"From Suffering to Citizenship. Tuberculosis, Pharmaceuticals, and Decolonization in Bolivia".

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Abstract

Este trabajo discute el doble vínculo que presenta la enfermedad: individualización o separación de lo colectivo (estigma, por ejemplo), y la adscripción a nuevos modelos de sociabilidad basados en discursos biomédicos y biotécnológicos. Al mismo tiempo, se busca analizar la experiencia de enfermar como parte de otros procesos sociopolíticos mayores, como es el proyecto de la descolonización en Bolivia. De esta manera, en este trabajo la enfermedad del "cuerpo indígena" se analiza marco de la construcción de lo nacional, desafiando así las formas tradicionales de entender estos procesos.

This work discusses illness and citizenship, with a particular focus on medical anthropology. From this perspective, illness presents the subject a double-bind, as it could be at the same time a mechanism of inclusion and exclusion (exclusion through isolation and stigma and inclusion through medicalization). Thus, I suggests illness sets the grounds for a form of citizenship that is "biologically" based, transforming sufferers into citizens. Based on ethnographic fieldwork conducted in Bolivia, I argue that the experience of tuberculosis implies a transformation of sufferers into citizens who are integrated to the state through the engagement with a mandatory pharmaceutical treatment.

In 2004 Eva learned that her cough and pain was due to tuberculosis (TB). At that time she did not really understand what it meant for her life. For her, the doctor's diagnosis implied that she had to follow a treatment and thus cure herself, and got back to work as usual. Unfortunately, healing turned out to be a lot difficult than she expected. Not only she found out that now she would have to bear a huge social stigma, but also her body was not responding to the pharmaceuticals as the doctors expected. Few weeks after her disgnostic, she started to feel headaches, stomach pain, itchy skin, among other symptoms of severe allergy. She had to be *internada* into the TB ward of the Hospital del Tórax in La Paz. Under the strict supervision of one of the specialist in TB, she learned that she was developing "strange" allergies to the medications. This, of course, delayed her TB healing, as she was struggling to survive the allergies. She was not only a "pacientita" but also a "rafita," which is the way that doctors and medical staff call TB patients who develop RAFA (adverse allergic reactions).

In Bolivia, Aymara indigenous people have the highest rates of TB prevalence (205 per 100,000 pop).[1] In Bolivia, as well as in other countries of Latin America, this illness has been medicalized and "racialized" at the same time. In view of this, diagnosed TB patients are stigmatized for both being "Indians" and "sick", which turns them into a target population of "unhygienic Indians." Because of the chronic character of this illness, I argue that in the case of TB there is also a "stigma without recovery" – as presented by J. Jenkins and Carpenter-Song (2005) in their analysis of schizophrenia.

Medicalization refers to the transformation of suffering into a condition of the body that needs to be treated by medical professionals. This process alludes to the expansion of the state authority and to the consolidation of modern forms of social control, which in the case of TB took the shape of a global WHO recommendation: directed observed treatment short course (DOTs). By the same token, pathologization consist in a process of labeling and transforming others into medically abnormal (E. James 2011). DOTs consists on a cocktail of 5 antibiotics given directly by a medical professional

[1] Includes TB+HIV cases (WHO 2011).

(hopefully a medical doctor) to the diagnosed patient. These strong medications are administered for several months (6-24), and therefore for this treatment to succeed the patient needs to complete the required doses. If not, there is high risk of developing multidrug resistant TB (MDR/XMDR), which right now is a threat to public health in developed and developing countries. Therefore, non-adherence is a huge problem for public health. Something that public health agencies are struggling with, since for them abandonment of the treatment is a true mistery. How is TB to be cured if patients do not follow this "free" treatment? To highlight the relevance of agency within the medicalization process, I suggest to use the term "non-engagement" to refer to either the will of not following or abandoning the treatment. This term, proposed by J. Jenkins, has been useful for understanding the embodiment of pharmaceutical therapies and the current configurations of a pharmaceutical self (Jenkins 2010). Contrary to traditional such as non-compliance or non-adherence, non-engagement underlines the role of the patient in defining his or her healing. At the same time, non-engamente speaks of a negotiated healing course instead of a fix, non-flexible treatment to stick to. In this paper I argue that engagement or non-engagement to pharmaceuticals is key in understanding how is it that a chronic infectious disease such as TB becomes a political space that redefines the world of the subject.

Tuberculosis as a Borderland

I suggest that TB constitute a borderland, a space defined by practices that bring together subjects that otherwise would not be linked (Mattingly 2010). At the same time, this borderland refers to a flexible social space where healing takes place. Thus, within this space, patients and their families are also at the forefront, close to medical doctors and other health agents. From this perspective, TB is not only a state of being, but a transformation of the self. A new way of being-in-the-world that is oriented towards transformation.

It is in this borderland where we can observe how national discourses of race, indigeneity, and health converge. Through illness, the self produces and negotiates practices inmersed in a political context: the state. Thus, the TB sufferer becomes a patient who will need to re-define his or her relation to the state from the borderland. TB sufferers reconfigure their world according to culturally (and historically) grounded notions of health, risk, and healing. Furthermore, the "sick" embodies the politics that sustain shared "medical truths" about illness recovery (i.e. biopolitics). Therefore, the pharmaceutical treatment proposed by WHO and the state is only a piece of the therapeutic process. What are the other components of healing?

Political framings of healing and indigenous bodies

Bourdieu and Wacquant's concept of sedimented memory (1992) is a fruitful way of looking at the embodiment of biopolitics. From their point of view, subjects frame their experience according to historically grounded notions and practices. In the case of TB indigenous sufferers embody state-led public health policies oriented towards health and indegeneity as a legitimate zones of state intervention. What has been the role of the Bolivian state in defining healing borderlines?

In considering the question of the meaning of health and well-being in the nation-making process in Bolivia it is important to look back at the numerous attempts to impose particular racial categories as ideals. Historiography shows that race has been a major category for including/excluding subjects from national political projects, particularly among modernizing Latin American nations. Bolivia's liberal state (1880s - 1920s) built a notion of indigeneity that identified the indigenous with the illness. In his 1911 work "Pueblo Enfermo," A. Arguedas discussed the nature of the indigenous peoples of Bolivia, arguing that indigenous peoples embodied the worst characteristics of the Liberal State: sickness, lack of higiene, and backwardness. This provocative argument have turned the discussion of race in Bolivia into a productive sociological discussion where race is a relevant dimension of "production of an

hegemonic language of contention" (Larson 2004/2008:13-14). From the point of view of the ruling elites in Bolivia, racial categories were in fact relevant for nation making. However, just like any social construction, racial categories change over time, something that is even more evident in time of war. The Bolivian case is particularly interesting in evidencing this process. For example, in periods like those of the Chaco war (1930s), when the state needed to recruit the indigenous for battle, gender became "the main modality by which political elites began to redefine the boundaries of difference and sameness (Larson 2005:55). It is worth mentioning that even though gender categories displaced racial ones as the main element of inclusion/exclusion, this does not mean that gender was not "racialized" in the first place. When the state puts forward representations of "ideal" national women and men, these images are already mediated by particular principles and values.[2] Thus, Larson affirms that the elites were blind to potential indigenous uprising – and to the 1952 revolution, for example – failing to contain discontent through institutions that could socialize an inclusionary national ideal, especially after the Chaco war. In view of Larson's argument on the flexibility of these social categories in relation to the historical context, I would like to turn to what is underlies these processes, namely: body politics. From my point of view, medicine has been the interface for the deployment of state' projects among modernizing nations in Latin America. In order to implement national political projects states used a biomedical institutional framework, which – although precarious from its beginnings - had all the means to intervene and discipline the national population, configuring "the national body". In the case of Argentina and Brazil, the state invested in public health offices to distribute health care resources across the country. At the same time, they also funded biomedical research institutions that influenced public health policies across South America. Bolivia, on the other hand, is a good example of how the context of war influenced public health strategies. During the Chaco war in the 1930s, Bolivia's military took responsibility for fighting against infectious diseases that had affected the population for decades.[3] The role of the military in setting up the biomedical institutions adds to Larson's argument on the process of exclusion and marginalization that the indigenous suffered in Bolivia. Although Larson does not refer to the role of medicine – instead, she emphasizes education – I think of medicine as another platform that Bolivian elites failed to implement: during the Chaco war, it was the military and not the governing elites who implemented biopolitics in Bolivia. I suggest that the biomedical institutions socialized and reproduced racialized – and later gendered – subjectivities about the indigenous body that allow an unequal social structure to work for almost all the twentieth century. Visions of the body, and embodied inequalities, were key in the articulation of sociopolitical exclusions in Bolivia and in the rest of Latin America (Rodriguez 2006) and grounded in those historical processes are still part of the political imaginary of citizenship. Moreover, by the end of the nineteenth century, smallpox epidemics resulted in the expansion of the state public healthcare initiatives even to the rural areas.[4] In this way, a citizenship regime based on scientific medicine echoed the notion of the indigenous as the non-modern other, reaffirming the idea that through disease the nation there could also a risk of contagion of indianness and backwardness. Therefore, the nation state needed to regulate social spaces and reorganize the politics of belonging, namely: citizenship. This is a good example of Holston's (2008) definition of citizenship as state's distributions of rights based on difference. Thus, medicine and the state articulate producing a particular modern subject, whose belonging to the nation state was mediated through his or her body.

"Proceso de Cambio" and Decolonization: challenging projects within a challenging context.

[2] An example of this is the advertisement for the national beer "Paceña" that showed a white-mestizo woman dressed as a cholita (with the skirt, the shoes, the hat, and the hairstyle) drinking beer on a glass. The picture stated: "beba cerveza boliviana nacional" (La Paz, *El Diario*, april 13th 1933).

[3] source: Archivo Histórico La Paz, Bolivia [ALP fondo prefectura].

[4] Due to the limits of this paper I will not expand this example. I have further developed this topic in my M.A. thesis on the history of tuberculosis in Chile (2008).

Early twentieth century Argueda's notion of "Pueblo Enfermo" contrasts with the current political context in Bolivia. After E. Morales election in 2005 and the collective construction of Bolivia's new constitution in 2006, indigenous peoples in Bolivia have controlled the state. Morale's decolonization political project questions the core of the historical domination of the elites over the indigenous populations: the language of contention. Thus, in Bolivia, decolonization: *(...)decolonization involves over- throwing the exploitative, unjust, and discriminatory order that persisted beyond independence from Spain and into the twentieth century; it evokes a range of related meanings from liberation to emancipation, democracy, and autonomy"* (Howard 2010).

What are the implications of decolonization in terms of healthcare? Are there any contradictions? And if so, How do they challenge Morales's decolonization project? B. B. Johnson (2010) refers to these contradictions as paradoxes of decolonization: difficulties inherent to the dessign and implementation of a formal state policy and the resulting exacerbation of historical tensions in Bolivia. In his view, decolonization in Bolivia is challenged by institutional oppositions, political oppositions, bureocracy and rivalries, and internal contradictions.

Growing tensions and contradictions between two crucial components of Evo Morales political project mark decolonization in Bolivia. On the one hand, social transformation and modernization constitute the way to answer long-awaited social demands for better national wealth distribution and social justice to overcome centuries of exclusion, if not abjection, of the indigenous majority in Bolivia. These goals require the swift construction of a modern state that actively engages in infrastructure building, democratization, poverty reduction, and improving public health indicators (particularly infant mortality rates, maternal health, and endemic contagious infectious diseases). In short, an all-encompassing modernizing state building process is required to achieve such ambitious transformation. On the other hand, demands for indigenous "affirmative action" that "re-center" traditional cultural values constitute a second pillar for

Bolivia's road to a "radical democracy" (Postero 2011). Alongside with the growing -and politically induced- visibility of indigenous cultural forms and values, currently there is increasing pressure, particularly from indigenous intellectual circles, to translate these claims into tangible public policies. The new VMTI institution is particularly revealing example of these attempts to place indigeneity at the center of the public sphere.

In this context, the question is how can these two components of the political project combine for pulling off Bolivia's change process or proceso de cambio? While there is a need for accomplishing the goals stated in the indigenous constitution Bolivia faces many challenges in terms of healthcare and education (among other problems). With a precarious state apparatus to execute these urgent social programs, there is also a political pressure for launching a decolonization project – which implies an independence from foreign aid). This is a particularly sensible situation, because Bolivia's health care budget is highly reliant in foreign aid like that from World Health Organization and other United Nation's agencies (development programs, child and education programs, etc.) Therefore, even though Bolivia is going through a tremendous modernization of the state, this is not completely adequate due to the high clientelistic networks that Morales administration is setting within the state structures. J. Montesinos (2011) describes this as a superposition of the MAS party (Movimiento al Socialismo) and the state administration of Morales. The result is a weak clientelistic state that moves towards a better distribution of wealth. Within health care and public health policies in Bolivia, there is a lack of human resources and technology to deliver health, especially in rural areas.

The Vice-Ministry of Traditional Medicine and Interculturality (VMTI)

As a result of Bolivia's new constitution, the state pushed for the inclusion of traditional healing into the already established – but fragile – medical "institucionalidad". In 2010, Evo Morales's created a viceministry of "Traditional Medicine and Interculturality" (*Viceministerio de Medicina Tradicional*

e Interculturalidad- VMTI). This institution is in charged of implementing a health reform that considers indigenous medical knowledge as a relevant cultural capital for the development of the Plurinational State. Linked to the Andean principle of *living well* (Suma Qamaña in Quechua), this reform is part of a dialog between two different - and usually excluding - medica models: biomedicine (alopathic medicine) and indigenous health systems. To place this indigenous ontological principle, that promotes values such as complementarity between human life and nature, represents the knot behind the process of decolonization. That is to say, overcoming the legacies of exclusionary and discriminatory colonialism that still permeate the Bolivian society. According to this decolonizing agenda, the privileged locus for such transformation is the state, since it is perceived that the state is the main engine that promotes the continuity of colonial structures. Hence, in this work I seek to problematize the issue of state governance in the context of decolonization by looking at the conflicted situation of installing a traditional health institution parallel to a biomedically oriented ministry of health. Thus, through an intercultural logic, Morales' government created VMTI to integrate the political project behind "vivir bien" into the biomedical dominion. This is mainly done by integrating traditional healers and midwifes to hospitals. As one can guess, it has not been well received by the biomedical professionals, who see this policy as a threat to the health of the population and to their own status. Amidst the difficulties in allocating resources for healthcare, Morales' government has increased promotion of health programs by distributing direct bonus to "compliant" mothers who take their children to the health care center for vaccination and controls (bono Juana Azurduy). Indigenous healers contribute to the health promotion by delivering preventive healthcare. Yet, despite this huge contribution, they render their service as limited when it comes to infectious diseases. The conflicted relationship between biomedicine and traditional healing in trying to "govern" illness is at the center of a broader process of decolonization that ultimately is targeting the "nation's body". Here I argue that within the process of decolonization we find multiple layers of meanings and practices that have been historically constructed.

Biocitizenship, Medications, and Risk

From the patient's point of view, debates about decolonization are seen to be extremely important, since they depend on the services that the state provides for curing TB (and other ailments). However, even though a decolonized healthcare system would underline the role of indigenous healers and their knowledge, there uncertainty about the outcomes of such a reform. On the one hand we find a strict medical treatment provided by the state; on the other hand, sufferers who need to become patients and "adhere" to this treatment in order to exercise their rights.

Retaking Eva's experience of TB in Bolivia, we can see the complexities of becoming a TB patient. In her case, the fact of developing strong allergies extended her treatment to more than two years. This helped her to strengthen her commitment to improving other patients's lives, and along other "rafa" patients she worked in Aspacont (tuberculosis patients association). She sees Aspacont as a window of opportunities for integrating - and "keeping" - TB patients to the treatment. For many, she said, "TB is a curse" (una maldición). Aspacont tries to show the patients that they can be cured if they follow the doctor's instructions. Among other things, Eva visits new patients ("pacientitos") to "translate" the diagnosis to a more comprehensible language. Eva described to me the different categories of TB patients, and how is it that they become involved in the organization. Membership starts, she said, by the moment of diagnosis: "once diagnosed with TB, one automatically becomes a member of Aspacont." However, she mentions that because of the characteristics of the treatment, "rafitas" are involved the most, as it is crucial for them to know about their medications and possibilities of accessing healthcare services.

The different categories of TB patients ressembles what happens in other contexts/illness, such as Leprosy in Brazil (White 2009) or Chernobyl victims in Ukraine (Petryna 2002). As described in

those cases, instead of being a "curse", illness becomes a mechanism for political inclusion and risk management. I call this a double-bind of illness because of the possibility of being a mechanism of inclusion and exclusion at the same time (exclusion through isolation and stigma and inclusion through medicalization), which sets the grounds for a form of citizenship that is "biologically" based. In her work, Petryna shows that there are multiple contradictions in becoming a "sufferer" – a citizen that can exercise his or her citizenship. This is particularly interesting in terms of identity politics, because of the importance of medicalized power relations in the subject-making process where the Chernobyl-personhood is a survival strategy that legitimates structures of social inequalities that are consequences both of the radioactive accident and of the economic transformation (and crisis) in Ukraine. Extending her argument to the case of TB sufferers in Bolivia, I suggest that the developments of TB biomedical treatment and its effects in the symbolic realm show how an "objective" natural disease is integrated into the nation's social mechanisms of inclusion/exclusion by framing the infection within social constructions of race and ethnicity. To put it differently, the state intervenes indigenous bodies through medical institutions, which turn to be the link to the political arena. Briggs and Mantini-Briggs explain this process by setting the concepts of sanitary citizen and unsanitary subjects.

(…) Those whose habits and mental dispositions seemed to place them beyond cholera's grasp were construed as sanitary citizens (…) The state assumed the obligation of protecting them from Vibrio cholerae after suggesting that they were in any case unlikely to be infected. Persons whose ignorance, place of residence, occupation, poverty, race, and unhygienic habits placed them at risk for cholera became unsanitary subjects (…) Because the bodies and minds of unsanitary subjects seemed to be inseparable from their despicable environments, the state had to protect them from their own natures and desires - in short from themselves. At the same time, the state isolated its unsanitary subjects because its sanitary citizens had to be protected (2003: 33).

These concepts are connected to medicalization, and, as I argue in this paper, are also linked to a pathologization processes. It is particularly interesting to me how these interpretations play out within the neoliberal state, a state that reduces control but needs disciplined bodies to "function" in a market-oriented society. In countries like Bolivia, privatization of healthcare resulted in decreasing state welfare for those sanitary subjects who had rights to it. Because engaging or not is so important for defining a biologically based political inclusion, the experience of "rafa" patients is a good example on the mechanisms at work. The increase in patients who develop adverse reactions is puzzling for Bolivian health authorities. Patients develop allergies so strong that could even kill them if not treated on time. Indeed, this conditions turns out to be an illness on itself. Thus, non-engagement, an "irrational" choice from the medical point of view, represents a reaction to institutional interventions from a state that excluded "unsanitary subjects" from the national society. A state that did not offered integration through medicalization, but rather excluded through pathologizing the unhygienic other, the "unhygienic Indian". The "unhygienic indians", however, developed their own strategies and framings of TB, their own ways of thinking about this terrible illness.

This research triggers multiple questions not only about the importance of medical discourse in shaping citizenship, but opens debates about the embodiment of sedimented inequalities within the neoliberal state.

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