of life prevailing over the right of a fully capable citizen to make decisions about her life and deal with any resulting consequences" (4th of september, p. 62). Jorge Neto Andalaft (FEBRASGO), by contrast, focused on the rights of doctors. According to Andalaft, the interruption of an anencephalic pregnancy "is a right of citizenship" to be requested by a pregnant woman from, her gynecologist, who is "her partner, her confidant, her caregiver" (28th of august, p. 11). The pro-choice side of the debate also sought to permit a variety of women's decisions regarding anencephalic pregnancies, ensuring the right to opt for interruption as well as to continue the pregnancy. "The right to choose is what makes effective the rights of women to reproductive health and to physical and mental health in the event of a fetal anomaly incompatible with extra-uterine life," said Eleonora Menicucci de Oliveira (16th of september, p.16). The Brazilian Psychiatric Association argued that women in this situation are entitled to government health assistance, especially with regards to their mental health (Talvane Marins de Moraes, 16th of september). Finally, Jacqueline Pitanguy brought up two specific rights violated in this particular context:

- 1) The right to health, established by the Constitution as a universal right and a duty of the State, taking into consideration physical risks and emotional consequences;
- 2) Access to the progress of science, as included in the Universal Declaration of Human Rights, given that ultrasound can diagnose fetal anencephaly at 12 weeks after conception (4th september).

24 The cardinal points of the ideology of modern western society are equality and liberty and the presumption of the unifying principle of the human individual, with each individual representing the essence of humanity. The individual is "almost sacred, absolute; nothing exists beyond his legitimate exigencies; his rights are only limited by the identical rights of other individuals" (Dumont, 1997, p. 53). According to this view, society is nothing more than a collection of these monads.

Eleonora Menicucci de Oliveira recalled the norms of the UN Human Rights Committee: making it impossible for women to interrupt an anencephalic pregnancy is a violation of their human rights with regards to reproductive health and the right to be free from torture and inhuman or degrading treatment (16th of september). Here, Oliveira once again compares lack of choice with torture or degrading treatment. These denunciations may also take inspiration from the concept of biocitizenship.

Few speakers mentioned the problem of the **secular state**. Those who did were usually representatives of religious institutions. Most criticism was directed towards the Catholic Church. Representing a splinter group of the Church, Maria José Rosado Nunes Fontelas stated the need to “reaffirm” the secular nature of the Brazilian State, due to possible political pressure from the Catholic Church which had been “accustomed... for nearly four centuries, to believe that it represented the nation and the State” (26th of august, p. 22). Openly antagonizing Brazil’s hegemonic religion, Carlos Macedo de Oliveira said that the Universal Church of the Kingdom of God, “understands the secularism of the State and respects and defends this, as well as the guarantee of freedom of worship, as determined by our Constitution” (26th of august, p 11)²⁵ The view generally expressed was that religion played a private role in modern secular society (cf. Berger, 1985): “To affirm the secular nature of the Brazilian State does not mean ignoring the importance of religion in people’s private lives and in the lives of our moral communities “ (Debora Diniz, 28th of august, p. 62)²⁶.

ADI 3510 and ADPF 54: convergences in the debate

I would like to now trace some comparisons between the various stages of the ADI 3510 hearings and those of ADPF 54. First, let’s look at the differences.

By proposing to legalize the therapeutic early deliver of anencephalic fetuses, ADPF 54’s stipulations related directly to the reproductive process. It dealt directly with the decision to carry pregnancies to term or not in a context where the parents are already anticipating the birth of a child, given

25 The Catholic Church played a large role in both of the debates I analyze here and I describe this in greater detail elsewhere (2010a). Machado’s analysis of the theme of abortion (2000) reveals that the IURD has constructed an image public which contrasts with that of the Catholic Church.

26 With regards to religion in secularized contexts, “religion manifests itself in a typically modern form as a legitimating complex that is voluntarily adopted by a clientele of their own free will. As such, it is localized in the private sphere of cotidian social life and is marked by characteristics that are typical of this sphere in modern society (Berger, 1985, p. 145).

that the diagnosis of anencephaly occurs around the third month of pregnancy. By contrast, the only reference to replication in ADI 3510 is indirect: surplus embryos from assisted reproductive that might serve as stem cell sources. The “genitors” who provided the germ material would not generally have reproductive use for it in this case, given that they had released their embryos to research after freezing them for three years.

The justification for the extraction of embryonic stem cells, (a procedure that involves embryo destruction) is that this might advance scientific knowledge and also allow for the creation of tissue replacement therapies. Political movements formed by patients are betting on these cells as a hope for a cure. Use of the embryos would thus benefit third parties. This argument is even used by those who oppose the use of embryos in research. Both the scientists at the ADI 3510 public hearing as well as the three justices who took part in it questioned this use of embryonic stem cells, on the grounds that this would transform embryos into a means while Kantian ethics clearly states that human beings are an end in and of themselves. The rationale for therapeutic early delivery of anencephalic fetuses, on the other hand, is that this would reduce the suffering of the mother and her family, given that they are aware of the lethal diagnosis.

In the public debates looked at here, we can identify three types of movements that attempt to constitute and support social subjects: the movement of patients who seek the right to health through biotechnological investment in such things as research into stem cells; the feminist movement, which defends women’s autonomy in deciding about questions regarding reproduction; and finally there is the pro-life movement, which defends the right to life of embryos and fetuses and mobilizes against any form of abortion and manipulation of human embryos, whether in *in vitro* fertilization or in stem cell research. We can thus see, in the words of Rabinow, that we are dealing here with the “formation of new identities and individual and group practices that have emerged from these new identities” (1999, p. 147). We also see displayed the individualizing and collectivizing aspects of biocitizenship (Rose and Novas, 2005): collectivizing with regards to the formation of these movements that mobilize around the rights of fetuses or embryos, women and patients: individualizing with regards to the recognition of somatic identities, such as the unique genetic identity of an embryo in a laboratory or the identity of anencephalic fetuses as representative of human biodiversity. It is precisely this individuality that, in the pro-life perspective, make both fetuses and embryos the subjects of rights.

In the discussions surrounding ADPF 54, the figure of the mother repeatedly appeared as one of the principal protagonists of the case. Here, we saw a clash between two subjects of rights: the pregnant women and the anencephalic fetus. It was discussed whether or not early delivery was justifiable in these cases, which would mean ending of life process of the anencephalic fetus in order to reduce the mother's suffering. Pro-life arguments situated the fetus' right to life in relation to the mother's suffering in such a way that the prerogatives of the fetus encompassed the mother's right to well-being. Those who favored the pro-choice approach argued that there was no reason to protect a totally nonviable fetus that had next to zero life expectancy outside of the womb. The context of the ADI 3510 was different precisely because issues regarding pregnancy weren't involved. Scientists opposed to the use of embryos in research referred to the mother only in order to affirm the autonomy of the embryo in relation to her, accentuating the embryo's capacity to develop by itself in accordance with its genetic programming. Those who favored to the use of embryos in research attempted to shift the debate away from issues related to abortion in order to avoid issues of illegality: this was the position of Supreme Court justices and of the scientists. In this debate, the uterus appears only as a means of signifying the embryos' viability, given that only when said embryos are inserted in this environment are they able to develop as living beings.

If the contexts of ADI 3510 and ADPF 54 are different, what about the similarities of the arguments and ideas that were expressed in the two hearings? Four speakers were present at both public hearings. The definition of the statute of extra-corporeal embryos and anencephalic fetuses joined the principal points of the two debates. Are they alive? Are they people? With respect to the concept of life, the scientists at the ADI 3510 hearings who were against the use of human embryos in research highlighted the embryo as "living" *in vitro*, based on its active biological processes and its active genome. Those who favored the use of embryos in research tried to deconstruct this concept. They argued that life is a process in which the gametes that originated in the embryo are already living cells. The quality of "living" cannot thus be attached to an individualized embryo, which needs to be implanted in a uterus in order to develop into a life. Finally, the pro-research side emphasized relativistic positions, saying that beliefs vary from religion to religion and culture to culture. The pro-research side also compared the condition of the supposedly live embryo in the lab to that of the really, truly live patients

who were in dire need of the therapeutic techniques which stem cell research could develop. Why were the lives of these real human beings less important than the notional life of an embryo? In the debates surrounding ADPF 54, the efforts of the pro-life side were concentrated on showing that anencephalic fetuses were, in fact, alive while the pro-choice side refuted this alleging brain death. They claimed that in the absence of a juridical interest that needed to be protected (life), therapeutic early delivery could not in any way be considered abortion. In this flow of biological and legal meanings which establish social identities, we can clearly see examples of Rabinow's claim (1999) that nature is reshaped through culture and becomes artificial.

In the debates surrounding ADPF 54 as the ADI 3510, it is questioned whether or not the *in vitro* embryos and anencephalic fetuses are people, with all the rights and obligations attending to this status. The representation in both cases is that of the individual as described by Dumont (1992): an asocial, atomic being disconnected from any relationship. The frequent deletion of the mother from these debates is due to the emphasis given to the fetus or embryo.

Here we find the value of life itself being debated: is human life sacred? The sacredness of life is a relevant question for lawyer and legal philosopher Ronald Dworkin, who distinguishes it from personhood, and also for anthropologist Didier Fassin, who points out that the value and the meaning of life and the concept of biocitizenship are the foundations of biocitizenship both in the design of life in general and in the concept of lives are sacred. The relator of ADI 3150, Justice Carlos Britto, said: "What is sacred in religion corresponds to what is inviolable in law"²⁷ Human life is inviolable and therefore sacred. In these cases hangs the question of whether the life of an anencephalic fetus should be more sacred than the pregnant woman who carries it, or whether the lives of frozen embryos have more value than the individuals who would benefit from their destruction in research. The comparison of the two cases reveals the articulation of the pro-life movements, which brings together issues such as the use of embryos in research and permission for abortion. The concept of sacred human life unites the two debates: the mother's life is sacred, so she must have the right to choose; the life of anencephalic fetus is sacred and it should have the right to life. The

27 The debate produces new sacred biological beings: in the ADI 3510 hearings, three justices (Carlos Britto, Carmem Lúcia and Ricardo Lewandowski) refer to the UNESCO declaration on the human genome, which proposes a new intangible entity, "the genetic patrimony of humanity".

same equation holds for frozen embryos itself and those patients who are the potential beneficiaries of the research conducted with them.

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The multiple meanings of ‘risk’:

Views on the abortion of non-viable fetuses among
Brazilian medical doctors and magistrates

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Resumo

O artigo tem como objetivo compreender as concepções de risco acionadas pelo campo médico e interpretadas pelo campo jurídico a partir da análise de decisões judiciais relativas à autorização do aborto de fetos com anomalias fetais incompatíveis com a vida e de entrevistas não-diretivas realizadas entre médicos e magistrados. Verificamos que a categoria de risco é bastante manipulada por médicos e magistrados na medida em que essa categoria é acionada enquanto uma justificativa para tornar moral o aborto de fetos inviáveis, com o objetivo de afastar o aborto da esfera da escolha individual da gestante para inseri-lo no âmbito do aborto terapêutico. Destaca-se também o caráter polissêmico do discurso sobre risco, tendo em vista que ele é utilizado tanto para conceder ou negar as autorizações judiciais para aborto, como para atribuir a responsabilidade da decisão sobre o aborto aos médicos.

Palavras-chave: Risco, Aborto, Campo Médico e Campo Jurídico.

Abstract

The article seeks to understand the conceptions of ‘risk’ produced in the medical field as they come to be interpreted in the legal field. It draws on legal decisions concerning authorization for aborting fetuses bearing anomalies incompatible with life, and on non-directive interviews with medical doctors and magistrates. The category of ‘risk’ was found to be subject to considerable manipulation by both doctors and magistrates in being deployed as moral justification for the abortion of non-viable fetuses. Abortion is thus displaced from the sphere of individual choice to the domain of therapeutic abortion. The article also highlights the polyvalence

of risk discourse, since this notion is deployed both to affirm and to deny legal authorizations for abortion, and to attribute responsibility for abortion decisions to doctors.

Keywords: Risk, Abortion, Legal Field, Medical Field.

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Prior to April 12th 2012, the abortion of anencephalic fetuses in Brazil required legal authorization. Although a Federal Supreme Court decision issued on this date overruled the need for authorization in this particular case, other types of fetal anomalies incompatible with extrauterine life remain dependent on assessment by the courts on a case-by-case basis. To obtain authorization, a legal case needs to be filed containing some kind of medical justification for the abortion. Medical doctors participate in these cases by submitting a report containing evidence that the pregnancy in question is generating a fetus with some type of anomaly incompatible with extra-uterine life. Since this medical report will support a legal case, it must comply with certain parameters, including a diagnosis and the indication of a medical procedure appropriate for treating the condition. According to the physicians interviewed, besides confirming fetal non-viability, the report must also recommend abortion as a medical solution to the problem – in other words, the fetus’s non-viability and the pregnant woman’s wishes alone are insufficient grounds for legal persuasion. It is up to the doctors, therefore, to advocate on behalf of the expectant mother by providing a medical justification for her decision to request abortion.

In the cases analyzed here, one claim frequently put forth as justification for abortion is the risk that this kind of pregnancy poses to women. ‘Risk’ is one of the categories around which modern society has been organized (Beck 1993, Neves 2004). Its importance is such that some authors have gone as far as to suggest that risk is at the core of the contemporary world – thus the emergence of a ‘risk society’ (Beck 1993, Spink 2001). According to Douglas (2002), risk means danger and implies a particular way of relating to the future. While the world’s dangers were once seen from a fatalistic

perspective, now these dangers can be domesticated, controlled, predicted and avoided through systematic observation (Luiz & Cohn 2006).

Epidemiology in particular has enabled the control and monitoring of individual health, and risk is a key conceptual tool towards this end (Ayres 2002, 2011). Through statistics, and in particular probability theory (Luiz & Cohn 2006), risk is translated into mathematical reason. For Rabinow (2002), as well as a mathematical measurement, risk is also a central notion in modern medicine's strategies of control, surveillance, and discipline. In his words:

Modern prevention is above all the tracking down of risks. Risk is not a result of specific dangers posed by the immediate presence of a person or a group but, rather, the composition of impersonal 'factors' which make a risk probable. Prevention, then, is surveillance, not of the individual but of likely occurrences of diseases, anomalies, deviant behavior to be minimized, and healthy behavior to be maximized. We are partially moving away from the older face-to-face surveillance of individuals and groups known to be dangerous or ill (for disciplinary or therapeutic purposes), towards projecting risk factors that deconstruct and reconstruct the individual or group subject. This new mode anticipates possible loci of dangerous irruptions, through the identification of sites statistically locatable in relation to norms and means. (2002: 100)

Even though the medical field describes risk in mathematical terms – and is thus represented as impartial, universal, concrete data – empirical observation showed the opposite: the ambivalent, elastic character of the notion of risk as it is operationalized and deployed in practice. In this sense, this article looks to understand the notions of risk put forth by the medical field and interpreted in the legal field, based on an analysis of legal decisions regarding authorization for aborting fetuses with anomalies incompatible with life.

The data set on which this article is based includes 27 legal decisions¹ on the abortion of fetuses with anomalies incompatible with life issued between 2001 and 2011 by the Rio Grande do Sul State Court of Justice (Tribunal de Justiça do Rio Grande do Sul: TJRS). Of these 27 decisions, 19 are requests for

¹ Since the analysis encompasses legal decisions made in both trial and appeals courts, I have opted to refer to all these instances as legal decisions.

aborting anencephalic fetuses, and 8 regard abortions linked to other types of fetal malformation. In the first group, three were denied, and another three were deemed compromised either because the decision had already been issued made by one judge alone through a temporary court order² or because the expectant woman abandoned the case. In the case of seven of the 12 orders authorizing the abortion of anencephalic fetuses, the three judges agreed to the request, and in four cases one of the judges refused to grant the order. Of the eight requests for abortion based on other fetal malformations, only three were granted.

To make better sense of the contexts in which these legal decisions were made, I also used a methodology based on non-directive interviews with physicians and magistrates possessing acknowledged experience in this kind of legal case. I interviewed nine gynecologist-obstetricians³ and six magistrates who took part in cases involving non-viable fetuses in the Rio Grande do Sul Court of Justice.⁴ The research project was approved by the Ethics in Research Committee of the Federal University of Rio Grande do Sul, and all informants were invited to participate in the research by means of a Term of Free and Informed Consent. Since this study aims to analyze risk-based justifications contained in legal decisions and interviews with medical doctors and magistrates concerning requests to abort anencephalic fetuses and those with other kinds of malformations, I shall henceforth describe this procedure through the term *abortion of non-viable fetuses*.⁵

2 The appeals court involves an assessment of the case and vote by three judges, one of whom is the rapporteur. But when a temporary order is requested (that is, when the interested party requests urgency), it is common for just the rapporteur to vote. Irrespective of this previous decision, the case follows the regular procedure and is assessed again by two other judges, who, in the cases analyzed here, concluded that the trial had been compromised since it was no longer possible to undo the decision (i.e. the abortion).

3 All doctors interviewed were affiliated with hospitals with recognized capacity for managing high-risk pregnancies, and with hospitals belonging to the referral network where abortions may be legally performed in Rio Grande do Sul.

4 Five of the physicians interviewed were female, and four were male. Of the magistrates interviewed, only two were women. Among both groups (medical doctors and magistrates), neither gender or affiliation to a particular religion appeared to influence the informants' views or stances on anencephaly. Both the medical and legal fields are associated with the male gender (where characteristics such as pragmatism and rationality are emphasized). They determine the way actors will position themselves in their field of practice regardless of gender – in other words, profession overlaps with gender. Almost all informants declared themselves to be Catholic, but most were favorable to the abortion of anencephalic fetuses. This does not imply that the physicians and magistrates interviewed did not hold religious or moral conceptions, or that these did not influence their views on the abortion of anencephalic fetuses. It does show, though, that religious belonging does not determine a person's stance on this kind of abortion.

5 Abortion debates involve a wide range of 'modalities' such as: voluntary interruption of pregnancy, necessary

Norm and Strategy: operationalizing the notion of risk among physicians

As mentioned previously, the interviewed physicians all stated that when writing a medical report it is not enough to describe the diagnosis and indicate a technical procedure for treating the problem in question. To convince a magistrate, further justification is required, especially in the case of procedures involving abortion. Doctors therefore deploy various strategies to improve their chances of success. The notions of norm and strategy proposed by Bourdieu (2007b) in his study of the Kabila marriage system can help make sense of how medical reports on the abortion of non-viable fetuses are constructed. Norm may be defined as a prescriptive system determining how things should be. Strategy, in turn, is informed by the 'practical sense' of agents involved in the game, which makes possible the manipulation of norms. Practical strategies become meaningful in relation to the larger universe of possible strategies, as defined by the habitus (Bourdieu 2007b). In the case of abortion, the norm is limited to cases of rape or risk of the expectant mother dying. Given that the medical habitus is governed by scientism and rationality, one possible strategy available is to deploy scientific expediences to justify a case for abortion that is not written in the norm. These strategies have translated into the definition of a fetal anomaly incompatible with extra-uterine life, scientific claims, and flexibilization of the notion of risk in order to frame pregnancies with anencephalic fetuses in terms of a category prescribed by the law – namely, therapeutic abortion. So, for example, one informant declared that writing a good medical report to support the abortion of anencephalic fetuses must involve:

abortion, therapeutic abortion, sentimental abortion, humanitarian abortion, selective abortion, abortion due to fetal anomalies, eugenistic abortion, anticipation of childbirth therapy, legal abortion, among others. In her analysis of law bills being reviewed by the Brazilian National Congress, Débora Diniz (2001) argued that the term is not limited to linguistic choices: on the contrary, this choice reflects the moralities involved in the debates, as well as the strategies chosen to defend different stances on the issue. In public debates on anencephaly, those supporting abortion deploy the expression 'anticipation of childbirth therapy,' while those opposing the practice use the term abortion. I understand the choice of the expression 'anticipation of childbirth therapy' as a legitimate political choice aimed at minimizing moral discussions on abortion and at making the abortion of anencephalic fetuses more ethically, legally and morally acceptable to society. For the purposes of this article, however, I have opted to use the expression *abortion of non-viable fetuses* to refer to the voluntary interruption of pregnancy in such cases. This choice is also political, inasmuch as I support abortion as a woman's right that deserves to be rendered visible as such.

First: certainty about the diagnosis. Second: certainty about the prognosis. And another thing: come up with a persuasive argument. How to do that: if I write that it's a case of brain death, they'll say it's not; if I say that the anencephalic fetus will increase the probability of pregnancy-related complications, that's not documented in the literature. But if I write that it increases risk, now that is documented in the literature, and then I add all the evidence for this. (Carlos, gynecologist-obstetrician, Hospital D and private clinic.)

The deployment of the category 'risk' is not a haphazard choice by the physicians, but rather a claim that enjoys high social appeal due to the part it plays in organizing modern society and how it relates to the future by minimizing the dangers inherent to life itself. Moreover, by establishing risk as a justification for aborting anencephalic fetuses, the focus is shifted away from the pregnant woman's moral decision towards a decision made within a technical sphere.

The meanings attributed to risk in pregnancies with anencephalic fetuses are quite flexible, and medical doctors have engaged differently with the matter both in theory (technical reports) and in practice (management of pregnancy). In the words of two informants:

In principle, no, it's about speculation. Let's suppose she reaches the end of her pregnancy and the baby is not born, she is cared for in an inappropriate facility or by someone who is not experienced, and eventually opts for a C-section, which is an unnecessary surgery involving anesthetics. (Paulo, gynecologist-obstetrician, Hospital A and private clinic.)

If the child has a tendency for increased amniotic fluid, if it doesn't swallow properly, then nature may interpret the fact as a lengthier pregnancy. So this kind of issue could be considered. This argument is often deployed in legal authorizations. But this is, let's say, a probability, not a prognosis. An increased risk. The best argument, I think, is that every pregnancy is risky (...) If you run this risk when all is well with the baby, that's just natural. But for a young, fertile woman to run the risk of serious complications for a baby that is not even going to live is unjustifiable (...) In the literature, you'll find a lot of people making this claim. It's a legally functional claim. But clinically, epidemiologically, it's different. (Claudia, geneticist, Hospital A and private clinic.)

These statements make clear that, in practice, risk is an exceptional possibility that may be actualized in extreme cases, such as increased amniotic fluid or an unnecessary C-section. But for the doctors, these factors are not epidemiologically significant: in other words, they would not by themselves justify an abortion. For them, the key justification for abortion is fetal unviability. Here, though, they have to persuade another agent – the judge – who may take into account factors other than the unviability of the fetus. Thus, the flexibility and malleability of the category ‘risk’ is part of a valid and persuasive strategy for justifying the abortion of non-viable fetuses. In this context, claims about increased risk become part of a rhetorical strategy aimed at associating the abortion of non-viable fetuses to necessary abortion – that is, cases where the pregnant woman’s life is at risk. This was a common tactic in the cases I analyzed, and has also been found by Diniz (2003).

Since the justification included in the medical report is relatively fragile, given that risk is not immediately evident, physicians resort to the production of ‘sub-evidence,’: that is, documents appended to reports in order to support their veracity. There is an understanding among doctors that, in the case of abortion of anencephalic fetuses, all reports must be accompanied by ultrasound images diagnosing fetal unviability. And since not everyone understands just how serious the lack of a cranial vault is, some teams include photographs of anencephalic newborns in order to show that this anomaly is not just a handicap:

...include a picture of an anencephalic baby to move them, because many judges don't know, they have no idea what they are dealing with. They think it's some problem internal to the head. They don't know there's no vault, the brain is rudimentary, you know, that extra-uterine life is impossible. (Ana, gynecologist-obstetrician, Hospital D.)

In this context, photographs produce truth in much the same way as image-based diagnostic exams. If ultrasounds construct the fetus as a person (Chazan 2007), so photographs of anencephalic newborns make it possible to visualize their non-viability – when the judge looks at it, she can come to her own conclusions about the possibilities of extra-uterine life. In his study of how the scientific literature is constructed, Latour (1987) argues that the references, citations, footnotes, graphs, tables and so on that make up a

scientific text signal whether the claim will be taken as fact or fiction, since to contest an article that includes many references requires all of them to be challenged. For a judge to oppose abortion from a medical perspective, therefore, she would need to contest the medical statement, the ultrasound, the assessment of the doctor who performed the ultrasound, the photographs of anencephalic fetuses, and the entire scientific literature appended to the report. Even so, sometimes a judge does indeed refuse to grant authorization. And since, according to the physicians interviewed, it is impossible to dispute all these elements, the reason for such a refusal can only be down to the magistrate's bad faith. In the words of one informant "the judge herself, her character, I don't know, her religion even, because even a judge has preconceived views" (Ronaldo, gynecologist-obstetrician, Hospitals A and B). In the face of clear and indisputable 'scientific evidence,' therefore, the only alternative left to explain the refusal to grant an abortion permit is the interference of some religious belief (defined in opposition to science).

Risk: a polyvalent category

It is interesting to observe that while doctors rely on risk claims to justify the abortion of non-viable fetuses, magistrates deploy the very same notion to both deny and grant abortion authorizations. Here Foucault's idea of the *tactical polyvalence of discourse* (Foucault 1990) can help make sense of how risk may be used to different ends in the same process. For Foucault, power and knowledge are articulated in discourse. However, the world of discourse is not split between the accepted and the excluded; rather, there are a multitude of discursive elements that can be recruited into different strategies. In this sense, it is risk's polyvalence that enables it to be deployed in the justifications put forth by different strategies and stances.

Risk-based discourse was present in more than half the legal decisions analyzed. The strategy involves either approximating or distancing pregnancies involving a non-viable fetus to pregnancies that pose a death risk to the woman, whether or not the procedure is explicitly framed as therapeutic abortion.

One essential precondition for granting permission to abort in these cases is certitude about the fetus' non-viability. Evidence to this end is

provided through medical reports appended to the case. For this reason, regardless of the outcome, debates during legal assessment have to address issues of a medical nature. In her analysis of legal permits for aborting anencephalic fetuses, Diniz (2003) also found that risk-based arguments concerning the pregnant woman's health are the most common in this kind of jurisprudence. Except for two cases (one of anencephaly and the other concerning a fetus with another kind of malformation incompatible with life) where the claimants' pregnancies were considered to involve risk of death, all other opinions stressed fetal non-viability and the need for a C-section. This leads to another issue regarding risk: although C-sections are generally associated with higher risks – hence the recommendation of abortion in the case of non-viable fetuses –, it is widely accepted among both obstetricians and pregnant women. Brazil has one of the world's highest rates of C-section births (WHO 1985, Víctora et al. 2011) and prevalence is higher among private hospitals than the public health system (Faúndes & Cecatti 1991, Yazlle et al. 2001; Fabri et al. 2002, Faúndes et al. 2004, Haddad & Cecatti 2011).⁶ This suggests that the higher on the economic scale, the more autonomy the woman has for choosing this kind of procedure, even if it is more risky. C-sections are considered to involve risk, but risk is inherent to any pregnancy. What makes physicians contraindicate use of a cesarean section in the case of non-viable fetuses, therefore, is not just risk. From the doctors' perspective, the interruption of pregnancy is equivalent to an abortion: to deploy a C-section to this end is thus unthinkable for them. As they explained during the interviews, it only makes sense for viable fetuses, not only because of the increased risk but because a C-section is not an abortion method. The only abortion procedure recommended for pregnancies above twelve weeks is pharmacological, which involves a method similar to induced childbirth.

As remarked earlier, doctors observe that the kind of risk cited in their reports is not the same kind written into the Penal Code. Women are not at risk of death and may take pregnancy to full term without harm to their

6 In their study of 86,120 births in the city of Ribeirão Preto (São Paulo State) between 1986 and 1995, Yazlle et al. (2001) found the C-section rate to be 32.1% in public hospitals, and 81.8% in private hospitals. Fabri et al. (2002) compared the rate of C-sections between one public and one private hospital located in the state of Minas Gerais in 1996, and found that C-sections accounted for 24.3% of births in the public hospital against 89.2% in the private hospital. Haddad and Cecatti (2011) found that the rate of C-sections in Brazil in 2006 was 30.1% in the public system versus 80.7% in private hospitals.

health. But the request to abort a non-viable fetus requires justification, and from the physicians' point of view, this justification has to go beyond fetal non-viability. Widening the concept of risk is thus deployed as a strategy to persuade magistrates to grant the authorization for abortion.

In the cases where authorization for aborting non-viable fetuses was granted, magistrates themselves emphasized the death risk faced by the pregnant woman. Indeed, legally this is the most morally acceptable claim, since it is clear to the judges that in the event of having to choose between the mother's life and that of the fetus, the former should prevail, as prescribed by Brazil's Penal Code. The passage below, taken from one of the cases analyzed, is emblematic:

(...) anencephaly is characterized by the absence of cranial bones and the brain, thus making the fetus incompatible with life after birth. It also poses health risks to the pregnant woman, since birth of a child with acrania may be difficult, and pregnancy itself may be delayed for over one year. (...) Physicians concluded that the pregnancy needs to be interrupted as an immediate and undisputed procedure, since death of the unborn is unequivocal, and ending the pregnancy will bring benefits to the woman. (Case no. 04, Appeals Court Judge A, 2002.)

In this decision, the magistrate accepted that pregnancy with an anencephalic fetus does pose health risks to the pregnant woman, since childbirth is more difficult and pregnancy itself may be delayed⁷ – the need for abortion being thus indisputable. Moreover, the fact that pregnancy last longer in this case suggests that anencephalic fetuses may not fit the category of 'humanity.'

However, risk-based claims are only successful when magistrates are already inclined to adopt a favorable stance to aborting non-viable fetuses. Judges who reject such requests (who, according to our data, based their decisions on a belief in the sacrosanct nature of human life and the need to control procedures they consider eugenistic) usually aim first at risk-based arguments. One example is a case involving a medical report that confirmed anencephaly and, therefore, incompatibility with extra-uterine life. The

⁷ The difficulties involved in giving birth to an anencephalic fetus and the need for a C-section are mentioned in all medical reports. The lack of a cranial vault makes vaginal birth more difficult. However, when abortion is authorized, it is preferably carried out through vaginal delivery, precisely the kind considered more complicated in the case of anencephalic fetuses.

request was denied because two of the three ultrasound exams presented by the claimant showed that the volume of amniotic fluid was normal, so the magistrates understood that there was no risk to life involved (even though one exam did show increased volume, which could pose added risks to health). The statement below is another example of how judges have used the notion of risk to deny authorization. Here, the Appeals Court judge recognizes that the ultrasound confirmed the fetal malformation. However:

It did not show that the patient is at risk of death or suffering from a serious condition. (...) Therefore, given that this is not a case of therapeutic abortion in any of its modalities [i.e., necessary (to save the pregnant woman's life) or prophylactic (to save her from a serious condition)], the request cannot be granted. (Case no. 25, Appeals Court Judge C, 2008.)

In these cases, what makes the abortion of a fetus with malformations incompatible with life acceptable or not is not the harm that the pregnancy may cause the woman. Those magistrates who use this argument in order to grant authorization employ a legal manoeuvre whereby such requests are included in the category of *causa excludente de ilicitude* (permissible illegal activity), which allows for abortion when the pregnant woman's life is at risk. In most of the cases analyzed here, this risk is virtual, since in most of the medical reports the risk of death appears as a prognosis inherent to any pregnancy. Nonetheless, this has clearly been an effective argument, given the high number of authorizations for abortion granted in cases where this was the central claim. One of the magistrates interviewed declared that

...to get an injunction, you need to get a lawyer. This happens within hours, minutes even – if there's a risk of death, you can't wait two days for an authorization and a warrant, can you? So there was this problem, I'm not saying suspicion, but, why would you make this request if the woman is dying? It should have been made already, it would even count as a case of medical malpractice [laughs]. (Antônio, Magistrate.)

For this informant, the very existence of a legal case shows that there is no risk to the pregnant woman concerned – had there been any real risk, there would have been no time to wait for a trial in order to perform the abortion. Another informant declared:

I haven't heard of any case of the refusal to authorize eugenistic abortions increasing death rates among mothers. I've seen many cases of mothers having children suffering from anencephaly, microcephaly and acrania where the children were born and there was no increased risk of death to the mother. (Laura, Magistrate.)

The magistrates who reject such requests realize that the risk-based justification included in the medical reports is a strategy for displacing the abortion of non-viable fetuses from the pole of selective/eugenistic abortion to that of necessary/therapeutic abortion. Those who grant authorization also recognize risk-based justifications as a legal strategy, and are well aware that this risk is virtual rather than imminent. However, matters in reaching their decision is not the risk itself, but fetal non-viability. For example, one of my informants stated that the elements he deems essential when authorizing the abortion of a non-viable fetus are “the unwillingness to take the pregnancy to full term, and a confirmation that the child does indeed have anencephaly” (Roger, Magistrate).

Referring to a peer who rejected a request to abort an anencephalic fetus, another informant said that:

But then Antônio expected a demonstration of full risk in the medical report, let's say: in the case of a desired, planned pregnancy, which mother would want to interrupt it? In principle, none. But then the doctor says that the possibility is one in a million, and you were the 'lucky' one. Some will want to take the pregnancy to full term while trying to deny the problem, waiting for a miracle. But today there's no way, previously we couldn't see the problem until after birth. Now there's no need to go through the entire process [of pregnancy]. But there are exceptions, and in the end they end up proving the rule. (Milton, Magistrate.)

According to the physicians and magistrates I interviewed, pregnancies involving anencephalic fetuses do not pose any additional health risks to the mother beyond those inherent to any pregnancy. Though not always successful, the risk-based claim is deployed because fetal non-viability and the pregnant woman's wishes are not considered valid justifications from a moral viewpoint. Doctors and magistrates favorable to the abortion of non-viable fetuses resort to the risk-based rhetoric in order to remove the weight from the woman's personal choice: rather than an individual desire, the option to abort appears as a medical recommendation.

It is interesting to observe a sharp polarity in terms of how magistrates have interpreted the medical data submitted in legal cases. There is one group that completely ignores the data brought by the doctors, thus delegitimizing medical science's expert knowledge. And there is another group that values technological advances in the medical field. One of the cases mentioned earlier illustrates how magistrates may ignore or manipulate the information contained in the medical reports: the request was denied because, even though the medical exams confirmed anencephaly and showed a difference in the volume of amniotic fluid, the latter was not interpreted by them as a sign of danger to the mother's health. Even though it was difficult to dispute the image of an anencephalic fetus shown in the ultrasounds, the medical report's recommendation to interrupt pregnancy was ignored because the exams failed to show any risk of death.

Another example was a decision issued by a judge who denied the abortion of an anencephalic fetus on the grounds that, "at the present moment, there is **only** a statement by two doctors claiming that a risk of death to the claimant exists should her pregnancy continue" (Case no. 22, Appeals Court Judge A, 2007 [my emphasis]). Use of the expression 'only' to refer to evidence intended to confirm the risk of maternal death is remarkable, as well as the fact that two different medical opinions were considered insufficient to prove the risk to the pregnant woman's health. The physicians and magistrates I interviewed all claimed that two medical reports are enough to prove fetal non-viability in cases requesting legal permission to abort. In this case, where the judge declared that there were 'only' two medical opinions, she was not stating that more reports were needed, but that the case presents 'only' the opinion of doctors. Both the medical and legal spheres can be framed as social fields in Bourdieu's sense (Bourdieu 1996, 2005, 2007a): that is, they delimit hegemonic ways of knowing, their own common sense and general laws. They are made up of agents and institutions that are socially legitimized representatives of the norms that guide each field. As such, they are authorized (and have the authority) to deal with certain issues – in our present case, issues concerning health and the law. In this sense, it can be said that while medicine is guided by science, law is guided by morality. There seems to be a struggle, therefore, between the medical and legal fields when it comes to the abortion of non-viable fetuses. While the medical field has the competence to define and diagnose a non-viable fetus, the decision

on what can or cannot be done about the fact lies outside its scope and is taken instead in the legal field.

On the other hand, magistrates have not disregarded scientific advances in the medical field over the last decades. All magistrates who granted permission mentioned technological advances in medicine and diagnostic precision as arguments for authorizing the abortion of non-viable fetuses. Nikolas Rose argues that:

Medical jurisdiction extended beyond accidents, illness and disease, to the management of chronic illness and death, the administration of reproduction, the assessment and government of 'risk,' and the maintenance and optimization of the healthy body (2007: 10).

For this author, medical technologies are technologies of optimization, insofar as they do not seek only to cure diseases but also to control vital processes. It is in this sense that magistrates point on one hand to technological developments in medicine (especially when it comes to image-based exams such as obstetric ultrasound), and on the other to the obsolescence of the Penal Code, as reasons for authorizing the abortion of anencephalic fetuses.

The silence of law versus failure to provide care: accusations between physicians and magistrates

While some physicians accuse magistrates of taking legal decisions based on moral views, it is the doctors who most frequently face accusations of neglect from the magistrates. These are the flip side of the coin of risk-based justification. On one hand, the rhetoric of risk is necessary for the doctors to justify the abortion of non-viable fetuses and for the magistrates who authorize the procedure to frame it in terms of the provisions for legalized abortion. But on the other hand, the demonstration of risk involved in the pregnancy of non-viable fetuses is not only unable to persuade those magistrates who stand against abortion, it may also lead to accusations of failure to provide care – in the sense that the physicians who identified a 'risk' did not act thereupon to preserve the patient's life or health. This claim was found in eight of the decisions analyzed. Some magistrates claimed, for instance, that abortion is a medical procedure on which doctors have to decide:

...my firm stance is that if there is any risk of death to the pregnant woman, it is not up to the courts to assess the degree of risk involved. It is up to the doctor, based on his expert knowledge, to assess the particular case. So, if the risk of death to the woman is supported by medical parameters, he can proceed under legal authorization, which overrides all others. (Case no. 28, Appeals Court Judge C, 2008.)

This view of risk differs from the one presented earlier: here the magistrates' aim is not to reach a decision but to establish that whenever a risk to the pregnant woman's health is involved, decisions should be made by the medical doctors rather than magistrates. Despite acknowledging the existence of risks, therefore, the magistrate turned down the requests for abortion on the grounds that this should be a strictly medical decision, meaning that it can be classified as legal abortion. This kind of argument is also based on Article 128, Subsection I of the Penal Code, but it comprises a literal interpretation: pregnancy can only be interrupted in the case of the risk of imminent death, if there is no other alternative for saving the woman's life. Many cases have included this claim, but one of them is particularly telling, since according to the medical opinions involved, the risk of death was real, not virtual, as in most other cases. This was a thirteen-week pregnancy of a fetus showing multiple malformations that made it incompatible with extra-uterine life. The medical report indicated the possibility of uterine rupture and ensuing internal bleeding, which could indeed lead to death. For the rapporteur (who authorized all other requests for aborting non-viable fetuses analyzed here), the medical report stating the risk of death was enough to warrant authorization. The second judge presented a long discourse on how immoral and eugenicist it was to interrupt the pregnancy of a malformed fetus, before granting the authorization in view of the risk posed to the pregnant woman's life – thus framing the request according to Subsection I, Article 128 of the Penal Code. However, the last judge denied authorization on the grounds that the matter was a medical rather than a legal decision. Another example of this kind of situation can be found in the vote of another judge:

It is impossible to grant legal authorization for abortion, just as it is impossible to grant legal authorization for legitimate protection of life or necessity. It is the agent [doctor] who must assess the situation and act in accordance with his or her own best judgment. (Case no. 7, Appeals Court Judge C, 2003.)

As far as these magistrates are concerned, then, it is the doctor's responsibility to evaluate the patient's health condition, and, if deemed necessary, carry out the procedure – given that the Penal Code already provides for exculpation in the case of necessary abortion. The question may also be raised whether medical doctors are not shirking their responsibility for these decisions, since in this and in other cases, the risk of death justifies the abortion of non-viable fetuses based on the Penal Code's Subsection I, Article 128 – thus waiving legal authorization. It is interesting to observe how in the case of a woman pregnant with a normal fetus who did run a risk of dying, tried in 2003, authorization for abortion was unanimously denied by the TJRS magistrates. Despite presenting a clinical picture warranting therapeutic abortion according to the Penal Code, her doctors thought that the request should be legally authorized, while the magistrates argued that only the doctors could make the kind of decision involved. Another informant further remarked:

I don't know why it has to go all the way to the courts. If the doctor is so sure that someone is dying that he'll remove organs from their body, why can't he remove a fetus that has no prospect of living without the need for authorization? (Eduardo, Magistrate.)

Diniz et al. (2009) note that a legal order is required to abort a non-viable fetus in Brazil's public health system. However, this does not necessarily apply to private prenatal services where abortion is not conditional on legal authorization. One of the magistrates I interviewed added:

...I would authorize abortion under several circumstances. One of them is necessary abortion, where the doctor performs the abortion without the need for authorization. Maybe that's why this stance is more rigid in terms of the view that it's only in the case of a risk of death. Perhaps the doctors feel a bit uncertain, but that's what the law states: the doctor is responsible, there's no better judge than the doctor, because otherwise the judge will be putting himself in the doctor's shoes (...) So I think this kind of request was made precisely for the doctor to safeguard himself from any risk, I mean, it's a kind of protection. But that's not what the law is there for, otherwise everyone would go to the courts in any circumstance, and clear themselves from any responsibility. (Antônio, Magistrate.)

This interviewee claims that authorization for abortion is deployed as a protective measure so that physicians can carry out an 'illegal' procedure

without being held responsible for their action in the future. Some informants seem eager to draw a clear line between the responsibilities of the medical and legal fields in such a slippery terrain as the abortion of non-viable fetuses, which is not limited to one area of expertise. It seems as though some magistrates would rather yield any decision-making power to physicians, and vice-versa. One of the doctors I interviewed said that he had been summoned in two cases requesting authorization for the abortion of anencephalic fetuses. On one of these occasions

(...) it turned quite sour because the prosecutor said, 'You want to cover your backside and leave it to us, so you don't have to bother.' A quarrel ensued and I said 'I just want to comply with the law,' and he replied, 'no, because if this was a private clinic you'd just do it and not say anything about it.' It was quite an ugly spat. (Carlos, gynecologist-obstetrician, Hospital D and private clinic.)

The informant in question argued that since the law does not provide for the abortion of anencephalic fetuses, the procedure cannot be performed without legal authorization. On the other side, the prosecutor claimed that doctors are exempting themselves from a responsibility which is by law theirs, and that were the same situation to have occurred in a private clinic, the abortion would have been carried out regardless of legal authorization.

It should be remarked that, in most cases, the magistrates are not opposing the abortion request itself, but rather affirming the legal provision that when the pregnancy poses a risk to the mother's life, the doctor may act without the need for legal intervention. If the case is rejected, the magistrates 'wash their hands,' the doctors have their 'hands tied,' and the woman is forced to take the pregnancy with a non-viable fetus to full term. Even a magistrate who approved all requests for aborting non-viable fetuses contended that the purpose of obtaining such authorizations is to protect the doctors:

The doctors could perform the abortion, therefore, but they are afraid to, because they could only do it [legally] in order to save the woman's life or in the case of rape. But then, can you imagine if he performs the abortion at the patient's request, and then there is some complication and she dies during the procedure, then the family comes along... so, doctors want authorization because there are no grounds for arguing that

performing an abortion in the case of anencephaly is not a crime: technically it is. But it is not up to us to provide this authorization, otherwise the wheels won't turn.
(Milton, Magistrate.)

According to this informant, doctors must decide on abortion in these cases. However, they have no legal grounds for performing the procedure, so they transfer the decision to someone else (the magistrate). It is clear how this kind of decision troubled all my informants, magistrates and doctors alike, such that each group tried to hand responsibility over to the other. This behavior was found even among those generally favorable to the abortion of anencephalic fetuses.

Behind risk: disputes between the medical and legal fields

The obvious unease about who takes responsibility for the decision is caused, firstly, by the fact that the procedure at stake is indeed an abortion, and therefore carries with it the weight of a Christian morality deeply ingrained in a society that criminalizes this practice. Secondly, there seems to be a dispute between the medical and the legal fields over the abortion of non-viable fetuses. This struggle surfaces, for instance, in the way that the notion of risk is deployed in the legal field, as evinced in the statement by a magistrate cited earlier, affirming that the case 'only' contained the opinion of two doctors – thus delegitimizing medical opinions on anencephaly. It was also notable how magistrates selectively deploy the content of medical reports, such as in the case where authorization was rejected, in spite of medical recommendation, on the grounds that, in the magistrate's opinion, the pregnant woman did not show any 'significant' increase in amniotic fluid.

On the other hand, some of the physicians I interviewed argued that one major obstacle for obtaining legal authorization for aborting anencephalic fetuses has been the bad faith of those judging the case. One of the doctors also stated that,:

I'll tell you this: if the judge had an anencephalic fetus, would he continue with the pregnancy? I'm certain he wouldn't! No doubt about it. But because it's someone else's problem... (Ana, gynecologist-obstetrician, Hospital D.)

In this sense, while magistrates may regard doctors as prone to act 'unethically,' the latter often accuse the former of issuing biased, and in some cases

‘unfair,’ decisions. Authors like Darmon (1991), Carrara (1998) and Rohden (2003) have shown how accusations and disputes between medical doctors and magistrates are far from new: in fact, they have been commonplace since the advent of the figure of the medical expert working in the legal system.

This means that when the two fields are called upon to act in concert, medical discretion is limited by legal powers. To understand the disputes identified in my data, it is necessary to go over some of the aspects of how the medical and legal fields were constituted.⁸ The data shows that science plays a prominent role when it comes to the abortion of non-viable fetuses. The notion on which moral authorization for abortion is based in these cases is fetal non-viability, which is backed by scientific advances, especially in the field of prenatal diagnosis. In this sense, the medical field has ‘hard’ and ‘precise’ scientific evidence to affirm fetal non-viability. This diagnostic method, as well as estimates of the fetus’s life expectancy, are based on rational, ordered, systematized and validated knowledge – that is, on scientific assumptions. This guarantees the recognition and legitimacy of medical knowledge concerning fetal non-viability included in the medical reports submitted in support of legal cases requesting abortion. However, my data shows that some magistrates are not persuaded by medical knowledge on fetal non-viability, nor by the very definition of fetal non-viability. The legal field is not directed by science, but by interpretation and subjectivity, as Durkheim underlined:

Law rests, then, on both objective and subjective causes at once. It is not only relative to the physical environment, to the climate, the number of inhabitants, etc., but even to preferences, to ideas, to the normal culture of a nation. This is why it is changeable and why something is required in one place and prohibited in another (1993: 82).

Evidence is crucial for any trial, yet in the legal field there is no scientific method for producing evidence or guiding decisions. In other words, the outcome of any trial is a moral decision. In this sense, the first difference between the legal and medical fields is that the practices of the former are guided by morals, those of the latter by science. This is the first source of the

⁸ A full account of how these two fields were constructed would require another article. Here I consider only those elements central to making sense of the disputes found in my data.

disputes found in our data: morality versus science. This observation helps explain why the physicians interviewed are mostly favorable to the abortion of non-viable fetuses (even those who are against the abortion of other fetuses), while magistrates who oppose abortion in general also oppose the practice in the case of non-viable fetuses (even when they acknowledge that these fetuses will be unable to survive outside the womb).

My data suggests that the medical and legal fields influence each other, but also that this mutual influence is asymmetric. The medical field influences the legal field insofar as, most of the time, the magistrates accept the medical reports appended to cases requesting the abortion of non-viable fetuses. This is a positive influence, therefore, since the legal field is deploying knowledge produced by another field in order to do its job. The legal field, for its part, influences the medical field by controlling it, determining whether a given medical practice is within legal bounds or not – a negative kind of influence, therefore. One example outside the issue of abortion is litigation for medical malpractice. Albeit not part of this study, these were not forgotten by the doctors I interviewed, as we find in the following statement:

I believe one exam is not enough. I usually forward it to other doctors, ultrasound experts whom I trust. In order to protect myself, you know, because here we're in this tricky area of medical litigation. (...) Today, there's an over-emphasis on preserving the fetus. There's this specter of legal action, malpractice for instance – in the past, we would assist vaginal childbirth, but today it's C-section. (Ronaldo, gynecologist-obstetrician, Hospitals A and B.)

The medical field has less refractive power, therefore, and so less autonomy because it cannot evade the law. The legal field, in turn, can perform its functions unperturbed, based solely on its own concerns: laws and morality. The autonomy of the fields is a second difference emerging from my data, and also a motive of dispute between the two.

Finally, another difference between the medical and legal fields worth highlighting is that medicine is located at the action end of the scale, and the judiciary at decision end. Even though medicine is based on scientific knowledge, enjoys broad public recognition and influences social life, it does not hold decision-making power – it can only implement or recommend action.

This is perhaps the sharpest point of dispute between the two fields, since magistrates are deciding on issues generally recognized as belonging to the medical domain.

To summarize the argument made by one of the magistrates: physicians require legal authorization to carry out the abortion of non-viable fetuses because, technically speaking, they have no authority or legal backing to make this decision on their own. From this viewpoint, when some magistrates assert that it is up to doctors to decide whether or not to abort non-viable fetuses, they are not abstaining from a decision by transferring responsibility to the doctors. Behind this claim is the view that it is the doctor's responsibility to ascertain whether the risk is supported by law and, if so, to act accordingly – otherwise it would be considered an 'elective' abortion and thus criminal and non-'authorizable.'

Concluding remarks

According to Freidson (1970), the social recognition of medical doctors' authority to treat issues concerning health and the body made medicine a 'moral enterprise,'⁹ capable of actively intervening in the social definitions of health and sickness, normality and abnormality, valid in any context. Commenting on the importance of medicine in our society, Simone Novaes and Tânia Salem (1995) remarked that, through their social legitimacy, medical doctors impose standards and guidelines for solving their patients' health problems. Their expert knowledge has shaped and defined how conflicts – frequently engendered by advances in medical technologies – can be solved. The scientific field is separate and independent of the medical field, yet the latter relies on the former to develop its practices – thus science becomes integral to medicine. The legal field, for its part, has no scientific basis, but is grounded instead on morality. Though different, the two fields

9 According to Freidson: "Medicine [...] is oriented to seeking and finding illness, which is to say that it seeks to create social meanings of illness where that meaning or that interpretation was lacking before. And insofar as illness is defined as something bad – to be eradicated or contained – medicine plays the role of what Becker called the 'moral entrepreneur.' Medical activity lead to the creation of new rules defining deviance; medical practice seeks to enforce those rules by attracting and treating the newly defined deviant sick" (1970:252). When defining illness, medicine classifies peoples as normal or abnormal – and this is where its 'morality' resides, in the act of conceiving illness as deviance, and the patient as a deviant. Moreover, although it condemns the disease rather than the patient, the latter may be held responsible for his or her condition.

may influence each other (Bourdieu 1996, 2007a). Insofar as the claims advanced by magistrates favorable to the abortion of non-viable fetuses are intended to authorize this procedure, the medical field becomes a source of supporting evidence – for instance, through innovations in prenatal diagnoses and the trustworthiness with which science imbues them. In this sense, even though these magistrates acknowledge that the risk involved in pregnancies of non-viable fetuses is virtual, most of them consider fetal non-viability to be an unquestionable fact – hence, there is no sense in taking this kind of pregnancy to full term. This kind of medical justification is further compelled by the centrality of the notion of risk in modern society (Rabinow 1996, Rose 2007). In most cases, requests were granted, and a risk-based discourse was deployed as moral justification for authorizing the abortion of non-viable fetuses as a medical decision and thus factual and necessary.

Nevertheless, my data also shows that fetal non-viability by itself is insufficient to authorize abortion. Abortion has to be *justified morally*. To agree that a woman may carry out an abortion ‘just’ because the fetus is non-viable amounts to recognizing that the woman’s wish forms part of that choice, and this usually is not sufficiently persuasive. Authors such as Wiese and Saldanha (2014) and Porto (2009) have demonstrated the generally negative view that medical doctors and legal experts have concerning selective abortion, which explains why these professionals discriminate against women who undergo clandestine abortions. Consequently, the chief argument made by informants to justify the abortion of non-viable fetuses was the risk that this kind of pregnancy poses to the woman’s health. The study found that both physicians and magistrates significantly manipulate the *category of risk*, since, as the interviewees affirmed, pregnancy with a non-viable fetus does not imply absolute risk. Instead, risk is a prognosis that may or may not be actualized. In other words, danger to the woman’s life is a possibility rather than an inevitability in this kind of pregnancy. When informants resort to the rhetoric of risk, therefore, in order to render the abortion of non-viable fetuses morally acceptable, their aim is to distance abortion from the domain of the woman’s individual choice by framing the intervention as a therapeutic abortion, recommended by the doctors as a procedure to safeguard the patient’s health. Though flexible, the category of risk is scientific: risk can be identified, classified, measured.

Another point to be emphasized is the polyvalent nature of the discourses employed to justify decisions on the abortion of non-viable fetuses. Regardless of their eventual stances, all magistrates took the notion of risk into consideration when framing their decisions. Risk-based rhetoric is deployed both to affirm the need for abortion and to remove the abortion of non-viable fetuses from the provisions for legal abortion, as well as to attribute responsibility for decision-making to physicians. My data showed that even though the magistrates' views on the abortion of non-viable fetuses are linked to fetal non-viability and the sacredness of life, legal decisions have to adopt justifications that are compatible with the legal framework. Claims made in legal decisions as formal arguments must always draw on the law and its interpretation. Thus, risk – which may translate into therapeutic abortion – is the argument that makes most sense in the legal field in order to ground decisions on the abortion of non-viable fetuses.

Behind the flexibility in the notion of risk observed in my data is a tension between the medical and legal fields concerning the abortion of non-viable fetuses. Both are hegemonic fields in our society, capable of establishing socially recognized norms and truths. But does one of them enjoy more legitimacy than the other? The answer has to be yes. At least when it comes to fetal non-viability, this study showed that the medical field is constrained by the legal field. While the medical field is about action, the legal field is about decision making. Decisions made in the latter are valid for all other fields: hence physicians' actions have to comply with legal decisions. Before the Supreme Court ruling on anencephaly, medical doctors were responsible for diagnosing the problem and recommending a procedure – abortion – for treating it. But the final word on what was to be done belonged to the magistrate, who would provide a judgment based on the law. Hence, it was up to the magistrate to decide whether the abortion of an anencephalic fetus was correct, ethical or moral, and the physician had no option but to comply with this decision. My data showed that in some cases medical reports on the abortion of anencephalic fetuses were entirely ignored by the magistrates, who evaluated the requests in accordance with their own views. When it comes to anencephaly, though, the tensions between the medical and legal fields are not limited to controls on medical practice. Decision-making on the abortion of non-viable fetuses seems to be marked by uneasiness between physicians and magistrates, with each side trying to shift responsibility over

to the other. This suggests that neither medical doctors nor magistrates are at ease with the decisions and actions surrounding abortion.

Finally, it should be mentioned that, even after Brazil's Federal Supreme Court ruled in favor of the abortion of anencephalic fetuses, other cases of fetal malformations continue to be judged on a case-by-case basis. Lack of consensus on the morality of aborting non-viable fetuses is likely to persist in struggles between the medical and legal fields.

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La production d'articulations et de mouvements pour la santé des hommes au Brésil :

La sexualité comme porte d'entrée

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Resumo

Esta investigação trata da medicalização da sexualidade masculina no Brasil, centrada na criação de uma nova farmacologia do sexo na passagem para o século XXI, via o foco na disfunção erétil e na chamada andropausa. Destaca-se a nova ênfase na noção de saúde sexual baseada no aprimoramento individual e uso de medicamentos, além da promoção do interesse masculino no desempenho sexual, como porta de entrada para se chegar ao tratamento da saúde do homem. A perspectiva teórica baseia-se na análise antropológica das redes sociotécnicas que circunscrevem estes processos. No que se refere à metodologia, foi realizada pesquisa documental em arquivos históricos, material de imprensa e fontes do governo, além de entrevistas e etnografia em congressos médicos e eventos públicos.

Palavras-chave: medicalização, sexualidade masculina, saúde sexual, disfunção erétil.

Abstract

This investigation deals with the medicalization of male sexuality in Brazil, focusing on the creation of a new pharmacology of sex in the transition to the Twenty-First Century, directed to treatment of erectile dysfunction and andropause. The article points to an emphasis on the notion of sexual health based on individual improvement and medication, as well as the promotion of interest in male sexual performance, as the gateway to the treatment of

men's health. The theoretical approach is based on anthropology and social studies of science. With respect to methodology, documentary research was conducted in historical archives and contemporary sources (such as material and press releases from the government), interviews and ethnography in medical conferences and public events.

Keywords: medicalization, male sexuality, sexual health, erectile dysfunction.

Résumé

Cette recherche s'intéresse à la médicalisation de la sexualité masculine au Brésil en se concentrant sur la création d'une nouvelle pharmacologie du sexe, au tournant du XXI^e siècle, destinée à traiter la dysfonction érectile et la dite andropause. Elle souligne le nouvel accent mis sur la notion de santé sexuelle fondée sur l'accomplissement personnel et l'utilisation de médicaments et sur la promotion de l'intérêt masculin pour la performance sexuelle comme porte d'entrée vers le traitement de la santé de l'homme. La perspective théorique se base sur l'analyse anthropologique des réseaux sociotechniques sous-tendant ces processus. Outre des entretiens et une étude ethnographique de congrès médicaux et d'événements publics, la méthodologie repose sur une recherche documentaire dans les archives historiques, les matériaux divulgués et les sources gouvernementales.

Mots-clés: Médicalisation, sexualité masculine, santé sexuelle, dysfonction érectile.

La production d'articulations et de mouvements pour la santé des hommes au Brésil :

La sexualité comme porte d'entrée

Fabíola Rohden

Les hommes, la sexualité et le bien collectif

Ces dernières décennies, le Brésil a assisté à un intense processus de médicalisation et pharmacologisation de la sexualité centré sur la création de nouvelles ressources technologiques, de catégories de diagnostics et de formes d'intervention incluant la promotion de politiques publiques. Ce phénomène se déroule selon un scénario où se distinguent des éléments tels que les médicaments, les sociétés médicales, l'industrie pharmaceutique, les médias, les consommateurs et des événements allant de la prescription de médicaments dans un cabinet à la promotion de campagnes et à la mise en place de programmes dans le système public de santé. Il peut être illustré par le biais d'un ensemble d'initiatives centrées sur la promotion du slogan « La santé sexuelle comme portail de la santé de l'homme ». L'idée fondamentale est que les hommes, qui auraient pour tradition de négliger leur santé, pourraient être attirés dans ce système par l'attention sur la fonction érectile.

Ce travail est le résultat d'une recherche visant à cartographier la création et la promotion de diagnostics relatifs au processus de vieillissement des hommes et des femmes dans leur interrelation avec les manifestations associées à la sexualité, en prenant pour référence la dimension des relations de genre.¹ En ce sens, il a enquêté sur la manière dont ces nouveaux diagnostics

¹ Projet de recherche *Différences de genre dans la récente médicalisation du vieillissement et sexualité : la création des catégories ménopause, andropause et dysfonction sexuelle* (sponsorisé par le Conseil National de Recherche - CNPq). Ce travail a été présenté lors du Colloque international *Produire du savoir, gouverner des populations - Anthropologie, science studies et politiques de santé. École normale supérieure, Lyon, 2013*.

Certaines données analysées ici ont été discutées de façon préliminaire dans Rohden, F. 2012. « Capturados pelo sexo: a medicalização da sexualidade masculina em dois momentos ». *Ciência e Saúde Coletiva*, 17: 2645 - 2654.

sont apparus dans le champ médical brésilien ces dernières décennies. Cette recherche à l’empreinte socio-anthropologique a privilégié l’articulation entre différentes techniques de recherche qualitative telle que l’observation participante, les entrevues et la recherche documentaire. Elle a eu recours à l’analyse d’articles de revues scientifiques, de sites de sociétés médicales, de reportages, d’émissions de télévision et des matériaux divulgués dans la presse, outre l’ethnographie de congrès médicaux et de campagnes, et la réalisation d’entrevues avec des professionnels des domaines concernés. La dispersion des sources a été essentielle afin de montrer l’étendue des processus étudiés et les réseaux sociotechniques complexes y participant.

Il convient de souligner que les études visant à cartographier historiquement un intérêt différencié de la médecine, dans sa réflexion théorique et sa pratique quotidienne concernant les hommes et les femmes, sont très récentes. Un panorama préliminaire montre que les femmes ont été bien plus visées par le savoir médical que les hommes même si, ces dernières décennies, ceux-ci jouissent d’une attention spécifique en vertu de la création de nouveaux diagnostics et pathologies (Marshall et Katz 2002; Rosenfeld et Faircloth 2006; Loe 2001; Rohden, 2009).

Le résultat de cette analyse devient plus évident lorsque nous contrastons ce récent processus de médicalisation de la sexualité masculine et le grand mouvement d’intervention du début du XX^e siècle, au Brésil, pour affronter la syphilis et lutter, de manière plus générale, contre les maladies vénériennes. Le choix de ces deux processus ne cherche aucunement à affirmer qu’ils sont analogues, car la distance historique et contextuelle impose de nombreuses différences. Cependant, cette opération analytique fait ressortir l’urgence de certaines structures discursives pouvant être comparées de façon productive. Je propose donc que la discussion de ces vecteurs analytiques permet de réfléchir avec une certaine profondeur sur les processus de médicalisation des hommes articulant sexe et santé par le biais d’agencements assez précis en ce qui concerne certaines conceptions normatives implicites.

Au Brésil, le mouvement médico-étatique contre la syphilis des premières décennies du XX^e siècle était lié à la promotion d’une morale sexuelle scientifique ancrée sur l’autocontrôle masculin. Le corps et la sexualité des hommes ont fait l’objet de grandes inquiétudes en raison des maladies vénériennes. Dans son analyse de la lutte contre la syphilis dans ce pays, Sergio Carrara

(1996) décrit la gigantesque mobilisation contre cette maladie qui, à partir de l'association avec la dégénération et l'affaiblissement de la race, deviendrait, selon les médecins de l'époque, une menace pour la constitution d'une population saine et pour l'ordre social.

Les investissements concernant la syphilis doivent être compris dans le cadre d'un processus de régulation de la sexualité et d'appréhension envers le futur de la population face aux aspirations de l'État. La construction sociale de la syphilis a alors été articulée autour du processus de configuration sociale de la nation car l'idée centrale en était la dégénération de la race. La lutte contre la syphilis met aussi en évidence la construction d'un nouveau modèle d'individu, capable d'autocontrôle, qualité qui serait nécessaire aux nouvelles structures politiques en cours de constitution. Il est notable que cet autocontrôle individuel se référerait principalement aux hommes et au comportement sexuel masculin. Au travers de mesures concernant la syphilis, les médecins et l'État semblaient chercher à atteindre le pouvoir oligarchique et patriarcal, traditionnel au Brésil à l'époque, par le biais de la remise en cause des prérogatives traditionnelles masculines se rapportant à la possibilité de contrôler l'accès aux femmes et, ainsi, aux plaisirs sexuels et aux alliances matrimoniales. Il semblerait que le corps des hommes, jusqu'alors plus impénétrable que celui des femmes, des enfants et des pervers sexuels, ait fini par se rendre à la médicalisation au travers de la perception des dangers de la syphilis (Carrara 1996).

Dans le contexte des débats autour de cette maladie, la fonction reproductive et ses organes étaient vus comme une propriété moins individuelle que collective. En fin de compte, la responsabilité biologique face à la descendance devrait passer au premier plan. Les hommes ont donc été visés à partir d'une maladie qui compromettrait leur descendance, même si, plus immédiatement, elle avait une incidence sur la dégradation individuelle elle-même. La science des problèmes sexuels masculins qui se développait alors était surtout liée à une maladie externe, venue de l'extérieur, et due à « l'excès sexuel ».

Un chapitre intéressant de ce processus de médicalisation de la sexualité, ou en un certain sens, des résistances qu'il a suscitées, est celui des tentatives du médecin José de Albuquerque pour promouvoir l'éducation sexuelle et la création de l'andrologie dans les années 1930. Toujours selon Carrara, ce

médecin a été responsable d'initiatives telles que la fondation du Cercle brésilien d'éducation sexuelle en 1933 et du Bulletin d'éducation sexuelle, publié bimestriellement entre 1933 et 1939 et distribué gratuitement sur tout le territoire national, qui a atteint un tirage de 100 000 exemplaires. Entre autres activités, comme exposés et conférences radiophoniques, ce Cercle a organisé la Semaine d'éducation sexuelle, en 1934 et la Journée du sexe, le 20 novembre 1935, soutenant que le sexe devrait être soumis à une « morale scientifique » (Carrara 1996).

Ce médecin, qui s'autoproclamait sexologue, s'est aussi investi dans la création de l'andrologie, une spécialité qui serait consacrée exclusivement aux problèmes de la « fonction sexuelle » et de « l'appareil reproducteur masculin ». Dans cette même ligne, Albuquerque a fondé le *Jornal de Andrologia* (Journal d'Andrologie) en 1932, édité jusqu'en 1938, également distribué gratuitement, qui a atteint un tirage de 30 000 exemplaires en 1935, année où il a commencé à être publié en cinq langues différentes. Son engagement a également fait naître une chaire de clinique andrologique à l'Université du District Fédéral, dont il a été le titulaire de 1936 à 1938, avant de démissionner en raison des problèmes soulevés par la nomination du catholique Alceu Amoroso Lima au poste de recteur de cette université. Dans la dispute entre spécialités médicales, il combattait aussi les urologues qui lui semblaient monopoliser indûment des problèmes tels que l'impuissance, la stérilité, l'éjaculation précoce et les maladies vénériennes, entre autres, lesquels devraient faire l'objet de traitements plus appropriés par l'andrologie (Carrara 1996).

Malgré le fort investissement de l'État et des organisations médicales, cet effort n'a pas suffi à consolider des politiques publiques consacrées spécifiquement à la santé de la population masculine, au contraire de ce qui a eu lieu à partir des grandes initiatives consacrées aux femmes (Rohden 2009).

La production d'un nouveau scénario au XXI^e siècle : sexualité masculine et santé publique

Le panorama décrit jusqu'ici contraste profondément avec les processus instaurés au tournant du XXI^e siècle, qui impliquent de nouveaux investissements médico-étatiques consolidés et associés à la médicalisation de la masculinité. Ce phénomène serait représenté de façon exemplaire par la création

de la Politique nationale d'attention intégrale à la santé de l'homme (PNAISH) officiellement mise en œuvre par le gouvernement brésilien en août 2009 et marquée par la pression des urologues face au gouvernement et à la société civile, comme le prouvent les diverses campagnes publiques et la divulgation dans les médias. Son accent retombe sur la notion de santé sexuelle et sur la promotion des diagnostics récents de dysfonction sexuelle et d'andropause (Déficit androgénique lié à l'âge), en étroite articulation avec l'engagement des industries pharmaceutiques pour encourager la consommation de médicaments associés à ces « dysfonctions » sur le marché brésilien (Carrara, Russo et Faro 2009).

Pou autant que la PNAISH soit le résultat d'une série d'intérêts, parmi les principaux agents ayant contribué à sa création se retrouve un groupe d'urologues très actif publiquement, représentés par la Société brésilienne d'urologie (SBU). Depuis 2004, celle-ci réalisait des campagnes et exerçait des pressions sur certains secteurs du gouvernement et sur des parlementaires, des conseillers de santé et d'autres sociétés médicales pour élaborer une politique dans cette direction. En 2008, cette initiative s'est concrétisée par la signature d'un accord de coopération technique entre la SBU et le Ministère de la Santé visant à promouvoir l'assistance à l'homme dans le système public de santé, par le biais de l'orientation des médecins et la divulgation de campagnes d'informations, dont la première, entre juillet et septembre 2008, a été consacrée à la dysfonction érectile.

Au-delà de la discussion plus profonde autour de la PNAISH (Carrara, Russo et Faro 2009; Gomes 2011; Medrado, Lyra et Azevedo 2009, 2011) et des processus contemporains de mise en œuvre d'une attention spéciale à la santé de l'homme, cible d'une série d'études (Schreiber, Gomes et Couto 2005; Schraiber et Figueiredo 2011; Gomes, Schraiber et Couto 2011; Pinheiro, Couto e Silva 2011; Couto, Pinheiro et Valança 2010), l'objectif est ici de se concentrer de façon privilégiée sur les associations entre sexualité et médicalisation (Gomes 2008). Pour ce faire, nous partons d'une citation qui est devenue de plus en plus récurrente et qui a marqué les événements récents autour de la médicalisation de la santé masculine, du moins en ce qui concerne les appels faits par les urologues et leurs entités associatives : le slogan « La santé sexuelle en tant que portail de la santé de l'homme ». Il n'est nullement question de chercher l'origine, la création, ni même les intentions primaires

de cette formule, mais d'observer comment il est de plus en plus utilisé et sert à promouvoir un ton spécifique pour ce qui est de l'articulation entre sexe, santé et médicalisation.

En 2008, cette idée était couramment propagée dans des reportages de presse, des matériaux mis au point par les laboratoires pharmaceutiques, des congrès médicaux et des événements publics. Ce thème apparaît à la une de revues à grand tirage comme *Veja* et *Isto é*, dont, par exemple, celle de la Section Spéciale du 19 mars intitulée « La Révolution bleue : dix ans après le lancement du Viagra, l'impuissance sexuelle n'est plus un fantôme masculin ». Parmi les principaux bénéfices du Viagra mentionnés, nous citons une plus grande facilité de diagnostic de l'hypertension et du diabète, problèmes dont l'un des symptômes peut être la dysfonction érectile. Cet article met l'accent sur la publicisation du thème de la dysfonction érectile et de l'utilisation du Viagra en tant que porte d'entrée vers la santé de l'homme (Buchalla 2008). La revue *Isto É* du 9 juillet 2008 traite de la création de la PNAISH en mettant en avant l'argument de ce que la dysfonction érectile pourrait entraîner des perturbations dans la vie des hommes et indiquer également la présence d'autres problèmes de santé, comme les maladies cardio-vasculaires. Dans le reportage du journal *O Globo* du 17 août 2008, le ton est le même, comme le montrent les affirmations de l'urologue José Carlos de Almeida, alors président de la Société Brésilienne d'Urologie (SBU), pour qui la dysfonction érectile est rarement la cause d'un problème, mais fondamentalement la conséquence d'autres maladies.

Dans les congrès médicaux, ce thème était également en évidence, et dans les exposés et dans les matériaux préparés par les laboratoires pharmaceutiques (Faro et al 2013). L'entreprise Bayer Schering Pharma, qui était particulièrement engagée à se promouvoir en tant que « premier laboratoire ayant une gamme axée sur la santé de l'homme », a distribué, lors du Congrès International d'Urologie qui s'est tenu à Rio de Janeiro en 2008 et lors du 10^e Congrès de la Société Latino-Américaine de Médecine Sexuelle, réalisé à Florianópolis, un même document intitulé « La santé sexuelle comme portail de la santé de l'homme ». Celui-ci comprenait trois articles : « La santé sexuelle comme portail de la santé de l'homme » de Ricardo Meirelles, (professeur d'endocrinologie à l'université PUC-Rio et président du Département d'endocrinologie féminine et d'andrologie de la Société brésilienne d'endocrinologie métabolique) ; « Déficit de testostérone et dysfonction effective en

tant que composantes du syndrome métabolique », de Farid Saad (professeur honoraire à la Hang Tuah University, Indonésie); et « Le rôle de la thérapie de recomposition de testostérone dans la santé sexuelle et somatique masculine », de Svetlana Kalichencko (Présidente du Département d'andrologie et d'urologie du *Scientific Research Center for Innovations* et leader de la filiale russe de l'*International Society for the Study of Aging Males*). Ce document « réservé à la classe médicale », qui renforçait l'association entre performance sexuelle, jeunesse et santé de l'homme, portait en couverture interne une publicité du Nebido, injection trimestrielle de testostérone indiquée pour le traitement du Déficit androgénique lié à l'âge (DALA).

Dans la Campagne nationale d'information sur la santé de l'homme mise en œuvre par la SBU à partir d'août 2008, l'accent retombait également sur la dysfonction érectile, sous prétexte que celle-ci est un important indicateur de maladies, car elle peut être liée à des cardiopathies, à l'hypertension et au diabète. Le site de la SBU mettait en avant que la « Dysfonction érectile est le thème de l'action, car il s'agit d'un indicateur de maladies. Ce problème atteint près de 50% des hommes de plus de 40 ans. Moins de 10% consultent leur médecin. Notre entité veut éviter l'automédication. » C'était également la marque des vidéos que la SBU divulguait à l'époque. C'était aussi le thème de la première émission de la TVSBU qui consistait en une conférence sur la Dysfonction érectile de l'éminent urologue Sidney Glina où, entre autres aspects, il soulignait que derrière la dysfonction érectile se cachaient d'autres maladies. Dans la série d'émission *Cidadão Saudável* (Citoyen en bonne santé), le lien entre la dysfonction érectile et d'autres maladies était aussi abordé, cette fois-ci par Antônio Barbosa de Oliveira (<http://www.sbu.org.br>).

Par ailleurs, il est intéressant de noter la façon dont cette notion serait présente lors d'événements liés à la création de la PNAISH. C'est le cas du 4^e Forum de politiques publiques et santé de l'homme organisé par la Commission de sécurité sociale et famille, de la Chambre des Députés, réalisé le 7 août 2008, à Brasília. L'audience publique avait pour thème « La santé de l'homme, aspects urologiques et le SUS – Système Unique de Santé : situation et perspectives ». Parmi les discussions réalisées, Sidney Glina se distingue de nouveau avec sa communication « Dysfonction érectile – abordage et traitement. Le Système unique de santé doit-il distribuer ces médicaments gratuitement ? » Il y évoque la dysfonction érectile comme question de santé publique et comme indicateur d'autres maladies à partir d'une série de

références bibliographiques, de données épidémiologiques et de documents internationaux pour souligner le fait que le « traitement de la Dysfonction érectile peut être la porte d'entrée de l'homme vers le Système de Santé ! » (www2.camara.gov.br/internet/homeagencia/matérias.html).

Dans les années suivantes, cette même perspective continuerait présente de forme significative dans ce scénario d'action publique des urologues, comme lors du 5^e Forum de politiques publiques et santé de l'homme organisé par la Commission de sécurité sociale et famille de la Chambre des Députés, le 20 août 2009. Dans une entrevue sur cet événement pour l'*Agência Câmara de Notícias*, Sidney Glina disait que l'urologie « est une porte d'entrée vers le SUS, où le patient peut commencer à fréquenter des médecins d'autres spécialités, comme des cardiologues. » (www2.camara.gov.br/internet/homeagencia/matérias.html) Ce médecin insistait encore sur l'importance, pour le SUS, de disposer de plus d'urologues.

Cette importance surgirait aussi parmi les urologues liés à l'Association brésilienne pour les études des inadéquations sexuelles (ABEIS), organisme important dans la trajectoire de la promotion de la médecine sexuelle au Brésil (Russo et al 2011). L'entrevue que Paulo Brito Cunha, alors président de cette association et membre de la Société brésilienne d'urologie, a concédé à la journaliste Lilian Ribeiro, de la radio CBN, le 15 mai 2010, en est un bon exemple. L'entretien se centre sur la relation entre dysfonction érectile et maladies préexistantes. Dans la première partie, le médecin cherche à mettre en relief la possible association entre médicaments pour la dysfonction érectile et problèmes cardio-vasculaires. Plus encore, il en vient à *affirmer que* l'utilisation du Viagra serait un bénéfice pour éviter des difficultés de cet ordre.

Il explique ensuite que le premier symptôme apparaissant avant une maladie cardiaque, le diabète ou l'hypertension sont les « troubles de la fonction érectile ». Puis il reprend l'idée de la fonction érectile ainsi que la notion plus vaste de « santé sexuelle », comme « porte d'entrée » vers le diagnostic et le traitement d'autres maladies :

« Vous voulez savoir si vous êtes hypertendus ? Demandez comment va votre situation... fonction érectile. Vous voulez savoir si votre cholestérol est élevé ? Demandez-vous comment va votre fonction érectile. La fonction érectile est comme une porte d'entrée vers cela [...]. Nous avons l'*Associação Brasileira para*

o Estudo da Inadequação Sexual, notre site est www.abeis.org.br. Qui s'y rend va trouver la liste des nombreux professionnels travaillant sur ce sujet [...] il liste les personnes les plus compétentes pour le traiter car, comme le dit l'Organisation Mondiale de la Santé, l'une des choses qui qualifie le mieux le niveau de qualité de vie des personnes est leur activité sexuelle. [...] » (www.abeis.org.br).

Soulignons, dans cette citation, la connexion entre le diagnostic d'hypertension et la dysfonction érectile, la mention à l'ABEIS et la promotion de ses associés en tant que professionnels adaptés au diagnostic et au traitement, la référence à l'OMS et la notion d'activité sexuelle, sans parler de celle de « santé sexuelle », comme meilleur indicateur de qualité de vie. À cela, le président de l'ABEIS ajoute, « sur les bases de la littérature internationale », que seuls 10 % des hommes ayant des difficultés d'érection demandent une orientation et que les médecins ne sont pas habitués à interroger leurs patients sur leur activité sexuelle. Ces données aident à corroborer l'idée qu'il faut donc attirer l'attention sur ce problème et promouvoir des initiatives concernant aussi bien les possibles patients que les médecins et les secteurs de la santé.

Ainsi, l'une des plus importantes initiatives en relation à la création d'une action publique pour la santé de l'homme a eu lieu de mars à septembre 2010 : le Mouvement pour la santé masculine. Axée sur la population masculine, cette campagne était organisée par la Société brésilienne d'Urologie (SBU) et recevait l'appui financier de l'entreprise pharmaceutique Eli Lilly. Elle comprenait un site web, « Mouvement pour la santé masculine » (www.movimentopelasaudemasculina.com.br), et une tournée appelée « Caravane pour la Santé Masculine », pour laquelle un semi-remorque a été aménagé en salle de consultation et a visité les 22 villes les plus importantes du Brésil pour fournir gratuitement à la population masculine des orientations médicales sur la Dysfonction érectile (DE), les Maladies de la Prostate et l'Andropause. Le projet incluait encore des spots publicitaires à la télévision et des annonces sur Internet. Son objectif était d'offrir aux hommes des informations et des éclaircissements sur les trois maladies en question, pour sensibiliser cette population aux « problèmes masculins ». Dans les villes visitées, les rencontres se déroulaient dans des lieux publics comme des places, des parcs, des aires de stationnement et des centres commerciaux. Pendant 78 jours, la Caravane pour la Santé Masculine a accueilli plus de 10 mille hommes. Ce chiffre montre l'importance d'une telle initiative et ses

répercussions possibles sur le plan national, indiquant que cette action peut être considérée comme le vecteur d'un réseau plus vaste.

Le Mouvement pour la santé masculine s'est organisé autour du thème central de l'association entre sexualité et santé. Depuis la mise en place du site web, où la dysfonction érectile occupait une place principale, jusqu'à la manière d'en parler et la description qu'en faisaient les personnes et les membres du convoi, une certaine conception de la sexualité masculine et du comportement des hommes face au sujet de la sexualité et de la santé a été décrite à plusieurs reprises.

Divers documents téléchargés sur le site pendant toute la période de la tournée mettent l'accent sur les problèmes de santé pouvant être à l'origine des difficultés d'érection. L'un d'entre eux, daté du 1^{er} mai 2010, affirmait que « L'impuissance, comme elle est communément désignée, peut être la conséquence d'autres problèmes, comme des cardiopathies (problèmes liés au cœur) et les diabètes. » Le témoignage de l'urologue de la SBU Carlos Antonio da Souza, du 21 mai disait : « Il convient de savoir que la dysfonction érectile peut être un premier symptôme de maladies systémiques plus graves, comme les cardiopathies, l'hypertension artérielle, le cholestérol, des triglycérides élevées et des diabètes, entre autres ». Une note publiée le 29 mai ajoutait que : « Il est très difficile pour un homme de gérer le problème de la dysfonction érectile, qui peut être causée par le stress, des problèmes psychologiques ou peut aussi être le symptôme de maladies comme le diabète et l'hypertension »; et un article du 17 juillet résumait : « La capacité sexuelle a des "ennemis importants", comme l'hypertension, le diabète, la cigarette, le cholestérol élevé, le surpoids et le sédentarisme. » (www.movimentopelasaudemasculina.com.br/ dernier accès le 5 mars 2011).

Le témoignage de l'urologue Renaldo Sacco, publié le 19 août sur le site de ce Mouvement, fait directement référence à l'existence de nouvelles possibilités pour soigner la dysfonction érectile et explique combien elles facilitent une meilleure connaissance de la maladie et de son traitement: « À mesure que nous avons plus de solutions, les hommes consultent plus leurs médecins. Avant l'arrivée des médicaments améliorant l'érection, celle-ci n'était traitée que sur le plan émotionnel, l'on ne prenait en compte que cette dimension. D'autres méthodes sont ensuite apparues comme les injections, puis des médicaments encore plus efficaces sont arrivées. » Outre un plaidoyer sur l'importance des médicaments contre la dysfonction qui ont

permis de mieux comprendre et diagnostiquer cette maladie, ce texte met en évidence les bienfaits spécifiques du médicament Cialis, produit par le laboratoire Elli Lylli, qui apporte son soutien financier au Mouvement pour la santé masculine: « Le Cialis est le [médicament] le plus efficace en terme de durée, il est efficace jusqu'à 36 heures. » (www.movimentopelasaudemasculina.com.br/ dernier accès le 5 mars de 2011).

La dysfonction érectile est également une raison, selon les témoignages enregistrés sur le site web, incitant les hommes à consulter plus. Le 29 août, l'urologue Antonio Fonseca Neto affirmait que le convoi avait rendu un important service en poussant les hommes à s'informer sur « l'aspect sexuel » qui « est un sujet qui les préoccupe énormément » permettant ainsi de pouvoir aborder les problèmes liés à la santé. (www.movimentopelasaudemasculina.com.br/ accès le 5 mars 2011).

Les différents indices cités montrent que l'accent sur la santé sexuelle en tant que porte d'entrée ou de capture pour le traitement de la santé des hommes est lié à une série de facteurs et de références récurrentes. Un argument constant est la conception de ce que, habituellement, les hommes ne se préoccupent que peu ou prou de leur propre santé, tâche qui est communément décrite comme responsabilité féminine. Néanmoins, ils seraient incessamment préoccupés par leur performance sexuelle, traduite en termes de fonction érectile. En proposant de traiter cette dernière, les urologues ouvriraient la possibilité d'attirer des hommes vers le traitement d'autres maladies. Pour que cette stratégie fonctionne, il serait donc fondamental d'assurer une présence plus représentative et continue d'urologues dans les services publics de santé.

Une autre référence fréquente est l'utilisation singulière de la notion de santé sexuelle. On ne saurait ne pas mentionner que ce concept est devenu si important qu'il est officiellement promu par l'Organisation Mondiale de la Santé elle-même. En outre, au-delà du contexte de discussion des droits sexuels, il faut noter qu'il est devenu un élément-clé très souvent associé à des intérêts divers. On observe qu'en plus de vider la notion de santé sexuelle, il la réduit, dans le cas masculin, à la dysfonction érectile, corroborant ainsi l'idée d'une sexualité masculine restreinte à l'érection, presque exclusivement pensée, dans ce contexte, sur des repères hétérosexuels. De cette manière, toute autre forme de perception par rapport à la sexualité masculine est ignorée.

Une nouvelle onde de médicalisation

À l'aune du panorama décrit jusqu'à présent, l'on peut argumenter qu'une nouvelle onde de médicalisation de la sexualité masculine commence à être observée principalement dans la promotion de diagnostics de dysfonction sexuelle et d'andropause ou Déficit androgénique lié à l'âge (DALA) (Rohden 2011). Barbara Marshall et Stephen Katz (2002) soulignent que, au XX^e siècle, le processus de médicalisation de la sexualité se concentre sur l'homme et circonscrit la sexualité masculine à la dysfonction érectile. Par le biais d'une problématisation plus générale articulant sexualité et âge comme des dimensions fondamentales du sujet moderne, il met l'accent sur l'importance des cultures de style de vie de la fin du XX^e siècle en insistant sur la santé, l'activité et le non au vieillissement en une procédure qui va être à l'origine d'un vaste champ d'études et d'intervention sur la capacité de pénétration de l'organe sexuel masculin. La grande nouveauté, selon ces auteurs, est que l'on passe d'une conception admettant le déclin de la vie sexuelle au cours du temps et où l'activité sexuelle dans la vieillesse est péjorativement suspecte à une autre où il est obligatoire d'avoir une bonne performance sexuelle jusqu'à la fin de sa vie. Plus encore, où l'on affirme que l'activité sexuelle est bien une condition nécessaire pour une vie en pleine santé et que la capacité érectile définirait la virilité pendant tout le cours de la vie masculine. C'est précisément dans ce contexte qu'a surgi le Viagra (citrates de sildénafil), médicament du laboratoire Pfizer destiné à faciliter et maintenir l'érection, qui illustre le développement d'une science moléculaire de la sexualité (Marshall et Katz 2002; Marshall 2006).

Pour garantir le succès de ce nouveau médicament, il a fallu transformer la dysfonction érectile en problème pouvant toucher n'importe quel homme, dans n'importe quelle phase de sa vie et, en même temps, garantir qu'un remède capable de résoudre ou de prévenir cette difficulté soit disponible. En ce sens, le Viagra intégrerait la gamme bien plus vaste de ce que l'on appelle les médicaments de style de vie ou de confort, destinés à améliorer la performance individuelle, un marché en franche expansion. En outre, Pfizer a également travaillé à promouvoir l'idée de la dysfonction érectile comme topique acceptable dans le discours public, ce qui conduirait à une plus grande demande de traitement (Lexchin 2006).

Cela impliquait la propagation d'une idée de masculinité en crise, illustrée surtout par la métaphore de l'érection. La notion de ce que cette dernière,

symbole de la virilité et de l'identité masculine, est effectivement instable, sujette à différents types de désagréments, semble acquérir de plus en plus de notoriété. Et, c'est justement pour combattre ce manque de contrôle ou cette imprévisibilité du corps masculin que l'industrie offre un recours tel que le Viagra, capable de garantir l'expectative d'une performance toujours meilleure (Grace et al 2006; Vares et Braun 2006; Loe 2001).

Un facteur important dans ce processus a été la présence croissante des urologues et leur rôle fondamental dans l'institutionnalisation du champ de la médecine sexuelle, moyennant la création d'organisations, de conférences, de centres de formation, de journaux scientifiques, de cliniques et de départements médicaux (Giami 2004 ; Tiefer 2006). Le « succès » de ces professionnels dans la promotion de cette nouvelle possibilité de médicaliser la sexualité masculine s'étendrait aussi au diagnostic de l'andropause ou DALA. Défini comme « maladie » qui affecterait les hommes à partir de 35-40 ans, dernier est caractérisé par la perte de la libido ou du désir sexuel, la diminution de la masse musculaire, la perte d'énergie, la dépression, la dysfonction érectile, entre autres symptômes dont la cause est le déclin de la production de testostérone. Même s'il s'agit d'une maladie reconnue comme organique et traitable depuis les années 1930, ce n'est qu'à partir des années 60 que son traitement a commencé à mettre en avant les problèmes d'ordre sexuel (Marshall 2007). Dès les années 90, l'utilisation de testostérone gagne du terrain et l'on donne de plus en plus d'importance à la restauration de la performance sexuelle, en parallèle aux traitements pour la dysfonction érectile.

Au Brésil, les urologues, représentés par la SBU, ont contribué de manière singulière à ce qu'une attention spéciale soit donnée à l'andropause et à la dysfonction érectile. Cette société s'est consacrée à la réalisation d'une série de campagnes et autres événements sur le modèle du Mouvement pour la santé masculine, réalisé en 2010, visant à sensibiliser la population au besoin de prévention et de traitement de troubles comme la dysfonction érectile, l'andropause et les maladies de la prostate. L'Unité Mobile du Mouvement (un semi-remorque équipé avec des cabinets et une équipe composée de trois urologues et d'autres professionnels de santé), sponsorisé par le laboratoire Eli Lilly, a parcouru les grandes capitales du pays pour offrir une orientation médicale gratuite.

La promotion de ce type de campagnes et le fait d'attirer l'attention publique sur le DALA et la dysfonction érectile illustrent bien que, ces deux dernières décennies, un nouveau regard sur la masculinité s'est façonné via la pharmacologisation de la sexualité. Cela passe soit par le biais de drogues facilitant l'érection, soit par la prescription de testostérone. Bien qu'une certaine perspective critique apparaisse, surtout avec la divulgation de données remettant en cause l'efficacité et la sécurité de ces thérapies, l'on peut supposer que la médicalisation a prévalu, aussi bien dans la pratique médicale que dans les représentations de sens commun qui se consolident. Dans le cas spécifique de la conjonction entre vieillissement et sexualité, il convient de noter que la promotion des nouvelles drogues et ressources chemine côte à côte avec la promotion de modèles de comportement centrés sur la valorisation du corps jeune, sain et sexuellement actif.

Le champ des savoirs sur la sexualité et le processus de médicalisation

Les données présentées jusqu'à présent suggèrent une différence importante entre l'approche de la sexualité masculine dans le contexte des campagnes contre la propagation de la syphilis et celui, récent, des politiques sur la médecine sexuelle. Plutôt que de décrire ici un parcours historique continu, nous entendons révéler des points de rupture, du point de vue analytique. Ainsi, il nous faut avoir recours à certains des auteurs les plus importants dans ce domaine pour souligner les transformations mises en relief dans cet article.

De nombreux chercheurs ont montré comment la sexualité, en particulier dans le contexte de la modernité, peut fournir des informations importantes sur les individus. Plus particulièrement à partir du XIX^e siècle, il est possible de voir surgir un intérêt croissant pour le sexe qui se traduit par le développement d'un ensemble de nouveaux savoirs comme la gynécologie, la psychanalyse et la sexologie. Tous sont intimement liés à la production de nouvelles subjectivités en même temps qu'ils reflètent les changements observés.

M. Foucault (1988) associe ce processus à une nouvelle approche et au traitement disciplinaire du corps. Plus encore, il identifie dans l'histoire de l'Occident un passage fondamental associé à l'invention d'une sexualité de culpabilité, à un moment unique, de « répression » et de « libération ». L'individu est perçu comme capable de déceler sa vérité à partir de ce qui est

dit ou non dit, réprimandé en relation au sexe. Cette approche nous pousse à considérer comment la sexualité a constitué un nœud de représentations fondamentales autour duquel se sont articulés des conflits se référant aux contextes sociaux, politiques et économiques depuis le milieu du XIX^e siècle, quand la médecine acquiert une place importante.

Dans cette perspective, J. Weeks (1985) analyse l'émergence de la sexologie qui, à l'origine, est immergée dans la production des gynécologues et autres spécialistes. En traitant particulièrement de la sexologie, de sa constitution en tant que science et de son usage pour définir de nouvelles identités culturelles, cet auteur argumente aussi dans le sens d'une perméabilité des discours et, au-delà, des effets inespérés que les propositions scientifiques peuvent avoir. Weeks part du principe que la sexualité est une invention sociale localisée, un produit de mouvements historiques exprimant les forces sociales en jeu dans chaque contexte.

La sexologie émerge comme un domaine de connaissance spécifique dédié au contrôle des individus en s'efforçant de définir ce qui peut-être considéré comme normal, en terme de relation avec le sexe opposé. Pour Weeks (1985), la sexualité est un champ de bataille, de construction de discours sociaux, et l'invention de la sexologie finit par avoir des conséquences diverses. Elle est également à la source de discours libéraux et permet de créer des identités sociales fondées sur les « découvertes » des médecins, comme dans le cas des mouvements féministe et homosexuel. Toutefois, il convient de souligner le rôle de la sexologie dans la réaffirmation des différences entre homme et femme, de l'attraction naturelle pour le sexe opposé et dans la création même du concept d'homosexualité – toujours lié à un signe biologique. Ces « découvertes scientifiques » apparaissent aussi à Weeks (1985) comme le résultat de demandes sociales, d'un panorama de changements exigeant de nouveaux codes pour gérer les rapports entre hommes et femmes et définir ce qui est acceptable dans la société qui se constitue. Pour cet auteur, les sexologues réussissent à traduire en termes théoriques ce qui est ressenti en tant que problèmes sociaux concrets, comme l'existence même de la sexualité des enfants et des adolescents ou la relation entre maternité et sexualité féminine. En réalité, une préoccupation plus importante envers les changements observés dans le rapport homme-femme serait au centre des spéculations produites sur la bisexualité, le travestissement, l'intersexualité et l'instinct de reproduction.

Weeks (1985) souligne que ce constat révèle une difficulté à définir les limites entre sexologues et réformateurs sexuels, eugénistes et moralistes. En même temps qu'ils apportent des réponses à l'exigence de nouvelles limites dans les relations entre hommes et femmes et de ce qui est normal en termes de sexualité, ils finissent par fournir de nouvelles bases scientifiques aux conflits sociaux. Les différences ont maintenant des bases biologiques, les pratiques déviantes sont classifiées, les féministes utilisent les arguments scientifiques, les homosexuels acquièrent une identité qui ne leur avait jamais été reconnue dans un autre contexte.

La complexité du champ des savoirs et les interventions autour du sexe ont aussi été la cible du travail classique de A. Béjin (1987a ; 1987b). L'une de ses contributions est l'hypothèse de ce qu'il existerait deux sexologies. La première aurait été produite dans la seconde moitié du XIX^e siècle, période où paraissent des œuvres de référence comme *Psychopatia sexualis*, édité par Heinrich Kann en 1844 et un volume publié sous ce même titre par Kraft-Ebing en 1886. Cette « protosexologie » avait pour objet la nosographie, en contraste avec la thérapie, et privilégiait les maladies vénériennes, la psychopathie de la sexualité et l'eugénisme. La seconde aurait émergé à partir des années 20 et un point de référence important en serait l'œuvre de W. Reich, qui a débuté ses publications sur la fonction de l'orgasme. L'édition de la première étude de A. Kinsey en 1948 aiderait à concrétiser l'orgasme comme thème central de cette nouvelle sexologie (Béjin, 1987a).

Cet auteur souligne également que la protosexologie se concentrait sur les difficultés relatives au fonctionnement de la sexualité reproductive, comme les maladies vénériennes, les « aberrations sexuelles » et les techniques contraceptives et n'était pas très encline à se différencier des autres branches de la médecine, comme la psychiatrie, la médecine légale ou l'urologie. En revanche, la sexologie actuelle n'aurait cessé de chercher son autonomie face aux autres disciplines, en particulier sur la base de l'objet particulier que serait l'orgasme et d'une norme fondamentale, « l'orgasme idéal ». En outre, la différence de base entre ces deux phases se doit au fait que :

« La protosexologie entendait étudier (et, bien souvent combattre) les anomalies, bien qu'elle puisse à peine dévoiler la norme qu'elle mettait en avant (essentiellement, le coït hétérosexuel reproductif). « L'orgasmologie » adopte un processus totalement différent ; elle commence par élaborer sa norme pour

en déduire des anomalies qu'elle se déclare immédiatement capable de soigner. Comme la norme – à l'exemple de « l'orgasme idéal » de la « Constitution » de Master Jonhson – représente souvent un objet empiriquement inaccessible, ces anomalies ne manquent pas. On peut observer que les sexologues modernes ne se réfèrent pas à ces anomalies, ces « aberrations ».

En réalité, ils substituent cette opposition marquée entre normalité et anomalie par un ensemble de dysfonctions. Face à la norme de l'orgasme céleste, nous souffrons tous de « dysfonctionnements sexuels ». (Béjin, 1987a :228)

Cet auteur (1987a) souligne encore que l'une des conséquences de ce fait est la génération d'une importante « clientèle », de plus en plus nombreuse, pour les sexologues contemporains, à l'inverse des pionniers qui ne traitaient que les « pervers » et les porteurs de maladies vénériennes. Ce mouvement a favorisé la création de cliniques et d'un enseignement spécialisés. De plus, alors que la protosexologie avait sommairement développé son éthologie, ne permettant qu'un contrôle *a posteriori* et répressif, en lien avec les prisons et les asiles, la sexologie actuelle a raffiné son éthologie et développe des moyens de contrôle *a priori* et *a posteriori*, qui se traduisent par les thérapies de l'orgasme et la prophylaxie des dysfonctionnements sexuels. Une fonction pédagogique toujours plus centralisée sur l'information est mise en avant.

Dans son livre *Disorders of desire*, Janice Irvine (2005) montre comment la sexologie s'est constituée aux États-Unis entre les années 40 et 80, en soulignant les aspects multidisciplinaires, la persécution et la controverse. À partir du travail d'A. Kinsey, cette auteure révèle les impasses des processus de professionnalisation, de légitimation culturelle et de création d'un marché autour du sexe. Les tensions politiques et les variations des contextes historico-culturels ont eu une influence importante sur la recherche, les interventions et l'acceptation de nouvelles références sur la sexualité. En outre, les débats ont été orientés autour de la distinction entre une « sexologie scientifique », s'appuyant sur les paramètres méthodologiques de la science, la pratique et l'autorité de la médecine et une « sexologie humaniste », fondée sur la reconnaissance de la sexualité comme objet de réalisation personnelle, de connaissance de soi et de satisfaction individuelle.

Dans le cas de la France, Giami et Columby (2001), mentionnent comme référence la création en 1931, de l'Association d'Études sexologiques sous l'influence d'Édouard Toulouse. À l'époque, la sexologie s'inscrivait dans un

courant néo-malthusien hygiéniste. Jusqu'aux années 60, dans ce pays, la sexologie était caractérisée par un ensemble d'initiatives diverses issues de différentes perspectives. Elle recouvrait les volets procréatifs et érotiques de la sexualité et s'intéressait aux aspects individuels et collectifs. Mais ce cadre à beaucoup évolué avec la vente de pilules anti-contraceptives sur le marché, la libération de l'avortement et le développement de l'éducation sexuelle de masse.

Actualisant une histoire récente de la sexologie, Giami (2000) souligne deux points fondamentaux. Le premier se réfère à la discussion sur la médicalisation de la sexualité et le second touche au débat plus actuel autour de la « dysfonction érectile ». Sa perspective accompagne d'autres travaux analysant ce champ, où il est coutume de montrer la différence entre la sexologie du XIX^e siècle et celle du XX^e siècle. Alors que la première mettrait en évidence l'aspect pathologique de la sexualité, celle du XX^e siècle (d'après les travaux d'A. Kinsey) se concentrerait de plus en plus sur la question de la « santé sexuelle ».

Pour ce qui est du processus contemporain de médicalisation de la sexualité, Giami (2000, 2001, 2004) suggère une suprématie des approches ou explications des problèmes sexuels en relation à la psychologie. Il identifie la médicalisation de l'impuissance masculine au cours d'un processus débutant dans les années 80 avec les découvertes scientifiques, comme l'effet de la papavérine sur l'érection. À partir d'alors, un groupe d'urologues a continué à proposer des définitions plus restrictives que celles du champ de la médecine organiciste, abandonnant les conceptions psychologiques qui avaient dominé au long des décennies précédentes et prenant ses distances de l'approche chirurgicale (auparavant dominante en urologie). Un reflet de ce changement est la création, en 1993, par le *National Institute of Health* (NIH), aux États-Unis, du terme « dysfonction érectile » qui vient remplacer « impuissance sexuelle ». Ces mêmes urologues se sont ensuite intéressés au terrain de l'épidémiologie et ont établi de nouvelles données sur la prévalence de l'impuissance.

En dépit de la réserve sur le maintien du terme « impuissance » par la littérature médicale, on peut observer que ce dernier fait maintenant référence à une conception plus large de la sexualité, incluant les dimensions psychologiques et relationnelles. En ce qui concerne le terme « dysfonction érectile » il semble plus restreint aux dimensions biologiques et physiologiques de

fonctionnement du pénis, considéré comme un facteur externe à l'homme et hors de son contrôle. Giami (2004) mentionne cependant une tendance de la substitution de l'éthologie psychologique de l'impuissance par une éthologie organique représentée par la dysfonction érectile.

La dysfonction érectile est définie comme « l'incapacité pour l'homme d'obtenir un pénis en érection comme partie du processus multiforme de la fonction sexuelle. » (HIH conférence 1993, p.83, in : Giami, 2004. Ainsi segmentée, la dysfonction érectile permettrait d'établir des niveaux de sévérité en incluant, sous une surveillance de la maladie, un large spectre de fonctionnement sexuel. Selon Giami (2004 :102) : « La dysfonction érectile se différencie de l'impuissance par une diminution de la maîtrise de l'érection, à éthologie organique, et par une extension de la prévalence incluant des formes plus légères » (Traduction de l'auteur).

Face à ce nouvel objet clinique qui venait de naître, l'industrie pharmaceutique a rapidement apporté une réponse sous forme de médicament, le Viagra (1998), contribuant à la diffusion des conceptions sur cet objet et ses transformations. Giami (2004) souligne la nécessité de comprendre le développement du Viagra comme un phénomène culturel sur différents plans. En ce sens, il met en relation le discours sur la stimulation sexuelle, sous l'influence du Viagra, et ceux de prévention relatifs au SIDA, pour souligner un paradoxe : alors que le discours sur le SIDA se focalise sur l'activité sexuelle des « jeunes », la multiplication des partenaires, les homosexuels et les pratiques à risque (comme la pénétration anale), le discours sur la dysfonction érectile s'applique à la pénétration génitale du couple hétérosexuel et s'adresse aux hommes âgés de plus de 40 ans. Deux approches de la sexualité qui s'ignorent mais qui en fait se montrent complémentaires : alors que l'impuissance touche la sexualité conjugale, le risque lié aux maladies sexuellement transmissibles menace la vie sexuelle hors du mariage (Giami 2004 :103).

Nous avons donc une relecture par les médias de la signification du Viagra mettant en relief son rôle d'aphrodisiaque et sa fonction récréative dans l'activité sexuelle. Un troisième sens peut-être proposé, si nous le considérons comme un médicament améliorant la qualité de vie. Giami (2004) conclut en soulignant l'apparition d'un processus paradoxal de « démedicalisation » graduée de la sexualité dans la mesure où les normes de santé et de sexualité passeraient toujours plus par l'exclusion de la prescription médicale

au profit du contrôle de l'industrie pharmaceutique. Une des raisons invoquées reposerait sur la possibilité de financement de la recherche et de nouvelles opportunités professionnelles. La soi-disant « médecine sexuelle » illustrerait un processus de consolidation de ce lien, représenté principalement par les urologues.

Il est possible de noter que même si le champ d'intervention de la sexualité se caractérise par la coexistence de différentes professions, l'approche biomédicale s'est imposée comme prédominante principalement à partir de la fin des années 90 et de la prescription de ce que l'on appelle des médicaments pro-sexuels. Ce cadre est associé à une nouvelle configuration d'idées et à un nouvel ensemble d'interventions concrètes que nous pourrions qualifier de nouvelle norme basée sur la performance sexuelle satisfaisante.

L'objectif des nouveaux discours et pratiques sur le sexe semble être de maximiser l'exercice de la fonction corporelle, en laissant croire que l'aspect relationnel/social de la sexualité serait éloigné des intérêts des nouveaux scientifiques du sexe. L'idée que les problèmes liés à la sexualité découlent en grande partie « d'absence » ou « d'insuffisance » de l'exercice sexuel est devenue prépondérante. Si, pour les sexologues du XIX^e siècle, la question pertinente était « l'excès sexuel » des femmes « nymphomanes » ou des hommes « pervers », le problème est maintenant lié au « manque ». L'individu moderne semble condamné à faire la preuve de sa capacité sexuelle pour pouvoir prouver son identité de sujet épanoui, satisfait et heureux. Les discours sur l'usage des médicaments, en particulier, se sont largement inspirés de cette nouvelle approche.

Il devient de plus en plus clair que l'idée de « santé sexuelle » gagne du terrain. Bien qu'elle fasse parfois référence aux droits et à la notion de bien-être individuel, ce qui est crucial dans cette notion, c'est l'établissement d'un nouveau paramètre de performance que l'individu d'aujourd'hui doit atteindre. Ce dernier paraît être obligé à jouir d'une activité sexuelle régulière, intense et très performante. Cependant, pour atteindre ce nouveau seuil, il faut avoir recours à des agents externes qui feront le diagnostic de la performance et prescriront les solutions adaptées. La responsabilité est donc transférée à ces agents externes, comme les urologues, qui s'occuperont du bon développement des fonctions sexuelles. Surgit alors l'image d'un individu soumis aux fonctions corporelles et à leur bon fonctionnement, sur la base de standards qui sont définis en dehors de lui. De plus, l'on construit un

lien fort entre santé sexuelle et santé en général, ce qui, dans le cas masculin, est représenté par la capacité d'érection qui devrait toujours être maximisée.

Ces arguments aident à analyser les différences entre les deux investissements dans la santé et la sexualité masculines évoquées dans ce travail. Comme nous pouvons le voir, la production de savoirs sur la sexualité qui se développe de la fin du XIX^e siècle jusqu'au début du XXI^e siècle est marquée par un intérêt croissant pour la notion de santé et d'amélioration de la performance individuelle, caractéristiques principales pour mieux comprendre les initiatives entreprises par les urologues liés au domaine de la médecine sexuelle, que l'on observe aussi au Brésil.

Perspectives concernant la médicalisation de la sexualité masculine

La récente médicalisation de la sexualité masculine, centrée sur l'ascension des diagnostics de dysfonction érectile et DALA, montre une série de contrastes intéressants par rapport au type de médicalisation qui a caractérisé le processus concernant la syphilis dans les premières décennies du XX^e siècle. Il convient d'observer que ces deux situations présentent sans aucun doute des contextes sociaux extrêmement distincts qui se traduisent par exemple en espérances de vie très différentes et en politiques publiques ayant des intentions bien contrastées. D'une manière générale, si dans un premier temps la question de la santé entre dans un registre plus collectiviste, de préoccupation envers la nation, dans le second, la référence forte se confond avec une idéologie plus individualiste, allant très souvent dans la direction contraire des discussions sur la promotion de la santé via la perspective des droits et de la citoyenneté.

Il serait possible d'indiquer certaines « permanences » ou points communs, comme l'idée courante de ce que les hommes sont énormément préoccupés par le sexe, ce qui exigerait des formes d'administration distinctes. Pourtant, même sur ce point nous aurions des différences significatives. Si, dans les campagnes contre la syphilis, la question se traduisait en termes d'autocontrôle des « excès » sexuels au profit du bien collectif ou de la nation, actuellement le point central semble être la promotion du soin de soi, comme manière d'atteindre un accomplissement personnel projeté. En outre, la syphilis apparaissait sous le registre d'une maladie externe et fragilisante qui pourrait affecter les hommes, alors que la médicalisation via la

reconnaissance de problèmes fonctionnels et biochimiques renvoie à des difficultés inhérentes au corps de l'individu lui-même et à son fonctionnement. Alors que le discours sur la syphilis accentuait les dangers de la dégénération collective, celui qui aborde la santé sexuelle dans le contexte contemporain met surtout l'accent sur une régénération de la puissance sexuelle individuelle.

La prédominance de ce courant plus individualiste, calqué sur l'amélioration de la performance et de la fonctionnalité et les résolutions pharmacologiques nous renvoie aux discussions récentes sur les processus de bio-médicalisation, associés à la conformation d'une nouvelle culture, ou « régime de vérité », centrée sur la responsabilisation individuelle. Dans ce contexte, la préoccupation pour la santé devient un attribut moral de l'individu, lequel doit être informé des nouvelles connaissances, des pratiques de soins de soi, de prévention et de traitement des maladies et disposé à consommer les ressources actuellement disponibles (Clarke et al 2009).

Cette argumentation prend de l'importance dans l'œuvre de Nikolas Rose (2007) qui s'interroge sur le rôle des sciences de la vie dans la production de vérités et de subjectivités contemporaines. Sa discussion des concepts de molécularisation, d'optimisation, de subjectivation, d'expertise et de bioéconomie est importante pour comprendre la dynamique des transformations impliquant la notion de corps sain centrée sur l'autogestion personnelle. Quand il parle de molécularisation, Rose met l'accent sur le passage d'une conception biomédicale centrée sur le corps à celle qui, maintenant, se spécialise au niveau moléculaire, ce qui pourrait être décrit en termes d'une nouvelle biopolitique. L'optimisation est présentée comme l'utilisation des technologies médicales contemporaines non seulement pour guérir des pathologies mais encore pour contrôler les processus vitaux du corps et de l'esprit. Ces technologies de l'optimisation sont associées à l'idée de l'accomplissement comme quelque chose dirigé vers le futur et à la possibilité de création d'individus consommateurs de ces nouveaux désirs et de ces nouvelles possibilités de contrôle de la vie. Le concept de subjectivation sert à décrire le processus par lequel le sujet est amené à croire que la promotion de la santé est une question personnelle, d'autogestion et de responsabilité.

Cela serait associé à la conversion de la santé en tant que valeur éthique importante dans la société occidentale, à partir de la seconde moitié du XX^e siècle et, de façon plus contemporaine, à la formation d'une nouvelle

éthique. Il s'agit d'une « éthopolitique », soit de la tentative de modeler la conduite des êtres humains par le biais d'une action sur les sentiments, les croyances et les valeurs axée sur la manière dont ils devraient juger et agir sur eux-mêmes et leur corps, en visant le futur. L'expertise, quant à elle, devient importante par rapport aux pratiques de biopouvoir émergentes qui sont liées à de nouvelles formes d'autorité. Les actuels « experts de la propre vie » ne se distinguent plus en fonction de la guérison de maladies, mais de leur capacité à améliorer les arts de l'autogouvernement. Médecins et autres professionnels de santé formeraient ce champ d'« experts somatiques », capables d'orienter les individus vers la recherche de l'amélioration ou de l'optimisation de leurs potentialités. (Rose 2007).

Il est possible de suggérer, dans le cas de la médicalisation de la sexualité masculine, que ces phénomènes plus généraux peuvent être articulés autour de certaines transformations importantes. En ce qui concerne le développement de nouvelles spécialités et de nouveaux « experts », l'on pourrait citer le contraste entre l'insuccès de l'institutionnalisation de l'andrologie, telle que proposée par José de Albuquerque et l'ascension de l'urologie, lorsqu'elle se convertit, du moins en partie, en médecine sexuelle. Bien qu'actuellement la Société brésilienne d'Urologie compte sur un département d'Andrologie, le plus important est que l'urologie elle-même s'est mise en évidence comme spécialité légitime dans le soin de la sexualité masculine. Si la proposition d'une science du sexe masculin, calquée sur des paramètres moraux et scientifiques n'a pas avancé au cours des années 1930, la nouvelle pharmacologie sexuelle se montre de plus en plus présente.

Il convient encore de noter que ce nouveau processus de médicalisation de la sexualité masculine ne se produit que lorsque la santé, notamment la santé sexuelle, commence à se convertir en bien valorisé en tant que tel, en contraste avec la médicalisation qui mettait en avant la maladie. Ce n'est que dans ce nouveau contexte que le discours public des urologues paraît connaître plus de succès. Cela revient à dire que, pour les urologues brésiliens, les hommes ne seraient attirés dans les services de santé pour traiter de maladies que lorsque des possibilités d'amélioration de leur potentialités et plus particulièrement de la fonction sexuelle sont impliquées.

Pour conclure, si dans le processus de médicalisation et contrôle par le biais de la syphilis, l'accès aux hommes passait par une maladie, externe, contagieuse et affaiblissante, qui porterait préjudice à la nation elle-même,

de nos jours la médicalisation opère par le biais de la menace de la faible performance et du besoin d'améliorer la fonctionnalité liée à des facteurs moléculaires. Il ne s'agirait plus de l'autocontrôle nécessaire aux citoyens des États émergents mais du soin de soi incontournable pour les individus responsabilisés pour leur santé, leur bien-être et leur accomplissement. On pourrait parler d'une médicalisation « par l'intérieur » et « pour l'amélioration », liée à la promotion de la santé en tant que valeur culturelle et bien de consommation.

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Tracing identities through interconnections:

The biological body, intersubjective experiences and narratives of suffering

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Abstract

The 1987 radioactive disaster in Goiânia – a ‘critical event’ – revealed the formation of new identities in opposition to the notion of *radioacidentados* (radiation victims), a classification established by the system of nuclear expertise and defined exclusively by the person’s absorption of high-level doses of radiation. In the search to give meaning to their illness and suffering, new social subjects have emerged and elaborated new interpretations concerning the materiality of contaminated bodies. In narrating their subjective experiences, they situate their identities as victims in relation to the embodied experience of the contaminated site and the attribution of new meanings to certain objects associated with the disaster itself and nuclear technology in general. The text focuses on this articulation between the biological body, narratives, memory, ‘things’ and the constitution of social identities. It provides a historical analysis, supported by a multivocal ethnography of the Cesium-137 disaster.

Keywords: Radioactive disaster; narratives; place; embodied memory; material culture; victim identity.

Resumo

O desastre radioativo de Goiânia – um “evento crítico” – expôs a formação de novas identidades sociais que se opuseram à configuração de “*radioacidentados*”, uma classificação estabelecida pelo sistema perito nuclear e definida exclusivamente pelas altas doses de radiação. Na procura pelo sentido da doença e do sofrimento, percebidos como causados pelo desastre, novos

sujeitos sociais emergiram e atribuíram novas interpretações à materialidade dos corpos contaminados. Narrando suas experiências subjetivas, eles posicionaram suas identidades de vítimas em relação à experiência corporificada do lugar contaminado e na resignificação de objetos próprios à história do desastre e à tecnologia nuclear. Este trabalho focaliza a articulação entre corpo biológico, narrativas, memória, “coisas” e a constituição de identidades sociais. É uma análise histórica com base em uma etnografia multivocal sobre o desastre com o Césio-137.

Palavras-chave: Desastre Radioativo; Narrativas; Lugar; Memória Corporificada; Cultura Material; Identidade de Vítima.

Tracing identities through interconnections:

The biological body, intersubjective experiences and narratives of suffering¹

Telma Camargo da Silva

Introduction

When society deals with risks, whether of aggression, natural hazards, or a controversial technology, it is engaged in a political process. The politics concern allocation both of tangible benefits and costs and of symbolic assets and liability.
Ingar Palmlund (1992)

The new scientific fields and technologies developed over the course of the twentieth century brought with them diverse forms of experiencing social relations, narrating suffering, and problematizing the power relations entangled in knowledge production, stimulating the social sciences to investigate and interpret these new configurations. Among these newly consolidated fields was radioactivity² and its gradual applicability in two areas that are closely interconnected, though understood by many as separate realms: the so-called ‘peaceful’ uses with ‘positive effects,’ and the misuse of the technology, grouped under ‘negative effects.’ In the first group of uses, an extensive literature has documented the use of radioactivity in research

1 A previous version of this work was presented at the roundtable ‘Biosocialities, institutions and spaces of identity from a comparative perspective,’ coordinated by Carlos Guilherme Octaviano do Valle at the 28th Brazilian Anthropology Meeting (28th RBA), held in São Paulo, 2-5 July 2012.

2 Radioactivity was discovered in 1896 by French physicist Antoine Henri Becquerel. “A uranium rock left forgotten on a blank photographic film led to the discovery of an interesting phenomenon: the film was stained marked by ‘something’ emerging from the rock, named at the time rays or *radiations*. Other heavy elements, with a mass close to that of uranium, such as *radium* and *polonium*, had the same property. The phenomenon was named *radioactivity* and the elements displaying this property were called *radioactive elements*” (Alves et. al., n.d.: 05). The name radioactivity literally means the activity of emitting rays (from the Latin *radius*) (Luz n.d.) As a tribute to this scientist, the unit measuring the number of nuclear transformations per unit of time is called a Becquerel (Bq) (Azevedo n.d.: 29).

centers, nuclear medicine, radiotherapy, agriculture, industry and energy production. The second group includes atomic bombs, radioactive disasters and nuclear weapon tests. In both cases, the discovery of radioactivity has led to particular forms of experiencing social relations permeated by the risk of radioactive contamination. While nuclear science has invented specific instruments and measurements to understand and control the materiality of something immaterial – radiation – without color or smell, flavorless and silent, the narratives of the survivors of the Cesium-137 disaster in Goiânia actively subvert the objectivity of the official dose classification used to determine which people have been exposed to radiation. The present analysis is informed, therefore, by the following questions: How do the experiences of people in a radioactive emergency situation compare and contrast to the technical rationality and disciplinary knowledge of nuclear experts? How has the materiality of the disaster exposed the power games involved in classifying the affected population? How has the ‘work of memory’ (Jelin 2002) appropriated technical-scientific knowledge in order to redefine belonging to the disaster?

In this work, I turn to my own earlier research³ on the Goiânia radioactive disaster,⁴ reviewing my previous inquiries (Silva 2010, 2009a, 2009b, 2007, 2005, 2004a, 2004b, 2001, 1998a, 1998b, 1997) in order to analyze how the contamination site is constituted by the bodily experiences narrated by different social actors of this event: the victims, *radioacidentados*,⁵ the neighbors of the

3 Ph.D research project *Radiation illness representation and experience: the aftermath of the Goiânia radiological disaster*, financially supported by the Wenner-Gren Foundation for Anthropological Research (Grant No. 5969 and Post-Ph.D./Richard Carley Hunt – Grant no. 7046). The analysis focused on the disaster and its aftermath over the period 1987-2001. The data collection involved active observation, audio and visual recording of open interviews and archive research. In this article, I have opted to use the real names of the people who have occupied (or currently occupy) public service posts, or who are prominent at an institutional-political level. Pseudonyms have been adopted for everyone else.

4 The Cesium-137 radioactive disaster, which officially occurred in 1987, was caused by the opening of a capsule belonging to radiotherapy equipment that had been abandoned by the then owners of the Goiânia Radiotherapy Institute (IGR), in the center of the city of Goiânia (Goiás – Brazil). The opening date of the equipment is stated to be the 13th September 1987 by some sources (IAEA 1988: 11) and the 10th September 1987 by other sources. The danger present from the 10th to 28th September 1987 is described as the “time of loss control” (sic) (Rozenal 1991: 10) of the nuclear experts, who only arrived in Goiânia on September 29th that year. Four people died in the days following the opening of the equipment and 249 others were officially found to have been contaminated (IAEA 1988). However, to date countless individuals have been trying to prove through the legal courts a cause-and-effect relationship between the disaster and their own physical and emotional suffering (Silva 1998a, 1998b, 2001, 2004).

5 A term invented by nuclear-medical expertise to designate the people who carry the physical marks of radiation on and in their bodies, whether visible signs of burning left by direct contact with the radioactive element (*radiodermites*) or the record of high-level doses of radiation absorbed and subsequently measured by various kinds of dosimeters in 1987.

radioactive contamination areas and the military personnel actively involved in the disaster management. Further ethnographic data from follow-up research undertaken in the field at different moments during the years from 2010 to 2014 is also evaluated. In order to define the place of contamination, the narrators picked out and gave new meanings to various 'objects' associated with nuclear-medical expertise: site hoardings, overalls, radiographs. I argue that the need for the effects of radiation to become materialized in people's bodies – a requirement for them to be classified as disaster victims – mobilizes different artifacts: the equipment specific to nuclear technology and the things created in the disaster experience. Thinking through this materiality⁶ provides a way for us to unmask the play of memory and power involved in defining the population affected by the disaster in Goiânia from a polyphonic perspective. This embodied place,⁷ arising from the body's experience, is signified by the narrativization of the subject (Casey 1996: 13-52). Place, body, artifacts, memory and narrative are, from this point of view, intertwined in the production of identities and able to express power relations and political processes.

In order to understand how identity is shaped in the context of a radioactive disaster – which, I argue, is in turn shaped by the embodiment of place – I highlight the central importance of the notion of radiation doses. Formulated in response to the demand for precision and objectivity, it is appropriated by distinct social actors and imbued with multiple meanings. The idea of scenario (Magnani 1996: 37-38), understood here as a product of dynamic social practices, allows us to locate the experiences of different social actors in the use of nuclear technology over the years. These actors include nuclear workers, non-nuclear workers, residents and the people affected by the radiation. The constitution of a field of knowledge – nuclear science – identified by the discovery of radioactivity, the invention of specific instruments and the formulation of measurement techniques particular to this new science are all reconfigured in the experience of radioactive disasters. The understanding of these scenarios frames the narratives that surround people's interpretations of radiation doses and shape the biopolitics of the Goiânia disaster, as I shall analyze over the course of the article.

6 Analysis based on the contribution of Daniel Miller (2010:10) who declares that: "the best way to understand, transmit and appreciate our humanity is to give attention to our fundamental materiality."

7 This concept is related to that of embodied memory, explored in my earlier work (Silva 2005).

Scenario One

Dosimeters and discipline: creating a controlled risk environment from the viewpoint of the nuclear expert

A nuclear technology scenario is configured first of all through the ambivalence of radiation itself, the immateriality of which presents a very real material danger. The physical characteristics of radiation demand the creation of new parameters of measurement and control, along with the invention of new equipment to check for and record its presence, the so-called dosimeters, including radiographic films,⁸ thermoluminescent dosimeters (TLD),⁹ Geiger-Muller counters and the pen dosimeter.

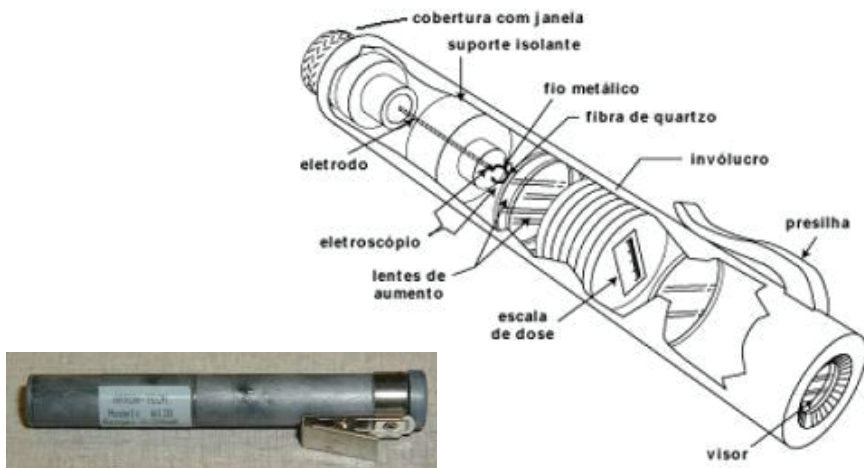


Image 1 – pen dosimeter¹⁰

Developed in response to the need to detect radiation, this technology reflects the idea that radioactivity can be objectively measured through the use of special equipment and analyzed with complete reliability in accordance with its own specific parameters, defined in order to quantify this new

8 “Radiation produces changes in the density of processed film (blackening). This allows the radiation exposure to be quantified. The use of filters helps to distinguish exposure to less penetrating types of radiation (beta) from exposure to more penetrating types (gamma)” (Oliveira n.d.).

9 “The thermoluminescent material used is based on the use of crystals in which the ionizing radiation creates electron-hole pairs. Through a thermal process, photons are released and can be collected by a photomultiplier. The number of photons released is proportional to the original load amount” (Oliveira n.d.).

10 The pen dosimeter was developed to assess the dose received by a worker during the performance of a given activity (Oliveira n.d.).

material phenomenon. The measurements – illustrated below – and their interpretation, along with the knowledge of how to operate the dosimeters, form part of the expertise of the nuclear specialist, articulated through the notion of radioactive doses. It is this capacity to measure the radiation dose (amount) to which an individual has been exposed and/or contaminated¹¹ that enables the nuclear risk to become a material reality.

- **Activity:** Bq. Number of nuclear transformations per unit of time
- **Exposure:** R (C/kg). Amount of load collected in a given mass of dry air
- **Absorbed dose:** D (Gy = J/Kg). Relation between absorbed energy and the affected volume (1 Gy = 100 rad)
- **Equivalent dose:** H = D.Q (Sv = J/Kg)
- **Effective dose:** E = D_TW_TH_T (Sv). Takes into account the irradiated tissue or organ. W_T is the weight factor of the tissue or organ. D_TW_T = 1

Figure 1: Quantities and units used to assess radiation in the body. (Azevedo n.d.:29)

For the nuclear worker, knowing the dose received during their professional activity and understanding the measurements cited above are a matter of personal safety and radiological protection. In her study on the social construction of risk at the Angra I Nuclear Power Plant, Gláucia Silva states:

These measuring instruments start to be seen as protection mechanisms: because radioactivity is invisible and odorless, affording no means for our immediate bodily senses to detect its presence, measuring the dose is one way of feeling protected. (Silva 1999:141)

However, in a society where radioactivity is present in many areas of everyday life, not only nuclear workers depend on the control of these radiation doses. In this new modernity and what can be characterized as a risk society – with the nuclear sphere being one of its constitutive elements – the capacity to overcome fear and control risks depends on the trust invested in the system of expertise, where the nuclear specialist is a fundamental actor (Beck 1993[1986], Giddens 1991). In this configuration, the nuclear expert is

¹¹ The National Nuclear Energy Commission (*Comissão Nacional de Energia Nuclear: CNEN*) states that: “contamination, whether radioactive or any other kind, involves the undesired presence of a particular material in a given location where it is not supposed to be. Irradiation is the exposure of an object or a body to radiation, which can occur at some distance, without the need for direct contact” (Cardoso et.al. n.d.: 17).

responsible for ensuring the use of adequate clothing and equipment not only for his or her own personal safety, but also for the safety of all those in contact with radiation. Here the access to dosimeters and the ability to interpret the registered doses – informed by a risk-trust relationship, including belief in the objectivity of the measurements – makes nuclear experts the central authorities when it comes to recognizing the new legal identities produced in a situation of radioactive exposure, whether the ‘victims’ identified in the Goiânia disaster,¹² or, for example, the ‘sufferers’ in the case of the Chernobyl disaster in Ukraine (Petryna 2002: 2).

In this society permeated by nuclear risk – of which the Fukushima disaster¹³ is one recent example – people’s bodies are regulated by techniques for detecting and evaluating radioactivity – techniques that have been created, implemented and regulated by the system of expertise developed by agencies like the International Atomic Energy Agency (IAEA) and Brazil’s National Nuclear Energy Commission (*Comissão Nacional de Energia Nuclear: CNEN*). In this first scenario, then, defined by nuclear scientific expertise, the body’s experience of radiation is perceived to be safe insofar as it is controlled by technological knowledge.

This disciplinary expert knowledge, which pre-determines bodily experience, is also pervaded by notions of time and space. Preventing the risk of cells being damaged by radiation is connected to controlling the period of time over which an individual remains in close proximity to a radioactive source and their specific distance from the same. In other words, the representation of the risk of radioactive contamination is understood through mathematical and objective parameters, while the technology has a disciplinary effect on the individual’s body. In this scenario, the narrative produced by the system of nuclear expertise on the effects of radiation precedes and

12 The term used in the documents that define appropriate medical care and grant federal and state pensions (Goiás State Official Gazette, Decree No. 2,897, of 11th February 1988, creating the Leide das Neves Ferreira Foundation; Goiás State Official Gazette, Law No. 10,977, of 3rd October 1989, granting special pensions to the victims of the Goiânia radioactive accident; Federal Official Gazette - Law No. 9,425, of 24th December 1996, determining the provision of special pensions to victims of the nuclear accident in Goiânia, Goiás State).

13 The Fukushima disaster was caused by failures in the structure and operation of the Fukushima I Nuclear Power Plant in Japan, exposed when the region where the plant is located was hit by an earthquake and a tsunami on 11 March 2011. The disaster is still ongoing since many people are still displaced, the radiation has not yet been contained, and claims for official recognition as disaster victims and demands for compensation are still being processed. As well as contaminating the air, soil, plants, people and animals, the disaster also contaminated the sea. The Tokyo Electric Power Company (TEPCO), which runs the Fukushima Nuclear Power Plant, announced in April 2011 that it had started to release 11,500 ton of radioactive water, accumulated in the damaged facilities, into the ocean. In Europe the disaster gave a fresh impetus to movements against the use of nuclear energy.

shapes the experience of radioactivity, disciplining the body through technology. Created to deal with the demands of a laboratory environment and developed to protect nuclear workers, what are the implications, though, of using this paradigm to understand a radioactive disaster occurring in an open space and to people living their everyday life for thirteen days without being aware of the risks to which they were exposed, as in the case of the Goiânia disaster?

To discuss this question, I suggest a second type of radioactive technology scenario (*Scenario Two*), shaped by the uncertainties and ambiguities that emerge from disaster experiences and foregrounding the subjective and political dimensions of the notion of radiation dose. It also raises questions about the objectivity of radiation dose evaluations and risk perceptions. In the case of Goiânia, ever since the first phase of intervention by nuclear experts, the so-called emergency phase,¹⁴ and reinforced over the years, the actions and relationships established with the affected people have been marked by inconsistencies and sometimes by secrecy – one of the motives for their social mobilization. Referring again to Beck's work (1993), this kind of society that he labelled catastrophic also contains a political potential, which can provoke reactions and mobilizations from the affected populations, as we shall analyze too in the case of Goiânia.

Scenario Two

Hoardings / suspicions / uncertainty: the experience of living in a contaminated site

During the practical implementation of a mathematical rationality for radiation measurement, the landscape of Goiânia was marked during the emergency phase by the construction of red-stained wooden hoardings. According to the narrative of the nuclear experts, these screens were used to isolate the places with high-level doses of radiation – the so-called 'hot spots' registered by the dosimeters. Inside the hoardings were the contaminated houses from which people had been removed and isolated for decontamination. Outside the hoardings were the residents considered to be

14 CNEN considers the emergency phase to be the period from September 29th to December 21st 1987. These activities are taken to have begun with the arrival of CNEN professionals in Goiânia and ended with the following actions: decontamination of sites with higher levels of radioactive contamination; demolition of contaminated houses and removal of radioactive waste to the Abadia de Goiás Temporary Radioactive Waste Storage Center (Rozenal 1991).

uncontaminated and therefore allowed to remain at home and circulate freely in the areas close to the hoardings. This fact generated numerous doubts and questions concerning the boundaries of the contamination and the safety of living in the vicinity of the risk area visually and physically delimited by the site hoardings. Hence the hoardings became a symbol of the later exclusion of these “neighbors of the hot spot areas” from classification as victims of the Cesium-137 disaster, signaling the limits between risk/non-risk, and the fear elicited by the danger of contamination.



Images 4 and 05 – The site hoardings
Photographer unknown – CNEN collection – 1987

The lack of official explanations capable of allaying the doubts provoked by these boundary markers and the fear of being contaminated mobilized the residents of the areas surrounding the hoardings put up in Rua 57. In December 1987 they created the Cesium-137 Victims Association (*Associação das Vítimas do Césio-137*). These feelings of fear and uncertainty were closely related to the theory found among some of Goiânia’s inhabitants that the government and the nuclear experts had kept the radioactive disaster secret for thirteen days. This theory was based on the fact that an international motorcycle race had been held in Goiânia during the same period that the radiotherapy unit had been removed from the *Instituto Goiano de Radioterapia* and opened up, and the radiation spread through the city center early in September 1987. Those maintaining this theory believed that, in order to avoid economic losses from canceling the event, a political decision had been taken to postpone the announcement that a disaster was taking place. In an interview I conducted with the Goiás state governor at the time, the latter, Henrique Santillo, denied any connection between the sporting event and the public announcement of the disaster by the government authorities.

Nevertheless, this interpretation of events is still maintained by some survivors even today, as I was able to observe during my fieldwork in 2014. Here it is also worth highlighting numerous other studies on radioactive disasters and nuclear bomb tests dating from the late twentieth century (Alcalay 1993 and 1995, Barker 1997, Bertell 1985, Garb 1997, Kaplan 1992, Paine 1987) which sustain a controversy over the beginning of these events. This topic has been given further impetus by the recent reports and media coverage of the 2011 Fukushima Daiichi nuclear accident, including accusations that the announcement of radiation fallout and the amount of radiation doses released into the environment is swayed by political rather than technical factors.

Returning to the creation of the Cesium-137 Victims Association, the outcome of a grassroots movement that sprang up in the wake of the Goiânia disaster, it is important to emphasize that this mobilization stemmed from: 1) the local population's unease concerning the methods used to evacuate residents from the affected areas; 2) the questioning of the secrecy surrounding the decisions and actions taken by the specialists during the emergency response phase of the disaster; 3) the understanding that a broader form of categorization was needed to acknowledge all contamination victims; 4) the clash with the federal and state governments over the adoption of a broader concept of healthcare, encompassing both physical and mental aspects and valuing people's nutritional needs; 5) the demand for individuals to be able to access the results of exams conducted by CNEN and the Leide das Neves Ferreria Foundation (FUNLEIDE);¹⁵ 6) the coordinated work at national and international level with other popular organizations and local university institutions seeking support for their demands.

In the process leading to the creation of the Association, the victim identity is constructed in direct confrontation with institutionalized biomedical knowledge: the victimized body is not only the physically affected

15 The Leide das Neves Ferreira Foundation (Fundação Leide das Neves Ferreira: FUNLEIDE) was created by State Law No. 10,339, of 9th December 1987, and instituted by Decree No. 2,897/88, of 11th February 1988, enacted by the then governor Henrique Santillo. It started to operate from the 29th February 1988 in the building of the OSEGO (Goias Health Organization) Health Monitoring Office, on Rua 16-A, Airport Sector. It was there that parts of the radiology equipment containing Cesium-137 were left by Maria Gabriela Ferreira. This was the first site where radioactivity was detected. FUNLEIDE would be responsible for "continuing the work being developed by the Commission for Monitoring Cesium Victims of Cesium (Comissão de Acompanhamento das Vítimas do Césio: Cocesio), which was installed at FEBEM to provide support to patients suffering from radiation exposure" (*O Popular* newspaper, Goiânia, 26th February 1988, page 5). The foundation's name is in homage to the child severely contaminated by Cesium-137 who became the first fatal victim of the disaster.

body, as in the understanding of physicians linked to CNEN who use the term *radioacidentados* to refer to those suffering from radiation-caused lesions when identifying victims of the disaster. Members of the Cesium-137 Victims Association claim that the ‘invisible’ marks of the disaster, such as the disintegration of social networks and family ties, and the loss of jobs, should be included as elements that define victim status. The notion of social suffering¹⁶ proposed by Kleinman, Das and Lock (1997) captures this sense of disaster victims. The authors argue against the fragmentation and separation of the causes of suffering into separate and isolated dimensions, classified into distinct areas of knowledge, such as those related to health, biology, economics, the social and politics. They use the term *interfuse* to emphasize the absence of boundaries between these different areas of interpreting the causal relations involved in pain (1997: xi). In order to encompass this broader perception of victimhood, members of the Association categorize the people affected by the Goiânia disaster into ‘direct victims’ and ‘indirect victims.’ The first group corresponds to the same definition of *radioacidentados* (radiation victims) used by the nuclear experts. The second group refers to the group of people who did not have direct contact with the radioactive source but who were nonetheless neighbors of the contamination hot spots.

The Association’s first board of directors, active until 1989, reflected this wider understanding of victim through its composition and through the agenda pursued over the period. The documents setting out its claims, jointly signed with the Abadia Residents Association, emphasized that the issue of the victim-disaster relationship needed to be included in a broader perspective. These wider concerns included the safety of the radioactive waste storage site and its social impact on the population of Abadia de Goiás where the site is located.¹⁷ The actions pursued by the association advocated the interests of both direct and indirect victims. For example, the campaign for state pensions, compensation for material loss and better healthcare supported the direct victims, while the campaign for exemption from property tax (IPTU) for properties located within the radioactive contamination area supported both groups.

16 “Social suffering results from what political, economic, and institutional power does to people and, reciprocally, from how these forms of power themselves influence responses to social problems. Included under the category of social suffering are conditions that usually divided among separate fields, conditions that simultaneously involve health, welfare, legal, moral, and religious issues” (1997: ix).

17 Located 20km away from Goiânia, on the BR-060 highway.

Hence, although membership of the Cesium-137 Victims Association includes the victims classified via the parameter of radiation doses, an externally attributed identity, it is important to stress that the association emerged from the agency (Ortner 2007) of neighbors who name themselves as ‘indirect victims’ of the disaster. This group of people, aside from having a predominantly residential sociability, also identify with each other through the fact that they lived in the area surrounding the site hoardings, which symbolically marked the experience of radioactive risk in the urban landscape. In this sense, it is the lived experience of place¹⁸ that testifies to the experience of radiation for these people. They equally inhabit the neighborhood, were equally excluded by the hoarding boundaries, and are equally seeking to be identified as disaster victims. In this case, a claimed rather than attributed identity.

The narratives constructed by the people living in the contaminated areas challenged the mathematical understanding and objective parameters – discussed in *Scenario One* – as the only interpretative framework available to classify victims of the disaster. In parallel to the technological equipment used to discover the physical effect of radiation on people’s bodies, the Goiânia case points to this other kind of physical materialization, perceived through lived experiences rather than being captured by dosimeters and other nuclear technologies. The ethnographic data also reveals the disdain shown by nuclear experts for the low-level doses of radiation exposure that are central to the questions raised by those living close to the hot spot areas. Although studies published during the second half of the twentieth century (Bertell 1985, Gould & Goldman 1991) have already highlighted the impact of low doses of radiation on people’s health and on cultural reproduction in post-disaster communities (Stephens 1987, 1995), this topic requires much further anthropological research. In sum, the community organizations and local knowledge explored in this radioactive technology scenario (*Scenario Two*) suggest that the study of low-level doses of radiation is a political issue involving the production of scientific knowledge as much as the legal dimension in the classification of victims.

As well as campaigning for a more inclusive categorization of disaster victims, the campaign work of the Cesium-137 Victims Association has

18 In the case under analysis, a space marked by relationship networks defined by neighborhood ties and by the sociability constructed in the search to be categorized as ‘indirect victims’ of the disaster, defined by the proximity of their residences to the site hoardings.

focused on two other issues over the years: the economic survival of the *radio-acidentados* who have been stigmatized by being considered contaminated and thus not fully incorporated into society; and the provision of adequate health care. Although legal responses had been given to these requests through the creation of special laws guaranteeing pensions and medical care, concretized with the establishment of the Leide das Neves Ferreira Foundation, a research and medical treatment center, the *radioacidentados* claim they still live in dire conditions. In 2014, 27 years after the disaster became known, the Cesium-137 Victims Association used local newspapers and social media to denounce a shortage of medications at the public health center and the discontinuation of the service for monitoring victims' health. The association members also demanded a readjustment to the value of their pensions in line with inflation.

This ceaseless struggle over more than two decades is another aspect of the social suffering analyzed earlier. If the red-stained wooden hoardings and the creation of the Cesium-137 Victims Association materialized the invisibility of the radiation disaster in the everyday lives of people living in a radioactively contaminated place, this continuous mobilization over the years also testifies to a kind of pain not accessed through mathematical rationality or through disciplinary expert knowledge. Simultaneously it also raises questions about the official closure of the Goiânia disaster. According to the nuclear agency CNEN, the disaster ended with the opening of the Permanent Radioactive Waste Storage Site in June 1997 (Silva 2002, 2009 a). However, the complaints and demands made by survivors in 2014 suggest an event that is still unfolding today.

Scenario Three

Clothing / radiographs: memory and the worker identity at the contamination site

In the first half of 1997, ten years after the opening of the Cesium-137 capsule, the media of Goiânia published reports from military police officers who associated their otherwise inexplicable illnesses to a common cause: contact with the radiation. Their symptoms varied: a brain tumor, a forearm tumor, brain damage, a malformed child, blotches on the skin, psychological problems, emotional disorders, intense sweating on the left side of the body, sexual impotence. Their narratives indicated a common work experience:

they had all been responsible for guarding the Temporary Radioactive Waste Storage Site in Abadia de Goiás and/or areas defined by the CNEN as radiation hot spots and indicated by the site hoardings, as we saw earlier. The denunciations made in the newspapers and the despair of isolated individuals were given concrete voice through an organized movement involving the Association of Military Police Officers of the State of Goiás (*Associação dos Cabos e Soldados da Polícia Militar do Estado de Goiás: ACS*) and a number of federal congresspeople. In April 1997, the list organized by ACS included 128 names.

The narratives constructed by these police officers reveal that, when faced with illness, they go over their past experiences and try to reconstruct their career history to better understand the present. In the process of searching their professional and family memories, they come face-to-face with the distinction between nuclear and non-nuclear professionals working in the radiological emergency – and it is precisely in this distinction that they discern the causes of their health problems.

In constructing a causal link between work, disease and radiation, one idea recurs frequently in the police officers' reports: they were contaminated by the radiation and their sickness is proof of the fact – because they were not trained or equipped to work in an area exposed to a health-damaging radioactive element. Faced with this unknown enemy, radioactivity, the realization that precautions should have been taken and special equipment used would only emerge over time, as some of the police officers stated:

No. We didn't receive any special recommendations. It even makes me smile thinking about it today. We didn't receive anything. There was the uniform we used, right? These boots we used whenever we stepped [emphasis] on contaminated ground. (Sergeant Alexandre. Interviewed 26th March 1997)

CNEN should have oriented the staff working there. Right? They should have provided them with protection. Instead of just using our [normal] uniform and spending 24 hours a day, working there non-stop, we should have stayed less time and been given other protective clothing. To be taken off and then discarded. Just like they did. Right? People from the... nuclear energy sector, they should have advised us. They have the know-how, they should have guided us too. So there was lack of advice. What was missing was advice. We should have been given disposable protective clothing. And spent less time exposed. Because the CNEN staff would stay there for... an hour maybe, half an hour. You know? Then they'd take their overalls off immediately and throw

them away. Their clothing went straight to the Waste Deposit. Our uniforms didn't. We'd use them again.

(Sergeant Paulo. Interviewed 7th April 1997)

While nuclear industry workers are trained to use dosimeters and wear adequate overalls, masks and boots to protect themselves from radiation, police officers are trained to handle guns and dress in military-style uniforms. The different body techniques – the articulation between body, objects and traditional socio-cultural practices (Mauss 1974) – practiced during professional training remained unaltered, but the enemy was now the same for all those dealing with the disaster: radiation. The perception of the so-called ‘Cesium police officers’ of these two different professional bodies working in response to the same event, the radioactive disaster, today causes discomfort and anguish. They concluded that the lack of adequate protection while performing the work resulted in their contamination and later sicknesses. This fact exposes the vulnerability of this group of professional workers and increases their suffering beyond simple physical pain.

The perception of the difference between these two bodies initially involved their distinct clothing. It is the use of special overalls by the nuclear workers in the field that metaphorically condenses the dispute between the system of nuclear expertise and the military police force. Anthropological studies based on different theoretical perspectives, as well as semiotic theory itself (Barthes 1967), have highlighted the communicative and symbolic aspects of clothing, whether through the qualities of the fabrics themselves, or after their transformation into clothing. Sahlins (1976), for example, suggested that the symbolism evoked by differences in clothing – including the use of cotton, wool and silk – is equivalent to the distinction established by age, social class and gender. Analyzing the symbolic and semiotic possibilities of the fabrics people use, Weiner and Schneider (1989) argue that these also consolidate social relations and mobilize political power. Bean's analysis (1989) of Gandhi's use of khadi, a handcrafted fabric, woven at home, as an element used in the fight for India's independence is an example of how fabrics are perceived in terms of their symbolic, communicative and political aspects. Echoing the remarks by non-nuclear workers in Goiânia on the vulnerability they experienced in their exposure to radiation, the young people from French Polynesia who cleaned up French nuclear test sites also claimed that they had been contaminated by radiation due to a lack of

adequate protective clothing (Barrillot, Villierme & Hudelot 2012). In both cases, clothing embodies the meaning of being affected by the radiation, revealing vulnerability to the risk of radioactive contamination, and becomes appropriated in a political arena defined by risk.

The nuclear experts with their white, orange and brown overalls entered the imagination of those more directly linked to the disaster and Goiânia's population as a whole. While the overalls reminded people of CNEN – a target of suspicion and criticism during the decontamination phase – it was specialists equipped with these overalls who the local residents saw cleaning the streets, houses and people themselves of contamination. They were vested, therefore, with the status of an authority with ambiguous characteristics: they aroused distrust while also being perceived as those who could save the city from this unknown substance called Cesium-137. My understanding, therefore, is that the overalls are a metonymic expression of the socialities, embodiments and work identities established during the disaster. In 1997, the overalls used by nuclear workers reappeared as one of the key symbolic reference points marking the differences between professional groups acting in a disaster situation involving radioactivity.

This analysis of the representations surrounding the overalls used during the Goiânia disaster is rooted in an understanding of the moral nature of the fabric and clothing: its capacity to embody and transmit social values. The uniform used by the nuclear workers was transformed as the disaster unfolded into a political sign that imbued its users with legitimacy and authority and, simultaneously, denied other identities, as in the case of the 'Cesium police officers.' As a uniform, the overalls functioned as a symbol of safety, suitable to confronting a risk situation, and thus became reappropriated by police officers in their struggle for official recognition of their claims to be suffering from work-related diseases.

However, the narratives of the 'Cesium police officers' concerning the different clothing were discredited by the nuclear experts. Their argument of mystification was used to deny the places constructed by the former subjects from their experiences of not being given protective overalls:

(...) there is a lot of mystification concerning the clothing used, the protective clothing. Actually these clothes don't offer any protection. (...) They weren't given the clothing because that wasn't their job, we were the ones working in a contaminated area, the police officers were responsible for controlling the area surrounding the exposure area, accessible to the public, an area with an acceptable dosage for the public, and they

stayed outside, they weren't subject to the same dangerous work conditions as the CNEN technicians.

(Alfredo Trajan Filho, representative of CNEN, in an intervention during a session of the Goiás Legislative Assembly, 7th May 1997).

The fear and panic resulting from the realization of having worked in areas of high radioactive risk without suitable protection has transformed the nights of many of the 'Cesium police' into nightmares and insomnia. A feeling of uncertainty about the future invades the lives of these professionals and their families, and, tormented by the idea, they are unable to find answers to their innumerable questions concerning the effects of radiation on the body over time. Alexandre and Carlos reported to me several suicide attempts. This perception of the risk experienced in performing their work during containment of the radioactive disaster is accompanied by the feeling of having been deceived by their hierarchical superiors and by the system of nuclear expertise. This feeling is expressed in the narratives and in the bursts of tears that punctuated many of the interviews I made. For these police officers, the deception was double. First they were deceived into following the orders of commanders who should have known how to respond even in a radioactive situation, instead of simply using the threat of punishment to ensure the completion of tasks that aroused fear and distrust. Second they were deceived by the fact that the nuclear experts failed to pass on vital information on radiological security to non-nuclear workers helping to contain the radioactive emergency. Here, therefore, being deceived refers to their distrust of the behavior of the Military Police Command, subordinated to the Goiás State Government, and of the governmental institution CNEN.

The memory of these police officers concerning the emergency phase of managing the disaster is central to these claims. Colonel Arthur, responsible for the Military Office of the State of Goiás, head of security at the Governor's Palace and coordinator of Goiás's Civil Defense, whom I call the 'Ground Zero Colonel,' recalled the activities of the police. He tells that among the first actions implemented when they realized that they were dealing with a radioactive event was to gather accounts from those people directly involved in the disaster, attempting to map individuals and places that needed to be evacuated and kept under guard. According to him, it was the military police officers who were responsible for entering the areas later identified as radiation hot spots. They then took contaminated people to the Olympic Gymnasium,

where they waited for assistance from the team specialized in nuclear emergencies. These are the same officers who, from the first recognition of the disaster and before the scale of the contamination was evaluated, secured the areas delimited as the physical space of the disaster. This measure was taken to prevent houses from being looted and, at the same time, to stop people from entering these locations and being irradiated and/or contaminated.

This was the moment, which Colonel Arthur calls the zero hour response to the disaster, when some police officers – without any knowledge of radiological protection – entered the disaster scene unprotected, just like the Chernobyl ‘liquidators’¹⁹ who also entered a contamination area without any prior information on the risk they were taking:

There are no more enemies. Just this colorless radiation everywhere. ‘So it’s like God. God is everywhere and is invisible.’ There are no more enemies. Likewise, is there anyone responsible? The first firefighters, the soldiers, those they call ‘the liquidators,’ they all set out unaware of where they were going, unaware of the risk they’d be taking. No one warned them, advised them or equipped them. ‘Everything is fine. Just wash your hands before eating,’ that’s what was told to people who had received doses a hundred times higher than an organism can normally bear. Who cared? Only the bosses had dosimeters, and those results were also kept secret.

(Vernet 1998:13-14)

The unanswered questions, the lack of support from the military police corps, the poor quality of the public health system, the low pay, the despair over the lack of resources to ensure personal and family medical care, and the failure to fulfil the promises made when CIPOLICE²⁰ was created: these are just some of the factors that led these police officers to break out of the confines of the police establishment and make their concerns public.

19 This designation appears in the literature on the Chernobyl disaster and refers to the first firefighters and police officers to arrived at the scene of the disaster in order to ‘liquidate’ it. Some authors cite the figure of 800,000 ‘liquidators’ dispersed among the population affected by the radiation disseminated by the Chernobyl power plant (Lochard 1996:107, Vernet 1998).

20 CIPOLICE – *Companhia Independente de Policiamento Especial e Controle Ambiental* (Independent Company for Special Policing and Environmental Control), created by the State Governor on 19th October 1987 (Decree no. 2,846) to accommodate the military police officers deployed from their battalions to perform activities related to the radioactive disaster. According to Military Police newsletters, the creation of CIPOLICE included the awarding of a bonus of forty percent on basic pay and on any additional benefits of the respective post or military grade, as well as medical leave for any work-related accident or illness shown to have been caused the work activity (POLICIA MILITAR. BI – 002/87, of 3rd November 1987). The time of service in CIPOLICE would also be doubled for pension purposes and three vacation periods would be allowed during the year.

In 1997, the anxieties of these police officers were no longer kept secret within the hierarchical disciplinary system governed by the internal regulations of the military police.²¹ Without any visible marks of radiation on their bodies (radiation lesions) and without any record of the radiation doses they had absorbed (a responsibility of the nuclear experts), the officers provided material proof that they belonged to the disaster by displaying their bodies and radiographic images. To give visibility to the invisibility of both their marks and their claims, they turned to the media. They showed their sick bodies in newspaper photos and television images: a head shaved for surgery to remove a malignant brain tumor, the loss of hair due to radiotherapy treatment, the blotches on their skin. They also posed to photographers holding their radiographs and the results of exams obtained during the investigations into the physiological causes of their health problems.



Image 16 – Report published in the *O Popular* newspaper, Goiânia, 23rd March 1997, p.3B

21 The internal regulations of the military police forces prohibit public demonstrations, especially when wearing uniforms.

By making this public display of their bodies, the embodied memory of the survivor (Sturken 1997: 254) emphasizes the place experienced by non-nuclear workers as one of the markers of their victim identity. The performative memory, understood as the recollection of the past conveyed and sustained by bodily practices (Connerton 1996:2), is set in opposition to the oral narratives used by the nuclear experts to discredit the suffering of the police officers. In this sense, the ritual performed by the officers at the waste repository involved and interconnected recollections and bodies, thereby exemplifying Connerton's proposal (1996:2) that embodied social memory is an essential aspect of social memory, and yet one still badly neglected by anthropological studies.

Scenario Four

Narratives and their audiences

*Stories make meaning
(...) Each telling depends on the context, the audience,
and the conventions of the medium.*

Edward Bruner (1986)

The narratives constructed in the previous scenarios show that the subjective experiences of the people affected by the Goiânia disaster have become historical and throw into question official narratives of the event. This reinforces the argument that experiencing a disaster implies 'an' experience,²² marked by a 'social effervescence' (Emile Durkheim, cited in Turner 1986: 35) in response to which we become not spectators but narrating subjects located amid the polyphony of the event. In this context, the scientific and technical knowledge deployed to narrate what happened through the language of doses and the parameters registered by dosimeters is placed in perspective with other types of knowledge generated by experience and activism. In the case of the founders of the Cesium-137 Victims Association and in the campaigns of the non-nuclear workers, the narrative process emerges as a performative expression that reappropriates elements of the disaster experience to

22 Turner (1986:35) draws a distinction between 'experience' and 'an experience.' The former kind are "simply the passive endurance and acceptance of events." The latter kind, which "erupt from or disrupt routinized behavior" (caused, for example, by a disaster), imply an internal response to such events in the form of an organized narrative with a structured beginning and a defined audience.

compose stories about it. The process of making sense of the fragmented experience of the first moments of containing the disaster acquires coherence and intelligibility through the appropriation of words and objects from the technical-scientific field. On one hand, the assimilation of a previously unfamiliar vocabulary into everyday language: doses, radiation, risk, radiological protection, contamination, *radioacidentados* (radiation victims). On the other, the appropriation of objects introduced by the system of nuclear expertise and which marked a rupture in the day-to-day urban experience of these people: dosimeters, site hoardings, overalls, radiographs. In this way, the constitution of identities reveals the dialectic between humans and non-humans – people and artifacts – at the same as showing how they are created and acquire agency and intelligibility: through the interconnections between bodies, memories, categories and places.

If activism unites the narrative processes formulated by these social actors, two other elements particularize their narratives: the audiences and the meanings given to their suffering. For the founders of the Cesium-137 Victims Association, the suffering extends beyond biological dimensions of physical pain to include the pain caused by the rupture of social relationships, the depreciation in property values, and dietary problems. As observed earlier, this is a pain characterized as a social suffering that goes beyond the physical limits of radioactive contamination. The discursive performance that took place in the legislative domain was aimed at creating laws that would expand the category of victim and guarantee State pensions to the affected population. For these people, attributing meaning to the experience of being impacted by the disaster meant explaining to the congresspeople how their suffering went beyond the radiation doses. In these narratives, the site hoardings symbolized the ambiguities contained in the answers given by the system of expertise to the questions raised by local population: was living close to the red-stained wooden hoardings a risk factor? Faced with the negative reply of the nuclear technicians and the visual experience of the residents as they circulated daily among the containers filled with radioactive material, the hoardings are reappropriated by the “neighbors of the hot spot areas” as a sign of their exclusion: I lived there. In this sense, the objects signal the controversy and engender an opposition between the experience of place and the oral narrative produced by medical-nuclear science knowledge.

For the ‘Cesium police’ movement, the main interlocutors were the judiciary and the military authorities. They were not requesting the creation

of new laws, but claiming the right to be included under pre-existing legislation. The narratives constructed to signify their experience of working in the radioactive setting emphasized biomedical language. When the nuclear experts contested their claim that they had become sick due to the failure to give them the same overalls as the nuclear technicians, they sought proof that they had received high doses of radiation and had worked in risk areas in their work schedule records. These documents could prove their location and time of permanence in the areas classified as contaminated. In the process, the search for records of their radiation doses and the display of radiographs in a media performance reinforced and privileged biomedical language as an expression of their suffering. While, symbolically, people from both groups sought to be “the authors of themselves” (Bruner 1986:12) in the construction of their narratives, the Cesium police officers, differently to members of the Cesium-137 Victims Association, have done so by reappropriating and attributing new meanings to the artifacts produced by biomedical-nuclear technology: doses and radiographies. In this sense, the narrative looks to define a biological citizenship (Petryna 2002). The subjective experiences of the police officers thus employ the biomedical-nuclear idiom to affirm their identity as victims of the Cesium-137 radioactive disaster.

Final considerations

Over the years, the classification of the disaster victims has been through two opposing movements. On one hand, strategies to restrict the number of people recognized as affected by the disaster and, on the other, campaigns to achieve such recognition. The resulting tensions and conflicts provoked mobilizations, wide-ranging discussions and public hearings in the Goiás Legislative Assembly, the Municipal Chamber of Goiânia and Brazil’s National Congress (Silva 2004 b), taking the dispute into the judicial sphere.

This conflict in interpretations has emerged since the very first moments of the specialists dealing with the bodies of the affected people. The narratives indicate meanings that go beyond humanitarian issues, health and radioactive decontamination. As in other situations involving critical events (Das 1996),²³ these disputes have involved a plot in which experiences of

23 Events and experiences that permeate diverse institutions, transforming the daily lives of individuals and families, affecting their relationships – among others – with the community, bureaucracy, the legal system, medical knowledge and the State.

health are infused with legal, bureaucratic and political dimensions (Das 1996, Petryna 2002, Todeschini 2001).

In the case of Goiânia, CNEN and the Leide das Neves Ferreira Foundation (FUNLEIDE) initially adopted different approaches to defining the victims. In the first year after the opening of the radiotherapy capsule and release of radioactivity, FUNLEIDE classified four groups of people as disaster victims, including those living near the contamination hot spots – the self-denominated ‘indirect victims’ – and the non-nuclear professionals (Silva 1997:75-78). In contrast to the ideas prevailing in the nuclear sector, the institution argued for the importance of monitoring and studying the so-called delayed effects of radiation, which may be higher for low-level radiation doses than for high-level doses (FUNLEIDE 1988). During the 1990s, however, these principles were not accompanied by any measures for including this wider population in either social protection measures or as research subjects in an area that remains controversial in nuclear science – namely, the consequences of low-level doses of radiation on human beings.

In the early twenty-first century, the work of grassroots organizations led to a change in how people affected by the disaster are classified. Following the mobilization of police officers and workers from the former Consórcio Rodoviário Intermunicipal S. A. (CRISA), demands were made for legal recognition of the relationship between their sicknesses and the work they carried out in 1987 in areas contaminated by radiation and in the transportation of radioactive waste to Abadia de Goiás. The Goiás Public Prosecutor’s Office (PPO) recognized their claims as valid, redefining the laws guaranteeing pensions to the victims and classifying a new group of people in the category of disaster victims. As a result, in 2007 the PPO legally recognized 628 people as victims of the disaster in contrast to the 249 listed in 1987 by the nuclear experts and based on high-level doses of radiation (IAEA 1988: 2).

The right to a pension established by this new mechanism for identifying the victims does not, however, assure these people access to the public health services delivered by the medical institution responsible for treating and monitoring the *radioacidentados*. In fact, members of the Leide das Neves Ferreira Radioactive Victims Care Center, formerly FUNLEIDE, reject any relationship between the sicknesses of the workers and the radiation disaster, despite acceptance of their claims by the PPO. While this controversy might suggest a new scenario, twenty years after the 1987 radiation fallout, I would argue that this merely adds a new element to the issues discussed over the

course of this article. First, the ongoing conflict between two forms of classifying victims of the disaster: one based exclusively on the use of technological and biomedical parameters; the other, privileging the narratives of people who lived and worked at the site of the contamination back in 1987-1988. Second, the disregard for low-level doses of radiation as a research topic and in the classification of the people affected by the disaster. I would further argue that this subject remains an open issue to be explored by biomedics, social scientists and technoscientists, and requires a comparative and collaborative research project in the emerging field known in the United States academic community as Disaster Science and Technology Studies (DSTS) (Fortun & Frickel 2012: 2). The Goiânia disaster indicates that the study of low-level doses of radiation is a political issue that concerns both the production of scientific knowledge and the legal responses related to the recognition and classification of victims.

The conflict in interpretations found in the narratives of the many social actors involved in the disaster – nuclear science authorities, community groups affected by the catastrophe, non-nuclear workers, neighbors of hot spot areas, *radioacidentados*, legislators – and expressed over more than twenty years interweave with the politics of memory analyzed here. In parallel to the work of memory, the Cesium-137 disaster in Goiânia and the experiences derived from the constitution of identities through embodiments, artifacts and the construction of places all contribute to understanding the interconnections between biological and social processes in the configuration of biosocialities (Rabinow 1996: 91-111).²⁴ These experiences and narratives challenge the scientific monopoly of the so-called ‘hard sciences’ and exemplify the formulations proposed by Beck (1993), Palmlund (1992) and Douglas & Wildavisky (1983) concerning the political aspects of risk perceptions, indicating the need for a processual approach. Finally, the narrative of the anthropologist, a native to these scenarios, also adds her own subjective experience to the polyphonic composition of this disaster.

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24 Based on his study on the Human Genome, Rabinow describes the constitution of new identities and individual and group practices derived from the emergence of new scientific knowledge, such as the new genetics. “There already are, for example, neurofibromatosis groups whose members meet to share their experiences, lobby for their disease, educate their children, redo their home environment, and so on. That is what I mean by biosociality [...] Such groups will have medical specialists, laboratories, narratives, traditions, and a heavy panoply of pastoral keepers to help them experience, share, intervene, and “understand” their fate” (Rabinow 1996: 102).

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La cosmopolitique de la dépression

Biosocialité dans une ethnographie multi-espèces

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Résumé

Ce travail est le résultat d'une ethnographie réalisée dans des animaleries et cliniques vétérinaires. Il aborde les transformations récentes des pratiques vétérinaires, spécialement au travers des relations avec le marché des animaux de compagnie, en se concentrant sur l'apparition de diagnostics psychiatriques, notamment de dépression, chez les animaux de compagnies et de leur traitement biomédical. D'une manière générale, il s'inscrit directement dans le cadre de récentes recherches anthropologiques sur les relations homme-animal. Dans ce contexte, cette relation nous permet d'aborder des thèmes comme la santé, la maladie et la biosocialité, en particulier les transformations biopolitiques de la nature.

Mots-Clefs: Animaux de compagnies ; Dépression animale ; Médicalisation ; Biosocialité.

Resumo

Este trabalho resulta de uma etnografia em *pet shops* e clínicas veterinárias no sul do Brasil. Nele, são abordadas as transformações recentes nas práticas médico-veterinárias, em especial, por meio da sua relação com mercados do segmento *pet*. A reflexão se concentra sobre o aparecimento de diagnósticos psiquiátricos em animais de estimação, notadamente os de depressão e suas formas de tratamento biomédico. De um modo geral, a discussão se inscreve diretamente em um quadro de recentes pesquisas antropológicas sobre as relações homem-animal. Aqui, esse recente campo é tratado como um meio privilegiado para o diálogo com temas como saúde, doença e biossocialidade,

especialmente no que se refere ao modo como a natureza tem sido sistematicamente modificada em favor de disposições biopolíticas.

Palavras-Chave: Animais de Estimação ; Depressão Canina ; Medicalização ; Biossocialidade.

Abstract

This paper is the result of an ethnographic research in *pet* stores and veterinary clinics in southern Brazil. Besides, it broaches the recent changes in medical and veterinary practice, in particular through its relationship with the *pet* segment markets. This reflection focuses on the emergence of psychiatric diagnosis in *pets*, mainly the depression and its forms of medicalization treatment. In general, the discussion falls directly in a range of recent researches on human-animal relations in anthropology. Here, this new field is treated as a privileged mean for dialogue with topics such as health, disease and biosociality, especially with regard to how nature has been systematically modified in favor of biopolitics dispositions.

Keywords: *Pets*; Dog Depression; Medicalization; Biosociality.

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Jean Segata

« Le conflit politique décisif, qui gouverne tout autre conflit, est, dans notre culture, le conflit entre l’animalité et l’humanité de l’homme. »

Giorgio Agamben – L’Ouvert

Ce travail est le résultat d’une ethnographie dans une clinique vétérinaire dans le sud du Brésil. Il fait partie d’un ensemble d’études où je me suis notamment concentré sur les dispositifs et les démarches entourant le diagnostic et le traitement des maladies psychiatriques d’animaux de compagnie (Segata 2011, 2012a, 2012b, 2012c, 2014)¹. D’une manière générale, la discussion s’inscrit dans un cadre plus large de débats en anthropologie sur les relations homme-animal, en particulier dans les milieux urbains (Digard 1990, 1999 ; Hodak 1999 ; Sabloff 2001 ; Grandrie 2005 ; Haraway 2008 ; Vicart 2014). Cependant, j’ai cherché à associer l’accent analytique de ce champ de recherches à la récente idée d’ethnographie multi-espèces, généralisée dans les travaux d’auteurs comme Helmreich (2008) et Kirksey (2014) :

Creatures previously appearing on the margins of anthropology - as part of the landscape, as food for humans, as symbols - have been pressed into the foreground in recent ethnographies. Animals, plants, fungi, and microbes once confined in anthropological accounts to the realm of *zoe* or “bare life” - that which is killable - have started to appear alongside humans in the realm of *bios*, with legibly biographical and political lives (Kirksey & Helmreich 2010 : 545)

Dans cette perspective, la relation homme-animal est considérée comme un *devenir* en référence à un terme qui traverse l’œuvre de Gilles Deleuze et

¹ Une partie des analyses présentées ici ont été publiés dans un article précédent : « Os Cães com Depressão e os seus Humanos de Estimação » (Segata 2012c). Je remercie Guilherme Sá (UnB), Carlos Sautchuk (UnB), Theophilos Rifiotis (UFSC) et Bernardo Lewgoy (UFRGS) pour leurs contributions lors de nos discussions sur ce champ de recherche. Je remercie également l’appui du CNPq à ma recherche actuelle : « Les Animaux et la Cité ».

Félix Guattari. Ainsi, l'ethnographie multi-espèces cherche à décrire « *new kinds of relations emerging from nonhierarchical alliances, symbiotic attachments, and the mingling of creative agents.* » (id : 546)

Toutefois, face au constat de ce qu'un espace spécialisé dédié aux études sur les relations homme-animal en anthropologie est encore en devenir au Brésil, j'ai essayé de me rapprocher d'autres domaines de recherches anthropologiques. Ce travail est un effort pour contribuer aux études sur la maladie et la santé, en particulier dans le cadre de ce dossier sur les études de la biosocialité. Je n'utilise pas ici le terme biosocialité au sens strict de Paul Rabinow, auteur très cité dans ce champ au Brésil, même si je fais référence à ses études sur « les pratiques de la vie » et la gouvernementalité des gens à travers la connaissance et le contrôle de la biologie (Rabinow 1996, 1999, 2011). Je partage avec lui deux idées générales. La première est la nécessaire dissolution de la catégorie du « social » pour surmonter la division entre nature et culture. La seconde, qui concerne la biosocialité, est que la nature est systématiquement modifiée pour répondre aux spécifications biopolitiques (Rabinow 1999). C'est notamment le cas, à mes yeux, des animaux de compagnie, avec la sélection de leurs races, le développement de leur nourriture, les technologies médicales appliquées à leur santé et à leur esthétique et, en particulier, le surgissement de troubles psychiatriques chez les chiens, que j'aborderai ici.

Le « Magasin de Marcos » et le nouveau monde *pet*

Les circonstances composant le terrain de cette recherche portent des caractéristiques singulières, bien que non exclusives : l'apparition d'espaces proposant des services spécialisés en matière de santé et d'esthétique des animaux – les *animaleries*.² Je présente ci-dessous les résultats d'un travail de terrain ayant duré environ quatorze mois dans un de ces établissements situé dans la ville de Rio do Sul, dans le sud du Brésil.

Rio do Sul est la principale ville de la région de l'Alto Vale do Itajaí, située à la confluence des rivières Itajaí do Oeste et Itajaí do Sul, cette dernière formant une vallée qui s'étend jusqu'à la côte de l'état de Santa Catarina.

² Tout au long du texte j'utiliserai les termes anglais « *pet* » et « *pet shop* » pour désigner les animaux de compagnie et les magasins qui leur sont dédiés conformément à ce qui se fait au Brésil, où il est très commun d'entendre « mon *pet* » ou bien « marché *pet* », « produits *pets* », etc.

Comme beaucoup d'autres villes de petite et moyenne importance au Brésil, sa population augmente fortement et ses caractéristiques politiques, économiques et géographiques se transforment. Fondée il y a à peine 80 ans, Rio do Sul est née de l'immigration allemande et italienne. Pendant plusieurs décennies, son économie s'est essentiellement basée sur l'agriculture et l'extraction et la transformation du bois. Néanmoins, dans le sillage de « l'esprit développeur » qui a caractérisé le pays pendant la seconde moitié du siècle dernier, auquel est venu s'ajouter la pénurie de ressources naturelles et la dévaluation de l'agriculture, cette ville a commencé à investir dans le domaine de la sidérurgie et de l'usinage de pièces mécaniques et dans la fabrication de *jeans*, une preuve que, en peu de temps, le Brésil est devenu un pays complètement différent. Aujourd'hui, la croissance de la ville résulte d'une petite immigration régionale attirée par les nombreuses offres d'emplois, de services et de places dans l'enseignement supérieur, ce qui a provoqué une urbanisation effrénée accompagnée d'une spéculation immobilière, puisque environ une douzaine de nouveaux bâtiments à plusieurs étages sont livrés par an. Quoi qu'il en soit, il ne s'agit pas d'une métropole, car, malgré sa croissance, la population de Rio do Sul est légèrement supérieure à soixante mille habitants. Compte tenu du fait que la population des villes des alentours ne dépasse pas, en moyenne, les dix mille habitants, il n'est pas difficile de comprendre pourquoi Rio do Sul s'est imposée comme capitale régionale. La « Rio do Sul urbanisée », qui a triplé sa population depuis les années 1980, a valorisé certains éléments symbolisant les nouvelles formes de consommation urbaine, comme les grands supermarchés, les galeries marchandes et les *pet shops*. De fait, les services vétérinaires dédiés auparavant aux animaux d'élevage tels que bovins, équidés et caprins, ont commencé à se réorienter vers les petits animaux comme les chiens et les chats (en particulier ceux de compagnie), dont beaucoup vivent dans des appartements récents. C'est le cas du « Magasin de Marcos », clinique vétérinaire à laquelle est associé le *pet shop* où j'ai réalisé la plus grande partie de mon travail de terrain.³

3 Franklin (1999) situe les années 60 comme le moment où les modes de relation entre humains et *pets* ont subi de profondes transformations. Pour lui, les animaux sont devenus domestiques et des croquettes industrialisées ont commencé à être produites. Après les croquettes standards, la décennie suivante a vu surgir des services nutritionnels et médicaux spécialisés, outre une variété de jouets, de vêtements, de parfums et d'accessoires pour ces animaux. Comme il l'écrit, « *the list of available services has grown considerably. Most involve extensions of human facilities to pets and cover every aspect of pet's life from cradle (literally) to grave* » (Franklin 1999: 92).

Pour un observateur comme moi, peu familiarisé avec ces environnements, l'impression d'être entré dans un monde nouveau, peuplé d'entités de natures diverses, est saisissante. Sur le canapé de la petite salle d'accueil, j'observais les lieux où il était toujours possible d'entendre, par dessus les aboiements, le son strident d'une incessante sonnerie de téléphone, le moteur d'une tondeuse et les climatiseurs qui ne suffisaient pas à diminuer la chaleur de la pièce. Pendant que je patientais, j'ai entendu beaucoup de récits émouvants de ceux qui venaient faire soigner leurs *pets*. Juste en face de cette salle, un empilement de sacs formait un couloir menant à l'entrée du magasin. La plupart étaient de croquettes pour régimes spéciaux – certaines contenaient des protéines, d'autres étaient spécifiques pour chiens végétariens, allaitants, en ménopause, en sevrage ou en croissance. D'autres encore étaient spécialement mises au point pour différentes caractéristiques anatomiques canine, comme petite gueule, gueule plate, gueule longue, animaux de plus de trois ans, de moins de trois ans, ayant des poils lisses ou courts, etc. Des vêtements, des bijoux, des paniers, des tapis, des jouets, des huiles de massage, des médicaments, des remèdes naturels, des thés et des onguents formaient une mosaïque sur un présentoir à côté duquel, fixée au mur, une affiche jaunie montrait l'image d'un chien vêtu d'un foulard et d'un bonnet rouge portant des lunettes de soleil, assis dans les jardins du Champ-de-Mars, faisant la publicité une nouvelle fragrance de parfum.

Dans la partie du magasin réservée aux soins, où, en général, les propriétaires des animaux n'avaient pas accès, se trouvaient des salles spécialement aménagées. La première était le bureau de consultation avec une table en marbre sur laquelle les animaux étaient examinés. Plusieurs comptoirs et étagères contenaient différentes sortes d'instruments que Marcos et sa fille Paula, elle aussi vétérinaire, employaient pour des examens ou de petites procédures comme l'application de vaccins ou de sutures. Il y avait encore un bureau, sur lequel ils remplissaient les formulaires et rédigeaient les prescriptions, avec un ordinateur pour enregistrer l'historique des visites et une bibliothèque contenant des ouvrages que je consultais éventuellement. La pièce voisine, réservée aux chirurgies, était interdite aux propriétaires. J'ai fréquenté différentes cliniques vétérinaires pour mes recherches, mais je n'ai pu assister à des activités chirurgicales, y compris en tant qu'assistant, que chez Marcos. En plus de la table d'opération, il y avait aussi une chambre

à rayons-X, des appareils d'échographie, des tensiomètres, des respirateurs artificiels et des équipements d'hémodialyse. Enfin, au bout du couloir se trouvait la chambre d'hospitalisation, où étaient réalisées les procédures cliniques, telles que l'application des médicaments ou solutés de réhydratation et la récupération. Cette pièce comptait plusieurs cages et chenils de différentes tailles, dans certain cas superposés, comme des étagères. Un grand nombre de chiens et de chats reçus souffraient de diarrhée ou de vomissements, ils urinaient ou perdaient du sang, de sorte que le matin, en général, l'odeur y était insupportable. Juste à côté se trouvait la partie du magasin dédiée au toilettage et autres soins de beauté pour animaux.⁴

Actuellement, le domaine de la santé des animaux, notamment des *pets*, ressemble de plus en plus à celui des humains.⁵ Quelques exemples de ces nouveautés technologiques sont les *holters glycémiques* et l'*insuline sans pics*, qui contrôlent les niveaux d'insuline chez les chiens et chats diabétiques ; l'*échocardiographie avec Doppler tissulaire couleur* et le *holter par téléométrie* pour surveiller et évaluer le rythme cardiaque 24 heures sur 24 (contractions, musculature et circulation sanguine) pour détecter d'éventuelles arythmies chez les animaux atteints d'insuffisance cardiaque ; l'*électrochimiothérapie*, qui injecte le médicament directement sur la tumeur à l'aide d'une aiguille, la *cryochirurgie*, qui utilise de l'azote liquide pour nécroser et retirer des tumeurs – deux techniques utilisées chez les animaux atteints de cancer ; la *tomographie par ordinateur* qui permet d'observer en 3D les os et cartilages

4 Swabe (1999) affirme catégoriquement que la relation entre les humains et les animaux a radicalement changé au long du XX^e siècle. C'est le cas des animaux d'élevage, avec l'utilisation de la science et de la technologie pour les confiner, dans le cas de l'agro-industrie, et, plus particulièrement, des *pets* et de tout ce qui touche à leur santé : "For many pet-owners, it has now become routine to pay an annual visit to the vet's to have their animals vaccinated, along with a general check-up. Consultations for vaccination and parasite control in fact account for a great proportion of the small-animal practitioner's daily activities and income. Animal disease control is, therefore, as large a part of the routine work of the small-animal practitioner as of the rural veterinarian" (Swade 1999: 126).

5 Beaucoup de magazines publiés sur tout le territoire brésilien ont récemment abordé cette question, détaillant les dernières technologies pour le diagnostic et le traitement des animaux domestiques. Ils affirment que le Brésil occupe déjà la deuxième place en nombre de chiens et chats, derrière les États-Unis, où les familles dépensent environ 700 millions de dollars par an en consultations, médicaments et vaccins. Selon ces publications, il est de plus en plus fréquent d'avoir des *pets*, car les animaux de compagnie ont la vertu de combler les lacunes émotionnelles de leurs propriétaires (Veja, 12 mai 2010 : 142-146). Ce travail insiste sur l'investissement en médicaments psychotropes : tranquillisants, antidépresseurs, ou coupe-faim. Entre 2003 et 2009, au Brésil et aux États-Unis, le nombre de chiens médicamenteux a augmenté de 25% à 77%. Ce même article indique également que 42% des chiens ont des problèmes de comportement et, dans l'ensemble, une propension 9 fois plus importante que les humains à développer des troubles psychologiques. Certaines données utilisées par ces magazines sont publiées sur le site du *Canine Inherited Disorders Database* <www.upei.ca/cidd/intro.htm>. Dernier accès en mai 2011.

et le *traitement par cellules souches* employé pour régénérer des tissus articulaires ou comme anti-inflammatoire chez les chiens et les chats ayant des problèmes orthopédiques ; la *gazométrie*, permettant d'analyser les quantités de calcium et de sodium dans le sang et l'*hémodialyse*, utilisée dans des cas d'insuffisance rénale graves ; le *tono-pen vétérinaire*, appareil numérique mesurant la pression intraoculaire et le *microscope chirurgical* aidant à réaliser des microchirurgies de la cataracte, des paupières et de la cornée chez les animaux présentant des problèmes oculaires.⁶

D'une manière générale, le « magasin de Marcos » était loin de cet univers de nouveautés et n'était même pas le plus sophistiqué de ceux que j'ai visités. Cependant, il recevait des nombreux clients par jour, et ce surtout en raison de l'expérience de son propriétaire :

« Alors que d'autres ne traitent que de vaches ou de chevaux, Marcos prend soin de nos animaux de compagnie depuis longtemps. Dans les années 80, je me souviens que des gens venaient de loin, de Lauretino, Aurora, Rio d'Oeste, Ibirama, Ituporanga et même de la ville de Lages [villes situées dans la région de l'Alto Vale (Haute-Vallée), cette dernière se trouvant à environ 150 km de Rio do Sul]. [...] Il a toujours été très attentif avec les chiens, il a toujours cherché à nous orienter sur leur alimentation et d'autres soins. Il a toujours été là quand on avait besoin de lui. [...] En fait, si vous regardez le nombre de cliniques existant ici aujourd'hui, c'était un révolutionnaire. »
(Carlos, propriétaire d'un Golden Retriever, Décembre 2008 – mes notes)

C'était une référence locale. Marcos travaillait dans ce secteur depuis trente ans et s'affirmait donc comme l'un des plus anciens de la ville. Ces mêmes personnes qui apportaient leurs animaux au magasin reconnaissaient que d'autres vétérinaires proposaient des technologies très avancées dans la ville. Cependant, Marcos effectuait des diagnostics et des procédures qui n'étaient pas si éloignées de celles pouvant être réalisées avec ces nouveaux équipements :

« Tout est question de pratique et d'expérience. Bien sûr, je ne peux pas nier que ces machines rendent notre travail bien plus aisé. Il est difficile de diagnostiquer quelque chose chez un animal – il ne peut pas nous dire ce qu'il ressent, où il a mal, etc. [...] Le temps se charge d'améliorer notre métier. Bien sûr, il faut travailler dur, lire ce que les gens étudient et découvrent. Mon père fait justement ça : il assiste à des conférences

6 *Canine Inherited Disorders Database* <www.upei.ca/cidd/intro.htm>. Accès en mai 2011.

dans ce domaine, il prend des cours pendant toute l'année, mais je suis d'accord avec lui que certains équipements disponibles aujourd'hui sont absurdes – certains ne font que ce que fait déjà un vétérinaire expérimenté. Mais les plus jeunes, ceux de ma génération, ne sont pas intéressés à apprendre. D'autres équipements par contre sont beaucoup trop chers pour notre réalité. » (Paula, parlant du travail de son père, février 2009)

Marcos était quelqu'un d'assez calme et, en fait, il se tenait au courant des nouveautés dans son domaine en lisant en même temps qu'il observait Paula travailler – peu à peu elle assumait ses fonctions dans le magasin. Par conséquent, moi aussi je me tenais informé de ces nouveautés, en lisant après lui les magazines auxquels il était abonné. Quand je faisais référence à des nouveautés, il rétorquait simplement qu'il pratiquait depuis déjà longtemps ce que font les « machines d'aujourd'hui » sauf que celles-ci rendent la vie plus facile. Néanmoins, dans le cadre de cette discussion, ce qui me paraît le plus intéressant est le fait que dans ce court laps de temps j'ai pu être le témoin d'un changement significatif des demandes de soins reçues dans sa clinique. Dans un premier temps, les procédures de vaccination et les chirurgies mineures prédominaient. Pour ce qui est des chirurgies, en particulier, il s'agissait de cas de désobstruction du canal de la vessie de chats, problèmes causés, selon Marcos, par l'excès d'aliments de mauvaise qualité disponibles à bas prix sur le marché. Des croquettes de mauvaise qualité, disait-il, entraînent la formation de « pierres aux reins », ce qui, toujours selon lui, était courant chez les chats. Venaient ensuite les problèmes gastro-intestinaux, généralement dus à des verminoses, puis des fractures dues à des accidents tels que des chutes ou des écrasements. Mais, peu à peu les cas traités ont changé, et ce qui était jusque-là une exception est devenu monnaie courante : les chiens dépressifs ou anxieux transformés en consommateurs de psychotropes. Un des premiers cas a été celui de Pink, une caniche qui avait été guérie deux ans plus tôt d'une tumeur au larynx et qui serait maintenant déprimée.

« C'est la Même Chose » :

Des chiens psychotiques et la cosmopolitique de la dépression.

Bia et Pink sont arrivées au magasin de Marcos au milieu de l'année 2009. Son portable à l'oreille, Bia parlait d'un ton sec et quelques larmes coulaient

de ses yeux, tandis que Pink était assise à côté d'elle sur le canapé de la salle d'attente. Dans sa conversation, elle disait que c'était sa dernière tentative pour trouver ce qu'avait sa caniche de neuf ans. Quand elle a raccroché, Marcos les a invitées à entrer dans son bureau et, comme d'habitude, je les ai suivis, j'ai mis mes gants et je me suis préparé pour l'examen physique qui est toujours pratiqué après l'anamnèse. La consultation avait à peine commencé quand Bia a fait part à Marcos de son habitude d'utiliser les services de la clinique du Dr Roberto, un autre vétérinaire de la ville te que ce dernier et un de ses confrères lui avaient dit que sa chienne était déprimée. Bia estimait que ce diagnostic était précipité. Pour elle, il y avait une erreur :

« Écoutez, une de mes collègues est dépressive et elle se comporte de façon bien différente de Pink. Vous êtes fous ! Cela n'existe pas, un chien souffrant de dépression. [...] Maintenant, ma petite va devenir accro aux "bandes noires". Je vais vouloir aller me promener avec elle, jouer et tout... mais elle sera shootée ! » (Bia, propriétaire de la caniche Pink, octobre 2008)⁷

Selon Bia, sa chienne gémissait et parfois même hurlait pendant la nuit. Elle avait perdu quelques kilos au cours des dernières semaines et avait progressivement arrêté de faire sa toilette. De plus, elle se grattait et se mordait au point de se mutiler et donnait l'impression d'être plongée dans une tristesse permanente. Bia doutait du diagnostic de dépression et imaginait plutôt le retour d'un vieux problème qui avait déjà attaqué sa chienne quelques années plus tôt : une tumeur au larynx.

Marcos a écouté l'histoire en silence tout en prenant des notes résumant la conversation, à son habitude. À un moment donné, il s'est arrêté et a regardé Bia et Pink, avant de reprendre ses notes, puis il s'est levé et les a invitées à le suivre jusqu'à la table d'examen où je me trouvais. Là, il a caressé le cou de la chienne, a tiré sur ses paupières, regardé sa gorge, pratiqué des mouvements de massage de l'abdomen et utilisé son stéthoscope pour écouter le cœur et les poumons. Après quoi, il m'a demandé de l'aider en tenant la gueule du chien pendant qu'il manipulait l'abaisse-langue et la lumière pour examiner la gorge. Malgré toutes ces interventions,

⁷ Au Brésil, les médicaments prescrits sont identifiés par une bande en couleur sur leur boîte : bande rouge, plus courante, médicaments sous ordonnance, bande noire, médicaments sous prescription restreinte, généralement des psychotropes.

contrairement à d'autres chiens, Pink n'a pas réagi. Bia était penaude. Elle a fondu en larmes devant nous et nous a raconté ce qu'elles avaient passé ces dernières semaines. Son regard nuageux et sans direction, son refus de se lever et son envie de pleurer sans cesse, indiquaient que quelque chose n'allait pas. Elles ont souffert et certains jours ne sont pas nourries. Tout était encore compliqué : leur faiblesse physique, leur déshydratation et le dysfonctionnement de certains de leurs organes exigeaient un traitement urgent. Marcos a suggéré que Bia prenne un rendez avec un médecin, pendant qu'il préparait les documents pour l'hospitalisation de sa chienne dans la clinique. Elles avaient besoin de récupérer et le vétérinaire voulait prendre ce temps pour réaliser des examens plus approfondis sur la chienne, notamment une biopsie pour évaluer un éventuel retour de la tumeur. Face à son ordinateur où il allait rédiger ses notes finales, le vétérinaire a alors demandé si elles passaient beaucoup de temps loin l'une de l'autre. Comme Bia a répondu que oui, le médecin lui a dit que la solitude était un déclencheur de dépression. Pink devait suivre un traitement médicamenteux à base de psychotropes. Bia doutait encore que la dépression canine soit un mal de plus en plus courant de nos jours, jusqu'à ce que le vétérinaire ait déterminé la dose exacte, en milligrammes, des comprimés conformément au biotype de la chienne, recommandant la fabrication du médicament par les traditionnels *Laboratoires Gemballa* de Rio do Sul. Au Brésil, il existe encore des restrictions pour la vente de psychotropes et médicaments pour chiens. Or, si *Gemballa*, dont le travail est reconnu dans la région, produisait de la fluoxétine pour chiens, il ne faisait plus aucun doute que la dépression canine existe réellement. Très sceptique au départ, Bia s'était laissé convaincre et sa souffrance était expliquée.

Après le passage de Pink, j'ai commencé à faire attention à ces cas et pendant la période où j'ai réalisé mon travail de terrain dans ce magasin, en moyenne un chien par semaine était diagnostiqué dépressif, soit près de 60 fidèles compagnons par an. Même si mes préoccupations ne sont pas statistiques, deux faits ressortent de ces observations quantitatives – le premier est que Rio do Sul compte quelques dizaines de *pet shops* et des amis connaissant mes travaux m'ont fait savoir que ce phénomène est régulièrement observé dans toutes les cliniques, le second est qu'une majorité de chienne souffrent

de cette affection. En effet, au moins deux tiers des cas que j'ai suivis ont été diagnostiqués chez des femelles.⁸

Mais le diagnostic de dépression est complexe, dans la mesure où il est nécessaire d'éliminer d'abord les « problèmes physiques », pour pouvoir ensuite se concentrer sur les « problèmes psychologiques ». Or, cette séparation n'est pas guidée par une méthode psychiatrique ou psychologique spécifique, comme la réflexologie pavlovienne ou la psychanalyse freudienne. Elle a été intuitivement fondée sur la conception occidentale de la scission corps-esprit. Comme l'expliquait Marcos, la dépression et la faiblesse physique résulteraient d'une mauvaise alimentation et d'autres pathologies, une combinaison pouvant donner l'impression que les chiens sont tristes, ce qui, pour les non-initiés, peut être considéré comme la même chose.

« Les gens repoussent leur visite chez le vétérinaire dans l'espoir qu'ils vont se réveiller le lendemain et constater que leur animal aura guéri tout seul. Cela complique la santé des chiens et des chats qui, malades, se nourrissent mal, se déshydratent, et développent d'autres maladies, ils souffrent des effets neurologiques, et peuvent finir par mourir... Il s'agit d'une réaction en chaîne. [...] En tant que vétérinaire, je sers plus à accomplir des miracles qu'à éviter un mal. Souvent les animaux arrivent ici à un pas de la mort. » (Marcos, mars 2009)

C'était le cas de Pink, et d'environ la moitié des cas que j'ai suivis pendant ma recherche. Dans le cas de Pink, dès le départ de Bia, Marcos m'a demandé de faire attention aux symptômes : le menton posé sur le plancher entre les pattes, la difficulté à se tenir debout ou à se déplacer, le regard fixe, les hurlements tristes, les pattes et la queue présentant des plaies et des morsures. Ces symptômes l'ont conduit à diagnostiquer la chienne comme déprimée, mais Marcos cherchait encore à en être certain. Dans la mesure où elle était trop faible, elle devrait être hospitalisée quelques jours, ce qui permettrait de réaliser certains examens. Le fait est qu'il y avait encore une possibilité à ne pas négliger : deux ans auparavant, Pink avait développé une tumeur de petite

⁸ En plus de la boutique phare, j'ai visité d'autres cliniques moins souvent dont une, appartenant à Alice, où de nombreux cas de dépression avaient été confirmés. Cependant, le fait que l'espace a une importance particulière – c'était un pet shop spécialisé en gynécologie et obstétrique et la plupart des chiens déprimés étaient des femelles ayant reçu un diagnostic de grossesse psychologique. Selon Alice, « elles commencent à gagner le ventre avec des trayons gonflés et quand vient le temps de créer le nid d'avoir des chiots. Mais les chiots ne semblent pas. Ensuite, elles sont déprimées. La solution dans ce cas est l'utilisation de contraceptifs et l'administration de psychotropes à base de fluoxétine – un médicament miraculeux. » (mai 2009)

taille à côté du larynx ; le vétérinaire a donc supposé qu'il pourrait s'agir d'une rechute. Paulo, un autre vétérinaire de la ville, avait réalisé la chirurgie à l'époque et soumis la chienne à des séances de chimiothérapie, éliminant complètement la tumeur. Mais c'était une hypothèse à considérer. Ainsi, Marcos a anesthésié Pink, rasé les poils de sa patte avec un rasoir, a fait une prise de sang et a prélevé un échantillon de tissu sous-cutané qu'il a envoyé à Belo Horizonte par courrier express. Je me suis chargé d'apporter son sang à pied dans un laboratoire d'analyses cliniques situé près de chez moi.

Tout était nouveau pour moi – la biopsie, l'examen du sang de Pink par le même laboratoire que j'utilisais pour réaliser mes examens annuels. Mais peu à peu, j'ai compris que cela devenait de plus en plus courant. En fait, le cas de Pink, le premier que j'ai suivi, a été aggravé par le fait qu'elle avait des antécédents d'autres maladies, comme sa tumeur au larynx. Cependant, dans la plupart des cas, le diagnostic est de plus en plus automatique, à partir de la caractérisation de certains symptômes comportementaux apparents, en particulier la tristesse. « Mon ami est triste » disait la majorité des gens, en parlant de leur *pet* avant d'ajouter « il fait une dépression ».

Lors de mes recherches sur internet, quand j'utilisais les mots-clés « dépression canine » ou « dépression – animaux de compagnie » sur des bases de données rassemblant les articles d'importantes revues spécialisées, nationales et internationales, je ne parvenais pas à trouver de travaux de médecine vétérinaire dédiés à ce thème. Ainsi, en raison du manque de littérature scientifique, à l'époque, j'ai commencé à m'interroger sur le statut médical de cette dépression canine. Cette recherche bibliographique m'a permis de découvrir que la médecine vétérinaire considère l'angoisse de séparation chez les animaux, dont l'acronyme anglais est SASA (Schwartz 2003), comme un problème ayant augmenté lors de la dernière décennie. Le SASA peut être caractérisé comme un ensemble de comportements indésirables, en particulier chez les chiens qui sont laissés seuls ou quand ils sont éloignés de la figure à laquelle ils sont attachés (Soares et al. 2007). Ces animaux hurlent et gémissent de excessivement et peuvent, dans certains cas, uriner et déféquer sur les lieux familiers de la relation à leur référent.

En pratique, les gens arrivaient au magasin à cause la dépression de leur chien. Ainsi, j'ai changé mon approche du sujet : j'ai arrêté de me demander si la *dépression canine existait*, je l'ai prise comme un fait et j'ai commencé à

demander aux gens comment ils savaient que leurs animaux étaient atteints de dépression. Pour reprendre une expression de Strathern (2014), ma recherche d'une explication scientifique pour la dépression canine était une façon de « couper le réseau ». Les symptômes et leur diagnostic, ainsi que les traitements proposés par les clients de la clinique se construisaient à partir d'un mélange d'informations et de pratiques relatées dans des magazines spécialisés, des émissions de télévision ou des expériences individuelles partagées en groupe lors d'événement dédié aux *pets*. La science n'est alors qu'un mode explicatif, parmi d'autres, de la dépression canine. L'on retrouve dans les paroles de vétérinaires comme de propriétaires *pets* un mélange de discours scientifique et vulgarisé. J'ai commencé à comprendre comment se formait leur compréhension de cette maladie chez les chiens, au fur et à mesure que mes informateurs laissaient transparaître leurs sources d'information dans leur discours :

« Aujourd'hui, c'est facile. Il suffit de lancer une recherche sur Google. Il y a tellement de sites Web spécialisés dans ce domaine. Les gens savent pas quoi faire quand il y a un problème parce qu'ils trouvent pas, car y a de l'information partout. [...] Je m'inscris sur des sites Web pour recevoir des nouvelles sur les soins des animaux. » (Carla, propriétaire d'un chien, JUIN 2009)

« Certains [sites Web] sont très complets, ils ont même des listes complètes de médicaments pouvant être utilisés sur nos animaux -y a des tableaux avec les races, tailles, âges et la quantité de chaque médicament pouvant être administrée sans danger pour la santé de l'animal. » (Aline, propriétaire d'une Yorkshire Terrier, 2009)

Ce qui commençait à devenir clair pour moi c'était que, tandis que je cherchais des explications scientifiques à la dépression canine, les soupçons ou les diagnostics des gens se rendant au magasin provenaient souvent de *blogs*, de magazines généraliste, de programmes télévisés ou encore de recommandations d'amis. La vulgarisation d'outils d'information sur Internet et d'autres médias a fait surgir une sorte de proto-professionnalisme dans le secteur de la santé du récent monde *pet*. Comment l'écrit Swabe (1999) :

Essentially, proto-professionalisation means that animal owners have become increasingly familiar with the basic notions and practices of the veterinary profession. They will borrow professional veterinary vocabulary to articulate

their animal's health or behavioural problems and will use their knowledge of animal conditions to determine whether or not they should solicit veterinary assistance. With this increased lay knowledge, animal owners may tend to view veterinary professionals more critically, which in turn places increased pressure on veterinarians to demonstrate their competence and medical expertise to their clients and to retain their medical authority (Swabe 1999 : 136).

Cette même piste m'a poussé à consulter les *blogs* recommandés par les habitués du magasin. L'un d'eux, intitulé « *Dog's Times* » contenait des définitions assez complexes de la dépression canine.⁹ Selon lui, le fait que les chiens peuvent souffrir d'états dépressifs a été ignoré pendant trop longtemps par les propriétaires et les vétérinaires car leurs symptômes étaient attribués au vieillissement, qui engendrerait un ralentissement de l'activité chez ces animaux. Cependant, cela a changé avec l'étude des pathologies comportementales, qui entre autre, propose de comprendre la dépression chez les chiens comme :

Un état particulier du système émotionnel qui peut se manifester de diverses manières sur le plan clinique [...] le chien déprimé est un individu apathique, inactif, pas du tout intéressé par ce qui l'entoure et qui manifeste un état d'angoisse permanent. Cependant, cet état peut s'alterner avec d'autres d'agitation, caractéristiques d'une des formes cliniques (Blog « *Dog's Times* »).

Ce *blog* caractérise trois formes cliniques de manifestation de la dépression canine. La *dépression de réaction*, « causée par le stress ou un choc émotionnel grave » où « le corps réagit à une surcharge de stimuli négatifs », comme une agression, par exemple, avec des états transitoires de dépression, pouvant durer entre huit et dix jours et qui n'ont pas besoin d'être traités par des médicaments. Qualifiée de très grave par *Dog's Times*, la *dépression de régression* serait « caractérisée par la perte des comportements acquis » (en particulier d'hygiène ou d'ordre appris pendant le dressage) et « par le retour à des comportements infantiles ». Dans ce cas, « l'animal cesse presque entièrement de se déplacer, il pleure pendant des heures et avale tout ce qu'il rencontre au long de ses déplacements limités ». C'est à ce moment qu'il faudrait intervenir avec des antidépresseurs. Apparaît enfin la *dépression cyclique*, considérée comme relativement courante, surtout chez

9 Voir <http://www.dogtimes.com.br/depressao.htm>. Accès en Octobre 2009.

les femelles dont les cycles durent entre deux semaines et deux mois et sont caractérisés par « l'indifférence, la tristesse, l'anorexie et la perte des comportements appris ».

Sur un autre *blog*, les caractéristiques de la dépression canine sont associées à celles rencontrées dans la littérature scientifique sur le SASA : « le comportement d'attachement est essentiel pour la survie des animaux sociaux. Il s'agit d'un mécanisme de coalition sociale. »¹⁰ Selon le vétérinaire Mauro Lantzan, auteur de ce texte, il faut faire attention à ce qu'il appelle la période de socialisation entre le chien et son propriétaire qui, selon lui, est cruciale pour la détermination des hiérarchies, de la communication et de la confiance entre eux. Si l'animal devient très dépendant de son propriétaire, des périodes de séparation, comme des déplacements professionnels, par exemple, peuvent déclencher ces comportements dépressifs chez le chien :

La dépression, ou état dépressif, peut être liée à l'anxiété et se produit lorsque l'animal est exposé à des situations de stress, de façon chronique ou traumatique, et commence à manifester des signes d'incapacité à accomplir ses fonctions biologiques, une apathie, un isolement social et un manque d'appétit. (Blog « Saúde Animal »)

Selon les informations de Bia, Pink souffrait d'« incapacité à exercer ses fonctions biologiques » et était visiblement apathique. Par la suite, j'ai aussi trouvé une explication disant qu'il y aurait des races plus sujettes à la dépression, en particulier, celles « sélectionnées comme compagnie ». Mais les changements brusques de routine et l'absence des proches, d'autres chiens ou des humains, sont les principaux facteurs déclenchant la dépression car ils rendent les animaux « vulnérables au stress ». Cependant, et surtout, le lecteur devrait être conscient du fait que « tout animal est un être unique et doit être considéré comme un individu aux caractéristiques propres. »

« Être unique », « individu aux caractéristiques propres », ces expressions, pour moi qui ai une formation en sciences humaines, étaient aussi familières qu'exotiques. En effet, elles étaient attribuées à des chiens. Mais j'ai poursuivi ma lecture :

La dépression doit être considérée comme un processus complexe. Une fois diagnostiqué le problème et définie la cause, le traitement peut comprendre

10 Voir <<http://www.saudeanimal.com.br/artig130.htm>>. Accès en Mai 2009.

des antidépresseurs tels que le Prozac. Les remèdes homéopathiques et les Fleurs de Bach contribuent au rétablissement émotionnel du chien déprimé et peuvent être prescrits par le thérapeute. Améliorer la qualité de vie de l'animal et prendre soin de son bien-être est aussi important. Ceci est la base de la thérapie comportementale (Blog « Saúde Animal »).

Il me semblait trouver à chaque ligne un terme de plus à discuter : « complexe », « Prozac », « les remèdes homéopathiques et les Fleurs de Bach », « rétablissement émotionnel du chien déprimé », « prescrit par le thérapeute » ou « qualité de vie de l'animal » tous s'enchaînaient, faisant écho à l'ensemble des diagnostics cliniques. Ces *blogs* traduisaient des éléments typiques du SASA pour parler de la dépression canine dont ils proposaient un diagnostic en fonction des états présentés par les chiens et des intérêts de leur propriétaire. Soit un processus de déviation d'objectifs au cours de l'action, tel qu'Akrich (2006) l'a présentée pour ce qui est du rôle des utilisateurs dans le processus d'innovation, car son étude repense la linéarité du processus conception-usage pour se concentrer sur les transformations que les acteurs impliqués déploient au quotidien.

Ma recherche des définitions de la dépression canine sur ces blogs était une façon de me rapprocher de la logique partagée par Marcos et ses patients. Ce dernier n'a pas construit ses diagnostics de dépression sur des théories ou des méthodes de la science vétérinaire. Il a mélangé sa sensibilité, développée en trente ans de profession, aux procédures techniques et aux croyances valorisées par ses clients et par l'industrie pharmaceutique. L'on retrouve dans les discours de ces derniers des concepts, produits des univers scientifiques, tels que fluoxétine, stress ou synapses, côtoyant des termes non scientifiques comme solitude et tristesse. Il s'agit d'une sorte de « vie ensemble » constituée de différentes façons de penser et de vivre le monde que Stengers (1997) définit comme le cosmopolitique :

Aucun savoir unificateur ne démontrera jamais que le neutrino des physiciens puisse coexister avec les mondes multiples mobilisés pour l'ethnopsychiatrie. Cette coexistence a pourtant un sens, et il ne relève ni de la tolérance ni d'un scepticisme : l'espace « cosmopolitique » où ces êtres peuvent être affirmés ensemble est celui de la rencontre entre les espoirs et les doutes, les effrois et les rêves qu'ils suscitent et qui les font exister (Stengers 1997 : 06).

Le dialogue ou la réconciliation sont des expressions fréquemment liées au politique, surtout en cas de victoire électorale, lorsqu'un parti devient majoritaire. En termes généraux, il s'agit de la victoire de la science sur les croyances, de l'expérience sur l'intuition, de la culture sur la nature, etc. Quand Stengers (1997) parle de cosmopolitique, il met sur le même plan d'existence la science et la magie, la religion et l'expérimentation de laboratoire, les psychotropes et les tisanes. Tous coexistent dans le même cosmos. Le politique est réestimé. Ce n'est plus l'idéal de la victoire de l'homme sur les choses. C'est une négociation de différentes façons de penser et de vivre le monde. Comme l'a expliqué Latour (2007) :

Elle [*Isabelle Stengers*] a réinventé le terme en le présentant comme un composite de la signification la plus forte de cosmos et de celle de politique, précisément parce que le sens habituel du terme cosmopolite [*selon Ulrich Bech*] supposait une certaine théorie de la science qui est maintenant contestée. Selon elle, la force d'un élément se vérifie par sa capacité à atténuer les autres éléments. La présence du cosmos dans les cosmopolitiques résiste à la tendance du politique à concevoir les échanges dans un cercle exclusivement humain. La présence du politique dans les cosmopolitiques résiste à la tendance du cosmos à concevoir une liste finie d'entités qui doivent être prises en compte. Le cosmos prévient le repli prématuré du politique, et le politique celui du cosmos (Latour 2007 : 71).

En apparence inconciliables pour l'analyse, des collectifs très distincts sont symétriquement liés, puisque, dans la pratique, les relations ne commencent ni par la distinction entre science et non-science, ni par la division moderne entre nature et culture. Le monde n'est pas strictement organisé ainsi, mais beaucoup de sciences qui l'étudient le sont.

Marcos prescrit des psychotropes à la chienne, mais il demande aussi de changer les comportements, les modes de vie. Il dit que Bia et Pink devraient manger des aliments sains et faire des exercices physiques. Selon lui, elles devaient trouver des choses pour égayer leur vie et passer plus de temps ensemble. Surtout, il reconnaissait les continuités entre les chiens et les humains.

Cette idée de « continuité » est très forte dans les récents travaux de Philippe Descola (2005, 2014a), qui systématise quatre grands modèles

ontologiques à partir de données empiriques provenant de différentes régions du monde.¹¹ Le premier concerne l'idée générale animant la pensée occidentale moderne, selon laquelle il y a une nature commune entre humains et non-humains où les premiers se distinguent des autres par le privilège de la reconnaissance d'une intériorité distincte. Il l'appelle le *naturalisme*.

Apparaît ensuite l'idée d'*animisme*, dont l'élément central est une intériorité partagée entre humains et non-humains : les plantes, les humains et les animaux possèdent des matérialités distinctes, mais une intériorité commune, qui permet la communication. Cela implique que, dans ces systèmes, les non-humains disposent aussi de caractéristiques sociales telles qu'une hiérarchie des statuts sociaux, ses comportements basés sur des règles de parenté, des codes éthiques et des activités rituelles, c'est-à-dire qu'il y a une reconnaissance des qualités intérieures partagées entre les existants.

Une autre ontologie traitée par Descola (2005) est le *totémisme*. Largement exploré dans les travaux de Lévi-Strauss, le point central de cette ontologie contraste avec l'animisme dans la mesure où êtres humains et non-humains possèdent des intériorités différentes, mais peuvent partager des habiletés corporelles – la vitesse du jaguar, la dextérité de l'anaconda, la capacité de camouflage du caméléon, le chant de l'Uirapuru, les couleurs du toucan. Il existe ainsi des matérialités similaires, mais des intériorités distinctes.

Enfin, ce qu'on pourrait considérer comme une nouveauté pour la discussion anthropologique inaugurée par Descola (2005) et qui intéresse plus directement notre discussion (sous réserve des particularités de contextes ethnographiques) est l'*analogisme*. Pour cet auteur, il s'agit du mode d'identification dont la caractéristique centrale est la multiplicité des essences. Ici, l'identification se nourrit de similitudes, de sympathies, d'apparences. Les

11 Il convient de noter que ces données proviennent de peuples que nous classons habituellement sous le label général de non-modernes, ce qui signifie de toute évidence qu'elles ne servent pas directement à élucider le problème du domaine de recherche sur lequel je travaille. Pourtant, elles peuvent illuminer ce débat. Sur cette procédure comparative, deux considérations sont importantes. La première est celle de Strathern (2006 : 33), qui critique la façon dont certaines catégories empiriques de connaissance sont élevées au rang de catégories philosophiques ou analytiques, pour la compréhension d'autres contextes. Selon elle, « d'ordinaire, la procédure comparative, comme elle examine des variables traversant différentes sociétés, décontextualise les constructions locales pour travailler avec des constructions contextualisées analytiquement. » La seconde apparaît dans l'idée générale de symétrie de la Théorie de l'Acteur-Réseau. De cette perspective, « les mêmes causes doivent expliquer les croyances vraies ou fausses » (Bloor 2009 : 21). Dans les termes de Latour (2005), cela exige de l'anthropologie le même type de traitement pour les modernes et les non modernes.

composants moraux et physiques des existants sont divers et fragmentés, leurs intériorités et physicalités sont discontinues et l'analogie consiste à établir une harmonie ou une continuité.¹²

Un exemple empirique de cette continuité dans mon contexte de recherche était l'expression qui se prête à un ensemble de procédés autorisant et naturalisant l'utilisation des technologies médicales et de médicaments commune aux humains et aux *pets* : « c'est la même chose ». Marcos et Paula me l'ont dit. Et ce qui m'intéresse plus particulièrement dans nos conversations est justement la facilité et la naturalité avec lesquelles se déployaient leurs longs récits sur leurs expériences de travail dans des *pet shops* et cliniques vétérinaires. Pour eux, l'avancement de la médecine vétérinaire et l'apparition de chiens dépressifs étaient considérés comme « très normaux ».

C'est à cette époque que j'ai visité les *Laboratoires Gemballa*, vers où étaient dirigés de nombreux propriétaires de chiens souffrant de dépression pour commander de médicaments. Lucas, un des biochimistes du laboratoire, était un ami de longue date. J'ai commencé à l'impliquer dans ma recherche et je lui ai notamment posé certaines questions sur les prescriptions de fluoxétine pour chiens :

« Je vais être bien franc. Tu sais que maintenant je travaille plus là-dessus, je suis pharmacien titulaire chez Gemballa, je signe des papiers, j'aide à vendre, mais je *travaille plus dans la production*. C'est d'autres gens qui font les manipulations. Mais c'est simple : pour moi, en tant que pharmacien, le but ultime du médicament ne fait aucune différence. »

[Et si ça fonctionne pas, du fait que ça se destine à un chien ?]

« Eh bien, quelqu'un avant moi s'est certainement déjà inquiété de ça, au labo, dans l'industrie ou dans une université – quelqu'un s'est consacré à savoir si ça marcherait ou pas : ils ont dû faire des études en double aveugle, des

12 Plus récemment, Descola (2014a) a exploité une critique de l'idée que ces modèles décrivent différents points de vue sur le monde. Pour lui, parler d'ontologie c'est désigner un niveau analytique, pour étudier « la mondiation », plus élémentaire que celui ordinairement adopté par l'anthropologie. Selon lui : « *There can be no multiple worlds, in the sense of tightly sealed containers of human experience with their own specific properties and physical laws, because it is highly probable that the potential qualities and relations afforded to human cognition and enactment are uniformly distributed. But once the worlding process has been achieved, once some of these qualities and relations have been detected and systematized, the result is not a worldview, that is, one version among others of the same transcendental reality; the result is a world in its own right, a system of incompletely actualized properties, saturated with meaning and replete with agency, but partially overlapping with other similar configurations that have been differently actualized and instituted by different actants.* » (Descola 2014a : 277-278)

tests avec des placebos, réaliser des contre-épreuves – bref, ils ont dû suivre le protocole. Alors, maintenant pour quelqu'un comme moi, qui travaille au département commercial et pas dans la recherche, c'est pas ce qui est en jeu, l'affaire est plus directe et objective : je dois respecter la formule, ni plus ni moins, si la prescription dit X, je vais faire X. Ça m'intéresse pas de savoir à qui ou à quoi ça se destine. C'est triste, mon vieux, c'est ce qu'en sociologie vous appelez la division des tâches, de l'aliénation, enfin [...] Eh bien, Jean, tu sais, la prescription dit pas de quoi l'individu souffre, elle dit simplement ce qu'il doit prendre. Certes, nous savons à quoi ça sert, car nous connaissons les médicaments – la pratique fait qu'on finit par connaître par cœur les compositions et les dosages. Mais si la prescription dit « Alice », pas moyen de savoir si c'est une dame ou une chienne. C'est pareil – *c'est la même chose* : que ce soit un chien ou une personne, c'est pareil – le médicament doit marcher. Et c'est pour ça qu'on le fabrique et qu'on le vend. » (Lucas, biochimiste et pharmacien, juillet et août 2009).

Le « c'est la même chose » qui apparaît dans ces discours est une des clés de la composition d'une cosmopolitique de la dépression. C'est à partir de la reconnaissance de certaines propriétés pouvant être partagées par les humains et les animaux que se mettent en place des modes d'identification et de relation tels que la cohabitation, l'utilisation de vêtements, le diagnostic et le traitement de certaines pathologies auparavant uniquement attribuées aux humains, et plus récemment, l'administration de médicaments sans distinction d'espèces.

Cette attention à ce qu'on pourrait appeler des problèmes de comportement chez les animaux de compagnie et leur médicalisation, selon Vlahos (2008 : 451), est devenue plus fréquente ces quinze dernières années. En effet, la prescription de médicaments pour ces animaux se base sur les traitements dédiés initialement aux humains, comme, par exemple la prescription de l'anticonvulsivant *Gardénal*® (phénobarbital, fabriqué par Bayer) aux animaux souffrant d'épilepsie, ou de l'anxiolytique *Diazepam*® (benzodiazépine, fabriqué par Roche), couramment employé en tant que sédatif avant des interventions chirurgicales mineures. Cependant, la stratégie adoptée par les grandes compagnies pharmaceutiques s'axe de plus en plus sur « la vente de médicaments modifiant le comportement et le style de vie spécifiques des animaux domestiques. » (id.) C'est le cas de *Slentrol*® et *Anipryl*®, de *Pfizer*,

utilisés, respectivement, pour les chiens obèses et souffrant de déficits cognitifs comme la perte de mémoire due à l'âge avancé. Plus spécifiquement, dans le cadre du problème dont traite cette recherche, il existe Clomicalm® – une version canine d'Anafranil® de Novartis, et Reconcile®, une version à mâcher, goût viande, du médicament qui a révolutionné le monde du traitement de la dépression : Prozac®, d'Eli Lilly¹³. Ces deux médicaments sont prescrits en cas de SASA, mais aussi, en raison de leurs effets antidépresseurs, aux chiens diagnostiqués dépressifs.

Avec le temps, la plupart des examens de Marcos se résumaient à une simple confirmation : les gens arrivaient au magasin avec une sorte de diagnostic préétabli, facilité par les informations disponibles sur Internet, assuré par les « on-dit » et la confiance en la manipulation des médicaments des *Laboratoires Gemballa*.¹⁴ En outre, dans ce contexte local, les chiens présentaient des symptômes suffisamment semblables à ceux que les humains présentent lorsqu'ils sont tristes ou déprimés. Et, si les humains s'autorisent certaines actions dans ces cas, tels que l'usage de psychotropes, pourquoi, par analogie, ne pas médicaliser les chiens eux aussi ? Après tout, « c'est la même chose ».¹⁵ Ainsi, si la littérature médico-vétérinaire définit le SASA, ses caractéristiques peuvent servir à décrire toute autre affection ou pathologie qui mettrait les chiens dans un état de tristesse et d'apathie apparente. En tant que modèle de vie contemporain (Roudinesco 2000) et avec les facilités pour son traitement rendues disponibles par l'immense mobilisation de ressources pour financer les diverses formes de traitements médicamenteux, la dépression canine, à l'instar de la dépression humaine, est devenue une épidémie (Pignarre 2001, 2006). Mais, en outre, dans mon contexte de recherche, la dépression était une forme de relation homme-animal. Dans ces cas, la dépression canine semblait pratique pour ceux qui étaient impliqués : elle simplifiait la compréhension des propriétaires, car elle constituait une sorte de terme commun pour une certaine tranche de la population qui fait

13 Voir l'intéressant travail de Fraser (2001) : *The nature of Prozac*, où l'auteur aborde la révolution provoquée par cette drogue. Selon lui, les explications du fonctionnement du cerveau accompagnant ce médicament font apparaître de nouvelles compréhensions légitimant son utilisation. Voir aussi Lakoff (2008) et Azize (2008 ; 2010).

14 Et ce parce que, au Brésil, il y avait, à l'époque, des restrictions à la commercialisation de psychotropes et médicaments spéciaux pour animaux de compagnie, comme ceux fabriqués par Novartis et Eli Lilly.

15 Je demandais parfois : « *Comment ça, c'est la même chose : les chiens c'est aussi des gens ?* ». Les réponses étaient, en général, négatives : « *Les chiens, c'est des chiens – on le sait tous, mais ils méritent d'avoir les mêmes privilèges que nous. Sur pas mal de choses, on est pareils* » (Joana, propriétaire d'une caniche, Septembre 2009).

de plus en plus usage de systèmes explicatifs du monde centrés sur le moi ou le subjectivisme, par la reconnaissance d'une intériorité (Duarte & Carvalho 2005). En même temps, ces personnes promeuvent les *pet shops* car ils les placent « sur la vague » de l'humanisation des animaux (Vlahos 2008 ; Kulick 2009), un mouvement qui participe à la réorganisation de la psychothérapie comportementale par la généralisation de l'usage de psychotropes (Pignarre 2006).

Évidemment, d'un point de vue psychanalytique, par exemple, il faut considérer que la mélancolie est productive et que la tristesse peut faire partie de la vie de quelqu'un qui peut quand même vivre heureux. Si une personne n'est pas d'accord avec cela, il lui appartient d'agir pour se mettre dans un autre état d'esprit. Cependant, la dépression, concept que se disputent la psychologie, la psychiatrie et la neurologie, conserve l'aspect négatif d'une maladie. Mais dans le même temps, l'idée de la dépression donne au malade la possibilité d'échapper à la responsabilité de sa propre souffrance. La dépression est un trouble de nature neurochimique dans la logique biomédicale ; il ne s'agit pas de choisir, mais d'être «choisi», ce qui supprime la responsabilité que le sujet (dont il est le produit) a sur lui-même, au point que, entre autres choses, il se résigne à médicamenter sa propre vie. La dépression est une question qui ne doit pas être gérée par lui, mais par la fluoxétine. Comme l'a dit Roudinesco (2000), la psychologie cognitive et la neurochimie ont produit une espèce de personne recherchant des traitements médicamenteux alors qu'un processus d'auto-analyse suffirait. Ce qui a été, par exemple, le choix de Bia, pour elle et sa caniche. Marcos les avait interrogés sur leurs routines - de longues heures de travail au bureau, l'isolement, leur mauvaise alimentation et leur manque d'exercice. Il leur a suggéré de changer radicalement de mode de vie avant de suivre une médication. Mais, comme cela est très courant de nos jours, elle a ignoré ses conseils et opté pour le médicament. Dans sa thèse de doctorat, l'anthropologue Rogério Azize (2010) nous aide à situer cette discussion au cœur des relations sur lesquelles se concentrent récemment les neurosciences et leurs effets, dans ce qu'il appelle « nouvel ordre du cerveau » :

Un vocabulaire lié aux « nouvelles sciences du cerveau » - neurones, neurotransmetteurs, synapses, sérotonine, etc. - fait dorénavant partie de l'acquis sémantique que le grand public peut utiliser dans sa vie quotidienne

pour parler de divers sujets concernant le comportement et les sentiments humains. Nous traversons un processus de vulgarisation de ce genre de connaissance, comme nous avons connu une vulgarisation des connaissances liées aux « psy », comme l'inconscient, le moi, etc. Les échos d'une « culture psy » s'unissent aujourd'hui de manière complexe à un discours où le cerveau prédomine sur l'esprit ; ou plutôt, où l'esprit est un épiphénomène du cerveau, conséquence directe de son activité chimique et électrique. Il s'agit de penser le rôle de diffusion scientifique dans ce processus. Mais aussi de réfléchir à un changement plus large dans la vision du monde, à partir de laquelle la notion de personne résidant dans le cerveau commence à prendre son sens. (Azize 2010 : 03)

Mais le fait est que ce nouveau champ sémantique, dans mon contexte de recherche, a non seulement conduit à expliquer le comportement ou les sentiments humains, mais il a aussi donné un sens à ceux de l'animal - celui qui est le plus humanisé, le *pet*. En vérité, ce vocabulaire autorise à dire que Pink est un être humain, qualité que lui confère cette « technologie alien multifonctionnelle » qu'est le cerveau.¹⁶ Lorsque le vétérinaire prescrit de la fluoxétine à un chien, il considère que sa souffrance s'explique par un dysfonctionnement du cerveau, ce qui élargit sa ressemblance avec Bia (dont il animalise le cerveau en le réduisant au même fonctionnement que celui du chien). Enfin, face à cette logique, nous pouvons même nous interroger sur la tristesse et l'apathie d'un chien et remettre en question une subjectivité qui transfère les affects d'une espèce à l'autre. Or, face à cette vague neuroscientifique, nous ne pouvons pas nier que ce sont à la fois le cerveau et les neurotransmetteurs avec les activités électriques fonctionnant, en théorie, à partir des mêmes principes. Suivant ces considérations, le cerveau et les médicaments ont réunis les humains et les animaux et « de nouvelles formes d'objectivité et de nouvelles formes de subjectivité sont confondues dans un discours associant le cerveau aux gens, les images techniques et les sentiments, la raison et l'émotion. » (Azize 2010 : 07) Alors, pourquoi pas une sorte de continuité entre l'homme et l'animal ?

¹⁶ L'expression est de Lende (2014) : "Our Brains as Alien Technology". Disponible sur : <http://blogs.plos.org/neuroanthropology/2014/07/19/brains-alien-technology/>. Dernier accès en août 2014. Daniel Lende dirige une nouvelle génération d'anthropologues cherchant à discuter la relation entre cognition et culture, en particulier le dialogue entre anthropologie et neurosciences. Voir aussi Lende & Downey (2012).

Conclusions :

La biosocialité multi-espèce

La biosocialité est un effort « pour analyser les nouvelles technologies biologiques qui reconfigurent (ou non) la notion d'être humain ainsi que les implications socioculturelles, politiques et éthiques découlant de ces changements. » (Santos, Gibbon & Beltrão 2012 : 09) Cependant, dans mon contexte de recherche, la mobilisation dans le discours des différents acteurs de leurs intuitions, de leur confiance en le laboratoire pharmaceutique, des informations trouvées sur Google ou des concepts scientifiques compose un mode de vie contemporain basé sur de nouvelles moralités où ces animaux urbains sont pensés comme une espèce d'être humain. Dans ce cadre, beaucoup de problèmes sont associés à la réorganisation de la psychothérapie comportementale, laquelle préconise maintenant la prise de médicaments psychotropes, ce qui a permis à Bia et Pink de partager le même médicament.

Cette relation née autour de la dépression résulte de nouvelles connaissances construites à partir du surgissement de nouveaux concepts, de nouvelles techniques et de nouveaux sujets de connaissance, comme le dit Foucault (2005). L'attention ne doit pas être portée sur le chien souffrant de dépression, mais plutôt sur les conditions qui la font apparaître et les moyens mis en œuvre pour la soigner. Je pense ici à la généralisation d'une référence bien connue qui apparaît dans l'œuvre de Michel Foucault (2005) : les liens entre ce qu'il appelle les systèmes de vérité et les pratiques sociales et les politiques d'une époque donnée. Pour lui, les nouveaux objets de connaissance naissent des domaines de savoirs les ayant produits. Dans le même temps, cette production est responsable du surgissement de nouvelles formes de subjectivité. Dans ce cas, « les pratiques sociales peuvent en venir à engendrer des domaines de savoir qui non seulement font apparaître de nouveaux objets, de nouveaux concepts, de nouvelles techniques, mais aussi font naître des formes totalement nouvelles de sujets et de sujets de connaissance » (Foucault 2005 : 08). Cette idée s'est éclairée lorsque j'ai choisi de suivre le cours des événements sur le terrain. En d'autres termes, mon intention initiale n'était pas de faire des recherches sur des chiens souffrant de dépression : j'ignorais complètement ce phénomène. L'incidence de la dépression commence à prendre forme, dans les mêmes proportions où un ensemble de pratiques se constitue comme de nouvelles routines médico-vétérinaires, lesquelles, par conséquent, stimulent des investissements dans de nouveaux

services et produits. Dans une certaine mesure, la médicalisation et l'apparition d'un « marché *pet* » sont une manière de transformer certaines natures et de les placer sous d'autres contrôles.

Quand je parle de cosmopolitique et d'une biosocialité multi-espèces, j'entends que la tristesse, la mélancolie, la dépression ou la fluoxétine constituent un monde commun entre les *pets* et leurs propriétaires. Dans ce cas, leur statut ontologique est moins intéressant que les arrangements qui les produisent. Comme l'indiquent déjà Langdon (2003) et Maluf (2007) dans le domaine de l'anthropologie de la santé, on constate dans certains modèles de vie une prédominance des explications cosmologiques permettant aux gens de comprendre comment ils ont été affectés ou envahis par quelque chose d'extérieur, comme un sortilège, un mauvais œil. Ces modèles coexistent avec ceux, biomédicaux, où le mal, trouble ou maladie, s'explique par des déséquilibres physiologiques, d'ordre congénital ou transmis par des bactéries ou virus. Le premier modèle est le monde d'une altérité produite par un dispositif nommé « croyance », selon Latour (2002), et le second est celui de la preuve, de la science. Cela implique diverses formes d'agencement, puisque si les gens (ou animaux) sont attaqués par des micro-organismes ou par des sortilèges et si le récepteur est désigné par des gènes ou des divinités, cela implique différentes compositions du monde mobilisant chacune des acteurs et des actions spécifiques¹⁷. Pourtant, je pense que la dépression n'est pas une « maladie » qui a attaqué Bia et Pink, mais un mode de relation liant cette femme et sa caniche. L'animal et le composé chimique incarnent « une présence » (au sens d'une altérité étrangère, comme le dit Lestel 2011). En considérant la manière dont Gell (2009) pense l'art, Bia, Pink ou la fluoxétine sont des sortes de contrepartie relationnelle ou chacune affecte l'une, l'autre ou les deux parties. Ainsi, plutôt que de traiter de la relation entre un humain et un animal, j'ai essayé de déplacer mon attention pour saisir la dépression comme une forme de relation produisant des manières d'être au monde indépendamment de qui est humain ou qui est animal.¹⁸

17 Suivant l'interprétation du monde du cosmopolitique, tous peuvent coexister transversalement. Aussi, comme le dit Descola (2014b : 60-61), le monde social n'est pas plat : il est tissé de conflits et de rapports de forces entre de nombreux modes d'exister où la politique est partagée par l'humain et le non-humain.

18 Comme l'écrit Strathern (2014 : 325) « il est impossible de fixer un hybride parce que ses caractéristiques ne résident pas en une partie isolée, mais dans la façon dont les parties travaillent ensemble ». Penser qu'un *pet* est un chien et une autre chose en même temps est un malentendu. L'hybride est une relation. Dans cette manière, j'ai concentré mon attention sur la relation. Je rejoins méthodologiquement Strathern (2014), quand elle aborde

Selon une formule générale de Manceron & Roué (2009 : 05), « à travers et avec les animaux, les différences et singularités culturelles se proclament et se définissent ; les places et les systèmes de relations entre les êtres s'assignent et se discutent ; la légitimité des savoirs et des pouvoirs se défend. » Mon intérêt pour cette question est lié au repositionnement des animaux dans l'ethnographie récente. Si les animaux ne sont pas une nouveauté dans cette discipline, la question essentielle est que les débats contemporains, surtout l'ethnographie multi-espèces, ont installé une critique de la passivité animale dans la composition des relations. Traditionnellement, a écrit Noske (2008), les anthropologues ont défini leur discipline comme l'étude de l'humanité (humankind) ; ils naturalisent notre peu d'attention au non-humain ou à l'animalité (animalkind). Parmi les nombreuses conséquences de ce fait, l'auteur suggère la transformation des animaux en une ressource, puisqu'ils n'apparaissent que comme faisant partie des écosystèmes anthropiques. Ainsi, dans ce modèle contemporain, les sociétés occidentales ont habituellement confié la capacité d'agencement à l'humain :

[...] animals tend to be portrayed as passive objects that are dealt with and thought and felt about. Far from being considered agents or subjects in their own right, the animals themselves are virtually overlooked by anthropologists. They and their relations with humans tend to be considered unworthy of anthropological interest (Noske 2008 : 22).

Enfin, je crois que les récentes études ethnographiques sur la relation homme-animal peuvent fournir de nouveaux horizons pour un débat courant sur des positions politiques, morales et épistémologiques. En d'autres termes, ces relations peuvent nous aider à comprendre les mouvements locaux et mondiaux, les transformations de certaines sociétés. Ainsi, les chiens déprimés du sud du Brésil ne sont pas importants ici pour leur valeur de vérité au sens de former de fait un phénomène pathologique reconnu par la littérature médico-vétérinaire constituant des nouveaux indices épidémiologiques. Ce qui les rend importants est leur rôle central dans la composition de certains processus permettant de comprendre des logiques locales ni définitives, ni exclusives : les politiques de développement, les nouveaux modèles de vie, les rapports

l'idée que les entités existent à l'intérieur de la relation. Cette proposition déplace l'accent de la description de la relation entre des objets - comme entre l'humain et l'animal ou entre la personne et les médicaments, pour traiter les choses comme eux-mêmes une relation.

à la science et la technologie. Mais surtout, une forme de biosocialité et des manières d'être au monde, comprenant l'homme et l'animal.

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Biolegitimacy, rights and social policies:

New biopolitical regimes in mental healthcare in Brazil

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Abstract

This paper discuss biolegitimacy as an instrument and device for the production of rights, recognition and access to services and care from the state, as a means to demand and conquer rights and as an expression of a new biopolitical regime. Biolegitimacy is articulated with a broader context of political shift, with an emphasis on the processes of pathologization, medicalization or biologization of social experiences, particularly concerning the production of public policies and actions of the state in the field of rights and citizenship. Despite the breadth of the issues that can be addressed through this concept in its formulation by Didier Fassin, the focus of this article is mental health policies in Brazil in the context of Brazil's Psychiatric Reform program, particularly those policies aimed at women. If on one hand the Psychiatric Reform is based on the principles of the human rights of the ill and of psychiatric patients, and on the democratization and universalization of access to healthcare, on the other hand, in various aspects these same policies reproduce the device of biolegitimacy. The focus is the notion of the "life-cycle" of women, a principle widely used in the documents and guidelines mainly in those specifically aimed at women's health.

Keywords: Biopolitics, Biolegitimacy, Mental Healthcare, Gender, Public Policies, Subject

Resumo

Este artigo procura trazer uma reflexão sobre um aspecto cada vez mais presente nas políticas sociais contemporâneas: a biolegitimidade como um dispositivo de produção de direitos, de reconhecimento e de acesso a serviços

e atendimento por parte do Estado, e também como meio de reivindicação e de conquista de direitos. Biolegitimidade se articula com um contexto mais amplo de deslocamento do político, com ênfase nos processos de patologização, medicalização ou biologização das experiências sociais, sobretudo no que diz respeito à produção de políticas públicas e às ações do Estado no campo dos direitos e da cidadania. Apesar da amplitude das questões que podem ser abordadas através desse conceito, a partir de sua formulação por Didier Fassin, o foco deste artigo são as políticas de saúde mental no Brasil no contexto da Reforma Psiquiátrica brasileira, particularmente aquelas dirigidas às mulheres. Se por um lado a Reforma Psiquiátrica tem como princípios de base os direitos humanos dos doentes e dos pacientes psiquiátricos, assim como a democratização e a universalização do acesso à saúde, por outro, em diversos de seus aspectos essas mesmas políticas reproduzem o dispositivo da biolegitimidade. O foco é a noção de ciclo de vida das mulheres, um princípio largamente utilizado nos documentos e diretrizes principalmente naqueles especificamente voltados à saúde da mulher.

Palavras-Chave: Biopolítica, Biolegitimidade, Saúde Mental, Gênero, Políticas Públicas, Sujeito

Biolegitimacy, rights and social policies:

New biopolitical regimes in mental healthcare in Brazil

Sônia Weidner Maluf

This paper reflects on an aspect increasingly present in contemporary social policies: biolegitimacy as an instrument for the production of rights, recognition and access to services and care from the state, and as a means to demand and conquer rights. Despite the breadth of the issues that can be addressed through this concept, the focus of this article is mental health policies in Brazil in the context of Brazil's Psychiatric Reform program, particularly those policies aimed at women. If on one hand the Psychiatric Reform is based on the principles of the human rights of the ill and of psychiatric patients, and on the democratization and universalization of access to healthcare, on the other hand, in various aspects these same policies reproduce the device of biolegitimacy. In this article I will discuss two of these dimensions: the way that certain subjects are considered and described in government documents as more vulnerable to problems of a psycho-social order, and the place that medications occupy in the policies for democratization and universalization of health care. This shift in demands and social and economic rights to what we can generically denominate the "right to life," visible in the processes of medicalization and psychiatrization of suffering and of social demands, establish parameters for the legitimation of these demands that largely dilute their political meanings. It also involves a two-way process of political movement, not restricted to the realm of the state and its actions, but present in the scientific statements, in technological production and in the platforms of social movements, as well as in the individual and collective agencyings involved in the struggle for rights, justice and recognition.

Biolegitimacy and biopolitics

In his formulation of the concept of biolegitimacy Didier Fassin begins from the recognition that the right to life has gained priority on the human rights agenda in relation to social and economic rights. Fassin locates and problematizes the moral potential of this “right to life” (which is expressed in article 3 of the Universal Declaration of Human Rights of 1948), in contrast to a growing “moral debility” of social and economic rights (included in article 22 of the Declaration), as a historic and contemporary contingency. That is, there was an inversion of priorities in the contemporary moral and political field, in which the right to life would become more important than social and economic rights, and would impose itself in detriment to the others. He calls this difference between the two perspectives “the conflict of two ethical communities that have an unequal legitimacy” (Fassin 2010: 193).

There are numerous examples of this shift or inversion of priorities in the political field, and the author addresses some ethnographic cases, including the significant increase in the concession of asylum for therapeutic treatment and decline of political asylum (Fassin 2005). Another case discussed by Fassin concerns controversy in AIDS prevention and treatment policies in Africa, in which the medical community and that of specialists, defenders of the right to life of HIV positive patients and of the urgency for treatment, question government policies and the administrators of healthcare policies, which focus on issues such as management of the healthcare system and equitable distribution of the right to healthcare, or that is, issues related to social and economic rights (Fassin 2010).

The central issue for the author is that “human life has become the most legitimate value upon which the contemporary world bases human rights thinking” (Fassin 2010: 201).

If on one hand the centrality of life in modern politics had already been described by Foucault in his formulation of the concept of biopolitics, Fassin and other authors, such as Giorgio Agamben, have discussed how, since the second half of the 20th century, this dimension has become the basis for considering policy.

I consider the concept of biolegitimacy particularly useful for considering some aspects of social policies in Brazil, how the state relates to social demands and how social demands incorporate these new forms of legitimation. I can mention some examples related to studies that I have

coordinated or supervised. These include the broadening of the fields of the pathological and of medicalization in the context of mental health policies and of psychiatric reform in Brazil (which I will explore in greater detail in this article). Another is the recognition by the state of the demands of certain social subjects through their self-recognition as individuals who have a type of disability (for example rights related to the so-called “gender identities” of transgender subjects). To have their right to intersex surgery recognized, these transgender subjects must be diagnosed as afflicted with gender-identity disorder). Finally there is the adoption of medicamentous control of children and youth as part of children and youth policy, in schools, shelters and institutions for minors.¹

But this instrument extends beyond the state, reaching the movements and groups that work to defend rights, as is the case of the struggle for the rights of transgender people and the centrality given to biomedical or medicamentous intervention, whether through hormones or sex-change operations. Another example is the movements and individual or collective pressure from patients for the “right to healthcare,” expressed in the demand for free access to high technology medication or to the most advanced treatments existing.²

In general, bioglegitimacy as an device for production of rights and access to public policies is articulated in a broader context of political shift, which some authors have analyzed from different perspectives, with an emphasis on the processes of pathologization, medicalization or biologization of social experiences, particularly concerning the production of public policies and actions of the state in the field of rights and citizenship.³ One of the effects

1 About the diagnosis and medicalization of children in the mental health field see Brito; 2014 and Souza, 2013 and the work underway by Fernando Moura, about the diagnosis of ADHD in public schools and Maria Fernanda Salvadori Pereira about diagnosis of depression in children.

2 See, about this issue, Ferraz, 2009 and Ferraz and Vieira, 2009. A recent case involving a Brazilian prisoner in Indonesia, accused of drug trafficking is also emblematic of bioglegitimacy as a mode of justice. For a few days the Brazilian media reported that the only possibility for him to escape the death penalty would be a diagnosis of schizophrenia from an Indonesian psychiatrist, which would impede execution under the country's law. (Published on the site G1of Globo, on 12/2/2015 - <http://g1.globo.com/mundo/noticia/2015/02/laudo-de-medico-indonesio-pede-internacao-de-imediata-de-brasileiro.html>, accessed on 03/3/2015.

3 In addition to the processes of bioglegitimation and of bioglegitimacy analyzed by Didier Fassin (2005 and 2010), this political shift has been analyzed from different perspectives, some of which at times are discordant with each other: the psychiatrization of conflicts and of the experience of violence (Fassin and Rechman, 2011), the “biologization of poverty” (Teresa Gowan, 2012 and other authors), the medicalization of the homeless (idem), and even in broader approaches to contemporary policy, above all through the recent readings of the biopolitics of Foucault in authors such as Agamben (2002) and Roberto Esposito (2006), among others. Paul Rabinow and Nicolas Rose have sought to understand the transformation in biopower through the new biotechnologies, pointing to what would be the “individualization of biopolitical strategies.” (Rose & Rabinow

of this shift is the extension of the domains of the pathological to the field of social policies and recognition, through which the legitimacy of the needs and demands of groups, populations, communities or social subjects passes through the filter of recognition of a disturbance, dysfunction, disease or of some type of biological specificity or difference. In this process, biolegitimacy and the “right to life” become the determining factors for the recognition of the demands for rights that sustain these social policies. This dynamics has diverse and complex consequences, even in relation to the analytical tools, including the question of how much this process would represent a new biopolitical regime.

In his reflection about the concept of biolegitimacy and the imperative of the right to life in contemporary policies, Didier Fassin considers that life itself was an aspect not developed by Michel Foucault in his discussion about biopolitics.⁴ Life and the politics of life are one of the focuses of the contemporary revival of Foucault and of authors such as Georges Canguillem, Walter Benjamin and Hannah Arendt, through concepts such as “life itself”, “mere life”, “good life”, “life in it self”, “bare life”, *bios* and *zoe*, “precarious life” (Canguillem 1966; Fassin 2006; Rose 2013; Agamben 2002; Benjamin 2012; Arendt 1961; Esposito 2006; Butler 2006). My question in this article does not exactly involve a discussion about life, but about the concrete effects of these new biopolitical regimes and the forms of subjectivation engendered by contemporary biopolitics. My argument is that biolegitimacy as a tool that informs government practices, public policies and even social demands, can be considered as an effect of these new biopolitics.

Since his first statements about the concept, made at a lecture in Brazil about “The Birth of Social Medicine” in 1974 (later published in *Microfísica do*

2006: 38) Nicolas Rose conducts a criticism of what he calls the “pessimism” of critical sociology, considers the concepts of medicalization and biologization outdated and insufficient to explain certain contemporary phenomenon and takes another perspective (Rose 2007 and 2013). Rose is quite optimistic in relation to new biomedical technologies and also in relation to new psychopharmaceuticals as modes for establishing a “biological citizenship,” in dialog with Paul Rabinow’s concept of biosociability. He understands that we are now experiencing a new “somatic ethic” and the possibility for a “politics of life itself” (Rose 2013: 67). Despite considering his reservations pertinent, I think that in some moments the author adheres a bit easily and acritically to a perspective dictated by the biotechnologies and I have the impression that what he defines as politics of life itself is a perspective that winds up weakening his dimensions. In this sense I consider the concept of biolegitimacy more suitable to consider these new forms of citizenship and access to rights, reviving the critical and political dimensions presupposed by this concept.

4 “Ni la anatomo-política, que concierne a la disciplina del cuerpo, ni la biopolítica, que despliega la regulación de las poblaciones, abordan de manera central la cuestión de la vida” (Fassin 2010: 200). See also Fassin 2006.

poder) and in *The Will to Knowledge*, of 1976, Foucault developed the concept of biopolitics through his courses and published works, not only in a cumulative manner but also by transforming the concept and expanding it far beyond the field of social medicine, to reach the politics of population and finally to neoliberalism.

Foucault describes the emergence of biopower in contrast with sovereign power, exercised with a basis on the right to life and death of the sovereign over his subjects.⁵ This transition is described, not based on changes in political theory but on changes “at the level of the mechanisms, techniques, and technologies of power” (Foucault 2005: 288). In his book about the birth of the prison, *Discipline and Punish*, he emphasizes the emergence of a dimension of biopower, disciplinary power, or anatomo-politics, aimed at bodies and individuals. The other dimension of biopower would be developed in his later work, mainly in the triptych formed by three of his courses at the Collège de France, *Security, Territory and population*, *Society Must be Defended* and *The Birth of Biopolitics*, about the concept of biopolitics as politics aimed at the population and of population as a political problem.

A proviso is important in relation to these two modes of biopower: for Foucault, one does not substitute the other, they are juxtaposed, articulated with each other:

We thus have two series: a series body-organism-discipline-institutions; and the series population-processes biological-mechanisms regulators-state. An organic institutional set: the organo-discipline of the institution (...) and on the other hand, a biological and state set: the bio-regulation by the state (Foucault 1999:298.)⁶

One example is the issue of sexuality, which would be at the crossroads of the body and the population, and would depend both on discipline and on regulation. (Foucault 2005: 300-301). Another example of this articulation, according to Foucault, is medicine, “a knowledge-power that incides simultaneously on the body and on the population, on organisms and biological

5 One of his syntheses of this transition practically becomes a formula to distinguish the sovereign power of biopower: “The right to sovereignty is, therefore, that of the right to kill or to let live. And thus, this new right is that which is established: the right to make live and to let die.” (Foucault 1999: 287).

6 Foucault also discusses another juxtaposition, that between forms of biopower and sovereign power, from the right to death – mainly when he speaks of racism of the state and of Nazism.

processes, and which, therefore, has disciplinary and regulatory effects (idem: 302). It is not by chance that medicine and medical policies, and those of hygiene, wind up earning a detailed description in Foucault's works. It is at the heart of biopolitics, at the same time as which it constitutes one of the biopolitics (Farhi Neto 2010). Thus, questions such as public hygiene and the medicalization of the population, births and deaths, problems of reproduction, everything that refers to life, to the body, the population, from the organic to the biological, such as aging, to diseases and anomalies, that which removes individuals from the production line, but also the problems of the relationship of humans with their means of existence, from the swamps and the epidemics related to them (in the nineteenth century) to the problems of city, all this is the object of biopolitics. A form of government of bodies, individuals and populations.

In the 1979 course, *The Birth of Biopolitics*, in which he explored the various liberalism and in particular neoliberalism, Foucault developed another dimension of biopolitics, which is of interest to my discussion about bioglegitimacy, which is the formation of human capital as an expression of a regime of subjectivation based on the form of the enterprise, of the subject as an entrepreneur of him or herself. The production of subjectivities thus becomes the central aspect of neoliberalism.

I will dialog with two readings from this course and discuss its importance for the formulation of one of the dimensions of the concept of biopolitics as a dynamics of globalized capitalist politics, or, in the interpretation of Leon Farhi Neto, who wrote about Foucault's biopolitics (in the plural), of neoliberalism as a biopolitics, or as the very form of contemporary biopolitics. Farhi Neto classifies five variations of Foucault's biopolitics: the biopolitics of medicine, war, sexuality, the security pact and finally, biopolitics in relation to economic rationality.

For Fahri Neto, who attempts to conduct a conservative or restricted reading of the concept of biopolitics, the approach to liberalism and neoliberalism undertaken by Foucault in *The Birth of BioPolitics* refers to a contemporary mode of governmentality through the economy, in which the population is governed indirectly, with the strong presence of economic forces, the market and the privatization of social policy. Biopolitics would be pertinent here to describe the neoliberal techniques of government (Farhi Neto 2010).

Frederic Gros also seeks to go beyond the readings that see in this course

of Foucault, despite its title, an absence or even an abandonment of biopolitics. He seeks to establish a continuous line between Foucault's previous reflections on the two forms of biopower: the anatomical politics of bodies and individuals (represented above all in his analysis of prison) and the biopolitics of populations. Gros proposes a new definition of biopolitics:

... biopolitics is a set of requests through which the individual, in the plane of his vital potential, is submitted to certain directions in order to intensify the production of wealth and the power of the dominant classes.” (Gros 2013:38)

Disciplinary power, for example, would be a form of chronopolitics needed by capitalism: “to transform the time of life into useful and productive time” (Gros 2013:35). In the second major form of biopower, according to Gros, the governmentality of the population takes place through the public policies conducted by the state (2013:35). Now it is the “biological dispositions” of the human species that are the object of state action (idem: *ibidem*). The “biopolitical operation” would consist of depoliticizing the subject, who is presented as an economic subject in different modes: as a consumer subject, as human capital and as an entrepreneur of oneself, and finally in what would be a fourth step of capitalism not explored by Foucault - because it is more recent - that of financial capitalism. In this step, the subject, similar to capital itself, would be a set of flows more than a stable identity. It is in this dimension that Gros needs to improve his definition of biopower (and of biopolitics):

Biopolitics would thus be a strategy that seeks to transform certain vital tendencies or fundamental biological traits of individuals or of the human species, with the goal of serving to reinforce the economic-political forces. In fact, we find for each form of capitalism this scheme of transformation. (idem: 41)

And later, “Financial capitalism invites us to establish ourselves as a pure point of exchange of flows of images, of information of goods, etc. [...] a vectorialization of vital trends considering the increase of economic-political forces” (idem).

Gros also mentions Foucault's refusal to counter this process of domination, exploitation and captivation with “basic human rights,” based on a “metaphysical logic, whether enrooted in an eternal nature, or guaranteed

by a divine transcendence” (p. 41). To think, as does Foucault, that power is a relationship, is to also think that “to be caught in a biopolitical process gives us rights, including the right to not accept everything or to refuse this or that.” This is the “right of the governed,” the “resistance biopolitics,” “affirming the will to exist in another manner.” (p. 42). In Gros’ reading, it is liberalism itself that provides this opportunity for resistance, not an economic or political liberalism but something that he calls critical liberalism, that which “feeds the biopolitical resistances.” (idem). I will not discuss here the author’s questioning of Foucault’s more or less critical characterization of liberalism. I am interested in focusing on the discussion made by Foucault of human capital and how contemporary biopolitics, which go far beyond the state (in the *Birth of Biopolitics* Foucault describes a retraction of the state, in which the *laissez faire* of classic liberalism becomes a “do not let the state do,” in neoliberalism (idem: 339)), would approximate the human subject to forms of capital, whether as an entrepreneur of the self, or as space or point of flows.

In his discussion of neoliberalism Foucault shifts in a certain form the biopolitical process of the state and of the public policies to the market and economic relations. At the same time, we can consider that public policies themselves and government techniques wind up incorporating these new dispositions of capital. The focus of this new configuration of contemporary capitalism is the production of subjects and subjectivities. These three dimensions: shifts of biopolitical processes to the market and the economy, incorporation by the state of the new dispositions of capital, even in its social policies, and the production of new subjectivities, are present in the context and in the field of mental health.

The ambivalences of the state in mental health and women’s healthcare: the cycle of life and the medicalization of women

The questions raised above about the new contemporary biopolitical dynamics, which include indirect forms of governmentality and its shift to the market and to economic relations, have implications for an approach to public policies and the state itself. If on one hand we have public policies particular to the welfare state, which seek to integrate historic demands and agendas of the social movements, and which define procedures and modes

of operation of the state, on the other there are dimensions that run through these policies that are related to scientific and technological productions, and to interests and pressures from economic sectors (for example the pharmaceutical industry) and with values and moralities that circulate in these various spheres.

A first movement in this reflection is the analysis of the practices and actions of the state and its constitutive ambivalence in relation to social subjects, between care and control, dependence and autonomy, the processes of institutionalization and deinstitutionalization, and of the subjection and subjectivation of people who use services and are the target of public policies produced by and in the context of state actions.

An anthropology of the state, or more specifically of public policies, begins from the questioning of its existence as an organic entity, a substantive given being,⁷ seeking to understand it as practices, actions and discourses that involve a heterogeneous and contradictory set of actors or social agents, with different moral and subjective dispositions.⁸ Beyond laws, texts and documents, the state is also what is produced in the plane of what its agents do, who instead of being only executors of public policies are also those who, in their daily practices, also make public policy.

The ethnographic approach can offer an interesting perspective for an understanding of contemporary political and subjective processes by using a line that articulates the realization of public policies, the concrete action of the state, on one hand, and the experiences and agencying of the target subjects and users of these policies on the other.

This dynamic is quite visible if we take as an example mental health policies in Brazil and the expansion of psychiatrization of basic healthcare policies. The Brazilian psychiatric reform project⁹ calls for the progressive substitution of psychiatric hospitals for a psycho-social network of services, including reception and care for patients and users. Based on a broad “deinstitutionalization” program for patients, it sought to break with the asylum model, above all through the Ministry of Health’s Return Home Program,

7 This questioning was already found in Radcliffe-Brown (1940); and more recently in Abrams (1988); Trouillot (2001), and others.

8 Abellès (1992), Worsley (1994), Abrams (1988), Bevilacqua and Leirner (2000), Trouillot (2001) and Lima (2002), among others.

9 Lei 10.216, de 16 de abril de 2001.

which calls for the social reintegration of interned psychiatric patients. These government programs also propose the creation of a broad and disseminated public network of in- and outpatient care, both at basic health clinics, and in the creation of other spaces such as the Psycho-social Care Centers (CAPS), which are more specialized spaces aimed at cases considered by professionals to be of so-called “greater/higher complexity” or for some specific disturbances, such as alcohol or drug addiction (the CAPS-ad), or for specific publics, such as the CAPSi, for children and adolescents, among other measures such as therapeutic residential services. But as various authors have highlighted, the reform process is heterogeneous, unequal and contradictory, while it simultaneously falls short – yet at times goes beyond – that which is established in official documents.¹⁰ In addition to the measures established in the Psychiatric Reform, the mental health field includes instruments such as private clinics, at times informal shelters for the mentally ill and elderly, therapeutic communities and assistance centers linked to religions, associations of users of mental health facilities, various groups of alternative or dissident practices (such as schizo-analysis projects) and other forms of patient care, and which must coexist with the permanence of various psychiatric hospitals (which continue to exist despite the Law).

In addition, the more general context of implementation of these policies raises a series of factors that are determinant in the application of national policies, such as the growth and expansion of the domains of action of biomedicine and of its various measures, including new diagnostic procedures and the priority given to pharmaceuticals in the therapeutic processes (but not only this, consider for example the return to the use of electroshock therapy in recent years in Brazil). A broad range of experiences, which include suffering and affliction, the constitution of the Person and the production and reproduction of life, the guarantee of rights and the exercise of citizenship, shift to the field of health and biomedicine. Questions such as the medicalization of subjectivity, the pathologization of suffering, the therapeutization of individual choices and the biolegitimacy of the demands

10 Or even rhizomatic, according to the discussion of Fonseca et alii (2007). About Psychiatric Reform, Brazilian Psychiatric Reform and the process of deinstitutionalization of mental health see Amarante, Paulo (1994, 1996 and 2000); Desviat, Manuel (1999); Fonseca, Tânia Galli; Engelman, Selda & Perrone, Cláudia Maria (2007) and the recent thesis of Ana Paula Müller de Andrade (2012) among others. For a reflection about psychiatry and psychiatric hospitals in Brazil see Machado et. al. (1978), Costa (1989), Venâncio (2011); Venâncio and Cassília (2005 and 2011), Cardoso (1999 and 2002), Teixeira (1990), among others.

of specific sectors are treated by the most recent anthropological literature as signs of an expansion of the domains of action of biomedicine and of the extension of the field of the pathological to within what traditionally would be domains of the “normal.”

Thus, some aspects of the contemporary constitution of the field of “mental health” in Brazil accompany the Psychiatric Reform process.¹¹ In the first place, in the shift from an exclusively psychiatric and asylum focused model of care to an outpatient model, not only does psychiatry come to be exercised in the spaces of public healthcare, but issues related to “mental health” care and to medicamentous therapies in this field come to be largely exercised by other medical specialties. Secondly, and this is also not a phenomenon specific to Brazil, since the late 1970s, there has been a process of remedicalization or biologization of psychiatry and mental health,¹² consolidated above all with the publication of the Diagnostic and Statistical Manual of Mental Disorders (DSM III) of the American Psychiatric Association.¹³ Thirdly, the growth in the use of psychopharmaceuticals and psychotropics of all kinds in Brazil, mainly anti-depressants, particularly among women, and not only traditional consumers in the middle and upper classes, but now increasingly among lower income, rural and indigenous women.¹⁴

In a certain way, these different aspects are forms of growing biomedical rationalization not only of subjective life, from the perspective of the subject, but also of the rationalization of the social policies and ways of acting of the state.

11 According to Maluf (2010). One of the issues that I have discussed in these works is the problematization of the concept of “mental health” and its analytical and descriptive limits.

12 To speak of remedicalization of psychiatry does not mean that the psychiatries exercised previously were outside the medical field or did not have a bio-physical-organic orientation. The concept of medicalization used is related to a dual trend: on one hand, the reduction of the phenomenon of suffering and affliction to imbalances and disturbances of an organic or physical-chemical nature, on the other, an extension of the scope of medical action and intervention.

13 This process is deepened in DSM-IV and in the recent DSM-V, with a growing hyperspecialization of diagnosis and treatment.

14 This expansion is recognized in the documents of the Ministry of Health, such as the Relatório de Gestão 2007-2010, *Saúde Mental no SUS As novas fronteiras da Reforma Psiquiátrica* [Administrative Report, 2007-2010, Mental Health in the Single Healthcare System The new frontiers of Psychiatric Reform], which recognizes the increased consumption of benzodiazepines, anorexics, amphetamines and antidepressants among women, and as a result of a meeting held in 2008 with technicians, professionals and researchers in the field, in a partnership between the Ministry of Health and the Special Secretariat of Policies for Women, the recognition of a “growing trend of public healthcare and mental health services to emphasize medicalizing responses, in response to diffuse complaints of psychic suffering of women” (Brasil 2011: 76)

If on one hand these mental health policies and the very meanings of Psychiatric Reform in Brazil are those of universalization and democratization of access to healthcare, as well as the respect for the human rights of patients and users of the healthcare system, on the other we can perceive biopolitical and control measures in the resulting policies and practices.

I will more specifically address one of the dimensions of this process, which is the way that gender issues appear in some public documents about mental health and women's health and the discourses and practices specifically aimed at women and at what would be, according to these discourses, the specificity of their greater vulnerability to disturbances and problems of a psychosocial order. The focus is the notion of the "life-cycle" of women, a principle widely used in the documents and guidelines mainly in those specifically aimed at women's health, even when not explicitly. The "life-cycle" of women is understood here as the various phases related to their reproductive career: menarche, pregnancy and childbirth, post-partum and menopause. My investigation is not exhaustive and the examples raised from the public documents do not represent the force of this concept and its disseminated use beyond these documents, by professionals in the field, academics and researchers and even by social groups and movements. The broad use of this concept in the psychiatric literature aimed at women shows its scientific validation and the strength as a truth that it acquires when expressed in healthcare policies.¹⁵ By the social modes and territories in which it circulates, life-cycle winds up constituting a discourse, which is produced and distributed in various spaces based on different actors, constituting in this circulation a regime of truth about women's suffering, demands and rights.

It is important to emphasize that I do not consider that all mental health policies in relation to women are reduced to the notion of life-cycle. As I will describe below, the concept of life-cycle informs the ways that women appear in a number of these documents, along with other insertions, more closely linked to social, political or economic dimensions.

¹⁵ In a quick search on the site of the American Psychiatry Association (APA) and on sites of U.S mental health care centers, I found various ways that the life-cycle of women appears as the central element for defining probabilities, diagnoses and treatment. In the APA publications about women and mental health, I found various references to greater vulnerability of women to psychiatric disturbances and to the importance of the moment in a woman's life-cycle as the cause or context of psychiatric disturbances. Some books specifically address each phase of the life-cycle, with an emphasis on menopause and post-partum.

In the case of mental health policies, the concept of biological phases of life and of “higher risk groups” appears in the National Mental Health Guidelines of 1977, presented at Brazil’s VI National Healthcare Conference, defining, among other things, the need for primary prevention actions “aimed at high-risk groups: pregnant women, mothers, adolescents and the elderly, to reduce, in this population [...] the rise of alterations and the promotion [sic] of satisfactory levels of mental health” (*apud* Cardoso 1999:36). In this formulation, life-cycle appears both in relation to the phases of women’s reproductive career (pregnant woman, mother) and in relation to the age determination of risk (adolescents, the elderly). This logic reappears in other later documents, even if formulated in other ways.

In the first three National Mental Health Care Conferences (1987, 1992, 2001), women appear little. In the case of the I and II conferences, they are not mentioned and in the report of the III Conference they are mentioned alongside children, adolescents, the elderly, indigenous, the street population, the third age and “alcohol and drugs” (*sic*), still using the age or risk group logic (BRASIL, 2001). It is at the IV Conference, in 2010, that a significant change in this perspective appears, the need for a specific policy aimed at women is more explicit, together with the need for a gender policy.¹⁶ It is interesting that, in the report of this last conference, women move from being presented as a vulnerable group, particularly among certain age ranges (children and the elderly) to being presented as a specific identity (gender and race/ethnicity). In addition, the post-partum situation is defined with a basis on the father-mother-child triad, no longer only from that of women in post-partum.¹⁷ Here the influence is perceived from feminist debates and from other social movements, like the movement for racial equality, in a context where the Brazilian state is highly porous to these movements, many of whose leaders have entered the government.

Nevertheless, the same degree of politicization is not found in other documents, mainly in those that seek to detail the general policies, or establish

16 “634. To implement healthcare strategies, from the focus of gender, for the mental health of women to: 1) improve the information about women with psychic suffering in SUS; 2) qualify the attention to women’s mental health; 3) include the focus of gender and race (Brasil 2010:108-109)

17 “567. Establish, in maternity and infant hospitals, specialized teams or support nuclei in mental health to accompany the triad father-mother-baby (*sic*) during the gestation period, childbirth and the post-partum period” (*idem*: 97)

programs or action protocols. In the same way, this perspective is little reflected in the realm of the practices of the technicians, professionals and public employees who work at the point of the public policy, or that is in direct relation with users of the healthcare system.

In the specific case of healthcare policies aimed at women, the near totality of these policies (expressed, for example in the Women's Integral Health Care Program – PAISM, prepared in 1984, and which was reproduced in later programs) is occupied with the issues of reproductive health and prevention.¹⁸ This situation did not change substantially for nearly twenty years. In the PAISM of 2004, a section about gender and mental health was introduced, recognizing the need to consider cultural, social and economic factors of gender inequality in the mental health care policies (Brasil 2004). The I National Conference of Policies for Women, held in the same year, briefly suggested that mental health policy “contemplate actions of prevention, treatment and social inclusion, with a gender perspective and with the preparation of healthcare professionals to address women’s social, ethnic, cultural and biological specificities” (Brasil 2004b). The II National Plan of Policies for Women, approved at the II Conference, called for, among the priorities in relation to the item “Women’s health, sexual rights and reproductive rights,” the implementation of a model for mental healthcare for women, from a gender perspective, considering ethnic-racial specificities” (Brasil 2007, P. 15). And among the goals for the period: “To implement five pilot-experiences, one per region, of a model for mental healthcare for women from a gender perspective” (Idem, p.16). In the same item about health in the document, the emphasis is on “reproductive rights” and the notion of the “vital cycle” of women, defined by various phases of their biological cycle, as “climateric” women, “youth and adolescents” (idem).

Post-partum depression has also appeared in a more detailed manner in the concerns of the Ministry of Health. It is mentioned in various documents produced by the Ministry. The Technical Manual about pre-natal and post-partum periods, of 2006, dedicates an entire item to “Emotional Aspects of Pregnancy and post-partum,” suggesting that they include “psychological

18 Finding reinforced in the Report for 1998-2002: strategic, programmatic and financial aspects. Brasília: Ministério da Saúde, 2003, prepared by Correa, S. O.; Piola, S. F. (*apud* Brasil 2004: 19).

processes that permeate the pregnancy-post-partum period, notably, in the case of pregnant adolescents who, because of the psycho-social specificities of the development phase, experience an emotional overload brought on by pregnancy.” (Brasil 2006, p.35).

That is, even with the incorporation of the debates from the feminist field about gender inequalities and their socio-economic reflections, the concept of “life-cycle” as a succession of phases in the biological life of women, linked mainly to their reproductive cycle, continues to be central in the definition of the specificities of women in the preparation of healthcare and mental health policies and in the recognition of their rights.

In addition to official mental health policy documents, in the local dimension of the application of the public policies, the specificities of each context reveal a quite heterogeneous situation in relation to the healthcare practices, which range from distribution of psychotropic medication to the implantation of other forms of treatment or support, such as therapeutic groups, groups of the elderly, groups of women in treatment for depression and other disturbances, ranging to classes for stretching and gymnastics, acupuncture, homeopathy, phytotherapy, art therapy and others. But, even recognizing that the practices are not homogeneous, the weight that the distribution of medications such as benzodiazepines and anti-depressants has today in public healthcare cannot be denied (not only in the CAPS, which are specialized in mental or psycho-social health, but also and particularly in the basic health clinics). We have many examples of field research conducted in previous research phases, related both to patients and to professionals who serve in these units, in addition to data related to the distribution and consumption of these medications, which reveal the fact that the overwhelming majority of consumers of these medications in the public healthcare system are women.¹⁹ These data indicate that although there is still not an explicit and consolidated policy of gender and mental health in the official programs, it is perceived that in the application of the healthcare policy, in the daily activity of the healthcare clinics and of the Psychosocial Care Centers, a policy of difference is present and evidence of a discourse of gender difference sustained in a physicalist and biologicalized vision of this difference.

¹⁹ See report cited above (Brasil 2011) and, in the case of the field research conducted, the article by Diehl, Mazzini & Becker, 2010 and various other chapters of Maluf and Tornquist, 2010.

If the official documents and texts incorporate a gender discourse that emphasizes socio-economic issues, reducing the strength of the life-cycle rhetoric, it is pertinent to question to what point this advance in the discourse is reflected in the effective mental health policies for women. To what point do the procedures at the front line of these policies, where professionals are in direct contact with users of the healthcare services (of the basic healthcare at CAPS) reflect this rhetoric? Another dimension enters here, in terms of the establishment of the diagnosis and the therapeutics used: the diagnosis is essentially based on biological cycles and the treatment continues to be overwhelmingly medicamentous.

In a previous study (Maluf 2010), based on government documents and together with healthcare agents and professionals, we raised some issues for a discussion about mental health policies, particularly concerning basic and public healthcare, which I reproduce here: 1) the need to conduct a critical review of some institutional practices that wind up reinforcing gender inequality; 2) the finding of a reality of hypermedicalization and pharmaceuticalization of population segments, with an emphasis on women, with the use of psychopharmaceuticals; 3) the confusion between democratization and universalization of access to healthcare and the widespread distribution of medications, which would imply rethinking basic care in mental health in relation to the need for a therapeutic (and psychotherapeutic) policy which is less based on a medicamentous model; 4) the need for a mental health policy that offers other treatments in addition to pharmaceuticalization, such as systematic therapeutic accompaniment, among others; 5) the need to reconsider the models of care, health, disease, suffering and cure in the official women's health and mental health policies; 6) the break with a model of women's health based on the biologicalist vision of the "life cycle" and on phases of the reproductive life of women as determinants of greater or lesser "vulnerability" of women to mental health problems (Maluf 2010: 35-36). To these aspects, I would also add a seventh, which is the recognition of other forms of knowledge and dealing with the affliction and suffering that go beyond the biomedical or psychological paradigm.

The analysis of public policies, not only in terms of what they call for but also in relation to their concretization by agents and professionals who act in the name of the state, gives visibility to dimensions that otherwise would not

be perceived, and allows a critical reflection on these policies, and an evaluation of their meanings, effectiveness and effects.

Social experiences, practices and agencyings²⁰

It is precisely based on the different discourses and social experiences that the physicalist and rationalizing models of the experience of affliction - in this case represented by the notion of life-cycle - are confronted in a more evident form. By social experiences I am designating the dimension of experience and production of knowledge and discourses by those men and women who are precisely the “target public” of the public policies and of the action of healthcare professionals and agents. This perspective is not in any way a reification of the dichotomy between “fact” and “value,” represented in anthropological studies of healthcare with a phenomenological approach to the experience of individual subjects, on one hand, and of the social representations of disease, the body and the person, on the other. Our theoretical and reflexive understanding about issues such as disease, affliction and suffering and of the strategies of action and meaning given by the different social actors are based on the idea that experience and its social meanings are two complementary dimensions in an anthropological approach to healthcare.

The study conducted with women residents of peripheral neighborhoods of Florianópolis, contrary to the hegemonic discourse both in government policies and in the platforms of social movements, indicate other issues related to social experiences seen as “disturbing,” which are usually articulated to their daily experiences and to their social, cultural and economic context and not to a perception of phases in their “life cycle” as we discussed above. What issues are these? In general they are issues related to their daily life, to their dual or triple work shifts - since many of them, if not most, work outside of the home, in informal jobs or as house maids; to moral abuse at work (many of them report that they have been diagnosed with panic syndrome triggered each time they get to their work place); to violence in their neighborhood, with situations of death of children and husbands, violent

20 Part of this item reproduces some paragraphs from the chapter published in the book, *Gênero, saúde e aflição: abordagens antropológicas*, in which the initial results of the study were published (Maluf 2010 and Maluf & Tornquist 2010)

incursions by the police in their neighborhoods and the presence of conflicts and abuses related to drug dealing. In the case of the neighborhood of the study conducted by the team of Carmen Susana Tornquist, Ana Paula Muller de Andrade and Marina Monteiro, an issue emerged in relation to how, in the narratives of the women in the neighborhood, the situation of suffering they experienced at the time was countered to a moment, to a time of struggle and of leadership, reviving the process of occupation of the neighborhood by families, most of them led by women and in which they had a fundamental role. (Tornquist, Andrade & Monteiro, 2010) Two dimensions are found in these narratives and in these other statements that emerge from the discourse of these women, the experience and the knowledge. The experience, as described quite briefly above, concerns other issues that are not related to their life cycles, their reproductive trajectories; the forms of knowledge are triggered to understand this experience, to inform them, impregnate them with meaning. Certainly, in the composition of these experiences and this knowledge, the physicalist rhetoric of the life-cycle is present, through the diagnoses that many of them or their children, mothers-in-law and mothers, receive, through the consumption of psychopharmaceuticals, etc.. Nevertheless, this is not the dominant rhetoric, or in other words, life-cycle does not explain and express the totality of their experience. Their suffering and afflictions do not find easy translation in medicamentous diagnoses and treatments.

Contrasting one discursive and symbolic universe to the other (that of the public policies and that of the social experiences) two models or two perspectives of understanding of affliction are revealed, one that is physicalist (or, as I wrote in another moment, *physio-logical*) which emphasizes a biological conception of gender difference and of the processes of suffering and illness, and a conception or model that can be called *socio-logical* of their disturbance, centered on their different daily experiences and of these women's life histories and narratives. In a certain way, we have here what Fassin calls a conflict of two ethical communities, as I previously described, and as in the examples mentioned by him, ethical communities with unequal legitimacies.

What I am calling a *socio-logic* of the narrative of the women studied is the dimension that encompasses social and historic dimensions of their experience. As I presented, they relate their feelings of affliction to the context

of their daily life in the neighborhood, economic problems, a double work shift, participation in neighborhood movements etc.. This is a *socio-logic* that does not fail to incorporate or encompass the physicalist dimension of the biomedical discourses and practices (accepting the diagnoses, conducting the “treatments” taking the medications), but which resignifies them based on the women’s daily experiences and shared values and eventually incorporating them or combining them to physical-moral concepts of suffering and disease.²¹ In summary: what I call here a socio-logic to speak about their afflictions, expands the perception and discourses about disease and suffering beyond the concepts of body, health and disease, incorporating the social and political dimensions of the lived experience. An understanding based on the circumstantiality and on the historicity of the experience, beyond and outside of the biomedical ontologization of the person.

It is important, however, to note that I am not adhering to a sociological reduction by identifying the social condition as a cause of their afflictions. By a *socio-logic* model or perspective I am exclusively referring to knowledges mentioned in the women’s statements and narratives and to the recognition of these knowledges as legitimate, and at times in contrast to the biomedical scientific knowledge. This recognition is not made by the state, and public healthcare policies. It is not only the experience of these women that is not recognized by public policies, but their epistemologies, that is their modes of knowledge, perception of experience and of the world.

One question that also permeates my argument is that of the status of science and of the so-called technological advances, mainly in the case of the example discussed here, that of mental health. In a previous article (Maluf 2011), I discussed the place given to medications, above all the anti-psychotics, as a possibility for deinstitutionalization of the patients interned in psychiatric hospitals. This is an argument that permeates a wide variety of segments involved in the mental health field: promoters and public administrators of de-institutionalization, public health professionals and agents, users, the pharmaceutical industry, researchers from various academic fields, associations of users and movements for the universalization of healthcare

21 It is also possible to see how much the rationalizing logic of the relationship between cause and effect found in the use of medication, for example, is present and disseminated by other practices, such as the search for spiritual relief or cure, often frustrated by the impossibility of immediate resolution or instantaneous relief from suffering, pain or affliction (which a medication can offer, at least temporarily).

access. By these arguments, we are in a moment of biological citizenship (Rose, 2013), established by bio-pharmaceutical-medical technologies.

Evidently, anthropologists and social scientists in general have supported the universalization of access to knowledge and to benefits brought by science and technology. Nevertheless, in the equation between universalization of access to these benefits (including biomedical diagnostic technologies, treatment, surgery and medicamentous practices) and the question of the meaning of these technologies and of this knowledge, it is necessary to admit that it is not possible to only critically address the issue of “sociological privilege” (Santos, 2004) (with proposals for access, democratization, universalization) without approaching the “epistemological privilege” (Idem) (the historic and contingent sense of scientific production, offering the recognition and legitimacy of other forms of knowledge and other epistemologies, etc.). One of the contributions that anthropological study can offer is to give visibility to and allow the emergence of experiences and knowledge that are invisible and not considered both in the conformation of scientific knowledge and in the development of national social policies but also on the global plane.²²

Modes of subjectivation, biopower, and other politics of life

The concept of life-cycle produces a statement that unfolds in three aspects. According to this notion and by the way that it is used in different discourses and care practices in the mental healthcare field: 1) generic complaints of the women reflect on psychic or mental suffering as a phenomenon of an organic and biological order; 2) the “female” specificity of this suffering would be directly and unavoidably linked to the women’s biological cycle (that is to their reproductive cycle, given that these different steps traced in their life cycle are the phases that constitute their reproductive career) – reproducing the modern movement of reduction of the other (women, as is done with blacks) to an essentialized biological body; 3) it is

22 This is not to neglect this other field of the human sciences (anthropology in particular) which develops around the investigation of science and of laboratories, not only around their social consequences, but also from the perspective of revealing their technical dimensions and methodological and cosmological aspects. To bring science to the field of social, symbolic, political and cultural investigation is the complementary counterpart of having emerge and giving visibility and recognition to knowledge and forms of knowledge denied in their specific rationalities.

this biologicalized dimension of suffering and affliction that legitimates a public “mental health” policy, configuring a form of “biolegitimation” and finally 4) it is through the biomedical technologies, and mainly through the use of psycho-pharmaceuticals that the public policy and the access to the right takes place.

As discussed in the beginning of this article, the gradual transformation of life into a problem of power mark the threshold that Foucault called “biological modernity,” with health gradually becoming a question of governmentality, or, for Agamben (2004), of the state (while, for the later, Nazism is the biopolitical state par excellence – where so-called “biological life” is politicized). Biopolitics is not only and not exactly a politics of life, but the placement of the governmentality of life at the center of politics. For Foucault, social medicine (and the politics of health, as well as medical knowledges and practices themselves) is one of the forms of the instruments of biopolitics, or government of life, considering biopolitics as the mode of constitution of subjectivity, as a regime of subjectivation. He writes in “The Birth of Social Medicine”:

For capitalist society, it was the biological, the somatic, the corporal, that mattered more than anything else. The body is a biopolitical reality. Medicine is a biopolitical strategy. (Foucault, 1979a [1974]:80)

In this text, central for the formulation of the concept of biopolitics, Foucault, reconstitutes the three steps of formation of social medicine: “state medicine, urban medicine and labor-force medicine.”(80). He identifies Germany as the place where state medicine arose in the early eighteenth century, developing a focused medical practice. According to Foucault, it is in “the improvement of the level of the population’s health,” and developing “effective programs for improving the population’s healthcare,” that they were denominated as state medical policy or “medical policing.” (since 1764, but enacted at the end of the eighteenth century and during the nineteenth century). According to Agamben (2004), it is when the distinction between *politics* (the struggle against enemies and preservation of the state and the nation) and of *police* (procedures for the improvement of the health and welfare of the population) evanesce, that, the “*police* now becomes *politics*, and the care of life coincides with the fight against the enemy” (idem:154). (It

was also at this moment that biopolitics became a “tanatopolítica” (idem), a politics of death. For Foucault, it is in France and England that developed, in the late eighteenth century and early nineteenth century respectively, what he calls the “second” and third “directions” of social medicine; the French no longer based on the state, as in Germany, but on urbanization and on urban policies, and the English, as “medicine of the poor.” We are speaking here of the birth of social medicine and of the policies of governmentality and of the state related to the population’s health, to which today we can join to the contemporary expression “public healthcare policies.”

Elements of these three moments and directions of the rise of social medicine are present in healthcare policies today, they are: 1) the regulation and legitimation of the action of professionals and agents and of medical and biomedical knowledge itself by the state (and we can consider a set of contemporary discussions that refer to this aspect); 2) the need to produce information and knowledge about the population that is the target of these policies (above all with quantitative, statistical and epidemiological studies of health – and this dimension includes mental health); and 3) the adoption of healthcare programs, for providing public services at different levels and complexities and intervention of the state in the health of the population through systematic actions (the healthcare policies, the therapeutic programs, etc.) or specific ones (such as vaccination campaigns, fighting epidemics, and others).

A fourth aspect refers to new biopolitical regimes discussed in the first part of this article and the moral power of the “right to life” in detriment for example of socio-economic rights. At the same time, it is these socio-economic conditions of neoliberal capitalism that define the dynamics of these new biopolitics and the way that the moral economy of the right to life can be realized. The very notion of technological innovation with which the psychopharmaceuticals are presented, even as the great “actors” of the possibility of the Psychiatric Reform (Maluf 2011), are linked to these new biopolitical measures. Foucault discusses the question of technical innovation and progress not based on its intrinsic development and its forms of productivity, but as a form of renovation that the neo-liberal economists call “human capital,” which is materialized in the extension, to the subject, of the enterprise-form and of the idea of the enterprise-subject as a new regime of subjectivation. Beyond public healthcare policies, the individualization of the biopolitical

strategies in the field of mental health, which are focused on the production of increasingly specific individual diagnoses (the logic of the DSM) and forms of medicamentous treatment aimed at the subject, appear to respond to this new regime of subjectivation and the construction of a certain type of subject and subjectivity.

I describe this dynamic based on the concept of biolegitimacy, formulated by Didier Fassin as that which defines the crucial contemporary question, no longer the power *over* life (biopolitics), but the power *of* life as such. For Fassin, biolegitimacy refers to a “shift of legitimacies in the politics of life”: the shift from a political life to a biological life (of *bios* to *zoé*).²³

In the case of healthcare policies, these shifts between *bios* and *zoé*, from the political to the “biological,” at the same time that they can appear more evident (after all, questions of health are more easily understood as related to biological life or life itself) are more difficult to understand as objects of a critical reflection, The quasi natural relationship between healthcare policy and the maintenance, care and prolonging of the body and physical life (of each citizen) appears unquestionable. The two fields of healthcare policy in which the reflections presented here are located, however, open spaces for a critical reflection - perhaps because of the quality of their objects; mental health on one hand, and women’s health on the other.

Specifically related to mental health, public policies today are, as described above, focused on the realization of the Psychiatric Reform Project, which is focused on the so-called “deinstitutionalization” of mental health services, and of the people interned in psychiatric hospitals with their gradual termination. To do so, it discusses the forms of constituting a “network of psycho-social care” which cares for the universe in question: from care for the “deinstitutionalized” subject to the user of the public system who has a form of suffering or affliction that is “treatable” (an increasingly broader concept) with bio-psycho-medical knowledge, mainly

23 The difference between the Greek terms for “life” found in Aristóteles, is revived and developed by Giorgio Agamben (2004), who, inspired by Hannah Arendt, defines this difference as follows: for the Greeks, there were two terms to express the notion of life: “*zoé*, which expressed the simple fact of living common to all living things (animals, men or gods) and *bios*, which indicates the form or way of life specific to an individual or a group,” or “qualified life.” It is certainly necessary to be careful with the reification of this dichotomy. Butler criticizes a certain naturalist illusion in the formulation of the idea of bare life (p.2). For Butler bare life as such does not exist, to the degree to which life has already entered the political field in an irreversible manner (Butler: 69). It appears to me that the essential question is the way that a new hegemony of the idea of “life itself” (*zoé*) appears to define the dynamics of various contemporary political processes.

with psychopharmaceuticals. Nevertheless, there is a generalized recognition of the difficulty of implementing in practice what is called for in the foundations of the Psychiatric Reform. In various situations, the operational logic of the various spaces of public services created to effectuate these psychosocial networks (particularly the Psychosocial Care Centers – CAPS, but also the basic care network of public health, the substitute services and others) maintain an institutionalizing, medicalizing and eventually asylum-oriented logic.²⁴ That is, it is not only the dynamics of care in the post Psychiatric Reform period that reproduces in some situations the logic of the psychiatric hospital and of psychiatric hegemony itself, focused today on physicalist and medicalizing concepts of psychological suffering, as this same logic now extends to a much broader population, formed above all and mostly by women who consult the basic healthcare centers and clinics seeking (bio) legitimacy for their ailments. In this framework and context, would another “politics of life” by the part of the state be possible, in its mental healthcare policy? How can the state construct “social networks” for taking in these subjects beyond their medicalization and insertion in a regime of normalization? This appears to be one of the challenges facing Brazilian Psychiatric Reform today, concerning the realization of a certain set of ideals present in its fundamental principles (the definition of which obviously involved disputes and conflicts among the different social, political, ideological and corporate forces that participated in the development of this policy).

In relation to the politics of “women’s health,” which range from reproductive rights in their broad sense, passing through prevention of various types of afflictions, to breast and uterine cancer more specifically and reaching women’s “mental health” policies, the physicalist reduction of women to a biological body is returned to, which in turn is reduced to its reproductive cycle, its “life cycle,” to which I referred. In this case healthcare policies function as a “technology of gender” (Lauretis 1987), which refers to specific modes with which biopolitics and the technologies of the subject are shaped in the reproduction of gender differences and hierarchies. Considering the social dimension of the lived experience reported by the women with whom the study was conducted, how would it be possible to have this dimension be

24 See the doctoral study by Ana Paula Müller de Andrade, *Interdisciplinar em Ciências Humanas/UFSC [Interdisciplinary Human Sciences program]*(Andrade 2012).

incorporated to healthcare policy? Would it be possible to think of a women's healthcare policy that sought not the reproduction of difference but its deconstruction? How can another configuration of the biological and of the political be conceived today in women's healthcare policy – which shifts from the “living” to the “lived”, from the life-cycle to the “course of life,” from the biological to the biographical? How is it possible to construct forms of legitimation of another public policy, in a context in which, as I raised, it is precisely the biologized dimension of suffering and affliction that legitimate a public policy in “women's health” or in “mental health.”

But beyond this, it is necessary to discuss how the very procedures and methods used to elaborate and enact these policies wind up hiding, making invisible and preventing these other epistemologies, modes of understanding and even styles of thinking (Rose 2013:26) from being heard.

Anthropological research and qualitative and ethnographic research have demonstrated that other politics of life are being exercised by real subjects in their daily lives and experiences. It should be asked how much the recognition of these politics, knowledge and practices can contribute to rethinking the dynamics of the operation of the institutions and instruments of the state in the field of public policies, recognition and rights.

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The construction of citizenship and the field of indigenous health:

A critical analysis of the relationship between bio-power and bio-identity

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Resumo

O presente artigo discute dois contextos de pesquisa etnográfica em saúde indígena, através dos quais buscamos refletir sobre o tipo de cidadania que está sendo fabricada na interlocução entre políticas de governo e participação política indígena nas ações, normas e discursos da saúde. Tratando-se de mundos sociais em que práticas de governo incidem sobre corpos individuais e populações, nos perguntamos se é possível falar de uma bioidentidade emergente na saúde pública para os povos indígenas no Brasil. Nossos objetivos estiveram pautados, portanto, em dois momentos: (i) refletir sobre os efeitos das políticas de governo para a saúde indígena no campo rico e complexo das conexões entre a biologia e a política; e (ii) ponderar sobre o potencial compreensivo daquelas categorias para as identidades políticas em jogo neste campo.

Palavras-chave: saúde indígena/etnografia/cidadania/biopoder/bioidentidade

Abstract

This article discusses two contexts of ethnographic research in indigenous health, through which we reflect on the kind of citizenship produced in the political dialogue between the government and indigenous political

participation, considering their actions, norms and discourses about health. In the case of social contexts in which governance practices focus on individual bodies and populations, we ask if it is possible to speak of an emerging bio-identity for indigenous peoples in the Brazilian Healthcare System. We have organized our discussion in two stages: (i) reflect on the effects of government policies on indigenous health, regarding the rich and complex field of connections between biology and politics; and (ii) reflect on the potential of these categories to understand political identity in the field of health.

Keywords: indigenous health/ethnography/citizenship/bio-power/bio-identity

The construction of citizenship and the field of indigenous health:

A critical analysis of the relationship between bio-power and bio-identity

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Introduction

A question inspires and shapes this paper: what kind of citizenship is being constructed in the meeting ground of government policies and indigenous political participation in actions, norms, and discourses on health? As we are dealing with social worlds in which government practices affect individual bodies and populations, we ask whether it is possible to speak of an emergent bio-identity in public health for indigenous peoples in Brazil. When we specify our theoretical and ethnographic position in this debate, we must inquire how mutually close or distant are the concepts of “bio-sociality” (Rabinow 1999), “biological citizenship” (Petryna 2002), “sanitary citizenship” (Briggs & Martini-Briggs 2003), and, in a more diffused way, “bio-citizenship” (Filipe 2010), and “bio-legitimacy” (Fassin 2012a). After all, these are constructed categories, as they always are in the human sciences in specific empirical contexts, but, some more than others, have overflowed to very different ethnographic universes. Hence, we have a double purpose: (i) to reflect upon the effect of government policies on indigenous health in the rich and complex field of the connections between biology and politics; and (ii) to think about the power of those categories over our understanding the political identities at stake in this field.

With this in mind, we present two ethnographic anchors that support our analysis. Each will focus on both government discursive practices and indigenous rhetoric in action, observing their specificities. Lastly, we shall return to

the issue of the place of “life in itself” in the construction of indigenous political identities through the understanding of mediators and mediations of the technologies that take the body as a government object and instrument in the context of the broader political involvement of indigenous peoples.

First ethnographic anchor: indigenous participation in national “social control.”

The current indigenous health policy follows the legal landmark of the 1988 Constitution in which health becomes a State duty and a right of all Brazilians. It contemplates not only the improvement of health conditions, but also the democratic management of policies and health services in what became known as “social control” in government parlance, that is, social control exercised by organized society over the State. The articulation of the indigenous movement with the movement for health reform appeared in the initial phases of definition of the new health system, the Unified Health System (*Sistema Único de Saúde - SUS*), which was implemented with the return of democracy in Brazil.¹ This articulation guaranteed that a specific committee for indigenous health – Intersector Committee for Indigenous Health (*Comissão Intersetorial de Saúde Indígena - CISI*) – created in 1991, organized the first set of committees to advise the Council of National Health, the highest body of social control. At that moment, these committees assured the creation of a forum for institutional participation mostly composed of indigenous political leaders who, in 2006, were to gain two chairs at the Council of National Health, as well as CISI’s coordination.

In terms of organization of the health service, in the late 1990s, the institution acquired a sub-system for indigenous health. It permitted the decentralization of basic health services through the creation of the Special Indigenous Health Districts (*Distritos Sanitários Especiais Indígenas - DSEI*). These districts were directly under the Federal Government rather than municipalities, which the Indian movement regards as predominantly hostile to indigenous interests. Furthermore, the sub-system contemplated the opportunity for formal indigenous participation both at village and DSEI

¹ We should point out that in 1986, during the eighth National Health Conference, which defined the bearings of what was to be the Unitary Health System, the First National Conference on the Protection of Indigenous Health took place. It proposed the creation of a System of Indigenous Health Care.

levels. These spaces would be, respectively, local consulting councils and district deliberating councils.

Thus, indigenous leaders organized around regional and national political articulations and legally conceived spaces of participation within the State (“social control”), and, with the agreement of traditional leaders, were successful in stating the proposal to construct a sub-system with special attention to the Indians. That meant a service and a participatory organization, which contemplated these peoples’ specificities, according to the principles of universality, integrality, and decentralization that guided the creation of the SUS system.²

Given this scenario, we have elected social control – the process of legal participation – carried out at the government federal level as an analytical referent, due to its relevance vis-à-vis the indigenous movements, and its spinoffs regarding the central issue of this article. As an ethnographic framework, we focus on the participation of indigenous leaders in the process of change within the government body responsible for policy management and the health services to the Indians. This process culminated in 2010 with the creation of the Special Secretary of Indigenous Health (*Secretaria Especial de Saúde Indígena - Sesai*), after a strong resistance by the National Health Foundation (*Fundação Nacional de Saúde - Funasa*), previously responsible for the “mission” of managing indigenous health policies.³

Throughout 2009, we observed a number of public strategies on the part of Funasa to affirm itself politically, in order to retain responsibility over indigenous health. Among these, we stress the workshop organized in Brasília about a consortium⁴ contracted with funds from the World Bank to

2 The information contained in these brief paragraphs contextualizing the recent history of indigenous health and indigenous social control comes from Teixeira, Simas and Costa 2013. For more details, see the dossier on indigenous health published in *Tempus. Actas de Saúde Coletiva* 2013,7(4).

3 This research on indigenous health social control began when Carla Teixeira was a representative of the Brazilian Anthropological Association at CISI from 2006 to 2010. Since then, she has been a permanently invited expert to the committee. Part of her observations and documental surveys occurred in the context of the project of scientific initiation submitted to ProIC/CNPq/UnB in 2012-2013, carried out by Diego da Hora Simas, Nilton Miguel Aguilár de Costa, Sara Godoy Brito, and Marcos Júnior dos Santos Alvarenga.

4 Comprising Health without Limits, the Brazilian Center for Analysis and Planning (Cebrap), and the Institute of Development Studies (IDS) of the University of Sussex, England, the consortium was contracted in the context of Project Vigisus II, the result of an agreement between Funasa and the World Bank. It lasted five years, ending in late 2009. Project Vigisus II/Funasa is one of two components of the second phase of a Loaning Agreement (APL) between the Brazilian government and the World Bank for the strengthening of systems of health surveillance and disease control in the country.

present, for the first time, a proposal of goals and models for care, organization, management, financing, monitoring, and evaluation of the Indigenous Health Sub-system. In the first “technical” reports by consultants, the subsequent debates were moderate, according to the managing tenor of the event, but at the end of the first day, the Indians imposed a politicized agenda. While the consultants described their proposals with apparent indifference as to which government institution was leading the management of indigenous health (“Organization Responsible for Indigenous Health”), the Indians introduced to the debate the relevance of this definition and the health crisis in the villages. They did it competently and effectively, for these issues underscored the meetings that followed.

In focusing on this episode, we intend to systematize our thoughts about the rhetorical competence of the Indians in the processes of decision-making regarding indigenous health.⁵ We shall first focus on the arguments of a Shavante leader during the above-mentioned meeting sponsored by Funasa (we will spell out this choice below). Then we shall analyze the internal logic of his arguments, with the purpose of highlighting the discussion about indigenous citizenship as it is woven into the management of indigenous health policies, which concludes this section.

The national workshop: turning the tables

The “National Workshop” to discuss the reports of the above-mentioned consortium based on situation diagnoses of the various components established by Funasa (care, organization, management, financing and monitoring, and evaluation of the Indigenous Health Sub-system) took place in Brasilia on May 20-21, 2009.⁶ Among those present were the presidents of the Indigenous Health District Councils, indigenous regional representatives, members of the Inter-sector Committee for Indigenous Health, Funasa technicians and managers and other government bodies in some

⁵ This paper is part of a research that began in 2008 in the context of the Research Group on Political Anthropology of Health (sponsored by the National Council of Science and Technology (CNPq)). These efforts attempt to contribute to the understanding of processes of indigenous participation in areas known in the Ministry of Health as social control.

⁶ For those interested in the report presented at the workshop, see http://bvsmis.saude.gov.br/bvs/publicacoes/modelo_gestao_saude_indigena.pdf - assessed on January 5, 2015.

way connected to indigenous health, and a World Bank representative. The same proposal was presented at regional workshops, but it was the Brasilia national workshop that set the political tenor. It became stronger along the process that led to the creation of the Special Secretary of Indigenous Health in 2010.⁷

The program proposed for the first day the presentation of five reports and, for the second, a discussion among the participants about changes to the proposals presented. However, the organizers could not stick to that agenda, as the Indians present did not limit themselves simply to ask for clarifications about the first day, as scheduled.

A Shavante leader's intervention was the turning point. He spoke a few minutes after Dr. Antonio Alves, the current Secretary of Sesai,⁸ had made some remarks about the relevance of funding human resources (training, contracting, and paying) and indigenous sanitation (for its direct effects on health). Immediately afterward, we heard the explanation by the consultant in charge of the "Financing Component." According to her, the exclusion of sanitation from the diagnosis reference term was due to an incompatibility of logic and rationality between sanitation and health procedures. In her words, "we don't feel comfortable to incorporate and force [sanitation] into this model." Her interlocutor did not contradict her, and that phase of the workshop was apparently coming to a smooth end.

At that moment, when the activities of the first day were about to be concluded, the Shavante leader took on the issue of sanitation that had been previously broached by Dr. Antonio Alves, and made a long speech with much applause at the end. We have transcribed some excerpts of his speech, which, it is our hypothesis, expresses strategies that complement political action and key elements in the rhetoric of demands for indigenous health rights in Brazil:

7 Approved by the Senate on August 3, 2010 and published as a decree on October 19, 2010.

8 At the time of this workshop, Dr. Antonio Alves was the head of the Secretary for Strategic and Participative Management of the Health Ministry and coordinator of the Ministry's Work Group in charge of discussing the management of indigenous health. We can interpret his posing the issue of sanitation as a political act to provoke an explanation about the dispute around the destination of indigenous sanitation without directly confronting the Funasa managers present. Would it stay at Funasa, or follow indigenous health along the lines proposed by the Ministry's Work Group? We based our interpretation on the fact that sanitation was not part of the reference term presented to the consortium by Funasa, and, hence, this issue was not for the consultants, but for the Funasa managers to pose.

Your presentation was good, financing ... (...) basic sanitation is financing! Why didn't the consultants raise this? This is a disaster! A chaotic situation! I would like to put this on record. Dr. Wanderley of DESAI [Department of Indigenous Health] is here, but the director of DENSP [Department of Public Health Engineering] hasn't come ... I would like to put on record here that the whole Shavante Condisi [District Council for Indigenous Health] went to the Federal Public Ministry this past day, and in a few days we'll have a public hearing! About the entire situation that is under way. (...)

So, once more as a leader, a user, a village dweller, I'm leaving on Friday. I'm sorry, Wanderley [DESAI's director], but bring me one or four boxes! Of coffee filters, because where I live the children are filtering water! No one lives without water! Even the richest countries in the world are looking at Brazil's clean water. We need it, for God's sake! As a leader, I'm letting it off my chest ... (...) This is sad! Very sad! Even living beasts, reptiles, need water! To reproduce themselves! It's the same with human being, us ... (...) We want to strengthen the sub-systems, but we need a decent policy! Indians don't want to create a State against the country, no Sir! At least [we want] respect, dignity, to guarantee our rights. We want to survive! (...) We want to discuss sanitation.

The strategy to reinforce sanitation actions as relevant to the debate about the models of indigenous health management, started by Antonio Alves and advanced by the Shavante leader, at that moment, indirectly, brought forth the removal of indigenous health from Funasa. Why? Because for the majority of indigenous leaders, if health care were to move to a special secretary within the Ministry of Health, indigenous sanitation should also go, and Funasa betted on the possibility of keeping it. After all, the Department of Public Health Engineering (the absence of which the Shavante leader stressed in his speech) is responsible for all the sanitation actions at Funasa, and handles a good part of its budget. However, we must make clear that we do not mean with this comment to diminish the political dispute over financial interests.⁹ Rather, our remark points out the fact that indigenous sanitation, being separate from indigenous health in the institutional organization chart, its removal from Funasa sets in motion political forces that are not limited to managers and professionals involved in health services as such.

9 The budget for indigenous sanitation was not significant when compared to the other Funasa sanitation programs, that is, sanitation in municipalities with over ninety thousand inhabitants, which includes the majority of the approximately five thousand Brazilian municipalities.

These discussions unfolded on the second day of the workshop and, as we have said, resounded through the regional workshops that came later. The technical argument of the difference between the rationalities that guided health care actions and sanitation to justify the exclusion of the latter from the requested consultancy succumbed in the course of the political debate. The new secretary was created amidst the growing dissatisfaction with the services being offered, the accusations of political partisan use of Funasa's institutional apparatus, and mutual allegations between the Minister of Health and Funasa's president. In this context, the political participation of indigenous leaders was outstanding, as they took advantage of that broader conflict, guaranteed institutional change, and avoided the separation between health and sanitation services.

Indigenous rhetoric and the construction of citizenship

It was in this broad context that the Shavante's discourse politicized the event. But his arguments were radically different from the sanitation logic that underlined the speech of his antecessor. At no moment did the Shavante leader refer to the impact of sanitation measures on health, nor did he mention epidemiological data (although most indigenous leaders handle well the legislation and information on indigenous health). Instead, other elements appeared. Let us see.

After denouncing the chaotic state of sanitation on indigenous lands, the leader presented his viewpoint by affirming his triple authority to speak on this subject: "leader, user, and village dweller." He thus stated his position as a local leader (*cacique*), a representative of indigenous users of the formal structure of participation in the health system (as President of the District Council of Indigenous Health), and an Indian who knows the reality of his people (everyday experience of the village health conditions). He amplified the political scope of this statement when he later declared himself the spokesperson for all Indians, by declaring: "Indians don't want to create a State against the country, no Sir"! The generic Indian deployed here, besides the fact that it showed him to be in synchrony with the indigenous movement, not just with the Shavante people, rejected the rhetoric of certain national sectors (the military, big agribusiness producers, etc.) that generally

accuse the Indians of threatening national security. He thus succeeded in connecting not only local and national knowledge, but also life experience and political and institutional transit. Hence, he used his knowledge of formal mechanisms to call into question government officials in charge of indigenous health when he mentioned the juridical procedure at the Public Ministry and the expected public hearing. This demonstration of knowledge acquired a meaning that went well beyond his capacity to deploy formal expedients to denounce and demand better public health services. In part, he transformed his knowledge into a broad political strategy that crossed various spaces for applied work, discursive practices, and lines of action.

He further extended his construction of an authoritative position when he chose specific subjects to refer to the hardships of indigenous life resulting from insufficient sanitation, namely, women and children. The political force of this reference resides in the fact that these categories most often elicit the idea of vulnerability, a concept so dear to the field of health, in a sharper and forceful way. As epidemiological data show, women and children are the most vulnerable among those deemed vulnerable *par excellence*: indigenous peoples. Therefore, they are victims in the strong sense of the word, that is, people sacrificed to the interest of others without defense means. However, the indigenous life to which he refers is not only a way of life, what anthropologists would call culture or material conditions of existence. It is mainly vital existence in the biological sense. Hence, his comparison with reptiles makes sense, as does his allusion to water as necessary for reproduction.

It is as though sanitation policies, in dealing with access to water and disposal of human waste (garbage and residues) could bring to light the biological body in dimensions often hidden in public debate. This possibility arises in the disciplinary approach to the exercise of power, in the Foucauldian sense. Teixeira (2012) discusses this mechanism in her analysis of the Manual for Indigenous Sanitation Agents. It is a technical guide published by Funasa in 2006; it states as its goal the training of Indians in the maintenance of sanitary equipment, on the one hand, and, on the other, in health education with emphasis on combating intestinal parasites, that is, hygienic habits. Teixeira's article explores the disjunction between the images and the text in the manual, shows the precariousness of its technical information, and the eloquence and profusion of illustrations of Indians defecating on the ground and near streams and rivers. The argument is to teach the Indians the

transmission cycle of parasitic diseases. A close examination of the overlapping text and images in this manual showed its strong potential to produce and reinforce the feeling of disgust and repulsion that is diffuse, but recurrent in the dominant society regarding the Indians.¹⁰

However, at this point, what we wish to emphasize in the Shavante leader's speech is that the biological body, when inserted in the political field via State processes, also becomes a potential channel of demand for rights from State entities. The mention of scarcity of clean water, for instance, exposes bodily suffering that evokes a level of unquestionable legitimacy: the right to life in its crudest dimension, that is, physical survival. Here, moral suffering becomes inseparable from the illness of the body reduced to a precarious specimen of the *homo sapiens sapiens* species. At stake here, are not the Shavante conceptions of body and life, but the political management of Western categories in the construction of legitimacy of indigenous demands at that moment.

We can then find in a single discourse:

- political strategies proper to shared citizenship (denunciation to the Public Ministry, participation in sites of control of governmental actions, and the articulation between the position of user of the health system and of political leader);
- the affirmation of a specific membership (village dweller) and the evoking of citizenship rights (with emphasis on differential rights);
- the demand for moral recognition, dignity and respect; and, above all,
- the demand for rights based on the physical body, which, ultimately, do not emanate from the human condition, but are interlocked with denunciations of suffering of the body that might come about.

Thus, temporarily, the rhetoric of human and civil rights seems to have become secondary. In contexts of destitution of basic life conditions, the struggle for greater political efficacy in the application of rights already legally guaranteed turned to nature – irreducible and unquestionable in certain modern representations –for irrefutable arguments that the language of citizenship and democracy failed to provide. The body that government practices attempted to discipline showed here its underbelly and revealed its

¹⁰ For those interested in the maintenance of feelings of disgust and repulsion regarding the Indians in the context of education, see <http://www.diarioliberalidade.org/brasil/repressom-e-direitos-humanos/36752-chamados-de-sujos-e-fedidos-,ind%C3%ADgenas-s%C3%A3o-expulsos-de-sala-de-aula.html> (assessed on July 31, 2014).

multifaceted potential as a political tool in the arena of indigenous health and, more specifically, in its link with sanitation.

However, unlike what has been observed in other national contexts (Fassin 2012a), the discursive presentation of the physical-moral body as a legitimate argument in the struggle for rights displeased government authorities. It signaled a certain expertise of indigenous leaders to explore and enlarge the limits imposed by the rules of the political institutional game. Consider the meaning of this discursive expertise, its management of connections between biological body and political identity, specifically in the construction of a differential citizenship in indigenous health policies. This is what we shall do now.

Management of legitimacies in fighting for rights to indigenous health

In the event described above, we have noticed the dissatisfaction of State with the exposé and accusation by the indigenous leader of the precariousness in village life, the suffering of women and children caused by scarcity of water, and the comparison with reptiles. It culminated with the demand for action to diminish that dire situation, and for guarantees of survival. We have seen its immediate efficacy to shift the conduction of the event from technical and administrative to political terms; we have also followed the successful process of creation of Sesai in the terms aspired by the indigenous leaders (linking health care to sanitation). This success, however, occurred in the absence of feelings of pity and compassion and their asymmetrical sociological nature, which emerge in similar contexts of humanitarianism, as those dealt with by Fassin (2012a). In other words, what governors, congressional representatives, and public managers into action was not just solidarity with indigenous suffering, nor was this their main reason. The power relationship that qualifies the interaction between donors and victims failed to impose itself, despite the presence of elements that could potentially spark it. The ultimate truth about the body was always constrained within the framework of the political life also evoked by the Shavante leader at the National Workshop focused here when, besides demanding respect and dignity, he mentioned the Federal Public Ministry, his position as a political leader and a user of the health system, and the guarantee of rights.

Now, we turn to the meaning of the argument of life as a value in itself, in this specific context of political negotiation by indigenous leaders in the setting of State powers to establish public policies and to change the running of indigenous health. More broadly speaking, in what way is the life argument appropriated by indigenous representatives in the everyday construction of the State (as organization and ideology, Abrams 1988) and of indigenous citizenship in the field of health?

First, we must understand that the precarious context described by the Shavante leader has come into being, intentionally or not, as a daily reality that has deteriorated, but is not an exceptional moment. That is, it was not presented as an event capable of raising the moral feelings that move collective actions in situations regarded as intolerable for their dramaticity, exceptionality, and hence, with a sense of urgency (Fassin 2012a, Agamben 2007). The ongoing structure of degrading conditions of life in the indigenous villages moved the audience during the changes in the event in question. Nevertheless, it is important to underscore the fact that it was not regarded as a tragedy, nor did it create commotion. Therefore, it did not lead to short-term actions.

Second, and perhaps most importantly, the indigenous leaders attended the National Workshop as political actors struggling for recognition of rights, rather than as victims looking for benevolence and generosity. Life, as they wished to share, is the life of human beings who enjoy similar moral values, but find themselves in precarious conditions historically and politically created. The moral feelings they invoked belong to the field of injustice, which must be politically restored, whereas the physical body is both instrument and object of that struggle. It was not a matter, as on other occasions,¹¹ of claiming respect of cultural diversity or traditional practices, but rather of overcoming difference as inequality and disdain in the distribution of public services (health and sanitation) to which the Indians, as Brazilian citizens, are entitled. The politics of care and assistance that

11 In the Newsletter *Funasa Notícias* (May 2007), we read: “The Vigisus II Program also understands this importance, so much so that it includes in one of its sub-components the incentive and respect for Indigenous Traditional Medicine. ‘This is a work of respect for the cultural roots’, affirms the national director of the Vigisus II Project, Williames Pimentel”. One of the activities promoted by this sub-component was the II Meeting for Monitoring Projects of Indigenous Traditional Medicine (2010). Both authors attended the whole event and could make a comparison with the ethnographic contexts analyzed here.

disregards the other is at the core of health policies for indigenous peoples (but not only for them), but the political dispute described here seems to have shoved it aside. Another dimension of care present in indigenous speeches is a form of State action, which, in investing in the management of the precarious health of indigenous peoples, creates the necessary political elements to perpetuate this condition. After all, despite the chronic suffering of the Indians, the government administration has invested funds and actions to minimize it. This, in modern bureaucracy, seems to have become more relevant than the results achieved. It is a similar process to that observed by Gupta (2012) in India, when he considered poverty to be a kind of bio-politics. Gupta argued that governments in India, in including the poor in their agenda, revealed the intimate connection between care and structural violence, which constitutes a specific form of State action, namely, the legitimate exercise of sovereign power over life and death in the government of population. It would be far from “letting die” (the poor) from absence of care, as Foucault (1977) argued.

Lastly, we must consider that the identity of indigenous peoples in Brazil and elsewhere is anchored on distinction, which, in democratic regimes, requires the translation of cultural and historic differences into differential rights. Biological life or rather, the so-called bio-identities tend precisely to blur individual biographies and other collective belongings when they redefine trajectories and self-conceptions from the experience of illness and therapeutic relations (as we shall see below). What the experiences that have inspired our theoretical thoughts about bio-rights indicate is a certain erasure of historic, political and social diversity of individuals in favor of shared experiences based on bodily processes that allegedly equalized them all. In the case analyzed here, this erasure seems to be a tactical element to uphold indigenous political rights and articulate categories as weapons in political combat. At stake here is the construction of a certain indigenous citizenship, specifically, the power of the Indians to define the structure of health and sanitation organization and its place in this structure. Engagement of indigenous leaders in bio-rights would become a political tool in specific contexts, far from a moral adhesion to the value of life as such, or a redefinition of the indigenous identity in question.

Second ethnographic anchor: Some thoughts on bio-politics

In this section, we consider the possible spin-offs in use of the Foucauldian notion of bio-power in the relationships between government agents and contexts and the target populations of public policies for differential health. We set the issue of indigenous health in an ethnographic framework that stresses the daily actions of health care in the villages. Such considerations seem to us to be indispensable to the extent that we distance ourselves from any reification of care relationships as acts of disinterested benevolence. However, we should not confuse this epistemological position with accusations of incompetence on the part of specific health professionals, not even taken in general. To the contrary, the bibliography mentioned below seeks to highlight the relationship between the hygienic discourse and the hierarchy of powers, as manifested in different organization models of public health from which campaigns focusing on women and children are naturalized and their targets perceived as victims par excellence.

Therefore, we are interested in reflecting upon the political production of indigenous health as a process rather than as a model (what should be). We endorse a theoretical debate that takes the State (Abrams 1988) as a political practice rather than as an external entity that interprets political practice. To think about these practices is clearly to debate the actions of government agents, but it does not mean reifying their practices and identities. An analysis, inspired in Simmel (1955), of the conflicting scenario of basic care in indigenous health depends on thinking about its actors as complex subjects, also disputing identities and values in a daily process of negotiation of treatments, exams, etc. In this way, we can keep away from a merely normalizing perspective on the actions of health professionals. We thus avoid judging them as good or bad, but encourage a reading of this or that professional's actions as a trace of other moments, objects, relationships, and powers comprising the broad scenario and the subjects' crisscrossed trajectories.

Inspired by the concept of bio-legitimacy (Fassin 2012a, b) to think about the ethnographic context of indigenous health in Brazil, we can identify a political shift in the category of the sick in the contemporary world. At first, the concept originated in the French experience with changes in the policies for immigrants in that country in the last twenty years. The author incites us to think about the category of bio-power beyond the sphere of power

hierarchies, by intertwining a structured form of historical relationships related to the development of national states with the logic of the actions of government agents as a value order, which guides their actions in the political sphere. The author shows how the sick person's experience and his difficulty to access specific treatments have in general been taken as more relevant than the violence inflicted on bodies by authoritarian regimes, which was the common reason why immigrants had access to French citizenship. This overlap of a generalized human rights discourse on the more specific right to citizenship was incorporated to a theory that tries to recover a midway term between what Foucault called power over life (bio-power/ government agents) and what Fassin called power of life (bio-legitimacy/ representations of the body). Rabinow & Rose (2006) add to this analysis the perception that such transformation elucidates the emergence and strengthening of humanitarian organizations that have health as their main working tool. Far from engaging in a sharp critique of such organization models, the authors highlight the emergence of new collective forms of organization by bringing together different authors, interests, or even spatialities (Rabinow & Rose 2006). The main feature of these models is the connection between Bios and Polis. Still on the issue of bio-legitimacy, in considering contemporary human rights policies, the sick body has proved to be a central category. A change in discourse transpires in the dwindling value attributed to interpersonal violence (in civil wars, etc.), as compared to the violence generated by nuclear disasters or by the impossibility of people to receive treatment against specific diseases, such as cancer and AIDS in their countries of origin. We could understand this change as resulting from deeper changes in the conception of human rights and their target populations, that is, in the wake of a debate over the notion of bio-power. This is these authors' hypothesis.

This pattern allows us to visualize a new way to understand the responsibility of states in the health/illness process. This is because such experiences are part of a value order whose roots are in a conception of power of life in itself as an absolute and universal moral value, rather than of power over life situated in the debate on population control by national states.

This specific centrality of the body as a universal element of human existence – almost as a literal translation of 'human right' – highlights the opposition between a political existence and a biological or physical existence, and

seems to point out that this argument may make sense in similar contexts of human life control. The authors in Brazil who have worked on indigenous health have pointed out the enormous sociological void with regard to representations of the body in specific health policies (Teixeira 2012), particularly in favor of a notion of salvation of sick bodies, which unfailingly decontextualizes the accompanying political signs.

There is at least one problematic dimension that is common to the recent literature, particularly that which discusses indigenous health policies in Brazil since the 1988 creation of SUS (Chaves, Cardoso & Almeida 2006, Marques 2003, Magalhães 2001). The notion of the sick body – a result of infectious-contagious diseases related to the lack of effective sanitation measures – always seems to subsume the specificities of the ideas of body and disease, thus altering and shifting the meaning of cultural diversity, that is, the specificity of bodies is perceived as a lack of resources rather than of recognition of differences. Why should one annul the other? Precarious conditions of life and the diseases related to them have become the touchstone to reflect upon health policies, because this dimension is commonly confused with ways of life. Therefore, indigenous ways of life would then be obstacles. To this extent, ways of life become an element in a power hierarchy that administers indigenous lives at the expense of their cultural premises. We are far from reinforcing inequality. Our intention is to show the shift that authorizes action in the name of indigenous survival and at the expense of their own notions of health and well-being. To give an ethnographic example from this second anchor, the nurses at the Munduruku village where one of us did fieldwork frequently mentioned a high incidence of digestive problems. They raised several hypotheses: excess of industrialized food, excessive loss of teeth among the elderly, as well as excessive use of alcohol. They also attributed high blood pressure and diabetes to these same problems, although in smaller numbers. The nurses never considered any of these factors to be the result of interethnic relations, but to the choice of some Indians to live in this way and not look for assistance. Perception that the value of care in itself was the fundamental criterion explained the position of these health professionals, whereas for the Munduruku, what made sense of those diseases were the problems coming from a violent and always disrespectful contact. If, on the one hand, epidemiology tends to treat contagious diseases as the result of precarious material conditions, on the other, the clinic and its exams

emphasize individual choices as responsible for damaging results. For this reason, every diagnosis issued by health professionals as described in the ethnography has, for the purpose of this article, an interested and political character, although interests are diffused in the order of the most cherished values to the nursing teams, namely, care and its daily management (Dias da Silva 2014).

The political struggle ensued in the 1990s by indigenous movements and allied non-governmental organization (Garnelo 2004), and expressed in conferences on indigenous health (Teixeira & Silva 2013), tried to reverse this picture and open a space for the indigenous peoples themselves to manage health problems. The creation of the Indigenous Health Sub-system in 2000 was the most important measure in this respect. While it legitimated the sphere of action of health policies, which produces a not always conscious distinction between physical and political existence, this sub-system opened up interlocution channels through the mediation of Indigenous Health Agents under the premise of “cultural translation” from body/illness bio-medicine notions to indigenous notions.

In this second anchor, the data presented here are part of an ethnography carried out between 2008 and 2009 in one of the thirty-six Special Indigenous Health Districts in the country. It is located in the state of Pará and its main interlocutors were health professionals and indigenous health agents. The idea of cultural mediation is often used as a device in paradoxical situations, such as to convince relatives of the need for a medical treatment the meaning of which contradicted what the group attributed to the form of transmission of contagious diseases. Several authors have tackled this issue (Novo 2010, Smiljanic 2008, Langdon 2004) and called attention to the limits and possibilities of these agents when facing disputes of meaning and contextual political cleavages. We attempt to understand the attribution of mediator status to the identity of these indigenous health agents, as a government practice (technique and morality) to construct bio-identity. Therefore, we must keep in mind that the very idea of mediation is conceived by the national policies for indigenous health as being, in itself, the exercise of a shift in legitimacy. Hence, the most general justification for saving lives (empirical agents) seems to be part of the logic of action in the political sphere (persons). In focusing on the dynamics of relationships between members of health teams (especially Indigenous Health Agents and various

nursing personnel), we try to understand how the domain (order of values) of biological life manifests itself as a natural justification for life in society.

Furthermore, the contradictions resulting from the co-existence of health professionals and indigenous health agents unveil incommensurable aspects of a dispute, which, besides the power hierarchies easily identified within the Sub-system organization, is at the core of a moral economy and of a humanitarian reason (Fassin 2012a). That is, these contradictions can and must be understood by tackling a value system (political existence of the subjects) that includes cultural difference as an “embellishing” feature (it aggregates occult, mystical, and poetic meanings), but regards it as incapable of defining or guiding health actions, lest the precepts of life saving and humanitarian reason be lost. Thus, the “dialogue of the deaf” observed in the research cited above points at an opening for theoretical frameworks capable of identifying and making visible the forms of interaction that mark the relationships between government policies for indigenous health and indigenous policies for their own health.

We look at the indiscriminate use of the prefix bio- as a possibility to understand vast and distinct ethnographic contexts. On the one hand, we try to consider to what extent the form of dichotomous association between physical and political existence has been appropriated in demands, such as the right to a specific way of life. This is a central feature of indigenous health in Brazil. Indigenous leaders’ discourses have projected its inseparability from physical existence. Nevertheless, it is important to ask at this point in what way does the government’s discourse about life, taken as a power device, preclude the possibility of cultural mediation in village contexts. Outstanding leaders in the national scenario acknowledge the efficient management of this association. However, at the local level of assistance in the health post, health professionals have as a clear strategy a profusion of retaliations toward these peoples’ traditional knowledge (Langdon & Garnele 2004; Smiljanic 2008). They exercise a power of life, that is, a rhetoric that recognizes the right to live, on the one hand, and the right to a way of life, on the other. Therefore, our anthropological outlook questions the nature of this dichotomy as it has been engendered, lived, and perceived by government agents – particularly in constant and daily interaction with the Indigenous Health Agents – in order to identify the political tactics to shift the legitimacy of indigenous knowledge in the organization of health actions. The

bio-identity attributed to indigenous peoples – as societies whose value turns almost exclusively around the issue of survival – might be a valid theoretical tool to understand which interests are mobilized in the name of survival. We thus reiterate that both for Rabinow & Rose (2006) and Fassin (2012a, b) the discourse of physical preeminence is a political tactic to be thought via its daily strategies, better observed when we add this theoretical trajectory to a multilocal ethnography (Marcus 1995; Coleman & von Hellermann 2011).

These thoughts lead us to a value order the practical meaning of which thrives in terms of a cultural mediation that bifurcates into two scenarios: access to natural resources and bodies as such, and management of indigenous knowledge of their own resources and bodies. We shall now attempt to explore the way in which cultural mediation slips from one scenario to the other. We stress the limiting points of the arguments and conflicts of basic care, including the place of the Indigenous Health Agent (AIS) and the Indigenous Sanitation Agent (AISAN) regarding hygienic discourses. We attempt to show how their relationship to the so-called natural resources/nature and biological life, as well as the management of clean/dirty water, for instance, is inevitably shrouded in power devices of a juridical-discursive order (Foucault 1977).

Cultural mediation and bio-identity among professionals at the local level. To think of cultural mediation in the local context of indigenous health requires that we define a specific framework of bodily practices that would guide the routine of care and conflicts. We shall discuss corporeality or corporatized processes (Csordas 2008), starting with the notion of care/conflict established along an education front set up via professionals who operate at the local level. It can also come about via a way of life culturally given (hygienic practices), but mainly perceived as spontaneous (naturalized). The relation between hygienism and corporeality is not limited to the problem between environment and individual biology, but is rather an expression of power that legitimizes or delegitimizes knowledge/practices in the field of health. We thus explore the implications of taking such hygienic practices as a set of “care practices in themselves,” or as part of a “pro-active posture” intrinsic to professional competence, as commonly seen in nursing. This, it seems to us, is a converging point of bodies and powers through which “bio-legitimacy” in the discourse on access to citizenship is constructed by means of current public policies for indigenous health. Focusing on the link

between a specific conception of hygiene (that is hegemonic) and the idea of access to citizenship allows us to see how the (de)politicized body is at the core of humanitarian logic, which recognizes rights and guarantees access to health care in the villages. We shall approach this issue via two relevant points: (1) the dynamics between hygienic practices and the construction of AIS and AISAN identity, (2) the emergence of the notion of individuality as a bio-political expression of care in itself.

Hygienic practices and identity: power dynamics

We now present some excerpts of field diaries that clearly show the dynamics of care and daily conflicts involving body hygiene and identity (social markers of difference). The identity of the caretakers is infused with surveillance of the other's customs, particularly with regard to hygiene.

'It seems they don't love their children. They don't care.' This is the general opinion of nursing technicians and nurses. They don't recognize any sign of care or worry in the parents-children relationship. (...) Perhaps that's why they make dramatic speeches about the measures needed to treat flues that turn into pneumonia, malaria cases and other situations that can only be controlled with intensive care. These cases are always described as complicated when they blame the Indians 'in general' for lack of hygiene, lack of care, etc. (...) If anyone dies, especially children, accusations fall on dubious care behavior toward children or reluctance to follow the nurse's instructions. (...) If the patient doesn't get better, they blame the Indians' ignorance, their stubbornness in not following some procedures, such as avoid bathing at certain times, control the children so they don't walk in the rain, take medicines, go down to town, do exams, medical appointments, etc. (Silva, field diary, 2009).

These excerpts show a variety of lived situations of care provided by the nursing team at the health post in one of the Munduruku villages. With about seven hundred people, this is one of the largest villages, two hours from the nearest town where the Indigenous Health House (CASAI) is located. We notice that much of the nurses' talk about the universe of "care" tries to displace the legitimacy of cultural mediation when facing health injuries, whether shared or imagined. Shared or known injuries – those that are typical, such as the increase in malaria cases in the rainy season – are

associated to careless individual behavior. We must also notice the patchiness of technical recommendations, such as not bathing in the river at certain times, not taking the children to the fields, etc. Beyond their technical and allegedly neutral profile, these recommendations signal the construction of a reified and generalizing indigenous identity. However, health professionals could also attribute the imagined or anticipated injuries to a flawed infrastructure, such as paucity in transportation. Added to this is the supposedly superstitious behavior of Munduruku families who insisted in the presence and participation of shamans in their daily life. Thus, in their discourse on health care, the nursing team constantly invalidated the Munduruku type of prevention. Practices to safeguard the children, such as taking them to the shamans for cure, and the use of necklaces to protect them from typically infant diseases were subverted as superstitions. Common to both discourses is the concern that infancy is a period of additional care and critical vulnerability. However, whereas the Munduruku related hygiene and disease prevention to personal relationships within the logic of sorcery, the nurses expressed their concern with individual behavior and, ultimately, with the mother-child relationship. Everything the health professionals regarded as a problem of individual behavior (bodily practices and hygiene) they placed beyond the issue of interculturality. Rather than a dialogical and egalitarian premise, a socio-educational and tutelary approach superseded the scheme of cultural mediation. The way health education delegitimized the other's "culture" appeared in discourses and practices, comprising the most important meaning of hygienist habitus taken as a complex whole of actions, conducts, and values.

Meaningful examples from daily life were the frequent accusations flung at the Indians about the incidence of illnesses related to lack of sanitation. We could mention many other diseases in other contexts. However, our choice of infectious-contagious diseases derives from the strength these have had in anthropological analyses of indigenous health and related government policies, particularly on the issue of epidemiology (Santos & Coimbra Jr. 1994, Menéndez 1998, Coimbra Jr. et al 2003).

The dynamics of hygiene procedures appears in various scenarios of interaction as the feature that characterizes basic care. In the indigenous case, it is striking that the accusation of lack of hygiene and health care centered in "cultural" choices, bringing together, in ways not always discursive

or intentional, Muduruku life ways and a set of obstacles to improve community health. Much has been said about the possibility of making mediation pacts and that to invest in interculturality might be a possible and desirable way to guarantee recognition and specificities (Follér 2004). However, we may hypothesize a bio-legitimacy driven by the increase in health agents, that is, by the construction of the most recent identities in indigenous health – Indigenous Health Agents and Indigenous Sanitation Agents. We could then understand the extent to which this identity emerges as an extension of the hygienist habitus (in the Maussian sense) within the politics of health. There seems to be a privileged way to encompass the notion of interculturality within the hygienist demand in indigenous health. We suggest that this hygienist encompassment occurs via the creation of bio-identities whose political efficacy resides in contrasting culture, as an ideological and representational issue, to the irreducible nature of sick and sickly bodies. AIS and AISAN are crucial to think about the sort of correlation of forces built in the so-called interculturality process. Again, we argue that it is important not to reify the meaning of cultural mediation and observe the transitory stabilizations that occur in specific contexts.

The moments of identity building of both interlocutors in this ethnographic context – Munduruku families and professionals at the local level – referred to the embodiment of prevention/hygiene procedures. Through these elements relationships, dyads, and triads were constructed. Thus, the relationship between an AIS and a nursing technician was marked by the double membership of both in other relationships: the technician's discourse was similar to the flimsy manuals of individual procedures to prevent infectious-contagious diseases, whereas the AIS's resembled the criteria for the prevention of sorcery. This (mis)encounter was rooted in the corporeal abilities/anticipations to avoid the notion of cultural mediation, a power device for this purpose.

Bio-identity for whom?

In the numerous speeches about the universe of personal hygiene, the nursing group explicitly mentioned self-care. They often said, "I must take care of myself. One has to be careful." The ethnographer noticed that their concern was only meaningful when accompanied with an obligatory

socio-educational approach to hygienic conditions. In the wake of these broad naturalizations of health and body, it was common to see women refuse pre-natal exams, which would involve monthly trips to town for the so-called routine exams. This statement is good to think temporality of health institutions in the dominant society. As the concept of routine is linked to the idea of exam, unavoidably, a connection is made between medical procedures/treatment and ways of life. When we shift this concept of routine to the quotidian of Munduruku women, we do find a “routine,” albeit “another routine” that turns the production of exams into a simulacrum of other women’s bodies, of other women’s lives. These other temporalities enclosed in time concepts such as “routine” set up a specific way of life far removed from the life of Munduruku women. For this reason, they made an issue of it as expressed in their refusal to give up so much of their daily time to constant trips to town. “Life in itself” – an all-inclusive argument in health actions – appears as a political tactic through the logic of daily time and behavior. The Indians may question the authority of biological reason, but cannot ignore it, as it imposes itself in the very apprenticeship relation between nurse(s) and AIS/AISAN. Therefore, the expansion of professional categories centered in managing the environment and bodies on the precept that hygiene constructs bio-identities, to the extent that it shifts the legitimacy of the other’s cultural argument (his way of life) to life conditions related to infrastructure works and individual behavior. The confusion between ‘ways of life’ and ‘material conditions of life’ is not a blunder of the Indigenous Health Sub-system and its government agents, but rather it represents the major everyday tactic to implement the processes of so-called cultural mediation in local contexts.

The naturalized discourse on the relationship between individuals, as a political expression of care in itself, was not uttered exclusively in the village, where the presence of a nursing team was the strongest. It also occurred in town, at the municipal hospital, but here with regard to physicians. The Indians had access to doctors in private appointments when additional exams were requested. In a conversation between the anthropologist and one of these doctors, his vision of the relationship between the Munduruku and “nature” was so dramatic that he had to expand on his understanding of the (im)possibility of cultural mediation:

The doctor complained that his feeling in attending them was of an unrewarded effort. He was solicitous, treated them kindly, but got nothing in return. According to him, he was surprised when visited by nice, very polite Indians, who know how to engage in a conversation and even “melt” over the doctor. He was curious to hear which books on the Munduruku I could recommend, but soon afterward, he said he found some of their words guttural, letting slip he was interested in some sort of “primitivism.” This projection of an image about anthropology as the study of the archaic, frequently confused with archaeology, was also evident in our conversation. I replied that Munduruku language has more vowels than Portuguese, that is, a variety of forms to articulate more vowels unknown to us, which makes understanding quite difficult for Portuguese speakers. But this information, which suggests a similar or greater complexity than any other human language, was not “heard” or noticed. It was as though the Indians were completely alienated, with no sense of reality, living in a world comparable to that of disqualified persons, such as autists in our society. About attendance in medical offices, he gathered that translations by a third person, in general an Indian who worked at CASAI, an AIS or AISAN, leave him insecure about what the patient was saying and what was being said to him. He also remembered the case of a girl in the hospital who received the visit of a shaman who ordered the oxygen machine removed from her. He pointed out that when this sort of situation happens, they, the doctors, call the CASAI infirmary to ‘come and talk.’ He commented that culture ends up interfering in the procedures and the doctor is confronted with it and for them it must also be a confrontation. About the description of symptoms, he said one has to be careful with some questions. For example, to ask the patient directly whether he had diarrhea is no good, and he said he had tried to ask the question in that way and got a negative answer; but when he asked whether the patient had ‘the runs’ and a bellyache, the answer was positive. These were “communication flaws” that made Munduruku patients special to the doctor, in need of “special attention.” He actually kept a list of Munduruku words describing symptoms like headache, stomachache, bellyache. He would write as he heard them, but said he had difficulty in getting their words right, because people gave contradictory information, one would say that this means bellyache, the other, stomachache. They were, as he said, attempts to be independent from a translator (Silva, field diary, 30/06/2009).

What stands out in this report is that the form and content of this conflict do not differ much among health professionals, but, from the point of view of medical doctors, it was not up to him to mediate between knowledge and practice. We must remember that cultural mediation is inserted in the field of health education, hence, it is a problem traditionally associated to educators, nurses, and caretakers. That specific doctor speaks as a specialist and demands distance from the mediation process. Moreover, only educated individuals would be able to gauge the dangers of lack of hygiene and of refusal to follow medical recommendations. Therefore, it was always necessary to call the “CASAI nurse.” It did not matter whether the requested person was a nurse; he/she had to be, necessarily, someone from CASAI, that is, from the field of “indigenous health.”

How can we think about this logic, which orients the political dispute about illness diagnoses and meanings, as a privilege of the socio-educational approach to professionals’ actions and competence? Let us see the detailed content of this approach. 1. Communication flaws, on the one hand, are attributed to the translator’s unwillingness, thus brushing off the issue of dispute and political meaning as a strictly “technical” problem. 2. The feeling of “unreciprocated effort,” on the other hand, comes up clearly, when my interlocutor (the doctor) tried to explain his impressions of indigenous patients. It was as if they did not recognize the centrality of the doctor’s position. On various occasions during fieldwork, local indigenous leaders stated that it was difficult to distinguish between a doctor’s work and that of the nurses; they saw no complementarity, but only that the former were more absent and harder to access. Refusal to follow certain treatments was blamed on stubborn individuals. Attempts to persuade, often doomed, came in the wake of care, but even so, it was the most established alternative in everyday life. However, at no point was cultural mediation between knowledge and practices declared to be a political problem, but a one-way question of education; one needed to teach illness prevention, despite the fact that the technical means available were very poor. The AIS and AISAN always felt that their accountability for the field in the villages was like an accusation of incompetence and disinterest. The incommensurable relationship between the diagnoses of bio-medics and shamans was mitigated by the need to educate the Indians, particularly those who had never left their villages and had little “notion of reality.” In this context, the AIS absorbed accusations from both

sides. This situation is common to other indigenous sanitary districts in Brazil (Novo 2010, Langdon et al. 2006, Garnelo & Sampaio 2003).

Munduruku families mentioned several ways to deal with health professionals regarded as 'difficult': they ignored their presence, missed consultations, complained to the AIS, AISAN, and the village leaders. Health professionals had their own similar strategies: they ignored stubborn patients, made small word lists to 'resolve' the problem of communication, and complained to the AIS, AISAN, and leaders when people rejected emergency actions. Nevertheless, although these statements were similar, there were differences in the irreducible logic oriented by the power over life. Children were the object of care, and the frequent deaths among them became conflicts involving both sides. Women were also an important target of campaigns for pre-natal, gynecological, and other exams. Local and national government agents follow these indices closely, for they measure the quality of the services. However, to see the problem of indigenous health as a political issue, in the Foucauldian sense, is to understand that these favored victims, women and children, are not at the center of disputes because they are naturally vulnerable, but because they have countless spokespersons who legitimize and reproduce bio-power.

Final remarks

Following up our proposal to discuss indigenous health via two complementary ethnographic anchors, we affirm that relationships between indigenous peoples and government agents are contextually experienced. As a concept that encompasses both scenarios, in the present case, the perspective of power over life appears both as the confronting strategies deployed by the Indians in the villages and as structuring interculturality discourses delivered by health professionals, especially in attempts to regulate moments of irreducible conflict. We can see this "irreducibility" as a sort of interculturality performance. To the extent that it is often projected on everyday situations, it is questioned by many of the anthropologists cited here as a pseudo cultural mediation, because it fails to take the indigenous discourse seriously. As we have argued, the nature of these relationships can change when we shift from a local to a national scenario. In local relationships, government agents construct their legitimacy with the separation of Bios and Polis, in

opposition to the perspective of the Indians with whom they interact. They list, on the one hand, technical-organizational problems, and, on the other, difficulties with individual behavior regarded as cultural obstacles.

In the villages, the health professionals affirm the predominance of life in itself in defining their relationship with the Indians, but this was not the case when indigenous leaders and government agents met in the national scenario focused here. The National Workshop mentioned in the first ethnographic anchor revealed a complex discursive game, which flung the precariousness of village life at the Indians like a political weapon. To compare the Indians to animals was, in this context, to unauthorize government action not only in basic everyday assistance, but, especially, in the plan for the institutional engineering of indigenous health that government agents intended to reinforce. Although biological life was handled as the reality referred to by the Indians, at stake was to politically guarantee the construction of the Special Secretary of Indigenous Health in charge of managing health care and sanitation.¹²

It seems that the Indians' replacement of civic with biological legitimacy was possible within a clearly political framework and only temporarily. Their strictly political arguments were not sufficient to guarantee their active participation in the process named social control of health government policies. Thus, in a demonstration of oratory excellence, they gave up the political dimension by making bio-legitimacy explicit, in order to reshape the political game in their own terms. However, their position does not mean that life in itself has no value for indigenous leaders in political disputes, nor does it for men, women, and children regarding care in itself in the villages. However, here and there, material conditions of life are only the *mínimos vitales*, as the Colombian Naya people affirm (Orsina 2014). Alternatively, they are but a part of a healing process instituted by the Canadian First Nations (Royal Commission On Aboriginal Peoples 1993), from which they construct, affirm, and renew their indigenous identity as a nation within a nation.

From this point of view, if in the national political scenario bio-legitimacy can be an indigenous weapon, in the context of health services in the villages, this would not occur. After all, it is often the main way to deny

¹² For those interested in similar processes, see the fine article in which Kent (2012) examines the way in which the Uros (Peru) permitted and appropriated genetic research within the *Proyecto Genográfico* as a main strategic in their demand for political rights. Like in the context focused here, their management did not result in biologizing Uros identity.

an indigenous differentiated cultural and political life, by individualizing hygienism and health education provided by health professionals.

We adopt the view that takes values are central to political life, without reducing this life to a power system, government techniques, or interest conflicts (Weber 1999, Foucault 1977, 2006, Fassin 2012a, b). In this sense, the ranking of values in political contexts and in indigenous health assistance involves two distinct inclusions. At one level, the Indians give bio-legitimacy a leading position; at another level, government agents do it. At neither is life in itself as a value a stable core element in the constitution of the rights under dispute.

Therefore, it would be inappropriate to use in a definitive way any of the various conceptions of bio-citizenship mentioned at the outset. From the perspective of government basic care practices in the villages, we can see similarities between hygienism and sanitized citizenship, as did Briggs & Martini-Briggs (2003) when they analyzed the way the Venezuelan government handled a cholera epidemic in the early 1990s. Its measures included responsibility of the individual for the illness and its cure, emphasis on health education (with pamphlets about cholera showing stereotyped images of Indians defecating on the ground), and indigenous obedience to hygienic recommendations about the body, water, and utensils. These were conditions for the Indians' inclusion in the distribution of vital government services (sanitation, water, and health assistance).

Nevertheless, if we consider the indigenous political performance in formal spaces of participation in government policies, this does not occur. What stands out is the handling of various sources of legitimacy. Bio-legitimacy, as proposed by Fassin, becomes an instrument for the Indians to construct differential rights in more favorable communication conditions. In other words, we may not be able to speak strictly of a biological citizenship, but the power of life as a value allows us to connect politically the biological body to the political body. Undoubtedly, the biological dimension and its correlated valorization of life and of a universal body are fundamental in contemporary political disputes. Nevertheless, in observing Brazilian policies for indigenous health in distinct contexts, we realize that the combination of Bios and Polis has always to be scrutinized by ethnography, lest we disregard the meaning the subjects attribute to their interactions in specific processes and situations – precisely what originated anthropological thinking about bio-identities.

With this viewpoint, we now return to the question that opened this article, namely, the repercussions that our thoughts may have on the understanding of citizenship in the construction of indigenous health.

To summarize, the two ethnographic anchors presented here are the political dispute between indigenous leaders and State agents to define a government policy in the country's capital, and the indigenous everyday dispute in defining care vis-à-vis health professionals in the villages. They have allowed us to see the relational and contextual character of the arguments deployed in the affirmation of the indigenous condition in question. Moreover, they have mainly underlined the central place of the exercise of power in the villages by and for the Indians in the construction of their differential identity and citizenship.¹³ With these comments, we emphasize that, in none of the situations described here was the preservation of the objective content in itself the focus of discussion, be it as a cultural and political practice, or as a vital condition. Very clear to us was the process that connected in a differential way all of these resources in each ethnographic context. This connection would guarantee the recognition of the Indians' right to decide how to lead their lives in illness and cure, as well as in the organization of indigenous health services. Ultimately, these would frame the institutionalization of health care in the villages. Thus, the Indians in a leadership position or as subjects/objects of health services, managed to escape the trap of remaining atemporal in order to continue to be Indians (culturalist citizenship), and the reduction of their identity to the struggle for the preservation of a certain physical existence (bio-citizenship). However, we must consider the disjunction we have observed in indigenous citizenship. On the one hand, the recognition and prestige of indigenous leaders' political citizenship at the federal level; on the other, the daily disregard in health services, that is, in the exercise of civil citizenship. Therefore, everything points to an unequal inclusion of indigenous peoples and individuals in the current democratic process in Brazil.

This being said, we notice that in both processes (local and national), the exercise of citizenship by the Indians has redefined the guarantee of diversity and difference as a *difference in power* (political-strategic and moral). This

13 In these thoughts about the politics of indigenous identity, we praise the work of Roberto Cardoso de Oliveira on interethnic identity (especially his re-reading of identity studies in the 1960s and 70s in *Caminhos da Identidade* (2006). More recently, we mention the relevance of our dialogue with the Canadian situation based, specifically, on Shouls (2003).

difference in power is to be reverted in their favor, not simply, but also, as a conquest of specific rights guarantors of their specificity – as in the so-called “new social movements.” This shift permits that the frontier between indigenous and non-indigenous remains dynamic and demarcated according to the political, historical, cultural, and social priorities as lived by indigenous peoples in specific contexts. Thus, the indigenous struggle for a differential citizenship and for self-determination and autonomy (Teixeira 2010) concurs once more in the contemporary field of indigenous health, now in overcoming the dichotomy between Bios and Polis.

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Review

Ana Lúcia Pastore Schritzmeyer, *Jogo, ritual e teatro: um estudo antropológico do Tribunal do Júri*. São Paulo: Terceiro Nome, 2012.

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Over the past year, two decisions made by grand juries again shed a spotlight on the vexed history of race and criminal justice in the United States. In Missouri, a grand jury decided not to indict a policeman in the shooting of an unarmed young black man. In New York, a grand jury declined to indict another policemen who choked to death a vendor in Times Square, Eric Garner, also an unarmed black man. In both cases, the police officers and the majority of the members of the jury were white. Across much of the United States, and during much of its history, criminal grand juries have more than reflected prevailing attitudes about race: the composition of juries was an underlying motive for voter disenfranchisement in the South during segregation. Jury duty has long been connected with voluntary voter registration, so in the U.S. South, denying blacks the right to vote was a guaranteed way to make sure black people never sat in judgment of white people. Despite widespread scrutiny of the grand jury decisions in Missouri and New York, little seems likely to change: it has long been the case that grand juries are very likely to indict murder suspects, but very unlikely to do so when those suspects are police.

This is where it is helpful to have a fresh comparative perspective like that provided by Ana Lúcia Schritzmeyer, professor of Sociology at the University of São Paulo, in her book *Jogo, ritual e teatro: um estudo antropológico do Tribunal do Júri*. A work of legal anthropology, *Jogo, ritual e teatro* examines the dynamics of juries in Brazil, a country where they are not employed in most trials. In Brazil, juries only decide murder cases. These cases carry as a maximum sentence life imprisonment: Brazil was one of the first nations to abolish the death penalty, doing so in the nineteenth century. Schritzmeyer's study focuses on jury trials of murder cases in São Paulo,

carefully examining dynamics ranging from the layout of courtrooms and rooms for deliberation, the arrangement of people in the room, as well as the pageantry and ritual of the trial.

Schritzmeyer is particularly concerned with the ritual and performance of the re-imagining murders before the jury, in the courtroom. What she finds is a debate about the nature of murder in the case of someone's violent death. What constitutes murder in the attitude and actions of the accused perpetrator? What makes the actions not constitute murder? Schritzmeyer points to cases from the 1970s and 1980s in which men successfully argued that the murder of their wives was a legitimate act of preserving their honor. What she finds is that the performance of defense and prosecution before the jury is an act of asserting and contesting legal truth. As a consequence, what is often in debate is not whether someone perpetrated a deadly violent act, but rather the register of social and cultural values upon which that act is interpreted. For instance, did the violent act threaten, or defend, a beleaguered middle class identity amid a rising sensation of insecurity?

Schritzmeyer's study insightfully pushes us beyond thinking that a jury trial is an objective exercise of the law. Instead, she frames the jury trial as a ritualized performance space in which actors navigate a vast terrain of morality and values mediated by a broad set of social and cultural factors. In the United States, we tend to identify jury duty with civic responsibility, and in so doing, to consider it as an uncomplicated exercise of democracy. But bringing Schritzmeyer's perspective to bear, we instead are prompted to reflect on the manners in which jury decisions are about more than the law. As Paula Montero explains in the preface: "As she sets aside her original question - are participants on juries producers of democratic decisions? - and takes an approach that is plainly anthropological - how do juries narrate society? - the author confronts... contemporary questions that are hard to solve." (13) These questions apply to the United States at least as much as they do to Brazil.

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Review

WELCH, James R., SANTOS, Ricardo Ventura, FLOWERS, Nancy M. & COIMBRA Jr. Carlos, E. A. *Na Primeira Margem do Rio: Território e Ecologia do Povo Xavante de Wedezé*. Rio de Janeiro: Museu do Índio/FUNAI, 2013, 248 p.

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Wedezé is an Indigenous Reserve situated on the east side of the Rio das Mortes, Mato Grosso State, where, according to their oral history, the Xavante people established their first permanent settlement after relocating from Goyaz Province to the Rio das Mortes region in an attempt to escape colonial violence in the mid-nineteenth century. About a century and a half later, in 1970, the Xavante were relocated from there to the current Pimentel Barbosa Indigenous Reserve, located on the opposite side of the river. Nevertheless, this forced relocation did not separate them physically or sentimentally from the “first side” thanks to memories of the dead their buried and frequent visits to hunt, fish, and collect. Additionally, Wedezé is the Xavante village with the earliest occupation in the region, going back to 1850-1890, and one of the longest periods of permanent occupation (1956-1970).

In the 203 pages of *Na Primeira Margem do Rio*, the authors address the connection between the Xavante and Wedezé, or the Xavante from Wedzé. Ethnographic photographs used as narrative resource (42 figures and more than 28 full-page images) and instructive and necessary tables (24) conduct the reader to a human landscape described and analyzed with acuity and sensibility, a combination that proves especially productive. One of the most meritorious aspects of the book is precisely the fact that it resulted from the shared experience of four anthropologists engaged with the same ethnographic subject. This study population generously offered its knowledge to the authors for the production of an Identification and Delimitation Report (*Relatório de Identificação e Delimitação*) for an Indigenous Reserve of special relevance to them, a report published in turn in book format. In this sense, *Na Primeira Margem do Rio* constitutes a four-handed (possibly eight)

anthropological exercise, whose internal unity stems from the complementary relationship between the authors' various areas of thematic interest – history, migration, ecology, demography, and economy – regarding Wedezé, the first side of this river occupied by the Xavante.

The book's various thematic focal points complement one another but nevertheless receive highly specific and detailed treatments, which would hardly be possible, were it authored by a single anthropologist. The reader benefits from this configuration, which offers in a single source a multifaceted view of the Xavante, obtained by cross referencing ethnographic records produced by these four authors and other ethnologists who, like them, have contributed to the rich Xavante ethnology, as well as Xavante oral reports collected by the authors, which focus on their various historical movements and settlements near the Tocantins, Araguaia, and das Mortes rivers. Each family group tells a slightly different version of these events, versions that reproduce the same basic movements among the set of former villages identified by the oldest indigenous individuals from Wedezé and Pimentel Barbosa.

Na Primeira Margem do Rio is thus simultaneously a history of the enduring relationship between an indigenous people and its ancestral territory and of the process of mobilization to reconquer it, complemented by discussions of Xavante ecology and subsistence economy in the cerrado biome – both strictly articulated with the cosmological and ritual plane – and with the demographic profile of the population established in this locale for a century and a half.

This is a history of *longue durée*, intersected by the colonial and national history in several especially impactful moments for the Xavante. Over the period 1764-1788, when agriculture was beginning to replace the decaying cycle of gold mining, they roamed Goyaz Province, after which some crossed the Rio Araguaia and came to occupy the interfluvial region extending to the Rio das Mortes. From the mid-nineteenth to the early twentieth century, a significant portion of the population established itself to the east and west of this last river, in such villages as Wedezé and Sõrepré.

The March to the West (*Marcha para o Oeste*), under the Vargas administration, whose alleged purpose was to occupy and develop economically the central regions of Brazil through promotion of livestock production, identified the Xavante as an obstacle to be overcome, leading to increased efforts

in the early 1940s by the Indian Protection Service (*SPI - Serviço de Proteção aos Índios*) to establish contact with them. In 1946 a first group was compelled to do so, which triggered a huge influx of trade, followed in the 1950s and 1960s, when the Xavante were weakened by disease and clashes with settlers, by more or less widespread contact with the SPI and Salesian missions installed in the region. In 1970, after successive movements, the Wedezé group was pressured to return to the place known as Etênheritipá, later called Pimentel Barbosa, on the west side of the Rio das Mortes.

The pattern of intense mobility observed until then changed most notably due to territorial reductions accompanying increasing occupation of the region by ranchers and the impetus for sedentarization promoted by indigenous posts installed by the SPI and the National Indian Foundation. The latter sold a significant portion of the territory to private interests involved in large-scale commercial agriculture. The practice of trekking, a traditional activity involving prolonged hunting and gathering expeditions and associated with the high mobility of villages, in some cases temporary villages whose duration was determined by political circumstances and natural resource availability, became severely limited, which led to increased pressures on the environment in the immediate vicinity of villages and restrictions on ritual activities. The special relevance of these expeditions, held regularly until the 1980s, can be measured by the fact that most current Xavante villages are located in places previously used for camping.

The Pimentel Barbosa and Wedezé indigenous reserves constitute, according to the image communicated by our authors, green “islands” used for subsistence, raw materials, and ceremonial purposes, extensively surrounded by monocultures and pastures. The predominant vegetation is cerrado, which, with different phytophysiognomies – open grasslands, especially grasslands with small shrubs or palms; cerrado grasslands with herbaceous grasses, trees, and diverse shrubs; cerrado *sensu stricto*; dense woodlands (*cerradão*); and gallery forests – ensures plant and animal resources for Xavante biological and social reproduction.

This reproduction continues, as it did traditionally, supported by the combination of collecting, hunting, fishing, and practicing agriculture in the cerrado, and, since the 1950s, complemented by rice cultivation, wage labor, and social benefits deriving from the federal government. Cattle production,

previously practiced for some time, is now reduced to a few head in the Pimentel Barbosa reserve.

Collective hunts, frequently associated with ceremonial activities, often require the use of fire. This modality generally occurs in open grasslands early in the dry season (May/June), as well as in areas of cerrado and dense woodlands, closely associated with male moiety and age set systems (usually youth hunt and fish for secret ceremonial activities in locations distant from the villages). Wedezé, due to its abundance of large game animals, has been continuously used for collective hunts, which makes it a place of reference for cultural activities and for offsetting the environmental pressures affecting Pimentel Barbosa.

Recent studies have shown that fire is a distinctive feature of the cerrado due to an evolutionary history of fires (anthropogenic or not) that resulted in the development of a significant proportion of underground plant biomass. Thus, controlled burning regimes can have a positive effect on cerrado biodiversity, whether in the form of pollen and nectar availability for polinivorous and nectarivorous insects or better adaptation by many cerrado plants and animals. Accordingly, controlled fires are an important technique for environmental management, and the Xavante demonstrate possession of extraordinary ecological sensitivity and effective knowledge of the environment in which they live. Unsurprisingly, therefore, for them the burning of vegetation is not restricted to a hunting technique or landscape management strategy but moreover constitutes an important symbol of ethnic identity and a highly valued form of promoting social values and capabilities among young men.

Hunting with the aid of fire is not, therefore, randomly practiced, but is systematically planned under the leadership of elders who, in the course of conversations in the *warã* (men's council), consider a number of factors, among which are the appropriate time, season, position of the stars, weather condition, soil moisture, dryness of leaves, amount of dry plant matter on the soil surface, time elapsed since the last fire in a given area, and spatial distribution of fire events, considering the types of vegetation and availability of natural barriers such as waterways, wetlands, and gallery forests.

A significant portion of their traditional botanical knowledge is considered secret and therefore not likely to be shared by those who have no

ties to Xavante individuals, families, or social groups. In the face of such a restriction, the authors chose to focus on only two domains not considered of specific ownership, i.e., plants of dietary and technological relevance, except those guarded in the female domain (wild roots and tubers). With regard to fauna, 98 bird species of cultural value, less than the total number of bird species used by them, were identified and distributed into nine different types of landscapes and vegetation, namely cerrado areas (64.3%), dry forests with bamboo (63.3%), gallery forests (49.0%), inundated grasslands (46.9%), rivers (23.5%), anthropogenic landscapes (pastures, 21.4%), lakes (19.4%), buriti palm forests (10.2%), and mountains (2.0%) (cf. Table 6.6). Several species occur in more than one environment.

Territorial restriction and increased population growth in combination have given rise to internal village divisions and subsequent movement to form new villages. Presently, the Wedezé and Pimentel Barbosa indigenous reserves, which are two of nine Xavante reserves and comprise a total population of over 1,500 inhabitants, are characterized by a young population distribution, with more than 50% of individuals under 15 years of age and a small number of seniors for all villages. The total fertility rate estimated for the period 1999-2004 was 7.7% live births per woman, a level considered elevated even though it reflects a decreasing trend, on average at 1.4 fewer children per woman. Moreover, mortality rates are also high, especially infant mortality, which is five times higher than the national rate and illustrates a poor health and nutrition profile.

Future projections for cerrado conservation are not encouraging and there is no concerted public policy to change the unfavorable picture. An example of this is the divergent goals of the Ministry of Environment, which works towards increasing the percentage of protected areas in the cerrado (protected areas currently include 2.2% of the original area of the cerrado), and the Ministry of Agriculture, whose goal is to bring approximately 100 million additional hectares of land under agricultural use (MACHADO et al 2004, p.7¹).

If opening pasture for beef cattle used to be the main precipitating cause of deforestation in the cerrado, in recent years the pressures come from

¹ MACHADO, R.B et al. Estimativas de perda da área do Cerrado Brasileiro. Unpublished technical report. Conservação Internacional, Brasília – DF, 2004.

soybean plantations. Information from the Brazilian Institute of Geography and Statistics (*Instituto Brasileiro de Geografia e Estatística*) database (SIFRA – available at <http://ibge.gov.br>) indicates that the area used for soybean agriculture has increased enormously (MACHADO et al, 2004, p.7).

As part of this scenario, the advance of the agricultural frontier in the region between the Araguaia and das Mortes rivers constitutes a serious threat to the conservation of this rich ecosystem. The intensification of colonization in eastern Mato Grosso since the 1960s and 1970s has impacted the environment, resulting in extensive areas of deforestation, siltation of waterways, and erosion, principally along the banks of major rivers due to destruction of riparian forests. The establishment of soybean, rice, and sugarcane monoculture entailed impacts on the flora and fauna. Large-scale commercial agriculture has degraded the region's native vegetation and fauna, turning areas of cerrado into pastures and fields.

Consequently, the Xavante territory becomes essential for the region's environmental conservation because it is one of the few areas where extensive and continuous portions of cerrado remain. Occupied by the Xavante in 2009, which in turn led to the formation of the Working Group (*Grupo de Trabalho*) for conducting the studies that resulted in the Identification and Delimitation Report, the Wedezé Indigenous Reserve awaits a decision on its demarcation. If favorable, such a decision must be credited to the Xavante's persistency and, complementarily, the high ethnographic and ethnological quality of the studies that supported the decision and which are available to the reader of *Na Primeira Margem do Rio*.

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