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Ujuk Usu. Medicine, Tuberculosis and Race among the Aymara of the border between Bolivia and Chile.

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy

in

Anthropology

by

Paula Francisca Saravia

Committee in charge:

Professor Nancy G. Postero, Chair
Professor Thomas Csordas
Professor Cathy Gere
Professor Christine Hunefeldt
Professor Janis H. Jenkins

2015

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The Dissertation of Paula Francisca Saravia is approved, and it is acceptable in quality and form for publication on microfilm and electronically:

Chair

University of California, San Diego

2015

DEDICATION

To Jorge

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FIELDS OF STUDY

Major Field: Anthropology

Studies in Medical Anthropology

Studies in Global Health

Studies in Anthropology of Latin America

ABSTRACT OF THE DISSERTATION

Ujuk Usu. Medicine, Tuberculosis and Race among the Aymara of the border between Bolivia and Chile.

by

Paula Francisca Saravia

Doctor of Philosophy in Anthropology

University of California, San Diego, 2015

Professor Nancy G. Postero, Chair

This comparative qualitative multi-sited study examined the experience of tuberculosis among the Aymara in the border between Bolivia and Chile and the links between the illness experience of tuberculosis and the two biopolitical frameworks that are implemented by both states. I show the intricate ways in which Aymara across national borders deal with issues of health and illness; and the Aymara illness semantic network in connection to institutional biomedical practices and the Aymara medical system. Along both sides of the Bolivian-Chilean border, Aymara indigenous people suffer from tuberculosis at much higher rates than the mestizo-elite population. Based on ethnographic research conducted during three preliminary visits in the summers and winter breaks of 2009, 2010, 2011 and during a longer stay of eight months in 2012 and 2013, I analyzed the big difference between the prevalence of TB in these two countries by looking at the national anti-tuberculosis programs and the sociocultural and political mechanisms that shape the everyday life of indigenous peoples in each country. I found that on each side of the border, the Aymara patients struggle with issues of precarity in particular ways. In Chile, they face economic instability and political exclusion, they are highly medicalized. In Bolivia, instead, there are structural constraints that prevent the medical providers from fully delivering healthcare to Aymara communities. Aymara patients contest the treatment by integrating the indigenous categories of suma qamaña (to live well) to the everyday struggles for achieving prosperity and health for themselves and their families. The Aymaras refer to this as *"salir adelante"* (to come through). My analysis of tuberculosis among the Aymara demonstrates the political dimension of the medicalization process and its relevance in understanding the embodiment of structural inequalities that transcend national borders.

INTRODUCTION

When I was growing up, one of my grandmothers talked to me about the times in the early 1940s when she worked as a visiting nurse delivering care and education on tuberculosis to the people in the hills of Valparaíso. My other grandmother also told me about her experience as a TB patient in the early 1960s, and how difficult it was for her to be admitted in the hospital for several months while her children were at home. The emotional stress of this long-term separation left another scar in her body: she had a surgery intended to compress the infected lung, a medical treatment called pneumothorax. These two different experiences lingered in my life for many years until I learned more on the matter of emerging infectious diseases and culture. Why did they have such different experiences? How was this process linked to issues of inequality? What were the meanings of tuberculosis in contemporary Chile? Who was getting sick from tuberculosis in Chile and why? And, in trying to answer these questions it was evident to me that to an illness like tuberculosis is connected to larger sociohistorical and political processes that transcend individual life histories.

I was told that tuberculosis was a disease of the past, of poverty. Yet I knew that people were still suffering from this illness. How did tuberculosis patients deal with this illness? As I completed my undergraduate studies and research I formulated an even more pressing question. How do Aymara across the national borders deal with issues of health and illness? How to look at the subjective experiences of illness in connection to two very different state projects?

In this dissertation I elaborate an argument about the experience of illness among transborder Aymara communities of Bolivia and Chile, demonstrating that within indigenous contexts, chronic infectious diseases such as tuberculosis become a space of resistance to the different biodisciplinary frameworks imposed by each state. I discuss a relevant contradiction: biomedicine's significant contribution to public health and the impact of antibiotics in tackling infectious diseases, and the work of indigenous healing (and popular medical systems) in crafting meaningful illness experiences. On the one hand, TB patients all over the world would benefit from accessibility to good quality antibiotics. On the other hand, delivering antituberculosis treatment challenges indigenous therapeutic pathways.

In other words, in this research I present the biomedicine/indigenous medicine binary not as oppositions but as a continuum set of medical practices where the Aymara sufferer/patient navigates. Despite the multiple efforts for implementing a National Intercultural Health Program in Chile, or the Vice Ministry of Intercultural and Traditional Medicine in Bolivia, the practices promoted by allopathic medicine (or biomedicine) limit the possibilities medical providers have to integrate the necessary changes for delivering intercultural healthcare. In the biomedical framework, the relationship between medical providers and their patients requires passive patients' bodies. In Chile, this process is accentuated by the state-led neoliberal project that is oriented by discourses of race and nation in which the indigenous body is seen as backwards, and an obstacle to social change. In apparent different ways, in both countries, indigenous bodies become a space of governance crossed by racialized ideas and practices, which are produced and reproduced in medical encounters. Hence, I argue that both medical providers in different institutional positions and patients reproduce race-based discourses through everyday institutionalized practices that maintain structures of discrimination and social exclusion.

1. TUBERCULOSIS "SILENT KILLER"

The illness we know call tuberculosis is a contagious infectious disease caused by Mycobacterium tuberculosis, part of the complex tuberculosis *(M. tuberculosis, M. africanum and M, Boris).* It is transmitted via droplets from the throat and lungs of people with the active respiratory disease. These respiratory secretions, called *Pflüger droplets,* are produced when coughing, snoring, screaming, talking or simply breathing. According to the World Health Organization (WHO), even small amounts of these droplets result in infection; so if not treated properly, a sick person may "infect on average between 10 and 15 people every year" (WHO fact sheet 104). But in 90% of the cases people infected with TB bacilli will not develop any symptoms. This is because the role of the immune system is to encapsulate the TB bacilli, which can remain in the body for years, waiting for the immune system to be weak. A global leading cause of death, around 9 million people developed TB in 2013 (WHO TB report 2014).

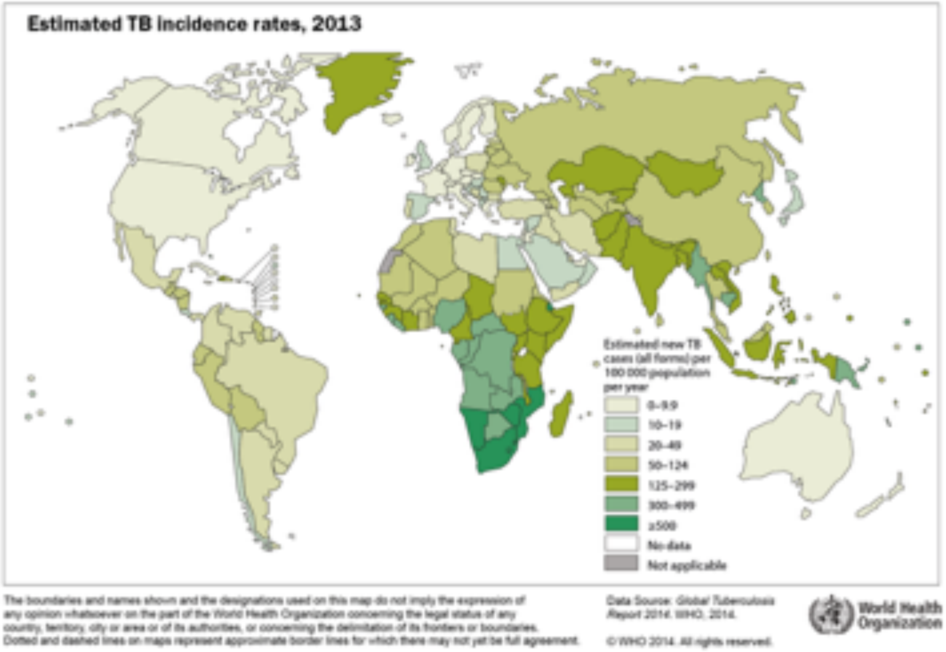

Figure 1 Estimated tuberculosis incidence rates 2013. Source: WHO Global Tuberculosis Report (2014)

Even though there has been an improvement in the early detection and diagnosis of tuberculosis, there are still regions of the world that have high burdens of TB (incidence, prevalence, and mortality). Tuberculosis is a curable disease, but a good treatment outcome depends on early detection and diagnosis, which is of course relative to the biotechnology available in each country to detect the bacilli, especially if it is a multidrug resistant case, or one linked to HIV Aids. If we look at the epidemiology or the distribution of this disease in the world we can see a projection of new cases that is higher in lower-income countries. In South America, the World Health Organization (WHO) statistics show that TB incidence[1] in Bolivia and Peru are higher than Argentina and Chile (figure 1).

By looking at these statistics in relation to national GNPs, we can also observe that it is not a coincidence that Bolivia (GNP per capita of US$5,750) has one of the highest prevalence rates of South America (209 per 100,000 pop) while in Chile (GNP per capita US$21,030) the situation is similar to that of the developed countries (25 per 100,000 pop). A traditional economicist explanation would be that TB is associated with poverty. Yet, if we looked deeper into the statistics themselves, we find that there is also a distinct association between this communicable disease and race. According to Heargreaves et al. (2011) besides TB diagnosis and control, health interventions should have a focus on social determinants of health such as race. How do racial categories influence TB distribution in Bolivia and Chile? How do poverty and epidemiology of TB map onto the indigenous demographics of each country?

1.1. Social conditions of tuberculosis

In Chile, where TB programs started in the early 1930s, Mapuche and Aymara indigenous people have the highest TB rates. The BCG vaccination program and the

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[1] Prevalence and incidence are two distinct concepts used in epidemiology to account for new cases in a geographical region during a year (incidence) and the total number of cases during a year (prevalence).

National TB control Program (1973) are of evidence Chile's national public health efforts in epidemiological control and surveillance. In this sense, unlike Bolivia, Chilean public health policies aim for a total eradication of TB (2018), targeting TB primary and secondary infection (particularly among the elderly). The fact that TB is higher among the elderly is considered in the differentiated strategies: young active TB patients (Arica main hospital) and elder Aymara *secuelados* (relapse patients) living in the highlands (non-infectious inactive TB).While indigenous peoples represent 62% of the Bolivian population (self-declared indigenous in the national census of 2012), in Chile only around 5% declared to belong to an indigenous ethnic group (national census of 2002). The Aymara indigenous peoples in Chile live mostly in the Arica-Parinacota region (see figure 2). According to Chilean Ministry of Health, Aymara indigenous peoples living in Parinacota area have the highest TB incidence rates (41.9 per 100,000 pop). In Bolivia, on the other hand, most of the Aymara live in the department of La Paz (see figure 3). Of the total number of cases, indigenous populations of the department of Santa Cruz have the higher risks of TB infection (Guaranies, Mojeños, and Chiquitanos). In the department of La Paz, Aymara of Yungas and Sud-Yungas also have high TB risk (PNCTB 2008). The national statistics, however, are not very accurate, which is one of the biggest challenges for public health interventions in Bolivia (WHO/PAHO). Aymara mobility across – and outside Bolivia - presents another difficulty to any standardized intervention because of the complexity of delivering healthcare to scattered and mobile population.

In Bolivia, the National TB control program started in 1982, and its main focus are diagnosis, treatment, and the implementation of preventive measures in primary health care facilities. Pulmonary type of TB accounts for 70% of the total number of cases. There has been a smooth but consistent drop in new cases, influenced by the implementation of DOTs in high-risk municipalities in 1994 (164 to 105 per 100,000 pop) and the increase in the BCG vaccination program coverage to newborns (94% in 2001). Both of these public health measures have helped to reduce the development of TB infection in the cities as well as in rural areas (World Bank 2004).

Figure 2. Tuberculosis Incidence Rates (all forms), Chile 2002-2012. Graphs and Map show that the regions with high indigenous population are also the regions with higher TB incidence. Source: Ministry of Health online database.

In view of its characteristics and history, tuberculosis has been called a "silent killer" (NPR 2013). It affects mostly groups of individuals whose living conditions are precarious, it can be a latent infection for years and unlike HIV-Aids, it may never show, it is highly stigmatized (due to its historical associations with poverty and inmoral living styles) and those who suffer from it usually experience a long and extreme treatment, which may even kill them before TB does. All of these social determinants shape the circumstances surrounding TB as an illness. Thus, tuberculosis is major health menace for Aymara peoples in Bolivia and Chile. For international public health officers working in Bolivia, non-compliance constitutes an obstacle for the success of TB control programs because abandonment of the treatment may result in multidrug resistant TB. Concurrently in Chile, indigenous TB sufferers are the main target of public health policies through their status of poor patients.

Figure 3. Indigenous communities of Bolivia. Source: Ministerio de Asuntos Campesinos y Pueblos indígenas Originarios de Bolivia (2002).

1.2. The biomedical treatment for tuberculosis.

Bacteriology and consequent developments of pharmacology such as specific antibiotics, effective vaccination campaigns, and chemical prophylaxis, have influenced contemporary framings of TB since the global introduction of the first line of antibiotics in the 1940s -streptomycin (1944) and isoniazid (1952)-, giving biomedicine the “real possibility” of healing. Before antibiotics, TB treatment relied on long periods of rest in a sanatorium, as well as risky and painful pneumothorax surgeries that helped to compress the lungs, like the one my grandmother had. A chronic illness like tuberculosis “was the means by which the mortal body, taking either a natural or accelerated course, began its inevitable breakdown” (Greene 2007:10). Since the global implementation of the new drugs regime, delivering antibiotics to the diagnosed infected TB sufferers became the dominant - if not only - global strategy for eradicating TB. This faster ambulatory treatment, however, requires timely diagnosis, understanding and trained medical staff, as well as adherent patients.

In recent decades, the WHO developed a global program to control tuberculosis with a recommended pharmaceutical regime: Directed Observed Treatment shortcourse (DOTs). This free-of-charge program is based on the principle that a trained health care provider will deliver the medications to the patient, and make sure that the patient takes the correct doses of antibiotics during 6 to 9 months of treatment. The DOTs program was created as a way to reduce the possibility of antibiotic exchange, for example, and thus blocking the emergence of multidrug resistance TB (MDR/TB) that results in part from patients' re-treatment. National TB control programs distribute the treatment regime recommended and provided by WHO within their national health care networks, so the success of the strategy is determined by both the engagement of the patient (adherence) and the institutional resources to identify the TB patient and keep him or her in the system. Medical doctors and nurses participating in DOTs are also required to keep rigorous records for global statistics.

DOTs patients receive a daily cocktail of antibiotics given directly by a medical professional (hopefully a medical doctor) in a clinic or, in particular cases such as isolated communities, in the patient's home. There are ten antibiotics available for curing TB, and five are the most common: isoniazid INH, rifampin, pyrazinamide, ethambutol, and streptomycin. Each antibiotic has different side effects, and the combinations depend on the scheme chosen by each country. These strong medications are administered for several months (6-24), and patients must complete the required doses to be cured. If not, there is high risk of developing multidrug resistant TB (MDR), or extreme multidrug resistant TB (XMDR), which is a global threat to public health.

There are two kinds of treatment: one for latent TB (when the bacteria is not active but still present in the body) and another for TB disease (active bacteria with possibilities of contagion to healthy individuals). For latent TB, the core of the pharmaceutical treatment consists in the regular intake of a combination of antibiotics: isoniazid (INH), rifampin (RIF), and rifapentine (RPT) for a period of 6 to 9 months. In the case of TB disease there is one recommended treatment regime, which is divided in 2: initial phase of 2 months and a continuation phase of 4 or 7 months depending on the characteristics of the patient (children and HIV patients, for example). There are 10 drugs approved by FDA but the main anti TB agents are: isoniazid (INH), rifampin (RIF), ethambutol (EMB), and pyrazinamide (PZA) (Center for Disease Control CDC and WHO stop TB program).

2. TRANSNATIONAL AYMARAS: ACROSS DECOLONIZATION IN BOLIVIA AND AUTHORITARIAN NEOLIBERALISM IN CHILE

The Aymara communities of Bolivia and Chile share a common historical Andean tradition. Having their own languages and social organizations, they form a diverse transnational ethnic group that traverses the highlands in multiple circuits that range between the Yungas in Bolivia to the coastal city of Iquique in Chile, and even beyond the Pacific Ocean to China. While contemporary Aymara people in Bolivia claim to be a nation, in Chile they are a target of homogenizing nationalistic discourse promoted by the Chilean state. Poverty and historical social exclusion are common elements for Aymara living in both countries, although the situation is changing in Bolivia (Tassi et al 2012).[2] The United Nations and the World Bank have identified structural conditions of inequality,[3] which limit indigenous peoples' abilities to participate in the political realm (Eclac 2012). Social constructions of race in the two countries still play an important role in determining human development and opportunities for social integration of the Aymara to national societies. Furthermore, economic policies and social structures are social determinants of health. Hence, race influences health conditions as well as access to health care. Yet, rather than discussing the issue of race, in both Bolivia and Chile there is an emphasis on ethnic differences and identity. There are some differences in how the ethnic/racial difference is confronted from the point of view of the state and the dominant classes, and from the perspective of the indigenous themselves, of course.

During the nineteenth century Chile experienced continuous processes of change in many areas. Including migration flows from rural areas to urban settings in the 1860s, such as, migration to other countries (including the U.S.), the 'War of the Pacific' (1879-1885) – which led to the control of the nitrate territories- and the so called *"Pacificación de la Araucanía"* in the south, aimed for the political integration

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[2] Eclac (2000) estimated indigenous population to reach 82% in Bolivia, while in Chile they represent no more than 5% of the national population (Chilean Census 2002). Unfortunately, there is no reliable data from the 2012 census to compare because of inaccuracies in the design and gathering of the data in both Bolivia and Chile. In the dissertation I rely mostly on national estimates or WHO data.

[3] These statistics also show that among both urban and rural Aymara and Mapuche households, poverty rates are at least 7 points higher than in non-indigenous. Furthermore, poverty among rural indigenous households is more acute (Agostini 2010). Of the total of households living below the line of poverty, 32% corresponds to indigenous people (compared to the 21% of non-indigenous). In Bolivia poverty has decreased from 61 to 49%, showing success of Evo Morales' redistribution programs (bono Juancito Pinto and Juana Azurduy, for example). However, there is still a high prevalence of poverty – and extreme poverty – in rural areas (80% of those are indigenous peoples).

of the Mapuche indigenous communities to the national territory. P. Richards's analysis of the violent role of the state in building the notion of race as associated with the national identity is interesting when considering the meanings of a *Raza Chilena* (Chilean race). In examining race and racism in Chile, P. Richards calls attention to the historical traces of state violence in current forms of racism towards the Mapuche in particular. She affirms: "The history of the *Pacificación* and initial colonization exposes very direct and physical violence against the Mapuche. After colonization, physical violence persisted, but new forms of material and symbolic violence developed as well, pursued in local courthouses and everyday interactions" (2013:42). According to her, there is a socio-symbolic foundation for the correspondence of race and nation in Chile, which coexist with the neoliberal reforms and structural adjustments imposed during the Dictatorship. In her view: "racial and cultural hierarchies not only played a pivotal role in shaping social relations in the Araucanía in the past, but also pose serious stumbling blocks for the future of Chilean democracy" (2013:9).

In this sense, the nation-making processes in Bolivia and Chile were different. In Chile, there was an accelerated and violent state-led "chilenization" process that started with the occupation of the Mapuche territories and that by the last decade of the nineteenth century promoted the institutional expansion of the state in the recently incorporated regions of Tarapacá and Antofagasta, a process that was "settled" mainly through education (elementary school) and health care (health care centers).

Almost a century later, during Pinochet's dictatorship (1973-1989) the continuous process of "chilenization" was accentuated by the latent military conflict between Chile and Argentina, which impelled the installation of military posts in the Andes. As a consequence of the latest "chilenization" campaign, there are strong nationalistic feelings among these communities, who identify themselves as "*Aymaras chilenos*."

I would like to bring up another way that the Chilean Aymara have for differentiating themselves from the Aymaras of Bolivia or Peru. They say: "we are not Indians like the Aymaras of Bolivia" or "the Aymaras of Bolivia are Indians, we are Chileans." There is also a strong association between gender and race within the national discourse in Chile, which is illustrated by assertions such as "we the Aymaras are the first line of defense of Chile." This statement echoes M. de la Cadena's argument about indigeneity and gender constructions in the context of race transformation in Peru (1995). Marisol de la Cadena argues that inner community differentiation – particularly gender – places women in much more precarious conditions because their labor is not socially valued as work as it is for men. Additionally, land inheritance and tenancy traditions do not favor women at all.

Despite these nationalistic discourses and the academic prediction of total chilenization (Van Kessel 1980, Grebe 1978), Aymaras in Chile share a lively traditional life in both rural and urban settlements. Like in Bolivia in the 1990s, in Chile neoliberal multiculturalism promoted ethnic pride among the Andean communities on the Chilean side. In this context, the Andean communities on the

Chilean side call themselves the “border keepers”, as they protect all Chileans from the less developed, backward “Indians” of Bolivia. During fieldwork in 2006, when I asked about this difference, instead of referring to the structural conditions of inequality and poverty, the Aymaras of Chile stated that high prevalence of TB is an expression of Bolivia’s underdevelopment due to the presence of “so many Indians,” demonstrating a clear association between tuberculosis, poverty, and indigeneity. The same was corroborated by the former ministry of health, Dr. Jorge Jimenez de la Jara, who talked about the homogeneity of the Chilean population as a facilitator for public health interventions and improvements as opposed to Bolivia. I further discuss this in chapter 1.

During the last 40 years Chile, has adapted to a liberal economy, which implied the adoption of different social dynamics (urbanization processes, new lifestyles, change in family structure and gender roles) that in the process have affected the health of the population. Following the Washington Consensus (Williamson, 2004), Chile implemented economic policies that imposed a neoliberal model based on fiscal discipline, trade liberalization, competitive exchange rate, privatization, and deregulation of the market (Schild 2008, Harvey 2005). As a result of authoritarian and focused health care policies, during these decades, Chile consolidated an epidemiological transition, dramatically reducing rates of infectious diseases and infant mortality rates.[4] A main feature of the structural adjustments of the early 1980s was the privatization of health care and the *municipalization* of public healthcare services. Consequently, care became an individual responsibility. Beyond the mere cost of care, the retreat of the state welfare was accompanied by the imposition of a national morality based on private property and individual risk management. The democratic parties coalition, called Concertación, that ruled for two decades after the recovery of democracy in 1989 (*recuperación de la democracia*) not only maintained the neoliberal project, but also strengthened it by developing strategies of social control aimed at achieving "social peace" (*paz social*). Such economic and social policies shaped the current epidemiological profile of the country. Nowadays, current epidemiology shows that the Chilean population suffers mostly from non-communicable diseases, and the prevalence rates are similar to those observed in developed countries (hypertension, diabetes, obesity).[5] In a few decades Chile transitioned from high infant mortality rates due to infectious diseases to what have been defined as "diseases of affluence." For a long time international public health institutions and the Chilean state itself presented this epidemiological transition as proof of the success of economic reforms. Also puzzling was how those improvements in terms of health care were possible in the context of privatization of healthcare and

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[4] Health care reform was one of what Pinochet and his "Chicago Boys" named as "seven modernizations" (1979), and a new constitution (1980) characterized the last decade of the dictatorship.

[5] The major risks for adult health are: current tobacco smoking (41% in 2011), alcohol consumption in liters of pure alcohol (9.6 in 2010), raised blood pressure (33.9% in 2008), and obesity (29.4% in 2008).

the reduction of public expenditure in healthcare? Fast epidemiological changes such as those experienced in Chile were, however, misleading. An emphasis on the lower rates of infant mortality were shadowing other health issues such as mental health. In fact, recent reports estimate that in Chile, neuropsychiatric disorders contribute 30% to the global burden of disease (WHO 2011).[6] In her ethnography on neoliberal subjectivities and health in Chile, anthropologist Clara Han brings up subjective experiences of suffering related to unresolved political violence after the dictatorship and increasing individualism and violence in the context of social inequality (Han 2012). She argues that in Chile there has been a continuity of different forms of political violence, some of which originated in the dictatorship, whereas others were developed as part of the reconciliation process. C. Han refers to two different kinds of debts, one related to overcoming the conditions of inequality established by the dictatorship neoliberal project (*deuda social*), and a second moral debt, that of bringing justice to the victims of human rights violation.

In summary, in Chile notions of race and nation are linked to but obscured by neoliberal multiculturalism discourses that render all citizens "equal" while violently discriminating against indigenous identities that question the homogeneity of the nation.

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[6] According to the WHO, approximately one-third (31.5%) of the population has had a lifetime psychiatric disorder, and 22.2% have had a disorder in the past 12 months. Over 60% of the total population expected to have a mental disorder do not receive treatment (WHO 2015)

For its part, in Bolivia issues of race and ethnicity articulate in slightly different ways. Just like in the Chilean case, indigenous peoples have been long stigmatized as dirty, "naturally underdeveloped," and backwards (*atrasados*). However, the forms of racism and the magnitude of social inequality between indigenous and non-indigenous took a different shape because of the particular developments in Bolivia. In his work, Bolivian intelectual R. Zavaleta Mercado puts forward a debate on the reformulation of national identities based on the relationship between what he names the "general national crisis" and the conjecture of a multiplicity of economic and social developments that together form a unique and differentiated society: *sociedad abigarrada* (1974). For Zavaleta Mercado, the political is embedded in diverse histories that produce "intersubjectivities in diversity". At the same time the idea of *sociedad abigarrada* means the perpetuation of Bolivia's unfinished foundation as a political collective: the lack of an authentic national and popular project. Zavaleta's discussions on the political formations in Bolivia as responses to crisis and heterogeneity have greatly contributed to current debates on race and ethnicity in the context of an indigenous-led/plurinational state.

Later, scholars like S. Rivera Cusicanqui have discussed the social history of race in Bolivia by focusing on the struggles of indigenous peoples in relation to the state. According to her, indigenous peoples in Bolivia have articulated their demands in terms of rebellion while the state has violently oppressed the indigenous (1980). However, historical exclusion and repression have shaped the very sense of agency among indigenous peoples. Paradoxically enough, indigenous consciousness and its emancipatory project are the result of sedimented memories of systematic exclusion. In other words, as racism, exploitation, and repression abided they planted the roots of the sociohistorical process that will overcome them.

Rivera Cusicanqui also argues that while oppressing the indigenous, the Bolivian state has also manipulated them (Rivera Cusicanqui 1980) by implementing social projects such as elementary education in rural areas. Some of these programs benefited indigenous communities, especially those linked to education and with access to land (agrarian reform). Yet, as noted by S. Rivera Cusicanqui and other scholars, in the long run, because of structural inequalities in terms of access to land, labor, and political inclusion, indigenous peoples have bore the brunt of most of the detrimental effects of the colonial regime, post-independence national projects, the rise of the corporate state (after the 1952 revolution), and lastly, neoliberal reforms (1980s-2000s). All of this left a legacy of poverty and structural inequalities in the distribution of income, which added to historical processes of racial exclusion that resulted in infused anger and frustration among the indigenous peoples, who employing the weapons of neoliberal multiculturalism overturned the process, changing the established political structures to their advantage (Postero 2013, 2007). By electing Evo Morales, the first indigenous president, Bolivian indigenous peoples unleashed a process of national transformation, at the core of which we find a contested discourse of indigeneity. As an indigenous-led government that is pushing forward a “decolonization project,” Morales’s government has transformed the ways in which citizenship is defined because, contrary to the previous decades, now indigenous people are rapidly achieving a leading role in defining their nation (Postero 2013). Morales’s project to transform the state works by articulating the important concepts of decolonization and interculturality (Johnson 2010). It also implies the transformation of the state into a plurinational state, which now aims to integrate national indigeneity and economic development (Bautista 2010, García Linera 2010). The two dimensions noted by B. Johnson are helpful to delineate some of the contradictions of the whole process. At the center of Morales’ challenge to the colonial state there was a quest for re-framing race. However, as R. Bautista observes, there is a basic unresolved question on the possibilities of a plurinational state without a plurinational content (2012: 166-167). Hence, to build a plurinational state depends on the transformation of modern institutions that are still based on a contempt for the Indian and the indigenous communities (2012:166). And, from my point of view it is in the critique of the race-based colonial structures that the intercultural and decolonization components of the political process converge. C. Walsh argues that a critical intercultural perspective is constructed from within the colonial structures that undermine the possibilities of the indigenous’ conditions of existence (2009:78). Thus, a critical intercultural project is a political project that involves indigenous and non-indigenous people.

Social indicators such as poverty[7] show that changes implemented during Morales's government have an impact on rural and urban indigenous and non-indigenous people. Good examples of these transformations are education and health programs. policies such as those analyzed by B. Johnson (2013, 2010). Current literacy programs implemented by Evo Morales have changed the historical trend of low life expectancy rates and high infant mortality and maternal death. Yet, these interventions are part of a broader problematic process of building a plurinational state looking towards a "new national culture based on indigenous principles" (Canessa 2012 in Postero 2013:109), which anthropologist N. Postero calls "Andean Utopias" (2007). In her work, Postero shows evidence of the difficulties of making possible the project of a plurinational state based on a particular notion of indigeneity while continuing to rely on the old neoliberal extractivist model (Postero 2007). Example of this is the preponderance of the Andean principle of *suma qamaña* (to live well) and the proclamation of the rights of Pachamama (Mother Earth) on the one hand, while building a highway in the environmentally rich TIPNIS (Fabricant and Postero 2013) or extracting oil in Tarija's lowlands (Anthias and Radcliffe 2013), on the other.

After a constituent assembly (2006-2008), Bolivia adopted a new constitution in 2009, and part of the consequences of this is a reorganization of the public health structures and policies. At this point, the state pushed for the inclusion of traditional

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[7] World Bank statistics show that poverty head count ratio at national poverty line decreased from more than 60% in 2005 to 45% in 2011.

and intercultural medicine into the biomedical dominion, creating a vice ministry (*viceministerio*) that could implement programs for integrating traditional healers and midwives to hospitals. Vice minister A. Camaqui undertook his position within Morales' government in 2010. Before that, he had worked with strong indigenous organizations that challenged the government in several instances, namely CONAMAQ (Consejo Nacional de Ayllus y Markas del Qullasuyu). Minister Camaqui was trained in the intercultural health approach by M. Sáez in Chile, and in his years in the vice ministry promoted intercultural initiatives as part of the plan Health for All (*Salud para Todos).* These plans have not been well received by the medical profession, who see this policy as a threat to the health of the population. Their concern is based on the fact that in a country with high prevalence of infectious diseases and a high infant mortality rate, the success of traditional medicine is very limited. The traditional healers are concerned about this as well. They agree in that traditional medicine prevents illness from happening, but unfortunately it does not cure infections. B. Johnson's research on issues of maternal health in the context of decolonization shows that despite its multiple achievements, the decolonization discourse has not succeeded in changing the power structures within the medical system (Johnson 2013). This is an important ongoing debate in Bolivia now (2015), when government and civil society are pushing for a long awaited health reform.

According to health indicators such as that of TB prevalence, in both countries indigenous peoples still embody social inequalities. In Bolivia there is a health program that aims to overcome this situation by integrating traditional medicine into the public health institutions; in Chile there is a persistent intercultural health policy that maintains biomedical authority, placing traditional healers in a secondary position. Nevertheless, in this dissertation I show that both health policies are expressions of neoliberal multiculturalism. I ask, from the perspective of TB sufferers, what are the consequences of both neoliberal – private – health care approaches and "postmulticultural" (Postero 2007) state projects? How do these two medical models shape possibilities of recovery?

This research contributes to the growing debate on race and inequality in the context of state interventions by presenting ethnographic evidence on the lived experience of indigenous peoples and their struggles to overcome structural conditions of precarity.

3. RACE AND NATION IN BOLIVIA AND CHILE

Current anthropological definitions of race emphasize social constructions of difference that have visible implications in the ways people experience everyday life. Moving away from biologically based definitions of race, P. Wade argues that race is a discourse in which we find cultural representations and practices that are grounded in power relations (Wade 2003, 1997). As M. Weismantel argues, rather than a question of biological difference, race originates in history (1998). What is the history of those power relationships in the Andes?

Thinking about race in Bolivia and Chile from a historical perspective contributes to understanding the trajectories of national discourses and their link to colonial encounters as well as the transformations of the national frameworks where racialization occurs and racial categories operate.

In this dissertation I draw from M. Foucault's theorizing of power, particularly biopower and governmentality. I find Foucault's elaboration on modernity appealing as he analyzes the role of enlightenment, governmentality, and the technologies of the self in configuring modern political structures. Foucault argues that the "modern" self is the one who is aware of his or her time and the challenges and contradictions of power (2010). Thus, the modern self becomes an important actor in the actualization of ideas of modernity that enlightenment pushed within Europe and its colonies, especially those ideas related to race. However, a historical analysis shows that it would be wrong to assume that the colonies imported said discourses of race. On the contrary, scholars like N. P. Applebaum, A. S. Macpherson and K. A. Rosemblatt demonstrate that different racial classification systems coexisted and overlapped in Latin America, and that those systems were not only based on biological categorizations but were also sustained by interpretations and cultural frameworks (Applebaum et al. 2003:10). Furthermore, they argue that in Latin America, "race and nation have been conjointly constructed and projected in spatial terms" (Appelbaum et al. op. cit.). This argument is compelling when thinking about transnational Aymara communities, as it grounds racial ideologies into particular territories - not bound by national borders. Consequently, along the transnational modern state's subject there is an implicit process of social construction of the excluded "other," which is crucial for understanding modernity as a diverse discourse that is historically grounded. Both the "modern" subject and the excluded "other" articulate a discourse of modernity, which in turn constitutes a discourse (or discourses) of alterity (Trouillot 2003). Thus, as Trouillot points out, this very clear relationship between modernity and race shows that, contrary to the assumption of modernity as a given, modernity is a relational construct that had the colonies as a reference all along the process (Trouillot 2003). Hence, race and modernity were co-constructed, and the systems of racial classification that consequently emerged have resulted in different alterities, which in Bolivia are problematic because the national discourses have consistently excluded the indigenous, while in Chile there is a strong gendered nationalism, as illustrated by the above mentioned concept of *raza chilena*. These frameworks of race have continued to have an effect in contemporary times. For instance, scholars like anthropologist P. Richards have argued that in Chile race is at the core of the neoliberal subjectivity where a "persistent entrenched racism informs practices and beliefs at the local level" (2013:218). This is the same as it was before in the early twentieth century when exploitation of labor was based on racial categories hidden by social status and class.

Building on these notions of race, my research on tuberculosis and race questions the conditions of structural violence that the Aymara of Bolivia and Chile experience in their everyday life. Structural violence as described by P. Farmer emphasizes the role of institutional structures that perpetuate inequality:

> Structural violence is one way of describing social arrangements that put individuals and populations in harm's way… The arrangements are structural because they are embedded in the political and economic organization of our social world; they are violent because they cause injury to people … neither culture nor pure individual will is at fault; rather, historically given (and often economically driven) processes and forces conspire to constrain individual agency. Structural violence is visited upon all those whose social status denies them access to the fruits of scientific and social progress.

Across the border, structural violence operated by accentuating race-based exclusion, on the one hand, and also by state discourses that promote particular notions of health and well-being, on the other.

4. A MEDICAL ANTHROPOLOGICAL PERSPECTIVE

At the center of this project are suffering Aymaras. Despite recent critiques of the concept of social suffering (Robbins 2013) from my perspective it is a relevant theoretical concept because it helps us to account for the subjective experience of inequalities, as well as to comprehend the experience of pain as subjective, diverse, and social (Honkasalo 2008, Kleinman et al 1997, Bourdieu 1993). How to reckon the quotidian experience of pain among those who are excluded from the benefits that others enjoy? Considering subjectivity as cultural and historical consciousness (Ortner 2006:110), suffering is pain with a meaning added by the sufferer within a context (Kleinman 1997). Bourdieu asserts that suffering is an expression of the habitus of a community because it is subjective and also historically constructed (Bourdieu 1993).

In her work, Finnish anthropologist M.L. Honkasalo defines suffering this way:

> Suffering as a phenomenon and as a notion is closely intertwined with illness and pain. The task of medicine is understood as alleviating pain and suffering. The question of suffering and its counterpart, evil, is ancient and has occupied human intellectual history in myths, theology, and philosophy. All the cosmologies include some kinds of theodicies – mythical or rational ways of legitimating suffering. For the research of health and illness, suffering is important first for the understanding of the illness experience in cultural and existential contexts; and second for the study of "social suffering" which connects different kinds of human problems, those that create pain or distress, with political violence or with other forms of human misery. The latter view of suffering defines affliction broadly as a social and political question extending from the realm of medicine and medicalization (2014).

Rather than a simplistic view of suffering as pain, in this definition we find suffering as phenomenon and as a notion connected to the individual experience of illness as well as to social suffering. While medical anthropologists have extensively documented how culture influences the way societies deal with pain and frame disease, transforming them into significant subjective experiences (Good 1994, Kleinman

1980), historians have also analyzed medical practices and representations of illness. I build on the work of historian C. Rosenberg, who affirms that “in some ways disease does not exist until we have agreed that it does, by perceiving, naming, and responding to it” (1992: xiii). Thus, the framing process refers to the three aspects of disease: diagnosis, name, and healing. Each of these aspects help individuals to first identify their experience (ideas), and secondly to do something about it in order to feel better (practices). Therefore, the name of a disease gives us an idea about shared medical conceptions and practices in a historical context. Rosenberg (1992) proposes to use the term framing to capture the illness experience as both a biological and a social phenomenon that is relative to particular historical moments in particular cultural geographies. To study an old disease like tuberculosis one should take into account the historical context that gives a particular meaning to this illness. Fitzpatrick (1984) also refers to the framing of disease, focusing on two elements: therapeutic process (treatment) and the time span of the disease (its chronicity). In this sense, the current form of tuberculosis shows an interesting set of elements influencing people’s experience of a chronic infectious disease and a harsh pharmaceutical therapeutic process. Besides the social history of tuberculosis, one finds the personal history of every patient, her or his trajectory and the multiplicity of practices and ideas that emerge from that experience. A biomedical definition of tuberculosis alone does not show us the subjective process of interpreting and talking about the symptoms or seeking healing, nor does it show the social dimensions of this illness and its impact on the person’s family or community.

A. Kleinman makes a crucial distinction between illness and disease (1980), where illness is more than a biologically-based medical category. He defines illness as “the psychosocial experience and meaning of perceived disease” (1980: 72). In distinguishing illness and disease, Kleinman contributed to our understanding of the individual experience of discomfort and the responses associated with said experience, which translates in social relations of care. In addition, B. Good proposes that the meaning of illness comes from the interconnection of elements within a particular cultural context (1994). By emphasizing a view of suffering in context, I aim to challenge public health’s static and unilateral construction of tuberculosis that separates TB from global economic process and political violence, for example. A second contribution of the subjective dimension of pain is the possibility of situating TB as a consequence of processes of structural violence (Farmer 2004), where TB and its framings are part of embodied institutionalized mechanism that constrains people’s everyday life (Green 1999; Farmer 1990). In this sense, questioning the concepts of mind, body, self, and emotions is necessary when looking at the body as a site of suffering and violence (Lock, 1993: 138).

T. Csordas proposes embodiment as a paradigm for the study of culture and self (1990), where embodiment is the “indeterminate methodological field defined by perceptual experience and by mode of presence and engagement in the world” (1999:

145). The body is not the object “to be described in order to understand culture.” Instead, Csordas states, the body became the center of fundamental contradictions and transformation “that has to do with the very meaning of being human as being a body that can experience pain and self alienation” (2000:3). Csordas argues that most of the time the concept of embodiment is taken for granted. However methodological and epistemological problematization of the related conceptual dualities distinguish the approach from the traditional “anthropology of the body” (2000: 7). Within this framework, the body is the “physical material entity”, and “the intersubjective ground of experience” (1999). Building on Merleau-Ponty’s phenomenology and P. Bourdieu’s theory of culture, Csordas claims that “the body is an agent, not a resource” (Csordas 1994). In addition, he asserts that cultural phenomenology should be the perspective to look at illness as an embodied experience, where the question of the relationship of biology and culture could be resolved beyond the traditional dichotomies of mind/body – culture/nature – and individual/society (2000). Following Csordas, I acknowledge the body as part of a social experience of suffering that is embedded in sedimented layers of meaning, which transforms the body not only as a repository of memories but on the contrary as an active space of agency, resistance and contestation (Honkasalo 2008). Agency becomes a key element in the experience of suffering: people not only cope, but engage with suffering (Ådahl 2007:68). The reorganization of the experience does not necessarily entail a negative consequence for the sick, as pain is also a way to be-in-the-world. Thus, emotions are culturally produced, contextualized, and they index social structures (Scheper-Hughes 1992; Lutz and Abu-Lughod 1990; Rosaldo 1984, 1980; Irvine 1982). Emotions mediate the experience of pain and illness between the self and the social and political levels by linking the material world with the subjective experience of it. Emotions (defined as feelings and cognitive orientations) would link the dichotomies of mind/body, individual/society. They ground this idea in medical ethnographic work where belief is an important aspect of illness but also of healing (Lock and Scheper-Hughes, 1987: 29).[8]

Emotions are also learned through socialization processes and the way each individual learns varies from one society to the other, and `emotions are closely related to language acquisition (Lutz 1988). I argue that an important aspect of the illness experience is that the patient needs to learn a new language (that of the illness) and also a new register of emotions. As I show in chapter 4, Aymara TB sufferers, for example, need to learn new ways of understanding how the Western notion of chronic illness and recovery through pharmaceutical treatment can coexist. Thus, I explore a number of key questions: if one is always going to be sick, what is the meaning of recovery? How does learning the biomedical language of TB influence Aymaras' illness experience? How do Aymaras embrace this new language? Do they contest the biomedical language with one of their own? Is the main social context of this learning process the medical encounter? These questions help further connect the literature on

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[8] They include in this argument the concepts of nocebo (pathogenic emotions) and placebo effect (therapeutic emotions) (1987:30).

illness, embodiment, and race by considering indigenous ethnomedicines and ethnopsychologies as embedded in broader embodied political processes.

5. METHODOLOGICAL ASPECTS OF THE FIELD RESEARCH

This qualitative comparative research followed a muti-sited ethnographic strategy, where I conducted participant observation and in-depth interviews in the border Aymara communities as well as the main urban contexts where Aymara live.

As an anthropologist I had worked in the Chilean altiplano, and I was familiar with the social and political organizations of the Aymara and their relevant views on health and education. At the same time, I was not familiar with the Aymara of Bolivia, however. In part because of a legacy of the strong national identity, within Chilean anthropology the national borders limited the scope of the research on indigenous peoples, as if they were not transnational communities. Hence, as the map in figure 4 evidences, there was not reference to the transborder feature of the Aymara communities. This previous experience helped me enormously to frame a research that integrated Aymara from Bolivia and Chile.

I conducted this research considering the customary Aymara exchange circuits in Bolivia and Chile as well as the medical rounds circuits in the Parinacota region in Chile (see figure 5). A multi-sited ethnography allowed me to observe different ways of being Aymara: in the rural communities, in the cities, in the street markets for the big celebrations *(fiestas)*. Also, sharing the experience of traveling, of moving, helped me to grasp the meaning of a notion of territory that transcends physical or material spaces. The Aymara embody their territory, and in their travels they are constantly referring to their *costumbre* (customs) as connecting the spaces they visit or where they will go.

This dissertation is based on field research conducted during three preliminary visits in the summers and winter breaks of 2009, 2010, 2011 and during a longer stay of eight months in 2012 and 2013. I shared the field work experience with my husband Jorge Montesinos, who was conducting his own dissertation project.

Figure 4. Map showing the Parinacota region in Chile and the Aymara communities visited with the medical rounds. Source: Estudios Atacameños. no.42 San Pedro de Atacama jun. 2011

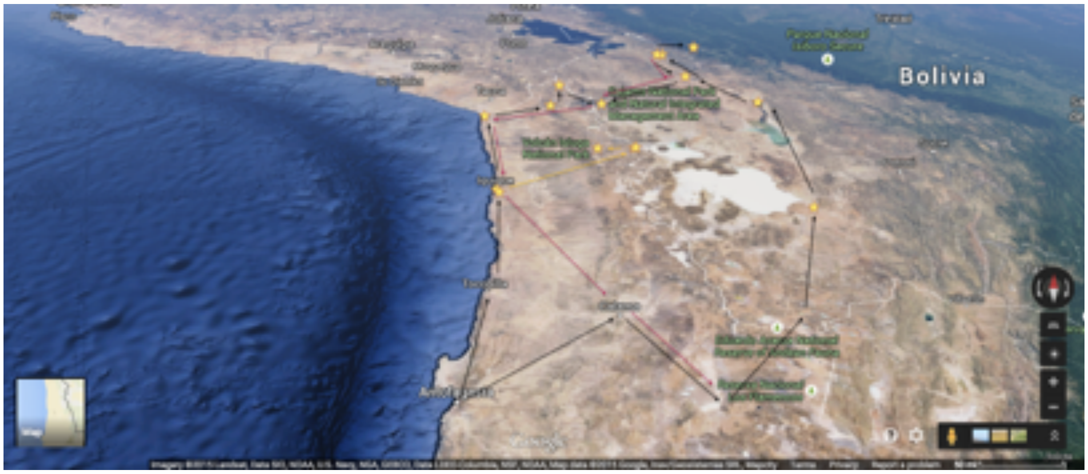

Figure 5. Map that shows the distribution of the ethnographic research field sites in Bolivia and Chile and the circuits followed. Source: google maps.

5.1. Research Participants

In this research I interviewed a total of 70 medical providers, who worked in the national TB programs in different capacities. I worked with international public health officials, national health program directors and supervisors, regional and local programs supervisors and medical providers in urban and rural healthcare centers. I interviewed Aymara traditional healers in both biomedical state settings and in their community practice.

I also interviewed 10 Aymara patients with TB diagnosis and 10 patients with other diagnosis, 30 community leaders, and lay people in the markets and other more random social gatherings as proposed. I considered the age, gender, and location of the Aymara participants.

5.2. Data gathering

Besides the interviews I conducted participant observation in the medical centers and Aymara community activities. I attended religious festivities in La Paz, Coroico, Isluga, Chiapa, and San Pedro de Atacama. I also attended to the Tri-National TB meeting in Arica in May of 2013 (further described in chapter 1).

During the summer of 2011 I worked with archival materials in La Paz, Bolivia (ADLP, BAHC, BUMSA, BAC) and I was able to examine in detail the communications between the public health office of the department of La Paz (Fondo Prefectura de la Ciudad de la Paz - BAHC) during 1913 and 1937. Bearing in mind the limitations of this data, I considered these documents as discourse, understanding discourse as the use of language in a social and political space (Iñiguez , 2006). The discourse analysis aimed to account for the establishment of medical institutions in Bolivia, and the expansion of its model to the national territory.

The qualitative analysis was based on the inductive method proposed by Glaser and Strauss (Grounded Theory). For meta-analysis I used Atlas-Ti, a data management software that was helpful in coding and transforming those codes in networks of meaning.

6. THE DISSERTATION CHAPTERS

This ethnography is organized in 5 chapters. In chapter 1 I present the frameworks of tuberculosis in Bolivia and Chile. I argue that the development of global and state anti-tuberculosis apparatus is related to historical processes of nation-state building and to discourses of race and nation that have contributed to particular framings of tuberculosis in these two countries. I sustain this by describing international and national public health tuberculosis control programs in Bolivia and Chile, on the one hand, and analyzing the transborder initiative for TB control across the border (Tri-national Referral and Contra-referral forms), intended to keep track and monitor indigenous peoples moving across the borders of Peru, Bolivia, and Chile. Thus, I to discuss this argument in the context of Foucault's framework of biopolitics, discipline, and surveillance as a way to question current explanations about the role of illness in shaping political participation and current biologically based citizenship assemblages.

Chapter 2 is an ethnography of medical encounters and misunderstandings at the local level in the Aymara towns of Coroico in Bolivia and Putre in Chile. How do these two different biopolitical frameworks influence the doctor-patient relationship in Bolivia and Chile? How do racial categories shape the medical encounter? How do the doctors see the indigenous peoples? How do the indigenous peoples see the doctors? I argue that there are two different biopolitical frameworks that play out in Bolivia and Chile. One is characterized by a strong authoritarian neoliberal discourse (Chile) and the other is sparked by a State-led decolonization discourse where the indigenous peoples are gaining political power (Bolivia). Yet, these two apparently distinct ways of governing the populations are displayed in the form of multicultural health policies where the biomedical categories of illness predominate over the indigenous ways of interpreting and acting upon pain and suffering. Thus, instead of crafting the desired intercultural dialogue, the medical encounter reproduces historically grounded racial categories that link conditions of abnormality to indigeneity. In this chapter I show ethnographic evidence of how medical providers mediate between national biopolitical projects and indigenous sufferers/citizens who resist State power by following a different therapeutic process that is inspired in indigenous ideologies of health and illness.

I describe the experience of TB patients in Bolivia and their struggle with DOTs in chapter 3, where I examine the non-engagement to TB treatment in Bolivia as a result of political negotiations mediated by pharmaceuticals intake. From this perspective, active engagement implies a commitment with the Aymara notion of *coming through*. Non-engagement with DOTs is part of the Aymara repertoire of responses to these larger processes. By actively engaging in the treatment, the sufferer accepts becoming a patient. Thus, non-engagement expresses at the same time resistance to the state’s intervention on the indigenous bodies and an allegiance to Aymara traditional medical system.

In Chapter 4 I present evidence of Aymara illness semantic networks through which individuals and their communities interpret and act upon severe health conditions such as tuberculosis. I examine the particular associations that Aymara make between the individual illness experience, emotional well-being, and indigenous identity in both countries. Building on previous ethnographic descriptions of Aymara medicine that associated TB to *debilidad* (weakness) due to environmental or labor hardships (Pedrero 2013), in this work I discuss the traditional hydraulic-topographic model of the body presented by J. Bastien (1972) and the importance of fat in relation to breath, sweat, and work as important features of tuberculosis semantic network.

Considering ethnopsychological theorization of emotions, I underline the role of both emotions and cultural conceptions of health in shaping the illness experience, creating particular ways of interpreting and signifying pain, understanding that emotions mediate the configurations of what is socially accepted, influencing not only the framing of disease but also the whole therapeutic process - including ideas about recovery. I argue that *renegar* (bitterness) and *compartir* (community engagement) are linked to larger indigenous discourses of *suma qamaña* or *vivir bien* (“living well”), which are currently enforced through the decolonization policies in Bolivia and neoliberal multiculturalism in Chile.

Finally, chapter 5 focuses on the discussion of the Aymara struggles in dealing with illness in precarious conditions and anthropological theorizations of emerging forms of biological citizenship, as ways of exercising rights through the embodiment of medical categories.

7. CONCLUSIONS

In this dissertation I discuss the problem of tuberculosis and race by bringing together theoretical perspectives from three different fields of anthropological study: political, medical, and psychological anthropology. My research also connects contemporary illness experience among the Aymara with historically grounded political processes such as the consolidation of public health apparatuses in Bolivia and Chile. I consider the medical encounters as spaces of convergence between the state and the indigenous citizens, where the medical providers reproduce state projects that convey national identities and racial categories. In this sense, my research contributes to current debates on racialization processes and emerging forms of citizenship in Bolivia and Chile.

A second contribution is the ethnographic account of the subjective experience of this illness as a transformation of the self mediated by medications intake. My analysis demonstrates that the political dimension of the medicalization process and its relevance in understanding the embodiment of structural inequalities that transcend national borders.

Finally, this dissertation contributes to the studies of illness and emotions by presenting an ethnographic account of the Aymara ethnomedical and ethnopsychological systems in the context of a “postneoliberal” and plurinational moment in Bolivia and a neoliberal state in Chile.

CHAPTER 1

FRAMING FROM ABOVE: INTERNATIONAL PUBLIC HEALTH AND STATE APPROACHES TO TUBERCULOSIS AND THE WORKING OF BIOPOLITICAL FRAMEWORKS.

chapter summary

In this chapter I set forth the biopolitical frameworks of tuberculosis in Bolivia and Chile, arguing that the development of global and state anti-tuberculosis apparatus is related to historical processes of nation-state building and to discourses of race and nation that have contributed to particular framings of tuberculosis in these two countries. I sustain this by describing international and national public health tuberculosis control programs in Bolivia and Chile, on the one hand, and analyzing the transborder initiative for TB control across the border (Tri-national Referral and Contra-referral forms), intended to keep track and monitor indigenous peoples moving across the borders of Peru, Bolivia, and Chile. Thus, I propose to discuss this argument in the context of Foucault's framework of biopolitics, discipline, and surveillance as a way to question current explanations about the role of illness in shaping political participation and current biologically based citizenship assemblages.

1. "UNIDOS VENCEREMOS A LA TUBERCULOSIS": THE STATE FRAMINGS OF TB.

While visiting a medical post in Putre (Chile) in 2013, I noticed a colorful image on a flyer (figure 6). It was a brochure for tuberculosis prevention depicting a diverse group of people, depicting an elderly couple wearing glasses and a cane, who were talking to a young girl. Next to them there was an urban "typical" family of four. At their side one could see an indigenous family of three, the little kid carrying a green truck. This engaging group of people was standing side by side under the slogan *"Unidos siempre le ganamos a la tuberculosis"* ("together we always defeat tuberculosis"). It was interesting for me to see such a message in a border Aymara community. I had seen the same slogan with a different image before in a central square in La Paz (Bolivia) in a billboard on top of the Ministry of Health building, and it also had a particular representation of "togetherness" (figure 7). Yet, in Bolivia the message alluded to the future. There, one could see Bolivian diversity represented as a chain of people where one can easily distinguish a *cholita* (urbanized indigenous women), a mestizo couple with their children. The inclusion of a figure of the *cholita* in this representation is significant, as it implies historically grounded meanings of indigeneity, race, and gender. The other shapes give the idea of lay people, but the *cholita* is indexing the presence of the Bolivian indigenous. In this billboard one can see a lung overlain by a rainbow with the colors of the Bolivian flag, and the slogan is *"Tu nos puedes* *ayudar…juntos venceremos a la Tuberculosis"* (you can help us, together we will defeat tuberculosis).

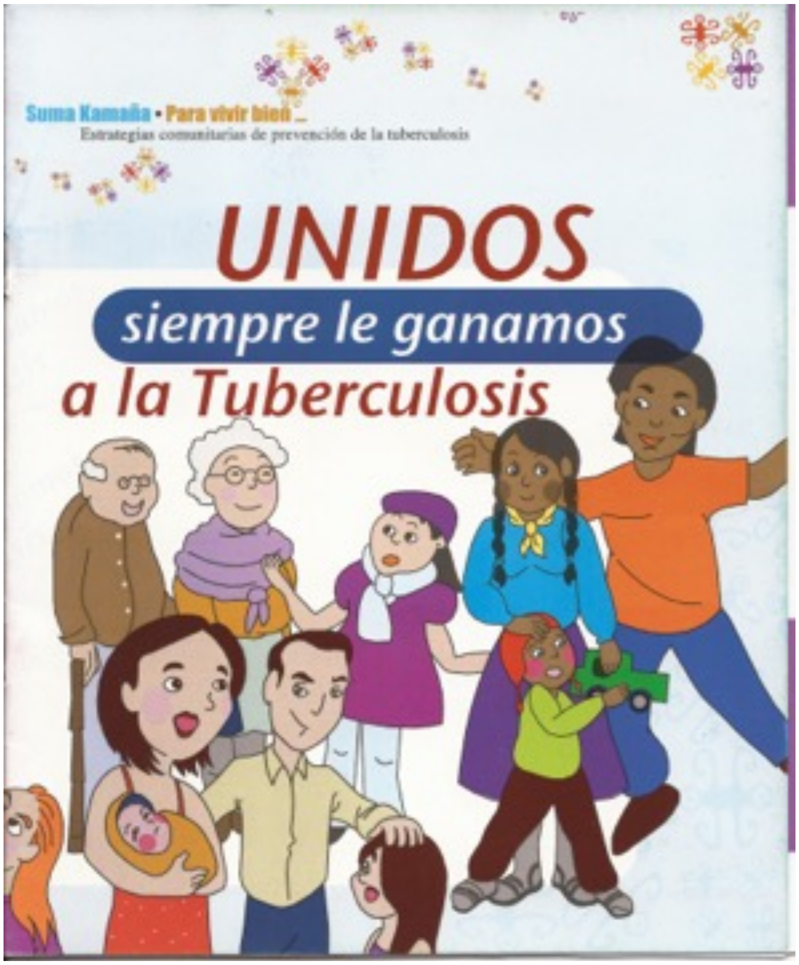

Figure 6. Anti-tuberculosis propaganda distributed by the public health office in Chile. Source: photograph by Paula F. Saravia.

Figure 7. Anti-tuberculosis campaign in the city of La Paz, Bolivia. Photograph by Paula F. Saravia.

All over the world, TB campaigns are of course aiming to call attention to the collective dimension of the illness, as well as to the idea that it is a potential risk to everyone, no matter racial, class, age or gender distinctions. Most of the content of contemporary public health guidance on infectious diseases preventions it's conveyed through images of people holding hands, sometimes "on top of the world" asking for awareness in creating a world free of illness, and free of tuberculosis. However, these messages also express particular representations of the collective, of the global, and of the nation. Historically, anti-tuberculosis campaigns have been a persuasive way to transmit basic knowledge about this infectious disease to the general public, along with political representations aimed at changing medical conceptions and behaviors among the population. For example, during the early and mid twentieth century before the massive use of antibiotics, national anti-TB campaigns in Europe and in the United States strove to change immoral behaviors labeled as risky, such as prostitution. Historians of medicine like P. Bourdelais (2006) and R. Porter (1989) have shown that the associations of TB and poverty were in fact a way to dictate state moral and ideas about the nation (particularly during WW1 and WW2). Only after the consolidation of the World Health Organization (WHO) as an effective public health program in the 1970s, and the emergence of HIV-Aids global epidemic in the 1980s did the campaigns changed their orientations towards preventing TB in the transnational community rather than limiting it to the national populations. Current global health campaigns focus on social awareness of risk of contagion and information about the symptoms and the treatment of tuberculosis in different parts of the world, emphasizing the need for timely diagnosis and compliance with treatments. Thus, national anti-tuberculosis plans in Bolivia (mostly funded by WHO) and Chile pivot on global framings of TB and its treatment (DOTs). Yet, as I will demonstrate in this chapter, the outcome of these campaigns differ in view of the historical and political contexts that influence the strategies of each government to call the attention of their citizens and integrate them to their national healthcare systems.

In this chapter I argue that the development of global and state anti-tuberculosis apparatus is related to historical processes of nation-state building and to discourses of race and nation that have contributed to particular framings of tuberculosis in these two countries. I sustain this by describing international and national public health tuberculosis control programs in Bolivia and Chile, on the one hand, and analyzing the transborder initiative for TB control across the border (Tri-national Referral and Contra-referral forms), intended to keep track and monitor indigenous peoples moving across the borders of Peru, Bolivia, and Chile. Thus, I propose to discuss this argument in the context of Foucault's framework of biopolitics, discipline, and surveillance as a way to question current explanations about the role of illness in shaping political participation and current biologically based citizenship assemblages.

2. THE DEVELOPMENT OF INTERNATIONAL TUBERCULOSIS CONTROL AND ERADICATION PROGRAMS.

Contemporary national tuberculosis control programs in Bolivia and Chile (as well as in the rest of the world) are based on the experience of early international health programs that emerged mainly in Europe and in the United States. The medical developments and findings of the late nineteenth century were used as scientific arguments to create "procedures, rules, and institutions through international law" (2001: 844). Hence, four international health organizations put into action those principles: Pan American Sanitary Bureau (1902), the Office International de l'Hyniene Publique (1907), the Health Organization of the League of Nations (1923) and the World Health Organization (1948). In his analysis of the history of the

Panamerican Health Organization, M. Cueto asserts that in the early twentieth century two main organizations were ‘competing’ for their influence in Latin America. On the one hand there was the League of Nations, and on the other hand the Rockefeller Foundation. Furthermore, Cueto argues that indeed, it would be a mistake to neglect the influence of such programs and interventions in current national structures of healthcare in Latin America. Cueto has thoroughly studied the influence of global public health in nineteenth and twentieth century Latin American welfare models, giving clear examples of the interplay of colonialism, ethnicity, race, and economic developments in the experience of epidemics all across Latin America, particularly in Chile and the early focus of tuberculosis doctors in eradicating this illness through improving nutrition (2006, 2001, 1994). He demonstrates how the medical professions in Latin American countries established a political platform for influencing law and policy guided by early european and American global health commissions. These medical associations, he argues, mostly run by upper class males, managed to accumulate political capital to a point where in countries like Chile medical doctors occupied political positions in congress and within the governments.

He shows how in the beginning of the twentieth century, international organizations funded health campaigns for vaccination and research all over the world. Different international actors were acting in the field of public health collaborating with broad programs against epidemics and specific contagious diseases. For example, the League of Nation’s Health Board gave assistance through the development of multilateral initiatives, including laboratory research. At the same time, Rockefeller and Kellogg foundations financed grants for academic formation abroad (AJPH 1977; Cueto 1994; Weindling 2006). Cueto also argues that one of the main consequences of the Rockefeller Foundation's aid in Latin America was that it facilitated the tendency of the state to assume leadership of public health policies instead of leaving it to the municipal administrations (2000:200).

David Fidler argues that in the mid nineteenth century there was a change in the public health orientation based on the concern for rapid transmission infectious diseases. He asserts that public health turned from a national to a global matter, involving international organizations and nonstate actors as well. A good example of this was the prevention and control plan concerning the bubonic plague epidemic at the beginning of the 1900's; right after the news of the presence of the plague in San Francisco (California) the Chilean ports were under alert. Bubonic plague arrived to the port of Iquique in the north of Chile in 1903. Reports and news about the "plague" were published in scientific journals and magazines in Bolivia and Chile.[9] For the Chilean authorities, it was particularly important to keep the ports and cargo safe, as the economy of the country depended on them. Valparaiso, Chile's main port, received large numbers of ships from all over the world, therefore during the big global epidemics, and following the international public health mainstream, authorities from

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[9] Evidence of this is the large correspondence between Chilean and Bolivian authorities in relation to the disinfection procedures of trains and passengers in Charaña to prevent bubonic plague from spreading (ANLP)

Chile and the other countries in the Pacific area agreed on specific measures. Bolivia, Chile, Ecuador and Peru met in the American Sanitary Congress in 1888, where they agreed on the reciprocal notification of diseases and planned an international agreement (Cueto, 2004). Part of the concern of the different countries was the risk of contagion due to immigration, which intensified due to the California gold extraction and the demand of labor in the guaneras and salitreras in Peru, Bolivia and Chile. Medical posts were established in the main ports to check immigrants and clean the trains or carruajes to avoid the transmission of germs.[10]

Finally, by the end of the twentieth century, the Panamerican health Organization (PAHO) crystallized the interests and political programs of competing League of Nations and Rockefeller foundation and the World Health Organization's model of health intervention and development became dominant. Especially after Alma Ata, the international health conference held in September 1978,[11] where the international community agreed on the main principles of primary health care delivery and preven-

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[10] AHNLP Fondo Prefectura.

[11] After the smallpox eradication at the end of the 1970s (WHO) the world "seemed" to be free from harm, and WHO's world-wide public health programs had less funding, which forced international health to focus on preventive primary care. The idea of a "healthy world" was a very strong argument for sanitizing those territories that could eventually represent a risk for the developed world. WHO's achievement in eradicating smallpox was a political statement that proved that biomedicine was the righteous way to fight against disease. WHO proved itself to be a successful institution in protecting global health, and thus the international community saw WHO as the main institution in charge of preventing and controlling epidemics and joint projects with other agencies were less and less executed. Smallpox eradication was the highest moment of the biomedical developments of the late twentieth century until the first cases of HIV-Aids changed this situation in the 1980s and biomedicine did not offer any kind of cure to the disease. As the cases increased, during the 1980s, the international community questioned WHO's strategies and its efficiency in determining the patterns of contagion and distribution of the epidemic. This change in WHO's public image provoked a shift in the global public health programs, which integrated other agencies in the health planning process.

tion. After proclaiming the eradication of smallpox in the 1970s, the WHO model focused on epidemiological surveillance and primary care programs. Besides the disease specific programs, WHO implemented a global alert and response system (GAR) that focus on retrieving information based on national public health systems. National governments send the data they collect to the GAR and by doing so WHO is able to respond more efficiently to health emergencies. National agencies like the "American Center for Disease Control" (CDC) or the "European Observatory on Health Systems and Policies" constitute key regional information centers for a coordinated global response to public health. This is particularly true for developing countries, especially those that do not have a powerful national database for health situations, and thus rely on WHO orientations for disease control. As a result of the new intervention guidelines and the problems imposed by the HIV-Aids epidemics in the 1980s, the WHO started to promote a model of partnerships with private institutions and NGOs who were willing to work on particular health issues. Hence, the "Stop TB program" founded in 2001 provides guidelines and resources for improving diagnosis, training providers, and delivering care to those infected by tuberculosis and the people around them (contacts). In 2006, the WHO elaborated a strategy aiming to reduce the global burden of TB by 2015 by securing universal access to "high quality diagnosis and patient-centered treatment" (WHO). The main anti-tuberculosis strategy is DOTs (directly observed treatment- short course), consists on a regimen of daily doses of strong first and second line anti-tuberculosis drugs (up to 10 antibiotics) that could last between 6 and 18 months.

This surveilled pharmacological therapy was designed by the WHO to prevent patients from creating resistance to these pills; a health care provider directly supervises the ingestion of each antibiotic. The medical provider in charge of DOTs at the local level also needs to keep track of every patient and maintain the statistics, updating the necessary information on the patient's file. From the point of view of the patient, the tremendous side effects of these pills may extend the treatment for up to 2 years or more, a challenging situation that implies an increase in state TB control expenditure, especially in terms of hospital care, laboratory work, and medications. In addition, complications with the management of the DOTs scheme at the local level such as difficulties in healthcare access, or lack of necessary medical staff to reach the patients, may eventually result in greater resistance to anti-tuberculosis drugs, causing multidrug and extreme multidrug resistant tuberculosis. This is, in fact, a major concern for those involved in TB programs.

From a medical anthropological perspective, DOTs is one of the most important aspects of the current experience of this illness, as it embodies disciplinary and security technologies that define the everyday life of those infected and their relatives - also known by the health apparatus as "contacts"). Indeed, DOTs strategy has been particularly interesting for anthropology in view of its political dimensions at many levels: it involves medical humanitarian organizations such as *Medecins sans Fron-*

tiers (MSF), NGOs, state health care systems – public and private – local governments, social organizations, communities, and individual patients and their families. On the one hand, this program needs a strong, widespread healthcare system that can efficiently deliver the medications and monitor the patients. On the other hand, the treatment requires compliant, obedient patients to endure a long term and painful healing process. Needless to say, the biomedical treatment is imposed over the patient's own illness experience, what A. Kleinman refers to as explanatory models (1980). As I will show, overall, the strategy's success in reducing TB prevalence globally comes at great economic and social cost for governments and civil society.

3. NATIONAL ANTI-TUBERCULOSIS PROGRAMS.

Following the WHO recommendations, tuberculosis is defined as a key health issue in most of the developing world. This usually implies detailed statistics gathering and mandatory notification of each TB case, treatment outcomes, etc. which require funds for health professionals and biotechnological platforms. Stop TB partnerships and alike support most of the programs, but this funding is conditioned to the income level of each country. Therefore, while Bolivia's national program (PNCTB) receives most of its resources from WHO, Chile – recently categorized as a middle income country by the OECD – contributes to the global fund and finances its own control and eradication program (PROCET). Although "Stop TB" does not have any formal role in defining each countries health policies, the funding is also conditioned to the implementation of WHO's recommendations (i.e. DOTs and else).

This presents several problems to the national healthcare systems, as they need to implement policies that are often times are not culturally or politically pertinent to the national overall needs. For example, even when the local teams want to implement a change to the treatment, they have little possibility of doing it because of stringent budget allocations from international funders. This is true for small rural clinics like Coroico or urban hospitals in Iquique, Arica, or La Paz that I studied. Besides the income level, another relevant issue for the implementation of the TB program is the country's epidemiological profile and the national organization of healthcare. As a result, there are major differences in the whole organization of the national tuberculosis care apparatus between Bolivia and Chile. The two TB programs work under their respective ministry of health. Nevertheless, both are organized differently: while PNCTB in Bolivia has a national office that directly supervises the regional and local services, PROCET in Chile has no control of the program's budget or the program's staff. Instead, the central office coordinates the work of each healthcare service throughout the country. I will further describe the particularities of each program in the following sections.

In both Bolivia and Chile, the national TB control programs coordinate initiatives within the national territories, and have particular technologies for tracking and monitoring patients. However, supported by the Andean Health Body Hipólito Unanue

Convention (ORAS – CONHU), these programs are developing mechanisms to secure the delivery of DOTs to TB-infected citizens living (or traveling) abroad.

3.1 "El efecto concreto": PROCET and the anti-TB framework in neoliberal Chile.

The office of the National Tuberculosis Control and Elimination Program (PROCET in Spanish) is located in downtown Santiago, inside the main building of the ministry of health. PROCET is part of the department of the epidemiological surveillance section (*vigilancia epidemiológica*), a larger national health surveillance system and its main task is to keep track of cases and treatment statistics. To my surprise, the whole office works with only two women: Dr. Cristina Romero, the director, and Zulema Torres, the coordinator. Both were happy to receive me, despite the amount of "memos" they had to write and phone calls they kept receiving from the regional offices. Our meeting in March of 2013 was later in the day, "it's the only time we have", they said. They described to me the program and its history, the treatment protocols, the changes brought by the global burden of TB, etc. At some point they referred to the responsibility of the Chilean state towards the eradication of TB and the contribution to the program to the global fight against TB during the first half of the twentieth century, which they said began "with the works of doctor Deformes and his brother, Viel, and later Salvador Allende and his influence on the development of social medicine[12], in a time when TB prevalence in Chile reached around 300 per 100,000 pop." Like other epidemiologists I interviewed in Chile, Dr. Romero was proud of the contributions of Chilean medicine to the TB control, particularly at a time when Chile was building the state infrastructure for healthcare, before the industrialization era (1930s-1940s). In fact, the program in Chile precedes the WHO and the Stop TB partnership, she affirms: "by the 1920s and 1930s, tuberculosis mostly affected people between 15 and 35 years old, so the economic consequences for the country were devastating. So, by the end of the 1940s we were already using the BCG vaccine. We had the Chilean Society of Pthisiology[13] and numerous dispensaries and sanatoria, we were not like other countries, we took care of this."

As expected, mortality rates due to TB decreased during the 1940s, when the first antibiotic became available. Indeed, the extensive use of the first line antibiotic isoniazide provoked a tremendous drop in the mortality curve (Romero and Moroder, 1957). However, Dr. Romero pointed out the role of the state in tackling the TB epidemic, she said "even before the national reform of the health care system in Chile in 1952 the mortality rates were low in comparison with the previous decades". Since the 1930s the Chilean Society of Pthisiology had great influence on the drop of TB mortality through the organization of the hospitals, dispensaries, and nutrition programs

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[12] Dr. Deformes (1866 - 1920) was a Chilean medical doctor who successfully represented Chile in the international conference of tuberculosis held in May 24-27, 1899. Him and his brother were very influential in dictating policies based on social medicine ideas, founding the scientific journal of medicine and hygiene in 1899.

[13] Pthisiology was the study of the lesions of the lungs provoked by the TB bacillus.

among the poor inhabitants of Santiago. During the following years, the Chilean state funded the construction of modern sanatoria close to Santiago (El Peral), Putaendo and Valparaiso. As a matter of fact, inspired by social medicine, "TB doctors" became politically involved at different levels of the governments and as senators and representatives, Dr. Romero says: "you know, president Allende was a TB doctor."[14]

There is great pride about medical advancements concerning TB and the positive changes in the country epidemiological profile in general among health providers in Chile. In the regional offices of the healthcare service in Iquique and Arica, TB specialists talked about the "profesionalismo" (expertise, efficiency) of the medical providers. Patricia Rubio, the nurse in charge of the planning of DOTS in Iquique is a young very dedicated woman. She shows great enthusiasm about the program, in spite of the many difficulties she and her colleagues face everyday, she said "we want to serve the people well, we need to be professionals, even in the smallest village" of the country (personal communication, Iquique December 2012). There is one *encargado* (supervisor) like Patricia in every regional office to oversee the delivery of DOTs at the local level, Patricia continues: "we pay a lot of attention to the 'casting' for the TB program, we need tolerant, kind, and non-discriminatory people". For each regional health service there is one TB supervisor, who needs to work with statistics gathered locally through the ministry's intranet (redsalud), as well as administer the budget for the program. These are hardworking people, who usually enter the healthcare appara-

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[14] For further information on the history of TB in Chile see Saravia 2008

tus through public calls for applications. Under constant evaluation of the central level (nivel central), each regional intervention needs to show results, the concrete effects (los efectos concretos) of the program. Over the last decades, the administration of health care programs has accentuated the impact of each program: “we need good numbers” Patricia says. As mentioned above, there is no special budget for PROCET in Chile; each regional service contributes to the implementation of the program in their territories. The regional office in Iquique has been focusing on urban and rural population at risk of TB. In order to renew their budgets for future years, they need to report good statistics. Therefore, each of the TB managers request funds each year, and that request is based on the success of the program (completion of treatment, number of sputum smears, etc.). TB supervisors agreed on the pivotal aspect of TB statistics in both getting more resources for the campaigns as well as better work evaluations. At the same time, these regional offices face constant drawbacks because of their lack of political autonomy. Also, while their work is under the supervision of the central governments, their budget comes from regional allocations. This is complex and presents important difficulties for achieving better results.

In view of the way the program works, it was clear to me that TB was not the highest priority for the national ministry of health: “basta ver donde queda la oficina” (just think where this office is), the PROCET director said. In fact, the PROCET office is a small and narrow room on a corner of the 4th floor. The office was indeed hard to find! Compared to other programs PROCET is small and under-funded.

3.2. The Making of a National Health Priority

Since I started my ethnographic research on TB in 2009 I have noticed that compared to other health problems, tuberculosis was a lower national priority. Of course, this is not an exclusive characteristic of Chile. In fact, TB experts around the world have reported that the invisibility of tuberculosis in terms of funding is a huge obstacle for local TB programs (Raviglione et al 2012; Lönnroth et al 2010). The meetings that I had with PROCET central team as well as my conversations with regional and local program coordinators, and patients, confirmed my impressions. Unlike HIV-Aids, hypertension, or even malnutrition, tuberculosis has no presence in national media, for example. Another sign of TB "invisibility" is the lack of information about the program, not to say about the names and phone numbers of those in charge. On the contrary, epidemiological data and up-to-date information about TB cases was easy to find online in the ministry of health website. What is this telling us about the place of the program within the state health apparatus? What can we learn from this in terms of the position of the patients, represented as mere statistics in a map? From my previous research on the history of TB in Chile I knew that the program emerged when TB was a national health priority in the 1940s.[15] Dr. Romero confirmed this:

> Our program was important in the past, when Chile had high TB prevalence…but we were close to eradication by the end of the 1990s and

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[15] The control of epidemics like small pox and cholera cemented the anti-tuberculosis programs in the 1930s and 1940s, which focused on dispensaries to deliver pain medication and sanatoria for longer treatments. Once the ministry of health was formed in 1952, after a healthcare reform, the TB program started to receive funding from the ministry of health.

> now we are not a priority anymore. We compete with other health issues, we have fewer resources and some of the (regional) teams are not even complete! We risk losing everything we have achieved…

A good example of the little support that the program has is that there were no major activities for the international TB day, that is the day that marks Dr. Koch's finding of the bacillus that caused TB (March 24th 1882). Providers working on "Elige vivir sano" ("choose to live healthy"), one of the intersectoral health programs created during the Piñera administration (2010 – 2014), undertook most of the local primary healthcare prevention campaigns, including those related to TB. This national system focuses on health promotion and wellbeing across government administration; funded mostly by the central government, "Elige Vivir Sano" also receives private funding for health campaigns from big companies in Chile like national supermarket chains, for example. The emphasis on the individual responsibility of choosing to live healthy evidently mirrors neoliberal ideologies shared in Chile. Further associations between individual agency and risk management are also part of the discourse behind this understanding of health as an individual option. Providers and staff working in the ministry of health at this time expressed their concerns and criticism to the initiative. In one of the meetings one of the persons who coordinates intercultural health and TB programs at the national level said "we need to be aware of how dangerous it is to think of health as an individual choice. What "choices" do people have? and what is the government doing for expanding alternatives and healthcare access? Health is not an option, it is a social right" (Arica 2013).[16]

In this context, the main event promoted for March 24th was *"actividad física"* (physical activities such as aerobics, dancing, and zumba). The fact that there was no particular work on TB related issues, or that patients were not included in the planning or further development of the activities is, from my point of view, a symptom of the fragility of the program compared to other health interventions. TB seems to be a medical category with the face of non-Chilean-others, as we learn from anonymous street graffiti or shared ideas about TB being a problem of indians from Peru or Bolivia.

In summary, the national office is responsible for the professionalization of TB *encargados* (supervisors and local coordinators) and their training, but within the hierarchy of the ministry of health, PROCET has no direct authority over the TB personnel. Lack of control over TB supervisors is complicated for the supervisors themselves, as they usually end up having TB control as an "extra" part of their job descriptions. For example, in the small Aymara town of Putre in the Parinacota Region, the TB supervisor was in charge of all the respiratory therapy as well as the periodic control of children under 5 ("Control del Niño Sano"). The conditions are not better in urban Santiago, where in local healthcare centers, the "TB person" also has several

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[16] Ethical considerations prevent me from disclosing further details of this intervention.

responsibilities. As a result of this, these providers feel that they are “overworked” and that their important role in relation to TB is very difficult to complete.

At the same time, there is an overall sentiment of frustration about the current situation of the program and the possibilities of reaching the eradication goal by 2020. Dr. Romero told me: “if the structural conditions don’t change, we will have TB for a long time (para rato)…” Dr. Romero thinks that there needs to be further connection with other programs working on social development at the local level, what is known in Chile as “trabajo intersectorial (inter-sectoral work):

> There is no collaboration…those groups (of people) at risk of TB, the complicated cases (pacientes complejos) depend on *intersectorialidad* and there is no collective work.

The *“trabajo intersectorial”* approach has been a major strategy for social development in Chile. Going back to the “Choose to live healthy” initiative, the intersectoral work is a consolidated strategy in the Chilean bureaucracy. And, as Dr. Romero confirmed, it is particularly important for the work of health interventions in the border regions of Arica-Parinacota and Tarapacá, where TB prevalence is higher. This kind of work is also important for including civil society in the implementation of social programs. Actually, participating in the “mesas intersectoriales” is one of the only opportunities that local NGOs and social organizations have to discuss any kind intervention. When it comes to integrating the community, Dr. Romero and others recognize that one of the difficulties that the program has in reaching patients and their communities is that the relationship between healthcare structures and social organizations "has always been very military or hierarchical," Dr. Romero affirms: "We follow the sanitary code and the TB protocols, but we still have problems detecting the illness. We have the mechanisms to make people comply with the treatment, legal backup, let's say. Still the information we gather is not complete. There are un-diagnosed cases."

The hierarchical mode of operandi of the Chilean state transcends bureaucracy and management to the actual implementation of state programs. The recent history of the configuration of a neoliberal project led by an authoritarian regime and abiding sociopolitical structures of race and class permeates contemporary political programs and their respective policies. Even more, the conception of health as an individual option versus a social right is part of the neoliberal governance in Chile, where the state apparatus succeeds in disciplining citizen's bodies and controlling health threats while at the same time is unable to reach it own intentions of healing the population, precisely because of the elusive part of this equation: citizenship.

Dr. Romero's understanding of the authoritarian approach of the medical system to the community could be seen as one of the consequences of the political restructuring of the country during the dictatorship (1973-1990) and the emphasis on stabilization and gobernabilidad carried out by the ruling party coalition Concertación for the following 20 years. The emphasis on gobernability is related to the concern on "working institutions" and stability in order to attract foreign investments. Following

Washington Consensus (Williamson, 2004) Chile sustained economic policies that tended to stabilization (fiscal discipline, trade liberalization, competitive exchange rate, privatization, deregulation, property rights).

In the 1980s the military government modified the health care system following recommendations of 'Chicago Boys'. Pinochet maintained low but targeting public expenditure, which would explain the infant mortality rate and other good health indicators in the context of increasing absolute poverty and impoverishing of the middle class (Reichard 1996). The reform of the Health Care System in 1981 as part of the Constitutional Reform of 1980 included the "right of all Chileans to health care". The system had four main features: fragmentation of the National System; reduction of public expenditure on health care; creation of ISAPREs; and decentralization of primary health care and hospitals management to municipalities (Uthoff and Sojo 2007). Pinochet's policies on public health (as in other areas) have to be understood under the principle of reducing public expenditure. The privatization of the health care system, particularly the creation of ISAPREs (private insurance and health providers) is a key element in this process. In 1990, among the available health care dollars, ISAPREs used 40%, however they only provide health care to 18% of the population. The situation is contradictory, as the poor layers of Chilean society contributed to the better health care of the upper classes (Waitzkin 1983). The authoritarian context of the dictatorship disarticulated potential opposition to the targeting public health policies. The functional targeting of the social reforms implicated neglect on public investment, as the programs tended to reduce the damage of the structural adjustment of the economy (Sojo, 2007). At the same time, the decentralization of health care was carried out with little public investment on infrastructure and human resources, pushing municipalities to take health care under their responsibility without extra budget, which has been a problem until now. In the context of decreasing public expenditure in health, how to understand better health indicators? In June of 2011 I attended a global health conference in Santiago. The Pontificia Universidad Católica (PUC) was collaborating in giving talks about the health situation in Chile and some of the successful public health programs implemented by Concertación between 1990 and 2010. heard former minister of health Mr. Jorge Jiménez de la Jara reply to a question from the audience. A young American anthropologist was amazed by the rapid improvements that Chile had in the 1990s, after recovering democracy:

> Anthropologist: Mr. Jiménez, what do you think made the difference in Chile's rapid improvements in terms of maternal mortality and health in general? Compared to other countries, Chile is different…
> Mr. Jimenez: The main advantage that we have is that we have an homogeneous population. Chile is not like Bolivia, for example, where you have 30 million people of different ethnicities…here we are all Chileans, and that makes it easier for implementing health care programs.

The answer did not satisfy the anthropologist who asked the question nor the audience in general. After listening to such imprecise reference about Bolivia and Mr. de la Jara's view on diversity as a difficulty I raised my hand and ask why was ethnic diversity problematic. Mr. de la Jara did not pay a lot of attention to my question, and then Helia Molina, a pediatrician who had worked in one of Bachelet's emblematic programs (*"Chile crece contigo"*) added that it was a question of discipline. Ms. Molina was later appointed Ministry of Health herself during the first year of Bachelet's second term in March of 2014. It amazed me to see how both medical doctors and public health policy-makers were embodying the Chilean state, as if it was so clear to them that they had the authority to target individuals and populations based on their scientific knowledge. The fact that they were adamant in solving any issue of difference without further consultation or research also shows that their authority is non-scientific but given by their position in the political structure.

When it comes to the inclusion of the community in the programs, it is very hard for the bureaucrats, the medical providers, and the people to communicate and work together in a more "democratic way". In my research I observed that a strong enforcement of the sanitary code allows the local health centers to deliver the treatment, but they have problems working with the communities in identifying potential cases, for example.

Having an authoritarian (*militar*) medical system working with national law enforcement agencies in following the sanitary code constitutes the epitome of modern biopolitics. In his work, M. Foucault conceptualized biopolitics as a "constellation in which modern human and natural sciences and the normative concepts that emerge from them structure political action and determine its goals" (Lemke 2011:33). Biopolitics refer precisely to the particular condition in which the state governs its subjects based on human's biological condition, but extending its power to other areas of human life beyond illness such as gender roles, education, religious practices, etc. By way of illustration of biopolitics at work in Chile is the suspension of the highly attended religious festivities of *"La Tirana"* and *"San Lorenzo de Tarapacá"* in July and August of 2009, based on concerns regarding the global alarm of H1N1 influenza pandemic that had not even striken Chile at all. Indigenous and non-indigenous people attend these religious festivities, which are celebrated each year in the towns of La Tirana and San Lorenzo, close to Iquique. However, that year the Ministry of Health suspended any kind of gathering that could threatened the population's health. The catholic church and popular catholic organizations protested in vain.

In Foucault's view, the government of life is only one expression of modern rationalities that orient political action. Hence, an authoritarian relationship between the medical system and the community is a relevant example of the overall political organization of the state and its role in shaping people's everyday life particularly through health discourses.

3.3. Biopolitics at work

In rural areas of the Chilean altiplano it is usual to see municipal vehicles driving up and down the Andes, usually taking with them social workers, school materials, or in nurses and medical doctors. Families living in the scattered communities in the highlands depend on these vehicles for communicating with the main state services, as there are no regular public transportation services available. Receiving medical attention and prescription refills is an example of this.   Thus, small settlements and estancias (ranchs) are periodically visited by municipal personnel. In my fieldwork, I traveled along the medical teams to the communities of Parinacota and Tarapacá in the Chilean altiplano in several opportunities, and in these trips I was able to get to know the experience of the medical providers and listened to their own views of the possibilities and limitations of health interventions in the Andes. The professionals stationed in Putre have a monthly calendar of visits to the different areas of Parinacota, and some trips last several days. In some towns, like Visviri for example, they stay at municipal accommodations where often times there is no heating or hot water. Yet, aware of their social role in delivering health, the providers are friendly and try their best to reach their patients and listen to their health complaints.

Once the medical technologist invited me to go to Puquio and find a patient who needed some urgent blood work. The municipal truck left Putre the next day before sunrise. It was at least a couple of hours away, and he needed to be in Puquio early that morning because the patient was fasting to get the blood work. The medical technologist in charge of the laboratory work told me that there are elderly men and women living in those ranches who hardly leave their home: “sometimes they travel to Arica with their sons or daughters, but hardly ever they leave the ranch for long”. The dirt road to Puquio is beautiful and so lonely that one can see guanacos, vicuñas, and vizcachas (andean rabbits). After a few hours I could see some houses from a distance. Once we approached the ranch, an elderly Aymara woman rushed towards the truck, and offering her arm to the medical technologist said: “blood, you need to take my blood!” Even the technician was surprised, as he was looking for another person (figure 8). The lady explained that she was going to travel with her family soon, and that she didn’t want to miss her future medical appointment. She said that it was a good opportunity to get the blood work done. Indeed, in rural areas around Putre, healthcare is a question of opportunity. Most people need to wait for the medical rounds or travel to get any kind of medical healthcare, so to see a municipal track with medical equipment coming to town was a big event. The lady was also worried about being a “good citizen”. She said: We go to the *controles* (check ups) at the medical post and they write down what is going on with us. They give us pills, do I need to take any pill? Is my heart ok?”, she asked. She felt so relieved and grateful about the whole thing that she prepared tea for us. When medical providers visit these ranches they connect people and communities. It is also a political connection: when the state meets the subject, as Foucault would say. And, who are those subjects?

If we pose the question of who are the targets of public health interventions, we may find that the authoritarian medical system focuses on some individuals over others. In other words, it is not enough to have a “strong” state, but also disciplined subjects who comply with the state regulations. There are also those excluded from the state intervention. In the next section I explore inclusion and exclusion mechanisms that are expressions of a particular biopolitical framework in Chile.

Figure 8. Medical technician performing a blood test to an Aymara women in Puquio. Photograph by Jorge Montesinos.

4. MEDICALIZATION AND PATHOLOGIZATION: RACE AND MEDICINE

Even before I could ask about it, the experts at the national and local level referred to the problem of immigration as a main cause of increasing TB burden in Chile. Phrases such as “before the flow of immigrants we were almost at the point of eradication” are common among medical providers. Indeed, in Chile tuberculosis is not only associated with poverty, but also with the indigenous peoples, to *“indio po-*

bre" (poor "indian"). From the medical system's point of view, however, not all indigenous peoples are the same. One of the doctors in Iquique told me: "in Chile we have the problem of the rural indians and the urban indians. The Aymara who live in the cities have more access to healthcare, but those living in the highlands have difficulties in getting any kind of service" (Antonio Guzmán, MD. Iquique 2012). But the question of the rural and urban indigenous has other implications within the medical discourse. In fact, there is an wide consensus in identifying the indigenous with the highlands, as if there were not indigenous peoples living in the cities. A similar situation happens in southern Chile with the Mapuche population. There, indigenous peoples associated either with rural communities in Araucanía o Temuco, or in the cities's outskirts. There is a difficulty in reckoning the indigenous in the cities, as integrated to the national population. From my perspective this is another example of the intensity of racialization and the multiple conditions that make race invisible in Chile. Furthermore, it is even more difficult for providers to visualize the Aymara being "authentic" in the cities: "They adapt to our way of life, to our medicine when they live in the city," a nurse from Arica mentioned. An urban Aymara, then, is not an "authentic" indigenous person. This limited essencialist perspective on indigeneity is particularly problematic when looking at what happens beyond the borders, to Bolivia and Peru.

A meaningful distinction for the providers in Chile is "extranjero" (foreigner) versus "extranjero chilenizado" (Chileanized foreigner). These categories do not denote the particular legal condition of the foreigner in the country, but to a sociocultural aspect that defines the ways in which people access the healthcare system and are disciplined enough to follow the treatment:

> People from Bolivia or Peru brought this problem. We didn't have it for a long time. The problem is that they are not aware that we have such a strict system. We follow DOTs'con pinzas' here (strictly) (medical provider, Tarapacá).
>
> In Bolivia people are exposed to TB all the time, then they bring it here. Those who come for short periods of time are at risk, and put all of us at risk. They need to adapt to our system (medical provider Arica).

Shadowing the experts and medical providers in Chile provided numerous opportunities to see the enforcement of public health on people's everyday lives. In the Birth of the Clinic, Foucault addresses the problem of power within the medical realm, defining medicalization as the process where pathologies were located in specific institutions or organs of society establishing a framework for interpreting symptoms and signs of disease (Foucault 1980). According to him, *medicalization* happened at the end of the eighteenth century when a particular medical comprehension- the biomedical academic tradition - overcame the lay knowledge of disease through the establishment of a set of institutionalized practices such as quarantines or sanitary cordons. The result was a new discourse about the bodily experience, which was based on the idea of the body as a machine (Bourdelais 2006; Foucault 1980). He argues that at that time, medicine developed a particular epistemology that banned the individual – and his or her subjective experience - from the formal state understanding of disease. Foucault insists on the importance of the structures of perception for the definition of disease, but what is most relevant in his analysis is that he relates these structures of perception to the formation of a political conscience -within the medical class- that pushed the medical knowledge away from the walls of academia, by establishing medical posts throughout France, each one of them accompanied by the medical police. These out-posted medical doctors started to control the individual experience of disease, and furthermore, extended the medical control over the social structures at the local level (Foucault 1980). Thus, defining what constitutes a medical problem, and which medical problem is more important than others is a question of power. Empowered epidemiologists and medical providers are usually those involved, they are able to impose their categories of illness in the biopolitical framework. In this chapter I am arguing that parallel to the process of medicalization, there was a "pathologization of indigeneity" that resulted in exclusion from institutional practices. The notion of "extranjero chilenizado" illustrates both concepts. At the same time, as Foucault himself explained, the normativity that emerged from the medical knowledge (and natural sciences) is part of a discourse that creates particular subjects. By the same token, these categories allude to the process of naturalization of socially constructed categories such as race. What are the subjectivities that these biopolitics produce? In the everyday medical practice, medical providers build relationships of power that target individuals as potential patients while excluding others, those who are "foreigners" not only because of their nationality but also because they are strangers to the state biodiscipline. At the same time, the foreigner subject avoids accessing healthcare because they are afraid of experiencing exclusion, discrimination, or in the case of the Aymara from Bolivia or Peru, deportation. Another example of these subjectivities that emerge in the process of medicalization and pathologization is the above mentioned "embodiment of the state" that medical providers and public health policy makers uphold.

The interplay of illness and race within the dominant biopolitical framework can be seen in the following two cases. First, is the situation of the mining camps or other camps like those of the companies upgrading the conditions of the international road between Tambo Quemado and Arica. The company rented rooms for the people working on the road, mostly non-indigenous men who came from other cities in Chile. The impact of this camp in Putre's everyday life was two-fold. On the one hand, it boosted the local economy as KODAMA's workers spent their money in lodging, food services and groceries. On the other hand, local men regarded them as a threat because they attracted "their" women with their affluence. The camp was deemed as "dangerous" or problematic for several reasons. Nevertheless, there were no associations between the camp and health risks such as STI infections, for example.

Thus, these camps are not target of state public health interventions. Furthermore, even though TB rates among men are higher in the Tarapacá region (where we find several mining camps), there is little research on the relationship between gender and TB (Health Service, Iquique). From the regional healthcare service, however, the associations between tuberculosis and race, are "clear": these men are not indigenous, so there is no risk of TB. This translates in limited action towards other vulnerable populations such as those imprisoned, male truck drivers, or men working in mining camps.

At the other extreme, let us examine the view of the indigenous peoples who immigrate to Chile. An indigenous immigrant from Bolivia who is TB-infected but does not follow the treatment would be a good example of the foreigner who is a danger to himself and others, who is "pathologized" and who is seen as carrying his or her disease to the cities. The many Aymara merchants who cross the borders to established their "negocio" (business) in the cities' markets of Arica, Iquique, or La Paz stay close to their posts in the market, often times they even sleep in small tents inside the markets, without proper shelter and access to sanitation. It is common for them to experience the scrutiny of the chilenos, who may consider them filthy. From the medical providers point of view, these individuals who travel in precarious conditions put the health of the overall population at risk. By the same token, the indigenous who approaches the healthcare services and "obeys" is an example of the Chileanized-foreigner, a medicalized subject who is willing to contribute to public health and safety.

In general terms, the control of tuberculosis in the border between Bolivia and Chile is also a question of state control of the territory through subject making: an authoritarian or militarized medical system needs a disciplined subject. On the contrary, as we will see in the next section, the situation of PNCTB within the state and the significance of the decolonization/intercultural program in Bolivia make this tuberculosis control program a unique example of an indigenous biopolitical project in a rapidly expanding state.

5. TUBERCULOSIS CONTROL IN BOLIVIA

The National Program for TB control in Bolivia is organized around territorial units. It has a national or central office that develops most of the programs, and specific staff for each area (ranging from epidemiological control to communications). Since it moved to a building in Sopocachi, an upscale neighborhood in La Paz, the office looks modern and connected to the rest of the public health services. The overall budget of PNCTB for 2014 was close to US$3.1 million, with a domestic contribution of 32% (WHO report 2014).

5.1. Illness and race in Bolivia

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. Scholars show that race has been a major category for including/excluding subjects from national political projects, particularly among modernizing Latin American nations (Zulawski 2007, 2000; Larson 2004/2008). Bolivia’s liberal state (1880s - 1920s) efforts in building an idea of the nation put notions of indigeneity side by side with 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 hygiene, and backwardness. Arguedas's provocative argument turned the discussion of race in Bolivia into a productive sociological debate 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 in relation to other social constructions, such as gender or age, something that is even more evident in time of war. The Bolivian case in particular, supports this point. For example, in periods like those of the Chaco war[17] (1932-1935), when the state needed to recruit the indigenous men to join the army and indigenous women to become caregivers, gender was more significant than race as it 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, especially about

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[17] The Chaco war between Bolivia and Paraguay was an armed dispute over the territories of the "Gran Chaco" that started in the 1920s when land-locked Bolivia pushed towards the Paraguay river as a way to access the sea. This was also an economic conflict for oil exploitation (Albó 2012). Scholars like M. Hughes and M. A. Centeno have described it as a tragic armed conflict involving two "extremely poor and autocratic countries" (Centeno 2003:58) and "South America's bloodiest inter-state conflict of the twentieth century" (Hughes 2005:412).

race.[18] 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 underlies these processes, namely: body politics. From my point of view, medicine has been a key site of the interface for the deployment of states' 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.[19] 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

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[18] 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).

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

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 of the twentieth century. In a similar line, A. Canessa argues that although there have been improvements in the integration of rural indigenous peoples through multicultural education projects, in Bolivia there is still an association between the historical militarization of schooling from the war years and the possibilities of being "civilized" and exercise citizenship (2007, 2004).

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). Grounded in these historical processes, epidemics are part of the political imaginary of citizenship. By the end of the nineteenth century, smallpox epidemics resulted in the expansion of the state public healthcare initiatives even to rural areas.[20] 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 also risked being exposed to contagious 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 pro-

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[20] For further information on this topic see Saravia (2008).

ducing a particular modern subject, whose belonging to the nation state was mediated through his or her racialized and gendered body.

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

The early twentieth century vision of Bolivia and the indigenous population presented by Arguedas in *"Pueblo Enfermo"* contrasts with the current political context in Bolivia. As I described in the introduction, after E. Morales election in 2005 and the collective construction of Bolivia's new constitution through the constituent assembly (enacted in 2009), indigenous peoples in Bolivia have gained political influence. What are the implications of decolonization and interculturality 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 design 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, bureaucracy and rivalries, and internal contradictions. An important aspect of this process is precisely what gets missed because of the ways decolonization is implemented: interculturality. This presents, for example, the dilemma of white mestizo health professionals learning aymara and other indigenous languages to decolonized themselves, instead of having more empowered and professionally trained aymara citizens.

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 Vice Ministry of Traditional Medicine and Interculturality is a particularly revealing example of these attempts to connect medicine and indigeneity. In this context, the question is how can these two components of the political project combine to pull off Bolivia's *proceso de cambio* (change process)? What kinds of articulation or contradictions, what forms of biopolitics does this involve? is this another phase of the state effort's? Is this a continuity of the liberal state project with decolonization nuances or is this emancipatory project? 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 sensitive situation, because Bolivia's health care budget is highly reliant on 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, there is still a lack of human resources and technology to deliver health, especially in rural areas.

5.3. 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 charge 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 dialogue between two different - and usually mutually exclusive - medical models: biomedicine (alopathic medicine) and indigenous health systems.

Mr. Elias Gomez, the person in charge of tuberculosis control among indigenous communities in Bolivia, has worked in the program for several years. He agrees with the general consensus among public health experts and Bolivian medical doctors about the difficulty of working with the current TB statistics in Bolivia: “There are a lot of cases that we don’t know about. But the worst is that there are several cases of treatment abandonment and relapsing that we can’t account for. Those cases are lost in the national statistics”. There is a need for statistics in order to plan and provide better care, he says. But at the same time, the whole national health care system in Bolivia is being reformed according to the new constitution.

Mr. Gomez told me that the program was including new components in the TB protocol, following the orientations of the Aymara principles of “suma qamaña” or vivir bien, the aymara notion of sustainable and healthy life: “we even have a new vice ministry, you see? we have the indigenous and traditional medicines vice minister who is also involved in policy making”. This did not surprise me, as the medical doctors that I had already interviewed talked about the need to reform and give “dignity” to the healthcare system. A health reform will imply a significant change in the organization of the healthcare system in agreement with the suma qamaña principles, and this translates of course into a different relationship between the state, the medical providers and the patient/citizen.

The suma qamaña indigenous principle promotes values such as complementarity between human life and nature, representing 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 (Garcia Linera 2010, Bautista 2010). 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 well as requiring medical providers and public service officials to learn at least one indigenous language. 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 bonuses to "compliant" mothers who take their children to the health care center for vaccination and controls (bono Juana Azurduy), like the Aymara women I met in the Coroico Hospital. 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.

5.4. When statistics are not enough

In Bolivia, even though there is high prevalence and the PNCTB receives continues funding through the Stop TB program, doctors and administrative personal had told me the same thing: "This illness is misunderstood. Fighting against TB is fighting against poverty. There is a rivalry with other illnesses, we spend more money but get little results" (Dr. Miguez, National Institute of Thorax, La Paz). Not only providers feel that there is a rivalry. Eva Limache, a patient and representative of the patient's association expressed this as well: "We compete with other illnesses, all the time. Now we are asking for brochures…we are waiting for the big healthcare forum in June (2013) so we can make known the experiences of TB patients". Another representative added "there is not good education about this topic, and sadly after the TB day everybody forgets" (Aspacont member, La Paz). Beyond official acknowledgement of the epidemic in international and national programs, is tuberculosis a state priority at all? To what extent is this illness important in the larger field of medicine? What are the processes that define a health priority? For the TB experts and government officials in Bolivia and Chile, tuberculosis is a neglected disease, a time bomb that will undoubtedly challenge all healthcare achievements. Why haven't they been heard? On the one hand, experts on each country work under the same health paradigm where they play a key role in keeping people healthy. On the other hand, they are aware that the knowledge that support their authority is constantly put into question by the increment of TB cases, and the failure of delivering universal care. From my perspective, in Bolivia it is not the illness *per se* that is neglected as in Chile, but those who suffer (or will suffer) from it, and this is related to structural conditions of inequality that still enforce categories of nation and race that particularly exclude the indigenous by making them invisible within the statistics, as well as limiting the access to public healthcare, including traditional indigenous medicine.

On the evening of March 24th, I was walking by "Plaza del Estudiante" where I had seen the billboard. It was the same billboard I saw the first time I went to La Paz in 2009, by then it was a shinny and colorful testimony of the significance of tuberculosis in Bolivia. Now is faded, weathered. I went inside a coffee shop and while I was going through my notes I witnessed how two workers were dismantling the billboard.

"There were right," I said to myself, thinking about the two representatives, "they are dismantling the billboard and the day against TB is not even over".

This comparative description of Bolivia and Chile's systems yields several preliminary conclusions. First, since a major task of these national experts is to foster the life of the "population," they only talk about "community" or "society" when they want to explain non-adherence to treatment. In doing so they match population with the compliant patient-citizen, while the community represents only cultural barriers to treatment adherence. The current decolonization moment in Bolivia is challenging this biomedical discourse (based on multicultural health), casting blame for failure onto the biomedical system. On the contrary, in Chile there is a predominantly neoliberal multicultural approach to indigenous health, which is an attempt to inform the communities of the biomedical terms in indigenous languages.

Second, while there is a basic idea about the relationship between tuberculosis and poverty, it is difficult for the experts to discuss the issue of indigeneity – not to say race. Consequently, in Chile the problem of TB is associated mainly with urban immigrants (who happen to be indigenous) while in Bolivia the issue of TB risk among indigenous peoples is open to question. Paradoxically, like F. Gomez remind us, "it is not easy to differentiate between indigenous and non-indigenous populations in Bolivia," which public health officials find critical in managing the TB policies and treatment proposed by the WHO. Like in Chile, economic changes and social differentiation among indigenous communities are shaping the emergence of a middle class, thus, altering the historical “indian” and poor link. As a consequence, like the Aymara told me “when we go to the cities we look like aliens, because we look like indians, but modern indians”.

6. TRI-NATIONAL REFERRAL AND CONTRA-REFERRAL FORM

I first heard about the international tuberculosis meeting when I met Margarita Saez in Santiago in January of 2013. Margarita Sáez is the director of the indigenous health program in the Chilean ministry of health. She is an experienced medical anthropologist who has dedicated several years to establish indigenous medicines as an important dimension of health policies in Chile. When I asked her about the working relationship between Chile and the neighboring countries of Bolivia and Peru she said:

> I think that we have walked a long path together these last years. And for that I am grateful to the Andean Health Organization [ORAS-COHNU]. Because they have facilitated this joint work, helping us to reflect on the health of the andean indigenous peoples. So in those systematic yearly meetings, of six countries! we have been tracing the collaboration of all ministries of health in the area of indigenous peoples, especially in terms of interculturality. And from there some joint projects, like the tri-national TBC one, and many more of other alliances - although some have not succeeded - we have re-enforce this relationship (M. Saez, January 2013)

The national antituberculosis programs in Bolivia, Chile, and Peru officially acknowledged the importance of having a clear mechanism to deliver the treatment to those patients who traveled across the borders. In one of the meetings organized by ORAS-COHNU the representatives of the three countries agreed on preparing a referral form to help the patients get the right antibiotic treatment when traveling. The anti-tuberculosis treatment is delicate in that each country picks a combination of antibiotics, and in addition to that, each dose depends on the weight and condition of the patient. In the Iquique office, Patricia Rubio mentioned that there was a shared concern about the possibilities of treating the patients abroad, she said: “they get the treatment here, our scheme [of antibiotics] but then once they are abroad we have no clue of how that patient is doing” (Iquique, December 2012). In Bolivia Mr. Gomez told me that it would be important that I attended the next meeting in May of 2013, he told me: “it is difficult the way it is [the treatment] set. Here in Bolivia we don’t know very well how it works in Chile, and they don’t know how it works here” (La Paz, March 2013). M. Saez and F. Erguetta were both looking after the meeting and to the agreement on an international protocol that could help TB patients as well as medical providers.

There have been several international meetings focused on TB during the last decade. Organized through the office of ORAS-COHNU, the meetings have been held in Tacna (Perú) and Arica (Chile). The purpose of the 2013 meeting was to twofold:

to share the advancements in the sanctioning of the form and to agree in a communication campaign to inform about its availability and use in all three countries.

Representatives of the TB national programs from Bolivia, Chile, and Perú as well as regional offices of the program, ministry of health, and international public health officials from PAHO-Perú and ORAS-CONHU attended the two days meeting in Arica. Don Inocencio, the only Aymara traditional healer present in the meeting held a ritual to ask for a good and productive gathering. Like other traditional healers that I met during my fieldwork, Don Inocencio was quiet and firm, confident of his knowledge and aware of his position in the reunion, he meticulously prepared the *mesa* and made the offerings of alcohol and coca leaves. Everybody else was following his prayers, respectfully paying attention to his instructions. I had seen this opening ritual before, in other Chilean governmental events. Because of the nature of this particular meeting I was hoping to see Don Inocencio as part of the organization of the whole conference. However, to my surprise, once the biomedical apparatus took over he blended in with the rest of the attendees.

After the intercultural gesture of having Don Inocencio first, the representative of the Chilean ministry of health - properly dressed with an impecable white coat - he thanked everybody for being there and welcomed the Bolivian and Peruvian delegations. Right after that the international TB experts spoke, presenting a summary of previous meetings. These two speeches were concise. The audience was sitting in round tables, waiting for the group work to begin. Margarita Saez announced the next presenter, medical anthropologist Malva Pedreros who gave a lecture about her recent qualitative study on the Aymara notions of tuberculosis and the treatment experience of patients in Arica.

As M. Pedreros was talking, the TB doctors and nurses started to get anxious. They told me that they have heard about these studies before, but unfortunately they didn't know "what to do with them", how to incorporate these ideas into their practice. The anthropologist and the yatiri did not speak to each other either: the study, well grounded and clearly written for a wide audience did not please Don Inocencio, he said to the round table later that day: "the issue is that there is still discrimination in the health care service." His complaint had no echo.

There is of course great value in the intercultural approach promoted by the Chilean state. Before the implementation of this program, there were not open discussions on how to improve health care access within indigenous communities in Chile. I will further develop this discussion in relation to social constructions of race and indigeneity in the following chapters.

But Don Inocencio's comment was not the only contentious one. As the meeting was developing, the three delegations realized that their expectations and ideas about the meeting were not shared. As the national presentations about the use of the form started, it was clear that the situation of the referral form within each country was in different stages of approval. For an instrument like this to work it needs to be officially integrated into the medical protocols, sanctioned by each government. While in

Chile the form had been sanctioned and it is working along the national referral forms, in Bolivia and Peru there is still a delay:

> PAHO representative: ok. Let's listen to each presentation. How is the form working in each country? Who wants to start?
>
> Chilean representative: well, every team was supposed to prepare a presentation…
>
> Bolivian representative: we don't have the form. How do you have the form?
>
> Peruvian representative: what do you mean you don't have the form?
>
> Bolivian representative: the program has been advancing a lot. There is a resolution from the ministry. I think that as a country we have advanced enormously, and same with the referral, with the medications. But as for the document, we have advanced a lot.
>
> Chilean representative: but…did you bring the presentation?…

The Bolivian delegation tried to explain that they were still discussing the form, that they had their own problems with the ways in which they categorize the patient who moves from one region to another, even within Bolivia. These explanations did nothing but upset even more the Chilean delegation. Around the table I could hear "is always like this, every time we meet…Bolivia never sends the same people, they are always late" Rula, one of the Peruvian representatives said. I felt sympathy towards the Bolivian experts, I knew about their problems in setting the TB program and dealing with the statistics, but in that moment there was nothing I could do to calm the

Chilean team. They just could not believe what they were hearing. Cristina Romero, the director of the Chilean office, stood up and said “I am going to reprimand you! we did our homework”.

The implementation of an international referral form sanctioned by Bolivia, Chile, and Peru in 2014 constitutes a concrete attempt to work beyond the national borders. Yet, the different conditions of the three countries, and their politics made it difficult to have the international form ready to use. From my point of view, the delay of the Bolivian delegation had not do only with the lack of technological means (use of email to notify cases, or have the TB software running in all places), but also with the political process in Bolivia, where there is a much more open discussion about policies and programs. It was not surprising for me that in Chile the form was sanctioned and in use as planned, as I see in that a particular political way of resolving “technical” issues without any kind of consultation. Once the meeting was over I was talking to Cristina. She was still “in shock” of the slow-moving process in Bolivia, but she understood that there are structural problems to the fast implementation of the form as well as a different way of governing.

7. CONCLUSIONS

It is important, of course, to keep in mind that the political projects of each state translate into discrete policies concerning health and disease, which in the case of tuberculosis are particular ways of implementing national TB control programs along the territories. Nevertheless, beyond the structural differences in terms of political projects, global health strategies such as intercultural approaches are present in both countries, thus becoming a common language for health care bureaucracies and medical providers. Hence, at the local level, practitioners and patients face similar practices. The above-mentioned slogan “together we will defeat tuberculosis” is part of that global health language that tends to “make invisible” local medical knowledge, like popular and indigenous medical practices, for example. Do the global strategies for controlling TB overcome national and local power structures? At a first glimpse they do not. The global strategies are dependent on the national structures such as healthcare systems and medical training. However, cultural features such as ideas about health and illness at the local level challenge international standardized programs. From a medical anthropological perspective, then, we should consider the following questions: How do TB control programs work in Bolivia and Chile? What are the challenges faced in each case? Are they related in any way across the border? How is it different to be a TB patient in Bolivia and Chile? What is the perspective of the medical apparatus on both countries? What does it mean to be a TB-doctor in Bolivia and Chile?

In the following chapters I will describe the perspective of medical providers in delivering the treatment and the and the patient's experience of the treatment.

CHAPTER 2

MEDICINE AND RACE

Chapter Summary

How do these two different biopolitical frameworks influence the doctor-patient relationship in Bolivia and Chile? How do racial categories shape the medical encounter? How do the doctors see the indigenous peoples? How do the indigenous peoples see the doctors? In the previous chapter I argued that there are two different biopolitical frameworks at play in Bolivia and Chile. One is characterized by a strong authoritarian neoliberal discourse (Chile) and the other is sparked by a state-led decolonization discourse where the indigenous peoples are gaining political power (Bolivia). Yet, these two apparently distinct ways of governing the populations (Foucault 2010) are displayed in the form of multicultural health policies where the biomedical categories of illness predominate over the indigenous ways of interpreting and acting upon pain and suffering. Thus, instead of crafting the desired intercultural dialogue, the medical encounter in both countries reproduces historically grounded racial categories that link conditions of abnormality to indigeneity. In this chapter I will show ethnographic evidence of how medical providers mediate between national biopolitical projects and indigenous sufferers/citizens who both resist and state power by following a different therapeutic process that is inspired by indigenous ideologies of health and illness.

1. DELIVERING HEALTHCARE IN THE CHILEAN ALTIPLANO

People in Putre refer to the healthcare center as a mini-hospital. It needs to be that way because since 1979 Putre has been the head of the Parinacota province and it is the biggest town in the whole area. A fertile valley surrounded by the Andean mountains where agriculture and pasture flourish, Putre has been important even since colonial times. With a population of 3,200 (mostly Aymara indigenous peoples), Parinacota is organized around two municipalities (Putre and General Lagos) that coordinate Chilean public programs for this area (economic development, poverty reduction, subsidies for housing, etc.). It is in Putre, however, where the state installed most medical resources, some very modern, including for example a dental ambulance capable of transporting the necessary equipment for delivering dental health care in the most isolated and "unreachable" corners of the highlands.

"Why did you come to work in Putre?" was the first question I asked the medical providers working at the health care center. Most of the medical staff are very young, but there are also experienced professionals who have been working in Putre for decades. They would answer in different ways: "I love it here, it is beautiful and people are nice" or "I needed a job, and Putre is close enough to Arica that I can still see my family on the weekends". In my fieldwork in Putre I stayed with one of the medical doctors, Carolina Montes, a young woman from Iquique who recently graduated from a private university. Her house, provided by the regional medical service, is close to the main square, and has a beautiful view of the valley. She enjoys the benefit of hot water and a good electrical system that allows her to have a small heater when it gets too cold. Although temperatures are milder in Putre, it is still at a very high elevation (around 12,000 f.). Like the rest of the staff, she would travel from Arica early Monday mornings and go back in the afternoon on Fridays. Every other weekend she had an urgency care shift and stayed in town. Although Putre is big, it is quiet and rural, "without distractions" she says. Carolina is very committed to her patients, and the patients like her a lot: "she laughs and she is nice to us", the Aymara said.

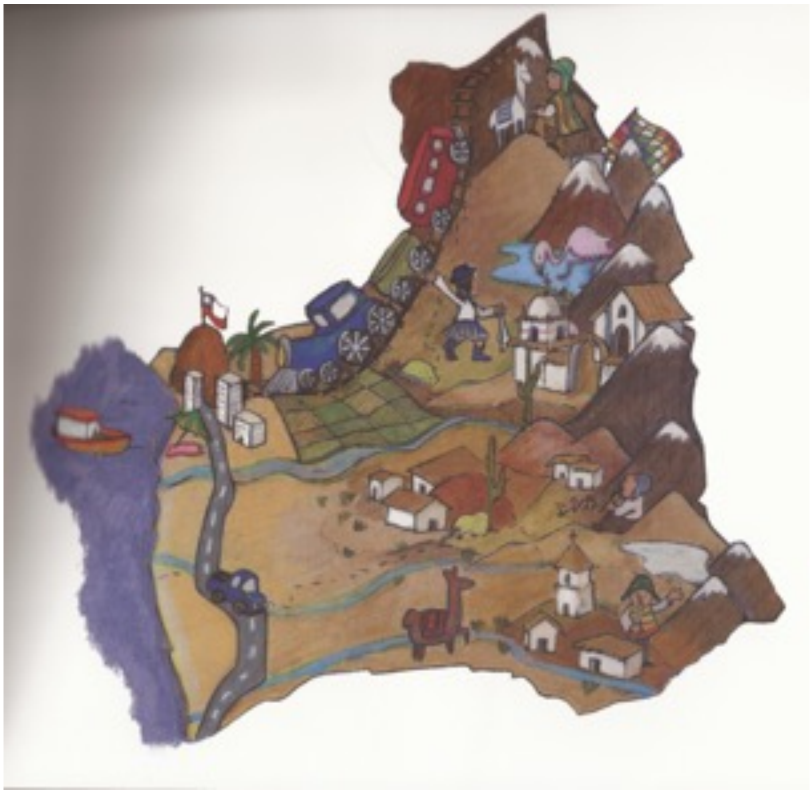


Figure 9. Map of Parinacota that shows the coastal city of Arica and the Aymara communities in the highlands. This map is a representation of the human geography of the region intended for children. Source: Soy José Mamani.

Besides Carolina and other doctors there are nurses, a nutritionist, a midwife (obstetra), a psychologist, a kinesiologist (who was also in charge of the TB program), a dentist, a couple of social workers, and the medical technologist in charge of the laboratory. There are also a few traditional healers who run the intercultural health program: Don Ramiro Tejerina (the yatiri), Doña Concepción (*partera*/indigenous midwife), and doña Lourdes (indigenous *masajista*). The staff travels in medical rounds to several small towns and estancias in the Sprinter, a vehicle capable of carrying a large group of people as well as boxes of medicine that the pharmacists hand out. The Sprinter represents the capacity of expanding the work of the healthcare service, and it is highly valued. Each two weeks they travel to Visviri, on the border with Bolivia and Peru, to see patients. Often it is snowing there, and for someone who grew up in the coastal cities of Iquique or Arica this is surprisingly beautiful. The accommodations that the healthcare service provides there are modest, but the teams try to keep up their enthusiasm. They told me: “It is hard to work in such conditions, but it is harder to live here everyday”. In Aymara Visviri means “where the wind blows”, which is not merely a poetic representation of nature—it is indeed a small dwelling where life is challenged by the constant wind. The small town of Visviri, “where Chile begins” (“*donde comienza Chile*”), is almost 120 miles distant from Arica, and 70 miles from Putre. These distances can me misleading, as the dirt roads go up steep slopes, climbing up to 15,000 f. making the trip between Visviri and Putre around 2.5 hours long.

Visviri was connected to Chile and Bolivia through the Arica-La Paz railway, built between 1904 and 1913 as part of the peace treaty between Bolivia and Chile after the War of the Pacific. The neighboring town of Charaña, in Bolivia, was the point of entry of most goods imported from Peru and Chile in the early twentieth century. Nowadays the people of Visviri take advantage of the weekly tri-national market at “Hito Tripartito”. In the previous chapter I referred to the Arica-La Paz railway and the Charaña train station as an important public health surveillance spot for the Bolivian state. In these times, the train is not operative, and both Charaña and Visviri’s train stations are abandoned.

Figure 10. Medical providers from Putre working in one of the medical rounds, Guallatire, December 2012. Photograph by Paula F. Saravia

Each week the team divides into various programs: maternal and child health, mental health, general consultations, etc. It is very intense, and the team works long hours. When I asked Teresa about the patients, she mentioned that the hard thing was to understand them:

> T: To really understand them, you know? (*¿cachai*?), sometimes we feel that we are not getting what they say.
> P: Do you think it is a language issue?
> T: Hmmm…maybe…we have to learn, I know some words, like *usutu*, for example. That means 'it hurts' in Aymara. But anyway, I wish we had classes, language classes.
> P: Have you had any "intercultural" training before coming to work here?
> T: Yes, they make us go to some courses (capacitaciones) so we know a little. But then you start working and you forget (se te olvida). (Teresa, 2013).

After a few weeks I asked them about the TB patients, and if they had any contact with the Bolivian healthcare system across the border. It is rational to think that the two medical systems would work together, at least in these parts of the highlands where one can literally walk from one country to the other. But they said that they did not have any idea about what healthcare was like in Bolivia or Peru. This was surprising to me, especially since most of the TB patients are indeed transnational Aymara. On the other hand, the fact that medical providers are uninformed of how things are across the border is not so shocking, knowing that for the most part, Chileans have "no clue" about Bolivia. In spite of that, Teresa told me about the intercultural courses that they take. I asked about the contents of those courses, and she said "they come from Santiago, anthropologists like you! Very nice people. They come and we learn about the Aymara, about their customs (*costumbres*), their culture." Do they ever talk about Bolivia? "No."

2. INTERCULTURAL HEALTH IN CHILE

One of the main principles of the intercultural health program in Chile is to build a dialogue between indigenous medicines and the state biomedical system. Within Chilean health policies, intercultural health is defined as "an approach to healing, rehabilitation, prevention, and health promotion, which aims to develop acknowledgement, respect, and understanding of the cultural differences between peoples and the complementarity of their knowledge and health resources" (M. Saez). The intercultural health approach is part of the law that regulates sanitation. According to this norm, the state should "formulate policies that incorporate the intercultural approach in healthcare programs in those municipalities with a high concentration of indigenous people" (art. 16 of the Ley de Autoridad Sanitaria). Medical anthropologists A. M. Oyarce and M.M. Pedrero, who work closely with the Ministry of Health in the Parinacota region in Chile, have defined the intercultural model as "a theoretical and methodological research strategy articulated by the negotiations of meanings of health, illness, life, death, healing and care, between the healthcare teams and the indigenous communities" (Oyarce and Pedrero 2006:7). The intercultural health program originated from Mapuche organizations demands in southern Chile, who wanted to integrate their medical practices into the public healthcare system in the Araucanía region. Indeed, the Makewe intercultural hospital near Temuco is one of the most successful international examples of an indigenous-administered healthcare center. The Makewe case also shows how state recognition of Machis (traditional healers) has influenced an upturn of the Mapuche identity (O'Neil et al. 2005). Unfortunately, it has been hard for the state to replicate the uniqueness of the Makewe intercultural hospital in other indigenous territories in Chile. In Makewe, the state funds the healthcare services but the hospital is owned by the Catholic Church.

Intercultural health refers to the encounter of different medical systems. Nevertheless, the dialogue between these different medical systems should be situated in the context of the state's political project. M. Saez agrees with the need for political support to promote changes so that indigenous peoples can access a healthcare system that heals "in context." However, from her perspective the problem lies in the cultural disconnect between these different medical systems.

Other hospitals, such as the Hanga Roa in Rapa Nui (Easter Island), have attempted to create this same harmonic relationship, yet in Rapa Nui it is the state who is in control of healthcare services. As noted by medical anthropologists M. Weisner and V. Fajeldril, in this case, the conflict emerges from the association of the hospital to the Chilean state:

> The rejection is not towards biomedicine, but to the hospital itself, which in the collective memory has inherited the repressive and precarious characteristics of the institution of the past, and by extension, to

> the Chilean institutions in general. The resentment towards the Government is based on the antinomic relationship of neglect and domination experienced (Weisner and Fajreldin 2009:158).

The Rapa Nui example of the interplay between memory, the experience of illness, and access to care shows that an analysis of current intercultural health interventions should also consider a historical perspective on the ways in which indigenous communities have related to the nation-state. What is the situation in Putre, a town that crystallizes the presence of the state in the highlands?

2.1 Making interculturality happen in the Chilean altiplano

The intercultural health intervention in Putre is evident to the naked eye. The *consultorio*'s (healthcare center) entrance wall is decorated with indigenous graffiti, and each door sign has an Aymara translation. It is similar to other healthcare centers I visited in Santiago and Iquique. However, in Putre, where there are Aymara speakers, the signs make more sense. The door for the DOTs room also has a name in Aymara: *tisiku.* This term originates in the nineteenth- and early twentieth-century notion of "pthisis" (infection of the lungs). Interestingly, the ones who use this word the most are medical providers working under the intercultural health model, not the patients or their community.

As the Aymara patients told me, it "doesn't make sense" because they identify tuberculosis with the West: "we didn't have tuberculosis before, it came with the Spaniards." *Tisiku* is just a reflection of the doctor's diagnosis. Thus, when asked about *tisiku* or TB the Aymara in either country merely repeat what they learned from the biomedical field: "by the bacilli [one] can be infected." The answer can be very different if we ask about tuberculosis just as an illness of the lungs:

> PS: How can one be infected by tuberculosis?
> R: According to gossip (*habladurías*), they say that [one] should not get close [to the sick], that [one] needs to get away, that when coughing or breathing, that must be [contagion]. We know how to get better, but not so much about getting closer…when I was little that was the first time that I talked to my cousin, but I never saw that he infected anyone. They say that it is contagious. I have never seen what they say about contagion.

Figure 11. The tuberculosis room in the healthcare center in Putre signaled with the biomedical post and its translation to Aymara language. Photograph by P aula F. Saravia.

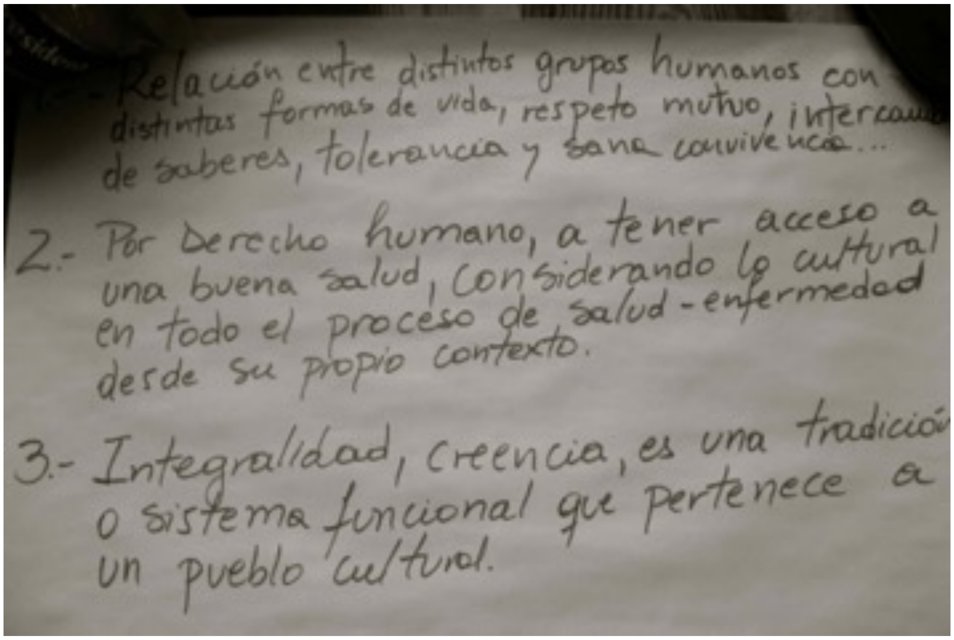
Andrea Carmona was the person in charge of the respiratory assessments and tuberculosis control in Putre. She grew up in the central south of Chile, so her experience is a little bit different from the rest of the team, as she had to adapt to the life in the highlands. She said that being the TB supervisor in Putre is meaningful because working in the rural areas is challenging. "You cannot take anything for granted," she told me.

> At the beginning it was difficult, we didn't have enough *baciloscopías* (laboratory tests), we didn't even have a *coleman* (cooler), now people are more aware of this illness, now they know that people can die of this, and nobody should die, because this illness is covered by law, it is free (of charge)! So anyone that comes and says "I've been coughing for more than 15 days, so I want a baciloscopía" should get the test right away. Even the medical staff is more aware now. And for me that is a big thing, that people are taking this illness seriously. A lot of these people, for example the *abuelitos* (elderly) told me what it was to be contaminated, like they say, with *tisis*. That is how they called TB. [They told me] about the medicines they prepared at home. Here in the cordillera, for example, you will see a lot of black dogs. In general, the skin of a black dog is used for protection, and according to them, to their faith, the lungs. So they sacrifice these dogs and when the person feels sick they place the hot skin [of the dog] over the chest. And in their logic, they get better. So here you cannot tell them "your remedy is useless", the idea here is to combine the traditional and the Western medicine.The Aymara medicine is rich in many things. Even I had to try many of the herbs that my patients take because the qulliris (traditional healers) say that they make people feel better. I answer to the qulliris. I can't discredit them, because that is the "plus" of working in the rural areas. To work with what the patients believe. And the qulliris have helped me a lot, truly, to get to the people. They have also given me some of their wisdom, they explained what the herbs are that the patients need, for example for tuberculosis, for asthma, for…for example, I grew up in the south, so all of my life I took herbal remedies, so, who am I to discredit anyone? What I do ask is that, for example, if a patient is [using] an inhaler, that he inhales at the time I prescribed. That if he is taking prednisone, that he takes the prednisone at the time

> I said, and that if he wants to take the herbal tea, he is welcome to do that. I don’t have any problem unless he discontinues the Western treatment, that is the only condition I have.

There are several themes concerning interculturality in this testimony. First, there are issues of awareness and trust. Awareness about the dangers of TB infection and trust in the medical system that can effectively heal the patient. There are also issues of trust among healers and the relationship between traditional healers and biomedical staff. People like Andrea are truly concerned about their patients, and the traditional healers help them to build a relationship of care based on trust. At the same time, the testimony shows that there is a tolerance of the traditional healing practices, but the “real” treatment is the one provided by biomedicine.

This is not a problem exclusive to the Putre healthcare center. In the neighboring region of Tarapacá, I observed similar attitudes from the biomedical staff of the regional health service, and also among physicians and nurses working in the intercultural health program. During one of my visits in 2012 they were very concerned because the national television had broadcasted a program called *“cómo nacen los chilenos”* (How Chileans are born) showing the experience of an Aymara woman in delivering her baby within the intercultural setting promoted by the state. The T.V. show was produced by F. Urrutia, P. Egaña and P. Gómez, and it followed twelve women's’ pregnancies in Chile, showing the different trajectories of each one. The episode about the Aymara intercultural birth was number eleven, called “An unexpected birth," and was broadcasted on October 28th, 2012. This was not an unexpected birth at all, and that was the problem. By showing this failure of the intercultural health program the national television had exposed the whole system. Fátima Sacre, the professional coordinating the safe-birth program asked me if I could help them lead a meeting to analyze what went wrong. We planned a workshop with the whole team, including the Aymara midwives and the hospital staff who participated in the unexpected birth. I was very excited to hear about what they wanted to say. Fatima said: "Paula, you understand that in Chile this is very serious. We can't have these failures, we can't risk the safe-birth of a kid, and that is for both indigenous and non-indigenous cases" (personal communication, December 2012). During the workshop there was a tension between the supervisors and the rest of the staff (including the traditional healers). I divided the audience into smaller groups, trying to embody the perspectives of the different health providers. Each group had to answer the following questions: What is interculturality? Why is it important to include an intercultural perspective in healthcare? What is Aymara medicine? After discussing the meanings of interculturality and birth each group wrote a summary of their observations on a cardboard poster (see figure 12). This exercise was helpful in analyzing the complicated situation of an unorganized medical procedure posed by the video. It was also an opportunity to talk about the problems that emerge from intercultural interventions, such as the "intercultural birth." Who is responsible for the success of said medical interventions? What is the role of the indigenous patient? Some of the groups mentioned human rights as a basis for interculturality within healthcare: “[We should include interculturality] for human rights, for having access to a good healthcare that considers the cultural context along with the processes of health and illness” (Intercultural Workshop, Iquique 2012).



-Relación entre distintos grupos humanos con
distintas formas de vida, respeto mutuo, intercam
de saberes, tolerancia y sana convivencia...

2.- Por Derecho humano, a tener acceso a
una buena salud, considerando lo cultural
en todo el proceso de salud-enfermedad
desde su propio contexto.

3.- Integralidad, creencia, es una tradició
o sistema funcional que pertenece a
un pueblo cultural.

Figure 12. Photograph from the interculturality workshop with medical providers in Iquique after the episode “An unexpected birth” was shown on national television. Photograph by Paula F. Saravia

I find this to be very important because it brings medicine, indigeneity and human rights together. In Chile there is still a close association between human rights violations and the military dictatorship. After years of inconclusive reconciliation, the debate on human rights in Chile is still very controversial. The current situation of state violence towards the Mapuche in southern Chile (Richards 2013) adds another layer of complexity to the relationship between human rights and indigeneity. In my experience in the field, I found that most medical providers in northern Chile were interested in working within the intercultural framework to make the patients more comfortable. Furthermore, I see that the problem of implementing an intercultural model is not so much about the attitude of the medical doctors. In fact, most of the medical providers tolerate cultural differences, at least in their discourse. They even express interest in learning more about the Aymara. Instead, the disconnect between medical practice and indigeneity is the neglect of racial issues and the view of indigeneity as a cultural artifact. The Aymaras from Bolivia and Chile already navigate between the two medical practices, alternating therapeutic processes according to their interpretation of the symptoms and availability of resources. Hermes is an Aymara from a small town in Potosí, Bolivia. I met him in San Pedro de Atacama, Chile where he works. Later that year I traveled with his cousin to their town (near Soniquera) and from there to Uyuni.

> One day he was telling me about tuberculosis:
>
> P: So, you were telling me about tuberculosis…
> H: Yes, I am from Potosí, and there tuberculosis comes to those who work at the mines. People start to work when they are around 14, 15 years old. Then, when they are 27, 28 they start to cough. There people don't have a lot of resources (*casi no hay mucho recurso*) and people there are poor. They work, work, work but they don't earn much.
> P: Why do you think that people get sick from tuberculosis instead of other illnesses?
> H: At the mines there are gases, inside [the mines]. And people working there don't know how to cough [the gas] it [out] and they cough, and the cough stays [imitates the sound of cough] and then they give it to the kids, and there it stays [cough].

> P: And what do they do? Do they go and seek help? Do they go to the health post (*consultorio*)?
> H: We live in the country (*campo*) and there is not a *consultorio* there. If anything there is a small health post (*posta*). And the person in charge is almost never there. So we use things from the country, herbs, those things we use.
> P: Which kind of herbs [do you use]?
> H: Those for coughing, the ones with thorns…we drink them like tea (*mate*) with boiling water, that we drink. Because in the country there is no hospital, [we] cannot see a doctor. So with [the herbs] we protect ourselves from illness, any illness.
> P: And is there a traditional healer (*médico tradicional*)?
> H: Not in my town, no. There are some ladies, but not a specialist. So among ourselves we cure any illness. People don't have economic resources, we do what we can, but there are some towns without any means of transportation (*movilidad*) and people have to walk a whole day, sometimes 4 or 5 hours and walk up the hills just to get to a *movilidad*. So we use the herbs, the medicinal plants. We don't have *yatiris*, but there are some men, but they don't cure you one hundred percent, maybe forty percent…
> P: What kind of men?
> H: They are like the Virgin, some people believe [in them], and if you believe then the saint cures you. If you don't believe you get punishment. Only a few saints heal, the others punish you.
> P: How do you know when they are punishing you?
> H: Once I was feeling ill, and I wasn't sure…if I go or don't go…so at the end I went just *"por fregar"* but I didn't go with faith. So I went undecided. I got to the place, everything was ok (*tranquilo*) but in the afternoon my ear hurt. I couldn't eat anything, drink anything. So I told the *curandero* (medicine man) that I had gone [to see the saint], and he said to me "the Lord (*el Señor*) has punished you because you have to go with faith." And then I knew that the Lord punishes you.

In this conversation Hermes displayed a diversity of healing practices associated with the Aymara culture. Yet, in his testimony he was not referring to a static "folklorized" cultural artifact. Rather, he was referring to their culture as integrated into the context in which they live. As other Aymara told me, depending on the illness, they would seek the biomedical doctor. At the same time, there is an association between illness and biomedicine that parallels an interesting connection between healing and the Aymara medical system. Whenever I asked about illness (*enfermedad*), the typical response I got was:

> The truth is that in my town people are healthy, for the most part we don't have those strange illnesses (*enfermedades raras*). We don't have hospitals, so people are healthy. [It] must be because everything is natural there, we don't have chemicals, and we only have plants (*plantitas*) and herbs (*hierbitas*), that's why we are healthy, I say (male from La Paz).

The Aymara I encounter in the Chilean highlands were aware of racial differences, but they did not want to talk about them. Neither did they want to talk about tuberculosis, another source of distress and exclusion. I also realized that in Chile racial differences were usually expressed through the connections between physical look (skin color, height), class (occupation), and place (urban or rural). While the Aymara preferred to talk about their *"costumbre"* (culture), the medical providers felt more comfortable talking about ethnicity, or indigeneity.

Other scholars have presented a reasonable debate on interculturality explaining the failure of the intercultural approach through the incompatibility between the biomedical and the traditional healing system. I agree with M. Weisner and V. Fajedrin in that it is not so much the biomedical system itself that is the problem, but its part in sustaining the state's role in restraining the flexibility of indigenous healing pathways.

Beyond the classic critique of biomedical providers, in this dissertation I am showing that the medical encounter mirrors the political relationship between the citizen and the state.

Figure 13. An intercultural medical encounter in Guallatire, Putre. Photograph by Paula F. Saravia

Figure 14. A representation of a Yatiri, the Aymara traditional healers and wise men. From the book Soy José Mamani.

3. RACE AND ILLNESS IN THE YUNGAS

> "[Coroico]…the old town, and capital of the second Yungas section, is placed high and located halfway up the Uchumani hill, which is the core of the best estates of the Yungas." (C. Doria, La Reforma, La Paz October 8th, 1873).[21]

The trip to Coroico began in Villa Fátima, in La Paz. Villa Fátima is the door to the Yungas, the tropical valleys in the Andes. The weather and the landscape change as the road descends, and tropical trees such as bananas appear. Noisy birds, waterfalls, and in a few kilometers the landscape is transformed. Along the road there are the usual tourists descending the "death road" by bike, the loaded minibuses full of passengers and cargo of different kinds (coca leaves to La Paz, food and other household goods to the Yungas).

The winding road takes the traveler to Coroico, a town full of life, with busy, hilly streets. The Yungas not only connect the Amazon and the highlands, but this fertile region of La Paz also sees the flourishing of the production of coffee, coca, and

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[21] The original quotation in Spanish: "[Coroico] pueblo antiguo y capital de la 2da Sección de Yúngas está colocado en una eminencia sobre una meseta adherida a media falda del cerro celebrado de Uchumachi, que es el núcleo y centro de las mejores fincas de Yúngas, contando en su derredor hasta 52 haciendas de coca, café y cacao, de cuya cumbre descienden en distintas direcciones abundantes arroyos, condensándose nubes constantes, que fertilizan con sus lluvias aquellos campos (…) casi igual número de valiosas propiedades cubren los cerros inmediatos, que rivalizan en idénticos y pingües productos a las del Uchumachi, cuya riqueza proverbial constituye la fortuna de sus propietarios y de la provincia, siendo su agricultura tan fructífera y de una constante producción que encierra más sólidas riqueza, que todos los tesoros explotados del afamado Potosí, pues aquellas masas enormes de plata que han circulado por todo el orbe, se puede decir que se han evaporado como la niebla a la acción del sol, sin dejar en bien del País una señal benéfica de su paso" (La Reforma, 8 de Octubre de 1873).

other products. Like Putre, the Yungas also have a particular history related to colonialism and the Bolivian state-formation process. There is a distinctive quality of the colonial legacy in the Yungas. First, there is the experience of an internal colonial "*hacienda*" structure through the production of cacao and coffee, which was based on the exploitation of indigenous labor from the Yungas, the highlands, and also the importation of slaves. Second, there is a relationship to colonialism through the exploitation of the indigenous population and the rainforest in order to extract quinine for exportation to India. The quinine from the Yungas, and also from Peru, was used for preventing *paludismo* (malaria) among the English soldiers in the colonies.[22]

The exploitative relationship between quinine extraction and labor takes an even grimmer connotation if we consider that the Yungas itself was known for having malaria outbreaks. Hence, the indigenous people and the slaves in the Yungas were in fact dying of malaria while sustaining the English colonial regime by supplying the precious quinine.

By the end of the nineteenth century, there were several accounts of the "savage life" in the rainforest. Bolivian voyagers from La Paz, inspired by the naturalists' expeditions, set out to register the life beyond the cities. In these early years of the Bolivian state, there were also political intentions of controlling the still unknown territories of the Yungas and Acre (on the border with Brazil). One of them was César Doria,

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[22] The quina (quinine) was extracted from the chinchona tree in South America. It was key in fighting paludismo (malaria) in India. For further information see: Quinine: Malaria and the Quest for a Cure That Changed the World" por Fiammetta Rocco (2004).

who published his account of a trip to the Yungas in a series of newspaper articles titled “Impressions of a Journey” (Doria op.cit). These accounts illustrate the social differentiation and racial classifications of the time, and the concerns about civilizing the savage rainforest “other”, those who were not “proper” indians like the Aymara or Quechua.

Those racial classifications still play an important part in shaping the radicalization process in Bolivia. In this sense, the concept of racialization, or the processes of ascribing ethnic or racial identities to a relationship, social practice, or group that did not identify itself as such, becomes fruitful in analyzing power and race in the Yungas. Even though not many “savages” and slaves survived the harsh labor conditions and illnesses in the highlands, those living in the Yungas elaborated a complicated cultural system that incorporated the Aymara language and social practices. Hence, in the Yungas, Afrobolivians identify as Aymara. This translates into an embodied socio-symbolic process where there are impositions of racial categories, a subjective experience of racial ascription, and a performance of said radicalization that leaves historical legacies. As French anthropologist D. Fassin argues, “the body is precisely where the three dimensions are articulated: the violence of racialization is exerted, experienced and performed through the body (2011:428). How do we understand racism and tuberculosis if these two linked experiences are rendered invisible? In the following sections of this chapter I will illustrate the connections between racialization and tuberculosis in the context of the biomedical healthcare encounter.

3.1. Challenges of healthcare

The hospital in Coroico is different from other rural healthcare centers that I had seen in rural areas of Bolivia. It is a public hospital, funded by Italian foreign aid and administered by Italian *monjitas* (nuns). Additionally, the hospital serves 109 communities located in a steep geography and mountainous landscape, which is marked by ravines and extremely high elevations (see figure 15).

The medical doctor in charge of the TB program, Justa Mamani, is a strong woman dedicated to serving rural areas. Her office and consulta, where she receives patients, is small but very organized. When I met her she had just come back to work from a long leave. Her life as a doctor in Coroico is not easy; she is away from her family and works unusual shifts (Tuesday to Sunday). Besides her job in coordinating the public health programs, she also works the 24-hour emergency shifts. Furthermore, she says that she does not live in Coroico. She told me firmly: “No, I don’t live in Coroico, I live in La Paz. I work in Coroico. Here we have some housing where we can stay, but I can’t say I live here. My home is in La Paz.”

Like the other rural medical doctors that I interviewed, Dr. Mamani is very aware of the structural limitations for a good, “decent” practice. She explained:

> I mean…the national program can come and leave us many tasks (*tareas*), it is easy for them to tell us [what to do], they don’t come and give us staff, for them it is easy to ask for results, but they don’t know how [we work]. Look, they just left an evaluation, now you tell me, if you had this evaluation, would you be enthusiastic about your work? (…) We work with 109 communities spread throughout the mountains, and

> we have around 10 active TB patients. It would be nice (*lindo*) to have all 10 patients in one community, but no! The patients that we have now live in different communities. I just don't see a serious policy to strengthen the work in the rural area. These new reforms, they won't do anything for the patients if we don't improve basic things like decent roads, transportation, and decent salaries for people in the health sector. Look, I work 210 hours each month, a person with my qualifications in La Paz works 160 hours and earns the same as me. We are not talking about serious policies, no. (Coroico, July 2011).

Her frustration originated in a recent report where the national TB program harshly evaluated the work of the team in the area. The team had recently designed a more pertinent intervention, DOTs *comunitario*, where community guarantors delivery the treatment.

Figure 15. Map of Coroico that shows the hospital at the center and the 109 communities that it serves. Photograph by Paula F. Saravia, 2011.

Figure 16. A view of one of the open markets in Coroico. Photograph by Paula F. Saravia

The local DOTS *comunitario* had good results. Dr. Mamani said that more people engaged with the treatment and it was also a way to educate young people about tuberculosis. The program starts with the regular individual diagnosis and laboratory confirmation of active TB, but then the patient and the guarantor receive instructions for taking the medications. Once every 10 or 15 days, the guarantor goes back to the hospital and receives a package with the medications. Dr. Mamani clarifies how to conduct DOTs with people who live far away:

> Well, according to the norms we should see that the people take the medications. But that is not possible here. There is no transportation (*no hay movilidad*)…so, we have created DOTs *comunitario*. We work with a guarantor, we look for someone who represents the community—popular health leaders we call them. We also had young students from boarding schools. When we don't have that, it needs to be some-

> one from the patient's family. They receive instructions from us, from the nurse. Each 2 months the patient needs to come for the mandatory lab work (*baciloscopia*) to check that TB is not active anymore.

The quality of the relationship between the TB staff and the patients depends on the flexibility of treatment. The nurse in charge of delivering the medications, Licenciada Beatriz, said: "this is an endemic zone for tuberculosis, but we also have other diseases, we have malaria, leishmaniasis, etc. Because of that, most people are familiar with these illnesses, and when they come they would tell us that they have been coughing, etc. They are aware, so it is easier for us to work with them" (Lic. Contreras, 2011). However, the economy of Coroico and this part of the Yungas relies on exchange and movement of people and products, "people are coming and going because of the coca plantations and harvest, we have a lot of migration here and that is hard because people travel" (Dr. Mamani, 2011). So what happens when people travel? I asked. Dr. Mamani and Lic. Contreras looked at each other and then Dr. Mamani said:

> Well, there is a referral form, but it is part of the many papers the patient and I need to fill, most of them don't even write. They come and they are leaving for a month or so. What I am supposed to do? Tell them that they can't go? Are we going to support them with just the pills and the paperwork? No! They need to work, ¿no ve? So we give them the pills and they leave. That is better than having them abandon the treatment (Dr. Mamani 2011).

In the previous chapter I discussed the biopolitical aspects of TB control at the national level in Bolivia and Chile. These testimonies on the difficulties in delivering care in the rural areas add to that discussion. Dr. Mamani told me that the problem with tuberculosis is that “it belongs to all, yet no one owns it” (*es de todos y no es de nadie*). What are the implications of these critiques to the healthcare policies that sustain the TB treatment in Bolivia? How does it compare to the Chilean case?

In both Putre and Coroico the medical providers were aware of the social difference between them and the people they served. They also knew about their patients’ difficulties in accessing healthcare, and how, like other city dwellers working in the *campo* (rural areas), they struggle with separation from their families. They had the idea that they “know” their patients, as they spend most of their everyday lives with them. According to Dr. Mamani, rather than blaming the patients and their non-engagement with the treatment, the difficulties had to do more with problems at the national level. In Coroico, Dr. Mamani argued, the problem was the lack of discipline and that there were no solid state-led public health policies. She compared Bolivia and Chile:

> Truly, we need to be conscious that us Bolivians don’t have a culture of completing tasks, we do everything by force (*a la mala*). We are not as aware as we wish we were, so when we had the pressure of the Italian foreign aid, all of us were into the task. Instead, now that we are the sole people responsible, we have not been taking enough care. I won’t say that we don’t do anything, but we have neglected those things that gave us good results. One of those things was the “cough professor” that we designed here, by ourselves. The laboratory person was in charge, not the one you just met, the other doctor…and that is the problem, the personnel is always in rotation, always changing. That makes it so difficult. (…) I think that in Chile you have a lot of advantages. I think that because President Bachelet is a medical doctor, now that she is in office she is doing her reforms…that is why I think, no matter

> what they say about Chileans, about Pinochet, is that he put things in order. And we are missing that. Here we learn everything by force.

It is not uncommon in Latin America to hear about Pinochet's dictatorship "contribution" to the Chilean national discipline. What I find fascinating about this testimony is that Dr. Mamani was longing for a stronger - or perhaps more visible - state, and for more discipline for all Bolivians (indigenous and non-indigenous). When I heard Dr. Mamani talk about her experience I recalled anthropologist A. Spedding's view on the Bolivian state in the 1990s:

> The Bolivian state is not consolidated. In the rural areas, the authority of the state is ineffective when not absolutely absent; one needs to search for the state, traveling to the capital of the province or department where the officers (*funcionarios*) live. The authorities are exclusively urban, the authorities could not care less in the rural affairs, and they let the communities of farmers organize their matters as they please. The more that the state does for the community is to send a teacher for their school, and this only when the peasants themselves have built the school. After keeping the teacher whose miserable salary reaches it almost always late. Other than that, most people only know the state when it collects taxes to bring products to the city, or *sentaje* (fees) if you sell at a fair (Spedding 1994:21).

The present/absent figure of the state in Bolivia is part of an ongoing debate. While there are some scholars like A. Spedding who argue that the state has been stronger in the urban areas and absent in the rural communities, other scholars like D. Goldstein are more in favor of thinking about the retreat of the Bolivian state (at least during the neoliberal period (Goldstein 2004). In this research I found more evidence of the former argument, at least in the view of Bolivian rural Aymaras living in the border with Chile, who were adamant in recognizing the differences between Bolivia and Chile not only in terms of health care and education but also in forms of state planning of the transportation systems, for example.

A second aspect that emerges from Dr. Mamani's observation is the sensitive comparison between Bolivia and Chile in terms of race. Particularly after the War of the Pacific, the Bolivian and Chilean states have framed the political tensions between both countries in terms of national identities. During the dictatorship of Pinochet, admiral José Toribio Merino (a former member of the Junta Nacional de Gobierno during the dictatorship of Pinochet), unhappy with the constant Bolivian claim for lost territories, constantly lessen Bolivian people (see figure 17). In 1993 he even referred to Bolivians as "auquénidos metamorfoseados who learned to speak but not to think" (metamorphosed camelids). There is of course an extension of this racialization of indigenous peoples from the Andes to those living in the Chilean highlands. Chileans refer to them as "llamas," for example. Hence, in this context of national identities and race, Dr. Mamani's opinion is significant. In the following section I discuss the experience of Bolivian and Chilean Aymara living in the border, and the racialization process that they face.

"Que Bolivia diga que sin mar no puede desarrollarse...Yo diría que el desarrollo de los países no está en función del mar. Primero hay que tener gente para usar el mar y después empezar a pensar en lo demás"

(Almirante José Toribio Merino, 1 de mayo de 1980.)

Figure 17. Admiral J. T. Merino referring to the Bolivian claim for sovereign access to the Pacific ocean: "That Bolivia said that without the sea there is no development…I would say that the development of countries is not conditioned by the sea. First you need to have people who knows how to use the sea and then think about everything else" (my translation). Source: http://chile-almirante-merino.blogspot.com/2011/05/prensa.html

4. RACE HAS MANY SHAPES

Race and indigeneity are important categories for the medical providers. From their structural positions, the medical providers participate in reproducing racial categories among themselves and the community they serve. What do these concepts mean for the Aymara on the border between Bolivia and Chile? How do they frame race?

My husband Jorge and I were in Colchane. We had just got back to Chile from Bolivia, and we were hoping to exchange some of the extra bolivianos (BS) we had. A group of ladies had their money exchange tables near the border, right by the former customs office on the Chilean side. We approached them, and said hello in Aymara, and asked where they were from, a common question in the highlands. One of the ladies got very angry. We did not understand what was happening, usually people were happy about us trying to speak their language. But not this time. The lady stood up and said to my husband:

> So you think that because my skin is darker than yours and because I am sitting here on the border that I am from Bolivia. No. I am Chilean just like you. Or am I asking you where you are from? No, don't you see (*¿no ve?*)

We apologized several times to the lady. In the meantime, the other *cambistas* were getting ready to buy our bolivianos. The lady sat down again, and asked us how many bolivianos we were selling. Everything back to normal: "*tranquilo*, *normal*" as they say in the highlands.

This is one example of the close relationship between race and national identities in Chile. The strong chilenization process of the Aymara territories and current social differentiation due to emerging business on the Chilean side of the border influence current framings of race. Rather than finite categories, race among the Aymara in Chile is a continuum of possibilities determined by national identity, indigeneity, and social class. Hence, the closer to the core of indigeneity (Bolivia), the more “indian” an Aymara is. From the point of view of the medical providers, however, they are all Aymara. Another important racial distinction is the one between “*indios*” and *“morenos.”* In the area of San Pedro de Atacama, for example, the term “morenos” (brown skins) is widely used to refer to indigenous peoples. Whenever a white, mestizo, or indigenous person wants to talk about the indigenous, they use the term morenos. For example, in the mining complex of SQM Salar, there were two cafeterias: the “normal” cafeteria and the one for the *“morenos.”*

That said, are these categories problematic? And if so, how are they interpreted? What are the meanings of race in the everyday lives of the Aymara on the border? I found that in Chile one way of expressing race-related discomfort is the use of the word “discrimination”. The conversation below between Hermes and I shows the difference between talking directly about race and talking about discrimination:

> P: Do you think that there is racism here in Chile?
> H: Racism, no.
> P: And in Bolivia, do you think there is racism in Bolivia?
> H: No, racism…no.
>
> P: Would you say that there is discrimination in Bolivia?
> H: Yes. There is discrimination…but most of all in the lowlands (Oriente), there you have white people and us the brown people *(los morenos)*…black people, that is how they call us. “Move away” they say! But now with this government there is no discrimination, we are equal. There is no white, no black, nothing, we are all the same. We are human beings, for now…I don’t know in the future.
> P: And what about at work? Would you say there is discrimination?

> H: No, at work it is about who knows more and who knows less. So, there is no discrimination. If they come from abroad they still come to work and they learn.
> P: And in Chile? You can tell me the truth *(diga la verdad no más)*!
> H: [laughs] No, at least I have not experienced it (no me ha tocado). Not this, with the Chilean people that I know they always are inviting me to barbecues, to play ball [soccer]… "Hey you *Boliviano* come to play with us, what is your name? We want to know your name because now we call you *chino* (Chinese)" So for now no.

Hermes referred to important issues. First, he talked about the different experience of race in Bolivia. In his experience in the lowlands, he suffered from direct exclusion, just because he was indigenous, he said. Then, he differentiates that situation with the current conditions of indigenous peoples after the election of Evo Morales. Although Hermes noticed improvements, and talked about equality, etc., he insisted in saying that he does not like Evo, but that voting for the other candidates will not take the indigenous anywhere: "It is the only choice we have," he said. Then, when he talked about his experience in Chile he said that he felt somehow included because he was able to "compartir" by playing soccer or sharing barbecues. He was still racialized, though, as "Chinese." In Chile this is very common, and even outstanding Chilean tennis players like Marcelo Ríos have received that nickname. In Chile, all Asian peoples are called Chinese (*chinitos*) and all Middle Eastern people receive the name of Turkish (turcos), even though most of the immigrants than came from the middle East were actually escaping the Ottoman Empire. Other racial categories used in Chile among friends and even among couples are "blacky" (*negro* or *negra*), "indian" (*indio*), and "red-haired" (*colorada*). These apparently kind ways of marking racial and social differences, however, can also lead to violent encounters, like the one described by Luna, a Quechua woman living in San Pedro:

> J: So you haven't got any trouble. Sometimes people say things, sometimes we (Chileans) are so obnoxious!
> L: Yeah, I have seen that. For the most part people are good, but there are a few that have been unkind. Even here I have a neighbor and I can't coexist with him (*compartir)*. Why? "Ah, Boliviano motherfucker I am going to smash your face, I am going to send you back to your country!" All of those things, I think they are discrimination. But there are one, two, three people, but for the most part everyone is friendly. But it exists, we experience this. We have a neighbor…and I think that is not right. Many times he has threatened us, but he is a coward and he runs away.

Luna told me than in the many years she has lived in Chile she has experienced racism in different ways: at the supermarket, at the public offices, and in her neighborhood in one of the Ayllus of San Pedro de Atacama. However, she said that she never felt discriminated against in the health care center or in the hospital in Calama where her two daughters were born. Luna said that the Aymara that she has met while living in Chile tend to think that there is racism against women who work as maids. This was confirmed by several women I met in El Alto and Arica, where they worked. One of them, Mariana, told me that she felt lucky because her *patrones* (employers) were nice and took good care of her, "my life is good in Chile. But it is not like that for every one, my aunt, for example, she worked in Calama and her *patrones* took her passport, and they never gave [her] any food. They ate chicken, meat, but they only gave [her] *tallarines* (pasta). She was very skinny when she came back home." Since the late 1990s scholars in Chile have studied the conditions of Peruvian and Bolivian immigrants working in Chile, particularly in relation to gender and racial discrimination (Baeza 2015; Garcés 2014; Nuñez and Holper 2005; Stefoni 2002, 2001). These studies show that in Chile there is a colonial imaginary of race and labor, which in addition to more recent social constructions of indigeneity sustain a social order that emphasize discrimination based on class, obscuring the racialization processes. It is important to point out that Luna's testimony also shows how violent the racialization can be. Lay Chilean people who comment online in newspapers for example demonstrate the ordinary expressions of this violent nationalistic discourse. Recent rallys against Colombian and Haitian immigrants in Antofagasta (Rojas 2014) are public demonstrations of forms of racism that legitimize violence against the immigrants and indigenous peoples (see figure 18).

Figure 18. Poster advertising a rally against immigration in the city of Antofagasta, Chile.

5. Conclusions

In this chapter I have addressed the display of discourses on medicine, indigeneity, and race at the local level in Bolivia (Coroico) and Chile (Putre), presenting evidence on the multilayered process of racialization in both countries. My research shows that in both countries race is framed in relation to discourses about national identity that merge with a colonial legacy of constructions of labor and class.

I also discussed the intercultural health program in the context of the biodiscipline imposed through the medical system in Chile, and the sociopolitical transformation in Bolivia. The medical encounter is one of the spaces where the state and the indigenous citizen converge. At the same time, even though the state disciplines its citizens through the imposition of biomedical practices and ideologies, from the perspective of the Aymaras, the medical encounters are not the main source of racism, which they associate with nationalistic identities.

CHAPTER 3

PRECARIOUS ENGAGEMENTS, CONTESTED COMPLIANCES AND RESISTANCE

Chapter Summary

Current anti-tuberculosis treatment requires the supervised daily intake of strong antibiotics, a treatment (free of charge) known as Directly Observed Treatment short-course (DOTs). In this chapter I examine experience of Aymara TB patients who struggle following a harsh and long treatment, which is mediated by pharmaceuticals intake. I focus on Bolivia because of the high non-engagement with treatment there, in contrast to the situation in Chile where there TB rates are much lower and there is more engagement to DOTs. I sustain that the experience of TB redefines the life-world of the indigenous subject, as elsewhere, but in Bolivia their resistance to the state intervention takes another dimension because of indigenous visions. From this perspective, both engagement and non-engagement with treatment are part of the Aymara repertoire of responses to these larger processes. Where active engagement implies a commitment with the Aymara notion of *coming through,* non-engagement with DOTs expresses at the same time resistance to the medical intervention on the indigenous bodies and an allegiance to Aymara traditional medical system.

1. MEDICATIONS AS LANGUAGES OF RECOVERY

> The patient trusts a treatment that can kill him
>
> (Alejandro Molina, MD. La Paz 2013)

Globally, TB is the disease of poverty, and in Bolivia (like in Chile) this notion feeds a discourse of race that frames the indigenous person as lower class, unhygienic, lazy, and simpleminded. Traditionally, the dominant class saw the presence of disease among the indigenous as “natural” or “normal.” As shown in previous chapters, The biomedical system is also involved in reproducing a discourse of race and class that naturalizes illness among the poor and most vulnerable, a discourse that makes invisible the structural violence that makes tuberculosis possible. Hence, by preserving the poverty/race/tuberculosis associations as scientific truth, the biomedical system cooperates in the perpetuation of broader national mechanisms of exclusion.

1.1 TB Diagnosis

The TB diagnostic presents many challenges to the patients. First, in both Bolivia and Chile besides the physical examination, there is a microscopic analysis of a culture of an initial sample (from patient’s sputum). This analysis is necessary to confirm the diagnosis. However, in most cases the treatment starts without the positive culture. This laboratory confirmation should report positive results on smears and cultures within 24 hours by telephone or fax to the primary health care provider and to the state or local TB control program, as required by law. From the point of view of the patient, the whole process is complicated. The experience of Eva illustrates this.

Eva Limache is an urban Aymara woman in her thirties who lives in La Paz. Although she does not identify herself as Aymara nor speak the language, she values the Aymara cultural knowledge of her parents (especially her mother)/ Her parents are Aymara speakers, who migrated to the city when they were young and started a small business selling fruits and vegetables in the busy Mercado Rodríguez, one of the largest of La Paz. They live in barrio Libertad, half way between El Alto and downtown La Paz. In 2004, Eva learned that tuberculosis (TB) was the cause of her long-lasting cough and chest pain. At that time she did not fully understand what tuberculosis was, or what it meant for her life, and what changes this illness would bring. For her, the doctor's diagnosis implied that she had to follow a treatment, that this treatment would cure her, and that she would go back to work as usual. The doctor said that after six months of taking pills she would be healed. Unfortunately, healing turned out to be a lot more difficult than she or the doctor hoped or expected.

Eva told me "first they give you a little container and they tell you to cough first thing in the morning and bring it to the healthcare center right away. If they see that the sample won't be enough, they ask you to come back the next day. They insist in this, that it needs to be the first cough of the morning without breakfast [fasting].

One needs to bring the container rapidly, because they say that heat damages it. Then they take it to the lab." Hence, even before having the medical confirmation the patient already faces additional tasks. At the same time, there are issues of acceptance of the medical category and treatment that emergence in the very moment a person is diagnosed with TB. Eva described it as *un balde de agua fría* (a bucket of cold water), something shocking and hard to digest. Besides the bodily pain, she had to deal with the social stigma of tuberculosis, which she said directly associated this illness with poverty and indianness (indigeneity).

How do patients make sense of their illness experience? How do they make sense out of their painful treatment? I see two different reactions to this illness and its treatment. On the one hand there is fear of discrimination and stigma, and on the other confusion and sadness. Even before starting with the medications, the sufferer is confronted with illness in an intimate way. Matilde, a patient from Coroico told me: "I was saying, how did this happen to me? They might have made a mistake…but then I saw the *placa* [x-rays film], and I had to *asumir* (to assume) my illness" (Coroico 2011). By framing illness, patients and healers create a particular chain of meaningful practices. This testimony shows the importance of biotechnologies in configuring the illness experience. M.J. DelVecchio-Good discusses the relationships between the subjective experience of illness and the biotechnological frameworks in terms of "biomedical embrace" and the medical imaginary (Del Vecchio-Good 2007, 2001).

Other patients that I met in La Paz described this moment as painful, as they feared social isolation and neglect from national societies, work (possibilities of being fired, for example), from the state, from their communities. Other forms of discrimination are grounded in historical medical practices that tended to maintain the infected in isolation, of course. These quarantines were very common before the use of antibiotics, and the notion of medical isolation is still fairly regular, especially when it comes to infectious diseases like TB.

At the beginning I had the idea that the isolation that patients were talking about had to do only with the medical quarantine, but later I learned that there was a deeper sense of belonging that was at stake: the belonging to the community and the political role of each individual within that community. Thus, Eva felt huge social stigma on herself and her family, and had to respond to discrimination and also protect her family from carrying the stigma of this illness.

1.2. Illness as emerging borderlands.

Eva also described to me her experience at the Thorax Hospital. She said that before having TB she never cared about sick people, that it was not a concern for her. But that everything changed when she was at the edge of dying in the company of others that just like her were suffering from this illness. In her work C. Mattinglys takes a phenomenological narrative approach to analyze the subjective world of the medical encounters where the body of the patients emerges as a borderland in connection to the experience of others, or “spaces defined by practices that bind people together who otherwise wouldn’t belong together” (Mattingly 2010:7). This borderland refers to a flexible social space where different actors, in different subject positions, negotiate healing and create communities of hope. Thus, within this space, patients and their families are also at the forefront, close to medical doctors and other health agents who represent the medical system and the state, and in order to feel comfortable within the borderland, sufferers learn the language of recovery: the technologies that support TB treatment, the names and correct doses of their medications, the name of their doctors, the name of other patients. In fact, I argue, this chronic illness is not only a state of being, but also a way of life. The sufferer integrates TB framing to his or her world-view and the daily intake of antibiotics implies a new way of living. An orientation towards healing that is mediated by the intake of anti-TB drugs.

Like other TB patients, Eva explained to me that it is difficult to accept the illness because of stigma and discrimination, but also because of the fear of not knowing what the medications will do to the patient’s body. After her illness Eva became involved in organizing TB patients, and in her work during the last years she has identified several reactions: depression, fear, shock, denial, and confusion. She states: “there are different ways to think [about it]. Some get angry, but mostly the *pacientitos*…we become sad and bitter (*renegamos)*”. Eva also mentioned that the complexities of

DOTs made people worried, but that “with time one learns.” She said that as the treatment progresses the patients starts remembering all the names and exact doses of the medications, with time, she says, one becomes proficient:

> Like I told you, it is important to explain to the patients (the treatment) and the patients need to learn the name of their medications. For instance, here in Bolivia, medications come in pills that are red, yellow, and white and each has a name. The red one is a combination of rifampin with isoniazid, the yellow is ethambutol, and the white is pyrazinamide. But I know that now they are giving rifampin with isoniazid with the regular red, and that ethambutol and pyrazinamide are white (…) It is a good thing that here in Bolivia the government brings each med in a pure form as well. The government has seen the need and brings the meds also in a pure form. Rifampin apart, INH apart, ethambutol apart, and pyrazinamide apart [separately]. And it is given to patients”

Eva had to learn the names of each pill because of her illness. When one is a patient who needs to take five or six pills each day, two times a day, medications becomes part of one’s lifeworld. In their analysis of personal stories in the context of alcoholism, Holland et al. noted “the transformation of the self into an alcoholic is not directly determined by how much one drinks, but by what alcohol has done in one’s life” (2003 [1998]:69). In a similar way, each pill has a specific effect on the sufferer’s body, and thus it refers to a particular corporeal sensation that lingers, becoming part of the sufferer’s identity:

> I am just beginning [to take the medications]. Let’s see what changes… I was just asking myself that (question), what changes do I see in my own body. And I just, I just have rheumatic arthritis, that’s all, my ar-

> ticulations. Because until now I have been well, I haven't felt any symptom of allergies, no nothing. Maybe I have, let's see…I am taking a [nutritional] supplement, I have *matecito* (tea), but the pills it seems to me that they make you feel satisfied, like I don't want to eat, I don't want to eat anything. But as I know that I have to eat…(MM, Coroico 2011)

There is a difference between being sensitive or not to TB medications:

> P: (you were telling me about) the need to learn about medicines (*remedios*), the different plans [of treatments]
> EL: At the beginning, when you are just starting, you don't care about the name of the medication as much. For you, they are just tuberculosis medications that you take to start the treatment. In the case of "paciente sensible" (those who respond positively to the medication) that medication, I mean, that is how I got to learn them: two red medications, which were rifampin and EMF), the yellow medication, and the white medication. Red pill, yellow pill, and white pill. It is very difficult. But, once the illness advances and you are elevated to the status of *(subes)* a RAFA or MDR patient you need to know the name, doses, if it works or not. Like I was saying, in a sensitive *(sensible)* patient it's six months, a few know, or decide to know what are the medications. Out of one hundred, forty percent want to know. But the rest says, "as long as the medication works, I am comfortable [not knowing].

Medical providers are also aware of this changes in their patient's bodies. Because of how these pills are administered (mostly within a clinical setting), there is little space for the patient to appropriate the space and means of recovery. By this I mean that the required compliance or adherence to this treatment is seen by the sufferers as passive - and demanding – foreign medical encounters where their bodies are "receptacles" of a drug that they have not chosen to take. Hence, from the patient's perspective, how can recovering be interpreted as active engagement? Even though the biomedical system expects that patients actively participate in their recovery, they can hardly do so if they face a rigid treatment. This is accentuated by the sophisticated language that the medical providers use to refer to the pharmaceuticals, which names patients need to learn. In this borderland, patients like Eva start to engage not only in therapy but also in the TB "idiom of distress," which M. Nichter defines as "socially and culturally resonant means of experiencing and expressing distress in local worlds. They are evocative and index past traumatic memories as well as present stressors, such as anger, powerlessness, social marginalization and insecurity, and possible future sources of anxiety, loss and angst" (2010: 405; 1981). This concept contributes to the understanding of illness not as an isolated entity that people interpret, but as an embodied connection between the individual and his or her cultural context. It is in the association of the experience to the context where individuals make sense of their suffering. Hence, it is not enough for the patients to learn about the nature of tuberculosis or the names of the different medications, but also about building new social relationships within this new borderland. Unfortunately, patients who suffer from allergies to the antituberculosis medications face even more constraints, as we will see in the following section.

2. HEALING THROUGH PAIN

Eva faced a second difficulty: her body did not respond to the pharmaceuticals as the doctors predicted. A few weeks after her diagnosis, she started to feel headaches, stomach pain, and itchy skin, among other symptoms of severe allergies. She had to be *internada* (institutionalized) in the TB ward of the "Hospital del Tórax" (specialized hospital of the thorax) in the Miraflores neighborhood of La Paz (figure 19) . Under the strict supervision of doctor Morales, one of the leading TB specialists in Bolivia , she learned that she was developing "strange" allergies to the medications. This, of course, delayed her recovery as she struggled to survive the allergies. Eva said that once patients begin the treatment, the medical staff calls them *pacientitos* (little patients) as a way of building a relationship of care.[23] One could also argue this practice is one of the mechanisms of structural violence that render the patients as invisible targets of health policy, and that by treating the patients as children, the biomedical providers are reproducing the existing political structures where the indigenous patient is not an agent but a recipient of care. However, in the Bolivian context, where the use of diminutives is highly spread, this is not so clear.

By developing allergies to medications, Eva was not only a *"pacientita"* but

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[23] The use of diminutives in Bolivia is an expression of care, not an insult. On the contrary it is a common way of talking among people who care for each other. Hence if a doctor or a nurse calls sufferers *pacientitos* they are framing the relationship of care within the power structures of the medical system.

also a “*rafita*,” which is the way that doctors and medical staff call TB patients who develop adverse reactions to anti-TB drugs (RAFA).[24] According to the medical doctor who treated Eva, before 2004 there were no second line medicines available for TB patients who developed adverse reactions in Bolivia. Dr. Morales explained to me that in fact Eva’s case triggered changes in the treatment offered by the Bolivian state, and now there are other antibiotics available in order to provide patients with allergies to certain medicines alternative combinations.

Figure 19. Hospital of thorax in the Miraflores neighborhood of La Paz. photo by Paula F. Saravia.

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[24] In Spanish: Reacción Adversa a Fármacos Anti-tuberculosos (RAFA). In Latin America, Rafa is also the diminutive for “Rafael.”

2.1. Don Saturnino

Fear of the side effects of medication is also known to contribute to poor engagement to DOTs (Awofeso 2008; Abos & Hernandez 2002). Furthermore, the medical providers (doctors, nurses, and others) refer to DOTs as a therapeutic failure precisely because the diagnosed patients are fearful of the consequences of the antibiotics in their already weak bodies. Therefore, "patients see tuberculosis as the illness of death, like a *espanto* (fright)" and they either would not start the treatment or abandon it after a few weeks if the medical providers do not pay attention to the whole process.[25] A good example of fear of the medications as part of TB idiom of distress that could result in treatment failure is the case of Don Saturnino and two of his younger brothers, who are from Caranavi, a rural area in the Yungas close to La Paz. Tuberculosis is endemic in the Yungas, therefore for most people it is a common illness. Like other Aymara, they work collecting coca leaves and selling their stock to the coca estanco [26] in the coca market of Villa Fátima, La Paz. I met Don Saturnino in the cold waiting room of the TB ward at *"Hospital del Tórax"* where we were waiting for doctor Morales. We were sitting on the wood bench right outside the multidrug resistance ward. He looked at me for a long time before asking I was a doctor too, and

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[25] Avoiding medical settings is not an exclusive Aymara practice. Indeed, the 2014 Ebola outbreak has shown that fear of hospitals and providers is a fundamental cause of biomedical failure to subdue the epidemic.

[26] The coca production and distribution is regulated by assigned quotas for each farmer. People travel from the Yungas to La Paz to sell their stock of coca leaves.

from there we started a conversation about him and his family. He told me that two of his brothers were taken to the Hospital after a relapse. The three of them have been diagnosed with TB on several occasions, and they have abandoned the treatment. When I asked don Saturnino about the treatment he described it in terms of taste and the effects that the pills have on his body. Unlike Eva, he didn't know the names of each medicine. He identified the treatment pills and the medicine (ranitidine[27]) that is supposed to help them deal with the stomach distress:

> I am scared to be *internado*, the treatment is *picante* (spicy), it feels like if you are burning inside. Syrup would be better, but the pill is *picante* (spicy), [instead] you can drink the syrup like *agüita* (water). They make you buy *jarabitos* (syrup) for your stomach [if you need them].

Don Saturnino's fear is indeed legitimate. The antibiotics cause tremendous pain and damage the patient's body in several ways, and if the patient is in the hospital ward there is "no escape." Thus, the shared fear of the antituberculosis medications is a problem when delivering even the ambulatory treatment. This is how Eva described her experience:

> I had a headache, I felt pain…it seemed to be a gallstone, like we call it. I mean mostly known as bile and vomits. Nobody…they, at the healthcare center thought I had a gallstone. Even so they gave me medicines like ranitidine, they didn't do [anything] and said that it was for my stomach, so I wouldn't puke. And it was worse. And then after that it was not only the stomachache, it wasn't only [unintelligible] plus I couldn't see anymore, my eyes hurt. It was not the puking only, my

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[27] Ranitidine is a histamine H2-receptor antagonist that inhibits stomach acid production. It is an inexpensive pharmaceutical, compared to the popular omeprazole. Medical doctors in Bolivia would rather prescribe omeprazole, but they cannot do it because of its higher price.

> stomach couldn't bear anything, and even worse I got granos [bumps]. So I passed from a mild to a moderate [state] and from that moderate - and I was still taking the [TB] treatment pills I passed to an acute state. That was when I already had Steve Johnson.[28] That was in phases, not from dusk to dawn. Monday stomachache, Wednesday with vomits, and a Friday they see me again [the doctors] and they tell me 'ah you have a virus' and Saturday passed, then Sunday passed, and next Monday [I had] a Steven Johnson.

When I talked to Eva about her painful experience of severe allergic reactions to the anti-tuberculosis medications I could not stop thinking on the paradoxes of healing through pain, like the experience of cancer patients who go through merciless sessions of chemotherapy or struggle with harsh medications and surgery for chronic illnesses such as Crohn disease, or struggling with pain and isolation, like persons living with mental illness, for example. As if the illness itself was not enough, people who suffered from this terrible infection also engage in a treatment that could kill them. I was also surprised about the many medical encounters that she had during the week of her severe allergy. Later in my fieldwork I met other patients who also suffered tremendously just from complying with the prescribed treatment, and they all refer to the allergies as something worse than their illness. Medical doctors in La Paz also insisted on the consequences of using these strong medications for long terms:

> There are several problems, for example, INH produces allergies and an alteration to the liver. Patients develop gastritis and they feel fear.

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[28] Stevens-Johnson syndrome (SJS) is the name of a severe chain of allergic reactions first registered in 1922 by American pediatricians Albert Mason Stevens and Frank Chambliss Johnson. Since 1993 has been adopted as a consensus diagnosis for milder epidermal necrolysis (TEN). The patient starts with fever, sore throat and fatigue, signs that are usually misdiagnosed. The patients also develops ulcers in the skin mucous membranes (mouth and lips and then genital and anal regions). It can scale up to conjuntivitis and a rash of round lesions (about an inch) arises on the face, trunk, arms, and soles of feet. In some cases the rash can spread to the scalp.

> Ethambutol provokes pellagra, or a mild icteric reaction. And all of this happens fast, during the first month [of the treatment] (Alejandro Molina, MD., La paz 2011)
> I've seen many people who show traits of suffering or that have suffered from tuberculosis: their eyebrows get bigger, their cheeks are prominent, their skin is soft and smooth. Even the nails and the fingers (change). These traits remain forever. (Sofía Salas, La Paz 2013)

Dr. Morales has called attention to the problems associated with the medications such as allergies. In 2004 she gave an interview to the national newspaper *"La Razón"* where she talked about the problems with medication intake and the need to do research on the allergies the Aymara experience.

2.2. Gender inequality and healing

Dr. Morales said that Eva suffered enormously because besides the burden of the therapy, the TB patient also bears the material cost of illness, which usually results in abandonment and isolation from their couples, family, and community in general. This is especially prominent among urban Aymara women in Bolivia, who are mostly merchants with stationary housing (La Paz, Yungas, and coastal cities in Chile). Unfortunately, women are usually abandoned by their spouses after being diagnosed, increasing the ill effects of vulnerability and social neglect. Because of lack of formal education, precarious labor conditions (low salary, if any) and great responsibilities within their households, indigenous women worldwide are more vulnerable to health problems (including maternal mortality and gendered violence). Reflective of the current situation of gender inequalities in Bolivia (Medeiros et al 2007), the lack of support from male partners and difficulties maintaining their own source of income because of TB treatment are detrimental for women themselves and their children. Hence, women tend to abandon their treatment and develop resistance to antituberculosis drugs. This doctor identifies social constructions of gender as another structural obstacle for DOTs:

> The living conditions of the average tuberculosis patient are the following: a woman with five kids, who gets up at three or four in the morning. Because of gender ideas the husband doesn't help her at all. So the woman needs to prepare meals, sandwiches, to sell on the street. This woman sells her products and then goes home, feeds her children, takes the kids to school…of course the husband doesn't do that because "he has to work"…at what time can this woman take her pills? How could we ask her to walk or take the bus to the hospital if she needs to work at home, cook lunch, pick up the children from school? So, it ends like this: the husband complains because she is not doing her job, and he either beats her or he leaves with another woman (Dr. Camacho IT, La Paz, 2013)

Hence, gender is part of the structural conditions of inequality that adversely affects the lives of women. I met Mariana, a young Aymara woman from El Alto, on her way to Chile. She works as a domestic worker in Arica, at the place of an important family there: "so it is a good job, you see? but I hardly see my family…well, I almost never see them really because I am always busy with the house work anyway. The children…I don't have children yet, but I help my sister and my mother in El Alto." Like other women in Bolivia, Mariana worked helping her mother and sister while taking care of herself. What happens when one gets sick? or when you don't feel good? She said: "imagine if that happened…luckily we don't get sick, we have our *matecitos* [herbal teas], we don't go to the hospital. When? at what time?" (January 2013). This was also what a young woman in Patacamaya said: "and [when] we go to the hospitals, and…the hospitals, [we] have to wait…or come back [to the hospital], the following week, the following day, you see? that [medical] care is not fast. There is not a fast [medical] care *(no hay atención médica rápida)*" (Patacamaya, July 2011). Yet, despite the many difficulties that women experience in maintaining their health and their families well-being, some like Eva still follow their treatments. In the next pages, I will show how the structural conditions described above are a base for healing through precarious engagements.

3. PRECARIOUS ENGAGEMENTS

3.1.How do medications exclude?

In the face of this biomedical treatment, sufferers develop their own idiom of distress for expressing their pain and recovering, making their own meaningful experience of the treatment. For example, they make sense of pain and healing by refashioning the pharmacological therapy to fulfill their own needs and expectations. Their medication calendar should be strict, however they manage to skip a dose saying that it is a "rest day" (*descanso*). They tend to skip a dose during traditional local and national festivities in their community, when they are called to participate. The Aymara refer to such participation in festivities or community gatherings as *"compartir"* (to share). Participating in the festivities tend to involve long days of catholic church rituals (usually to celebrate the patron saint of each town), collective meals, and lots of alcohol (mostly beer). The potential changes of changing their dose are of course problematic for them: "if we skip a day of therapy the nurses get angry and yell at us" (male patient, La Paz). Aware of the stigma of TB and their status as *"Indian"* patients, they see in the medication both a possibility for healing and a source of pain because of the medications' s effects as well as the several physical the medications leave in their bodies. Some of the patients said: "when you take those pills you have lots of nightmares, every night you have awful dreams and you can't sleep. You wake up in your own sweat. Then you get use to it, but when you take *descanso* you are back to the beginning. It is all a nightmare, you see? *(pesadilla no más es, ¿no ve?)*"

Patient's suffering and recovery are meaningful in that by dealing with the difficulties that both the illness and the treatment impose on them, they imagine a future for their ill weak bodies. More importantly, the interpretation of illness is mediated by the antituberculosis medications in a social context, which is problematic because of the stigma associated to TB and the exclusionary nature of TB-diagnosis. In other words, besides existing discrimination and exclusion, the patients is exposed to what medical anthropologist C. White calls iatrogenic stigma, where pharmaceuticals themselves become a source of exclusion (White 2008:34). The biomedical diagnosis formally declares the patient's condition of abnormality, separating her or him from the "healthy" and confirming pre-existing racial and social exclusions.

3.2. Active Engagement and Precarity

Examining the paradoxes of global consumption of pharmaceuticals, medical anthropologist Janis H. Jenkins (2010) formulates the concepts of "pharmaceutical self" and "pharmaceutical imaginary" to understand the lived experience of affliction and the institutional contexts of these processes(the nation/state). She defines these terms as follows:

> (…) if we understand the self as the sum of processes by which the subject is oriented in the world and toward other people, then a pharmaceutical self is that aspect of the self oriented by and toward pharmaceutical drugs. If we understand the imaginary as that dimension of culture oriented toward conceivable potentials of or possibilities for human life, then the pharmaceutical imaginary is that region of the imaginary in which pharmaceutical drugs play an increasingly critical role (2010:23 [2005])

In her work on the subjective experience of mental illness in Latin America and in the U.S., she describes the multiplicity of ways to struggle with what she calls "extraordinary conditions," like living with schizophrenia, for example (Jenkins 2015). Opposed to approaches that separate the individual experience from larger sociopolitical structures, she proposes, "pharmaceutical self and pharmaceutical imaginary are in fact reciprocal sides of actor's subjectivities" (2010:37). In this perspective, the use and distribution of pharmaceuticals are subjective processes in which meanings are multivocal.

Jenkins has described the role of social engagement in defining the course of illness, arguing "processes of recovery are complex, and often take on a sense of improvement at one turn and reversals at another, making for a considerable less than linear process" (Jenkins and Carpenter-Song 2005: 406). Moreover, individuals ~~can~~ actively engage in their process of recovery, beyond the constraints of pharmacological treatments and social relations. An Aymara cultural means for pursuit of such processes entails efforts to *salir adelante* (to come through or go forward), an active process that defines not only illness but also any challenge that individuals face in their everyday life struggling with precarity.

Precarity shapes the lived experience of tuberculosis sufferers and healers, who are already immersed in dreadful material conditions. Daily struggles for securing material conditions render their engagements with treatment all the more precarious. In other words, the tuberculosis sufferer's lived experience is a precarious livelihood characterized by economic distress, lack of stable jobs, makeshift housing, poor access to basic services - including health care and education as well as sociopolitical exclusion. Salir adelante, "to come through," means to be able to deal with this terrible everyday challenges and also refers to the concern that the sufferer has for his or her family.

However, precarity does not refer exclusively to the lack of material living conditions, or to uncertain expectations of the future. A precarious life, as J. Butler defines it, is an intersubjective mode of existence defined by established norms that define who counts and who is excluded (2004). In her view, these norms influence the way each subject depends on one another, a subjectivity she calls relationality. She says, “loss and vulnerability are ultimately linked to being socially constituted bodies since it is the attachment and therefore exposure to an other that puts us at risk of violence” (2004:20). Hence, precarity refers to the conditions in which suffering and violence are experienced by some and not by others. In her work on *Extraordinary Conditions*, Jenkins (2015) questions this definition by emphasizing the sufferer’s point of view of actively struggling in lieu of viewing the ill person as vulnerable victim. Jenkins’ theorizing of the ways in which individuals act upon their illness~~,~~ entails what she defines as “palpable insecurity” (Jenkins 2013). This formulation is closely related to what I have observed among Aymara TB patients who are willing to overpass the unstable situations of precarious - and often times liminal- lives.

How do the Aymara frame precarity? How do they deal with precarious conditions? *Salir adelante* and *renegar* are two categories that convey why medications are dubious means to arrive at the important Aymara notion of *“prosperidad”* (prosperity) as a desirable state of harmony where the individual enjoys economic success, health, love, and happiness. Let me explore these notions.

4. Aymara healing and agency: "coming through" and "prosperity"

I was walking around "Mercado de Hechicerías" in Linares Street, downtown La Paz; looking for clues about how urban Aymaras construct their notion of health. The so called "witches market" is a well-attended street with stores that sell mostly handcraft items and textile for tourists as well as items for traditional Aymara rituals, herbs, amulets, and so forth. The use of amulets and miniatures is a salient feature of Aymara rituals, especially when it comes to achievements. Desirable miniature objects represent what is to be achieved, such as small trucks, houses, computers, animals, etc. (figure 20). The *"Alasitas"* festivity in January is the time to set goals for the year and acquire these objects (usually small suitcases and money). Related to the figure of Ekeko,[29] Alasitas are material representations of individual and shared expectations. To my surprise, every time I asked for an amulet for health, I got a negative answer. "We don't have that here" the vendors said. I couldn't understand how was that possible in a city where you find miniatures of all possible businesses and occupations. Why was there nothing to help people be healthy? So I asked again:

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[29] The Ekeko is an Andean figure of prosperity and abundance that carries important items such as grains and money. It is common to light cigarettes for him.

P: do you have something for business?
V: yes, what kind of business do you want to have?
P: I am not sure. What about something to be happy?
V: we don't have that.

I remembered the Aymara notion of *suma qamaña* (to live well) as a framing for a good life. Since 2009, *suma qamaña* is in the Bolivian constitution, so it is a principle that rules not only Aymara people, but also Bolivia as a nation. As described in previous chapters, the principle of *suma qamaña* implies living in harmony with Pachamama (Mother Earth) and respecting the norms of the community. Hence, this time I asked a specific question:

P: What about something to live well?
V: Ah, so you are looking for *prosperidad* (prosperity)!
P: Yes, I guess that is it. Prosperity, will that help me be healthy?
V: Be healthy, yes. And have good business and smart children.

Aymara notions of *prosperidad* (prosperity) and *salir adelante* (to come through) are part of the *suma qamaña* principle of good living. Health and prosperity are important aspects of *suma qamaña* in that they allow individuals and their communities to maintain a harmonious life. At the same time, prosperity and health require active engagement in terms of labor, and work ethics where sacrifice for achieving success is highly valued. In other words, there needs to be an effort from the part of the individual and his or her community. R. Bautista argues that the principle of *suma qamaña* is a model that gives meaning to the decolonial process in Bolivia: "it is a model that, as a horizon, gives meaning to our walk towards progress. We aim towards what remains as a substance in all of our fights, not only like creole emancipatory fights, but also to what has made possible even those revolts: the indigenous re-volts. That is the reason *suma qamaña* persists as a horizon" (Bautista 2010:99). I argue that in Bolivia *suma qamaña* connects the experience of healing to the current political moment of contestation to the colonial structures. Thus, in the context of the precarity in which most TB patients live, recovery translates into sacrifice. For the Aymara's desire of an ideal prosperous life cannot be achieved without loss, what R. Girard (1977) described as "model-obstacle" of the monster double, a mimetic double-bind where achieving the desired object transforms the individual into an obstacle for achieving said desire. In the case of the Aymara, the desire for prosperity and community well-being finds within the community a worry of envy from others and their desire for having that harmonious life.

Figure 20. Alasitas: small trucks are very popular during the these festivities in La Paz. These were made by the prison inmates and sold by their families in the park of San Pedro.

Even though from a biomedical perspective DOTs leads to healing, for the Aymara patient it is a dramatic situation that requires their sacrifice (*sacrificio*). One of the patients in the tuberculosis ward said to me that tuberculosis was an obstacle for his work: "here we are always in a hurry. Everybody needs to work; so coming to the health care center is a sacrifice. But a sacrifice for my own good, they [the doctors] said." (male patient, La Paz 2013). As a matter of fact, La Paz is a busy city. The narrow sidewalks are always packed with people, street vendors, and even street dogs. At almost 13,000 or 14,000f. is surprising to see people walking so fast. I asked to the patient, then, why is it that people are always in a hurry? And he told me "we need to get to our business (*negocio*), we need to *salir adelante* (come through)." When Aymara people speak, they often look very serious. He said this to me with conviction. Noticing my surprise, he quickly added "we get up early so we can attend our business, our families. We always need to meet someone so we can do business." Among the Aymara, doing business refers to the condition of seasonal unstable work. Tuberculosis makes them feel emaciated, weak, useless to work, and the patients know that this situation may hinder their work and their family's welfare. Some weeks later I asked Eva how was it that patients endure an illness like tuberculosis, and she said "that's why we need to sacrifice ourselves, so we can attend our businesses and feed our children." In view of the length of the treatment, patients recognize tuberculosis as an obstacle to taking care of their families. The treatment takes precious "time" away from them, time that they would rather spend working.

Das and Das (2007) argue that people interpret the experience of illness according to a “stock of knowledge” that comes both from the social context and from the biomedical discourse. In their research in India they show that “the intersecting temporalities of work, cash flows, and the therapeutic practices of local practitioners have created certain ways of dealing with illness that emphasize immediacy and the short run rather than investment in cure” (2007:80). Likewise, in Bolivia TB sufferers integrate the biomedical treatment to their idioms of distress and recovery as well as the socioeconomic context in which they live – where tuberculosis is widely spread. Guided by the notion of coming through, the sufferer becomes a patient who is going to recover but never be cured. Patients do not necessarily share the doctor’s ideas of recovery from TB; on the contrary, they know that people can survive TB and get it again later in their lives.

Furthermore, the immediate world of precarity requires fast and effective healing in order to keep up with daily tasks. Sofía Salas, one of the medical doctors working with vulnerable population in La Paz explained this to me:

> P: do you see any difference in how middle class or low-income patients receive their diagnosis?
> NA: The ones who worry the most are the poverty stricken population. Because, generally they have 5 kids, or 6 kids and they support their family. So those are the ones who worry the most. Because the middle class (patients), I have noted that they have insurance, for example. So, as they have insurance they say “no (I won’t worry), I will take it easy, they will give me all of the medications (I need). Even though once you are diagnosed with tuberculosis the treatment is free. Then, even so, I

have noted that they are *tranquilos*[30] (calmed) (La Paz 2013)

In other words, if recovery takes too much sacrifice from the part of patients and their community, it is simply not worth it. Due to the struggles that urban and rural Aymara face everyday, a rigid therapy like DOTs seems immensely difficult to follow. In addition to the sufferer's "investments" in going through a painful treatment, the high risk of relapsing is another reason for dealing with tuberculosis as part of the "normal" in precarity rather than an unexpected and abnormal condition. One of the medical providers in Coroico, where TB is endemic, relayed that:

> Here everybody says "I think I have tuberculosis." Not long ago a lady came and (said to me) "I did all of the tests but I have asthma." She told me "I thought it was tuberculosis because I was coughing." They assume that they have it. Like the doctor says, they think it is (common like) the flu, they don't think it is a big deal. I mean, it seems like there is no tuberculosis control here because one can recover, but there is always somebody around who is spreading it to others. There is no good diagnosis and that is how the illness doesn't stop. (Virginia Plaza 2011)

This was also explained to me by don Saturnino: "we got sick because of working and sweating, our backs get wet. We have coughed blood, but I took care of it myself preparing medicine at home".[31] The interpretation of Don Saturnino illustrates the importance of precarity as a cause of illness and also as a "drawback" in healing:

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[30] To be *tranquila* or *tranquilo* is a meaningful category in Bolivia. It is a common expression of satisfaction, calm, and happiness. Usually associated with "normality," *tranquilo* represents a feeling of gratefulness. I will further develop the meaning of *tranquilo/tranquila* in chapter 4.

[31] See chapter 4 for a complete description of the traditional Aymara remedies.

> P: Don Saturnino, how come you are not taking anything? Aren't you
> afraid of getting sick again?
> S: there are a lot of people out there who are sick and they don't take
> care of themselves. Why should I take care of myself, then?

Here, Don Saturnino gives a good explanation of how useless it seems to recover given the situation in which he lives, where others will spread it despite his efforts.

Jeremy Greene conducted ethnographic research of non-adherence to DOTs in urban Bolivia, questioning the established public health notion of cultural barrier for TB treatment. He argues that the focus on culture obscures other important conditions such as the costs of transportation and the tight schedule for delivering the drugs. For Greene, non-adherence "describes the failure of potentially curative treatment that occurs when a patient does not fulfill the therapeutic regimen" (2004: 402). Although he acknowledges culture to be important in the therapeutic process, Greene argues that there are other social dimensions that affect patient's access to the multidrug treatment, and that cultural aspects have been overemphasized. Building on Paul Farmer's concept of "immodest claims of causality" (Farmer in Greene 2004: 403), Greene asserts, "culture-specific arguments can ignore the positioning of an individual or population with respect to transcultural institutions such as poverty, discrimination, and systemic injustice" (2004: 403). Even though cultural practices influence the patient's decision to continue or not with the treatment, Greene finds no direct causality between the use of traditional medicine and the non-compliance with the biomedical treatment in Bolivia. Greene demonstrates that although they use a wide range of medical resources, people suffering TB prefer the biomedical approach to the indigenous medicines. Thus, he showed that shared ideas and beliefs about TB and the pharmaceutical treatment are only part of the problem that providers have in engaging Aymara of La Paz to DOTs. More importantly, Greene argues, structural economic issues in addition to structural mechanisms are the impediments that limit the access to the medications. Some of the structural conditions are the location of healthcare centers that deliver DOTs, transportation costs for the patient's family or caregiver, the schedule of DOTs (organized according to the healthcare center hours instead of the patient's), poor provider-client relationship, lack of trust in potential healing, and malnutrition related to poverty are all key obstacles.

According to the medical doctors in Bolivia, DOTs is problematic because of its bureaucracy (it demands constant records of every patient) and also due to the lack of resources for delivering the pills to the patients. This has been a continuous fight for Doctor Morales, who has not only denounced the situation of the abandonment of female RAFA patients and their need to have better pharmaceuticals, but also publicly presented her complaints to the international public health community in La Paz. Doctor Morales affirms that the lack of resources highly impact the development of allergies among patients. In her own words:

> You see how I am running to visit the patients. I try to pay attention to their symptoms so they don't suffer allergies, but it is impossible to

> work like this. We don't even have beds for them, we don't have x-rays [*placas]*, we have trouble diagnosing because of the lack of materials. How can we even think about having good statistics!

A medical doctor in Coroico said,

> We have the pills, but the government doesn't provide human resources or even fuel for going to the rural communities. Here in Coroico we are only two persons in charge of DOTs and the WHO and the government expect us to deliver the treatment to 109 communities. Tuberculosis is endemic here, we "breathe" it everyday, there is no way we can fight it like this (Justa Mamani, MD. Coroico)

Don Saturnino's brother was diagnosed with multidrug resistant tuberculosis (MDR) and was receiving his treatment at the hospital. The other brother went back to Caranavi to work and get the necessary money for the expenses they had (around US $200 for ambulance and US$100 for prescriptions). Don Saturnino stayed to take care of his ill brother, although in his condition he might have to be *internado* as well. A doctor at Hospital del Tórax describes the impossibilities of applying DOTs in the Bolivian context that make people like Don Saturnino abandon the therapy:

> How could we ask these patients to come and comply with the treatment? They live in their colonies (rural areas) two or more hours away. Are we able to come after all of hem? Of course not. The geography of this country is brutal, and we don't have enough training for humane physicians (…) something that I think would work is to go to the universities and get the medical students to help, they are sluggish, they don't do anything, anything! When I went to medical school we went to the *campo* (rural areas) and what did we do? Nothing, we did nothing! We just did all the work of the professors. We should have had shifts, do some education, something. I know the first level doctors, what do they tell their patients? "You have tuberculosis, Koch bacillus" just like that, they don't talk to the patient. That is what we are missing, more

> humane doctors, at least some of these young students could be like that, we could train them. Because not all of the people can do this, Paula, just a few. This is what I think would help the patients, more humane doctors willing to talk to them.

This demonstrates that Greene's argument is correct in that folklorizing indigenous medical practice is part of the problem of DOTs. YES Furthermore, the biomedical system itself is problematic because it reproduces a social order based on the objectification of the sufferer's illness experience. In contrast, the indigenous Aymara medicine proposes a dialogue between the healer and the ill person who negotiates the meaning of illness. Unfortunately, in the case of tuberculosis and other bacterial infectious diseases, pharmaceutical intake is a fundamental part of this negotiation as a step towards recovery.

The term active engagement refers to the patient's decision and acts of following or not following or the treatment. As I will explain in further detail in chapter 5, I understand the pharmaceutical self within the biological citizenship framework, where illness becomes a resource for building citizenship and being included (Bielh 2010, 2004, 2001; Petryna 2013, 2004, 2002). I choose to analyze the experience of tuberculosis patients in these terms because, contrary to traditional terms used by public health, such as non-compliance or non-adherence, active engagement underlines the patient's agency in defining his or her healing. At the same time, active engagement speaks of a negotiated healing course instead of a fixed, non-flexible treatment to which patients need to adhere.

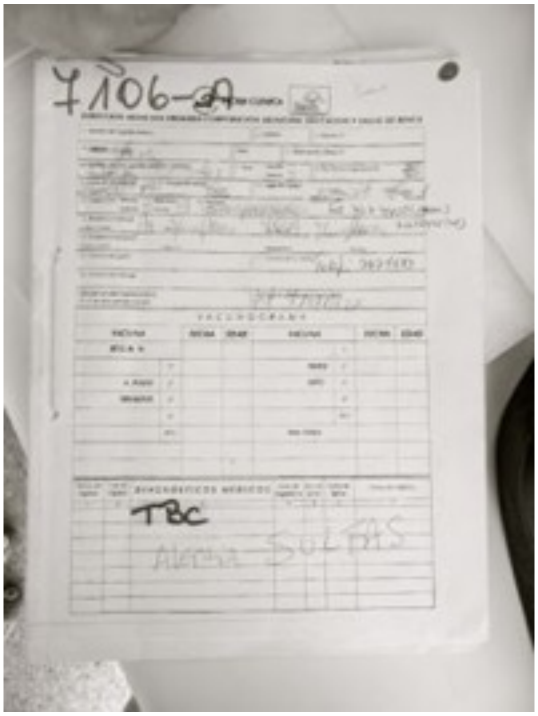

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Figure 21. A medical record of a TB patient in Chile showing the patient's diagnosis and the allergic reactions to medications.

Figure 22. A regular TB corner in a CESFAM in Chile that shows the sets of gloves, masks, and laboratory materials necessary for the tests.

5. Conclusion

This chapter shows that once diagnosed the TB-sufferer goes through a complex and painful process of recovery, which could lead to the abandonment of treatment. Both public health reports and anthropological studies have focused on the concept of non-compliance to explain the patient's attitudes and perceptions towards DOTs. However, these explanations fail to account for the agentic dimension of the illness experience in the context of indigenous framings of illness that bring together social meaning making processes and structural conditions that influence abandonment of therapy. In this chapter I have shown the nuanced strategies that Aymara TB sufferers develop to deal with tuberculosis in their own terms. I have argued that there is much we can learn by looking at the experience of TB from a sociopolitical perspective where illness is part of peoples' everyday struggles for achieving prosperity and health for themselves and their families. This is accentuated in Bolivia, where current political discourses of medicine are integrating the indigenous frameworks to the official biomedical system.

CHAPTER 4

A STRIKE OF COLD, A SENSE OF BITTERNESS: EMOTIONS AND THE AYMARA EXPERIENCE OF TUBERCULOSIS

Chapter Summary

In this chapter I present evidence of Aymara illness semantic networks through which individuals and their communities interpret and act upon severe health conditions such as tuberculosis. I examine the particular associations that Aymara make between the individual illness experience, emotional well-being, and indigenous identity in both countries. Building on previous ethnographic descriptions of Aymara embodiment of emotions (Tapia 2006) and Aymara medicine that associated TB with *debilidad* (weakness) due to environmental or labor hardships (Pedrero 2013), in this work I discuss the traditional hydraulic-topographic model of the body (Bastien 1972) and the importance of fat in relation to breath, sweat, and work as important features of tuberculosis semantic network.

I underline the role of both emotions and cultural conceptions of health in shaping the illness experience, creating particular ways of interpreting and signifying pain, understanding that emotions mediate the configurations of what is socially accepted, influencing not only the framing of disease but also the whole therapeutic process - including ideas about recovery. I argue that *renegar* (bitterness) and *compartir* (community engagement) are linked to larger indigenous discourses of *suma qa* *maña* or *vivir bien* ("living well"), which are currently enforced through the decolonization policies in Bolivia and neoliberal multiculturalism in Chile.

1. TALES OF THE MOUNTAINS

The two Aymara men, Don Ramiro Tejerina and his friend Don Sebastian stood before the harsh landscape of Sajama, gesturing the various mountain picks before them (figures 23 and 24). Don severo explain the vista before us:

> Doctor Sajama has known how to walk just like men, just like a human. And doctor Sajama was very smart, a total womanizer (muy mujeriego), even though he had a wife. So… here is Parinacota, here is Pomarapi, these two were a couple. Sajama fell in love with Parinacota's woman, then, with their slingshots [they fought]. They didn't have weapons, their slingshots were their weapons. Sajama, with his slingshot hit Parinacota's head…[it] went to the sea…the Morro. So, because he was a womanizer, his woman didn't like it, and that is why she went away. She had two kids with him. There was one of eight months, and he was crawling…following his mother, and there he stayed. You see it like a kid who is crawling, his hair is kind of messy (chasconcito). The two ladies are together. Then, Parinacota called for help to fight against Sajama. In the old times, they say, that rabbits were the size of a mule. And then they started to dig, and Sajama asked for help from his sister, that is Illimani. And Illimani send don Juan, and he was a fox. She said "don't look at them" (the rabbits) but the fox is very curious and he couldn't help to look. He said "why is it that I can't take a look" and he exploded. And the fox was carrying a heavy load. So then it started to rain and to snow, and don Juan stayed by

> himself, and he died of cold. That is why Sajama is covered with snow.
> (Don Sebastian, Sajama)[32]

As this description makes clear, the Aymara narrate the life of the mountains. In these stories mountains are smart, foolish, sometimes they drink and end up alone, they flirt, they travel, they are related to one another. “They are like people” the Aymara say. The term they use in Andean Spanish is *gente* (people) or *humanos* (humans). And in their human-like form they have emotions, so they also fall in love, feel envy, and get angry, or even sad. In this chapter I discuss the role of emotions in shaping the Aymara experience of tuberculosis. I argue that the Aymara experience illness - and tuberculosis in particular - in association with emotions that express historically grounded embodied experiences of precarity and social exclusion through racism.

In the previous chapters of this dissertation I have described and analyzed the biopolitical frameworks of tuberculosis in Bolivia and Chile that also craft the illness experience, and the perspective of the medical bureaucrats and medical providers of the process. In the following pages, I build on the works of M. Tapia (2006) and V. Gavilán (2005) to sustain that for the Aymara, tuberculosis is an illness associated with colonialism, practices of racism, and forms of structural violence .

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[32] In our conversation, Don Ramiro, the Aymara yatiri of Sajama and Putre sanctioned don Severo’s version of the story: “ever since the mountains have white snow, they say. Those are the highest [mountains]. That one that is like cut is Parinacota, and the head could be a part of el morro, just next to the morro (in Arica). And the fox died, because he was curious. It is fine, that is a law here. And there you see his son “Chascacollo”, and he said ‘don’t call me like that, my name is Jacinto’ and there you see the two daughters with their mother - Ana and María Colqe, which means money (plata). That is.” (Don Ramiro, Sajama 2012).

2. SAJAMA

It was 2011, and my third visit to the Aymara community of Sajama, a town very close to the border. In fact, Aymara people from Sajama take tourists to Chile all the time. In the last decades there has been an increasing growth of tourism around the Andes's highest peaks, such as Sajama and Parinacota (see figure 25). The tourists "hike" Pomarapi and Parinacota mountains – with the precious help of the Aymara guides who carry most of the baggage. Although I was excited about being there again, I was feeling the altitude slow motion kind of feeling (it is almost 15,000 feet above sea level). Sajama was crowded because of the national "Día del Campesino" holiday[33] so it was not easy to get a place to stay.

Figure 23. The Sajama mountain in Bolivia. Photograph by Paula F. Saravia.

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[33] This holiday was further described in chapter 1.

Early that day Jorge and I drove from La Paz, a tremendous achievement considering how hard it is to drive across El Alto. It is such a contrast with the tranquility and solitude of the altiplano. Aymaras from the cities of La Paz, El Alto, and Patacamaya were also traveling to the rural communities that day. We wanted to go by ourselves because there is an old lady who lives on the road from Patacamaya to Curahuara de Carangas, right next to a line of *chullpas*, ceremonial burials where the Aymara make offerings to the *apus* or ancestors (Figure 26). We met her in 2009 on our first trip to Sajama from La Paz. We stopped because our guide, an Aymara tourist agent from Cochabamba wanted to show us the *chullpas*. I guess it was also a good idea to stop and spend time there because of the altitude, almost 14,000 f. These *chullpas* were the tallest I had ever seen! While standing by these amazing structures we saw this lady coming out of her house speaking to us. At that time we were starting to learn Aymara, and she didn't speak any Spanish. It was challenging to communicate with a monolingual Aymara speaker, so we couldn't understand much of what she said, except for "t'ant munta" (I want bread). She liked our attempt to talk to her in Aymara, she laughed at us (which is common when we speak Aymara with a very strong Chilean accent), and then Erminia, our guide, started to translate for us. From the way she spoke about her husband I had the idea that he was in the fields with the animals, or something like that. However, in our later visits she told us that she lived there by herself, her husband had died years ago run over by a drunken truck driver. That is why she said that he was in the field; it is the place where she mourns him, where she does the ceremonial offerings to him. The Aymara talk about the ritual offerings as *"pagos"* or payments that could be sacrifices (of blood, fat), or coca leaves, cigarettes, alcohol, and corn. Yet, these rituals are only part of the complex repertoire for connecting human and not humans as active referents for everyday life. An important part of the link between humans are non-humans are the representations of the landscape. The Aymara represent their territories in terms of social relations and personalities of the mountains (figure 27). G. Damonte Valencia (2011) refers to these sociosimbolic connections in terms of territorial narratives. He argues that "territorial narratives as social products and territories as political project are a result of social practices that subsists on diachronic and synchronic processes" (2011:98). Within this perspective, the stories and rituals above described are integrated into social practices that are connected in explicit ways to the physical and social space (Damonte Valencia ibid.). This perspective on historically grounded practices that produce and reproduce meaningful connections between humans and non-humans evidence P. Bourdieau's and L. Waqant's conceptualization of the double historicity of habitus and the structural embodied mechanisms for social reproduction, what they call sedimented memory (1992). According to G. Damonte Valencia, the territorial narratives are historically grounded, contextual, inherently collectives, interrelated and defined by a sentiment of ascription rather than territorial domination (2010: 98).

Figure 24. The Pallachatas, Parinacota and Pomerapi mountains. Photograph by Paula F. Saravia.

Figure 25. Aymara men taking care of the load after a climbing tour to Sajama (Sajama 2011) photograph by Jorge Montesinos.

Figure 26. Chullpas located on the road to Tambo Quemado, near the border between Bolivia and Chile. Photograph by paula F. Saravia

Figure 27. A touristic map showing the mountains in Sajama and Parinacota. Source: World Cart/RV Verlag's Südamerika, Süd. ISBN 3575332827.

3. THE AYMARA BODY/MOUNTAIN METAPHOR.

The question of the Aymara connection between the human existence in terms of other non-human entities has been a concern in the anthropological literature of the Andes (Arnold and Yapita, X. Albó, J. Bastien). In their recopilation of Aymara literature, X. Albó and F. Layme present this riddle, which I think illustrate the body/mountain metaphor in relation to memory:

> We the Aymara, like this big mountain,
> keep enduring
> hundreds of year of abuse (1992).[34]

I find the riddle intriguing in that it associated not only the evident physical representations of the mountains as a projection of the human body, but also links the experience of the Aymara with the experience of the mountain. We can understand her way of describing this with the help of anthropologist – and former priest - Joseph W. Bastien. In his 1970s and 1980s works, he described the Aymara culture in terms of the metaphor of the mountain as the human body (1972:79). In his work among the Kallawaya, the Aymara traveling healers or *yatiris*, Bastien showed how Andean communities configure the territory and orient their lives according to the projection of the human body to the landscape and to the connections between nature and culture. This paradigm, he affirms, allows the Aymara and other Andean societies, to link their

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[34] The original text in Aymara: Jiwas aymaranakaqa, uka jach’a qulljamawa, patak patak maranak jakaskatanwa, taqi jan walinaka (Albó and Layme 1992: 202).

environment, territories, and social organization and to apply the mountain-body metaphor to their rituals. As we shall see, it is indeed more than a projection, it is a different way of understanding the world in connection to modern ways of life. Indeed, it is more than a projection, it is a different ontology, or way to understand the universe.

In the Aymara framing of the human body, emotions and thoughts are contained in the inner body (where internal organs are located). In this context, the lady that in the text I call doña Jacinta, does not "pray" or do the offerings to the mountain to calm her own spirit, but to empower the mountain feeding it with blood and fat. Mountains are powerful protective beings, and one should respect them The Aymara think of the body as a flow of blood, fat, and air. In the Aymara of La Paz and Sajama, *Yawar* (blood) is the source of life, and *wira* (fat) what gives energy. Bastien argued that through very sophisticated rituals, the Kallawaya Andean healers could identify different types of blood: strong, weak, and frightened (1972:82). Within the human body-mountain paradigm, thoughts and emotions reside in the most important part of the body, which is the *sonqo* (heart) because it keeps the blood flowing, and a wise Kallawaya healer could also know about the kind of heart people had: sad, happy, or sick. The fat, instead, is produced in the bowels and internal organs. Fat is precious in the Andes, as shown by the works of Bastien himself, as well as many

"Andeanists" (Arnold and Yapita 1996; Canessa 2000; Crandon-Malamud 1991; Juáres 1999;1998; Spedding 2011, 2005; Weismantel 2001,1994).

In the following sections I show the interplay between the metaphoric connections between the human body and the mountain in relation to the experience of illness, particularly of TB. For the Aymara experience of illness is not a finite set of symptoms, but a disconnect between the self and the community (including mountains, water, clouds, the ancestors, etc.). Illness constitutes an expression of loss of strength, loss of morale, or loss of energy. Illness itself is a symptom of a deeper disconnect that needs to be repaired and healed.

4. *Usuña aruskiparañani*: Let's talk about pain, and illness

> Sister, How are you doing?
> Not too well…
> What happened?
> I am sick, I am tired, I am tired and I have a lot of work.
> I am sorry…I hope you feel better.[35]
>
> Or is it that some persons are sick here?
> .. he coughs constantly.
> What illness could it be? He coughs?
> Yes, he coughs constantly, he has said.[36]

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[35] Original text in Aymara: Kullakita kinjamastasa. Janiw waliktti , Kamachtamsa . Usutatwa…qaritatwa… Qaritatwa ukjamarakiwalja Llakisä, walirasimaya

[36] Original text in Aymara: Akan khitinakach usuta. Ujuk uju ,Ujucha. Jisa, ujuk uju…ujuk ujusiwa

Although tuberculosis (TB) is highly prevalent among Aymaras of Bolivia and Chile, it is a silent, kind of “invisible” illness. The Aymara avoid talking about illness in general (TB included), but they are more open to describe or discuss symptoms. They complain about the cold, the uju (constant cough), and the back pain. They also complain about those who complain all the time, people who are “renegones” (bitter). They told me that those who are bitter get TB, those who are not happy with their work, those who isolate themselves from the community, or don’t share (*“los que no comparten”*), as rural and urban Aymara people told me, or those who are angry. At the same time, because of the stigma associated with TB, infected persons usually become bitter and withdraw from their community. Tuberculosis infected patients, and their families also feel sadness, what the Aymara call “lläqui.”

In my research I found out that the other reason why asking about illness was complicated: for the Aymara pain (*dolor*) can vary. They have at least five different ways of referring to pain: usuña (to suffer pain, to be in pain, also means to give birth), ch’isiña (acute pain like when one uses alcohol or iodine), Japuña (burning pain), mach’xtaña (pain from a bad movement, pain in your muscles or joints, t’ajaña (strong and acute pain), k’aphalliña (pain caused by laugh or walking). All of these different experiences of pain translate into particular emotions like renegar, lläqui (sadness, *pena*), and resentment, which the aymara refer to as ñanqha. Therefore, someone who is *rencoroso* is ñanqhasiri. A very interesting connection is the one between sadness, resentment-bitterness and pain (usuña).

Medical anthropologists have accounted for differences in the ways people experience illness; like the one I am describing here. The theoretical work of A. Kleinman (1980) is very helpful when understanding the differences between what the biomedical field has identified as a disease (in this case tuberculosis) and people's shared conceptions of the experience of it (i.e. illness). He, and others after him have argued that medical knowledge is constructed everyday from a collective body experience where we may find a negotiation that is historically contingent. By emphasizing the collective aspect of illness, A. Kleiman (1980) and other scholars like B. Good (1994) and N. Scheper-Hughes (1992) account for the meaning making process that sustain bodily feelings. So, Why is discussing these categories important? How do these categories speak of the everyday life of the Aymara? From a medical anthropology point of view, disease and illness are defined and interpreted as part of a cultural context in a particular time (Kleinman 1980). In my work I build on the work of medical and psychological anthropologists who focus on the subjective experience of illness - not to show suffering as a gory, kind of pornographic depiction of people's pain, but because there is much that we can learn about the meaning of being human by paying attention to the multiple ways in which humans cope with pain, resist or contest violence, and heal. I consider illness to be a space of transformation, a meaningful political process where the "sufferer" (sujeto) negotiates healing. Thus, I engage with questions and debates that come from the work of A. Kleinman (1980) and his distinction between disease and illness, T. Csordas's theorizing on embodiment (1994), B. Good's framing of illness semantic networks (1994), DelVecchio Good's work on postcolonial disorders (2008) and the biotechnological embrace (2007), P. Farmer's concept of structural violence (2004), and J. Jenkins's work on mental illness and violence (2008), psychopharmaceutical self (2011) and precarity (2015).

B. Good's concept of "illness semantic networks", calls attention precisely to the chain of symbols and experiences that together configure illness. As B. Good states "illness has meaning not simply through univocal representations that depict a disease state of the body, but as a product of interconnections" (1994: 171). What are the interconnections that give meaning to the experience of tuberculosis among the Aymara?

4.1. The Aymara tuberculosis illness semantic network.

In this section I will explain the connections between the Aymara body/ mountain model in relation to illness and to the experience of pain (figure 28). The body needs both physical strength (ch'ama) as well as a disposition or mood related to the spiritual strength (ajau). Fat (wari) and blood (yawar) give the body ch'ama, while breath (samaña) is related to the ajau. Whenever the Aymara talk about illness in terms of cold (frío) they are referencing wind and flows of air. Don Aurelio, the yatiri of Colchane, explained that a strike of air can disturb the *animo* (ajau). When I asked him about tuberculosis he said to me: "you can get sick because of cold, because of a strike of cold (un golpe)". On the other hand, lack of fat or blood affect the ch'ama in "terrible ways", don Aurelio told me. Furthermore, in combination with blood, fat is what gives vital strength and ethnic belonging to the Andean peoples, so any lost of blood or fat is seen as a cause of illness (Fernández 2008). A critical figure that evidences these conceptions is the *kharisiri*, who may take away fat from the body provoking serious illness and even death (Spedding 2004).[37] The kharisiri is not a metaphorical or mythical figure. As A. Canessa points out, in the context of the Andean meanings of fat, the kharisiri represents not only anxieties towards the outsider non-indigenous other, but also indexes the indigenous categories of race and class (Canessa 2000). From a biomedical stand, lack of fat and problems with blood, in addition to alteration in mood may be related to TB symptoms. However, for the aymara, these experiences of weakness do not reflect TB symptoms. On the contrary, the relationship between TB and blood originates in the figure of the medical doctor and the uses of blood in the biomedical procedures. As Fernández (2008) and Spedding (2011) suggest, it is more an issue of perceived dispossession rather than bodily experiences.

Other sources of disturbance of ch'ama and ajar are places of shadows, where the person may lose the ajau and even die. The shadow or ch'iw refers to a rupture that only a yatiri could restore. Anthropologist M. Pedrero (2013) reports that in Tacna (Peru) and Parinacota (Chile) the Aymaras refer to the symptomatology of tuberculosis as the lost of ajau:

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[37] Among the Andean indigenous communities in Peru and Ecuador, the figure of the kharisiri is also known as pishtaco (Weismantel 2001, Theidon 2009)

> The lost of the ajau is the widespread etiology- pathology (it is not possible to set limits) in the area, although there is great diversity in how it is conceptualized. In the context of health, it is more important than any physical affliction. Furthermore, often times the physical affliction only finds it explanation and is the symptomatology of the lost of the *ajau-animu* (Pedrero 2013: 43).

Pedrero's work on tuberculosis constitutes an important contribution to the overall ethnographic knowledge on indigenous conceptions of tuberculosis in Peru and Chile. However, her scope is limited to the description of tuberculosis in relation to the biomedical description of this illness. Hence, her work is mostly oriented towards translating the Aymara notions to the biomedical framework, and in doing so, she leaves a crucial aspect of the experience of tuberculosis among the Aymara: emotions.

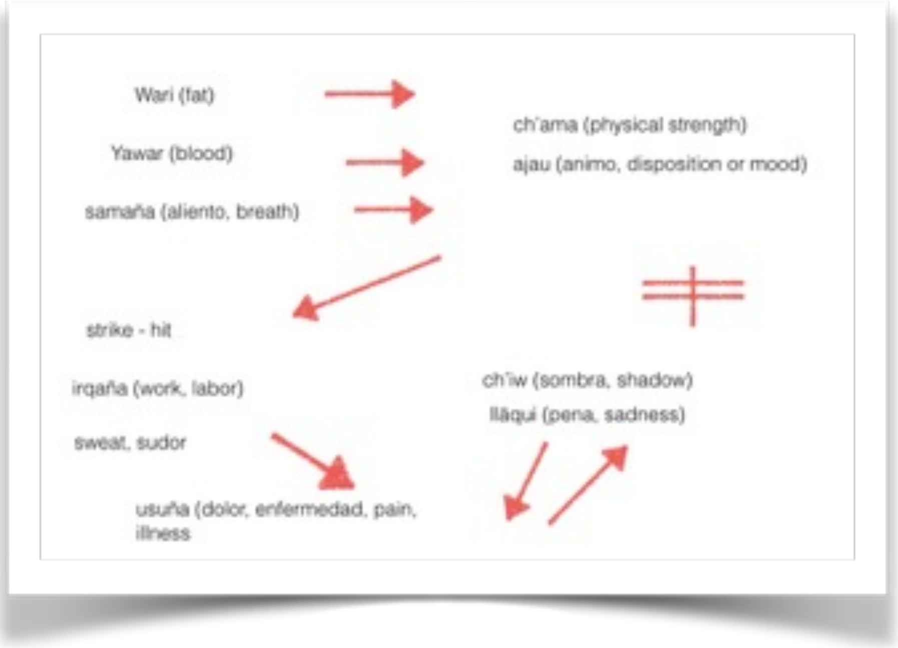

Figure 28. Scheme of the Aymara illness semantic network that shows the connections between the body and potential threats to the well-being of the person. Elaborated by Paula Saravia.

Pedrero describes the ajau/animu and reference the emotion of sadness (lläqui) only as part of the overall symptomatology. However, I argue that understanding lläqui is essential for connecting the Aymara ethnomedicine to processes of ongoing transformation at the national level.

Aymara people also relate tuberculosis to lack of strength, or not been in the mood for something because of a strong weakness. There are different ways of experiencing illness, and tuberculosis is a medical category that needs to be grounded in deep Aymara values such as suma qamaña. An aymara woman in Patacamaya said: "I sell food…so we are eating… and there… they [customers] have spoken (they talk) about tuberculosis. They speak like that, they speak of cold (frío)." Another lady added to that "when one is not well fed (mal alimentado), the person is healthy but "appears" with tuberculosis, what has happened? Or has this person been partying - and drinking - all night? There it has taken you (te ha agarrado)." The Aymaras also talk about golpe, or a blow that weakens people's bodies, so illness gets them: "When one falls down, people said" (Aymara man, Patacamay). Another man told me that tuberculosis begins with cough: "One coughs more, begins with the cough *'no más'*. It advances and doesn't stop. It continues, it continues and one coughs blood. That you cannot get rid off [it]. Then they don't want to eat, then they cough white. Then it is not possible to get rid of [it], it stays. Because it lasts forever." A key aspect of tuberculosis is the association between illness, cold, and work. A person is more prompt to TB depending on the kind of work one has. Hermes, an Aymara man from Potosí working in San Pedro de Atacama mentioned that it was because of the gas inside the mines (samaña/breath), while Don Saturnino, who is from Caranavi in the Yungas said that tuberculosis gets to the person because of sweat.

In her ethnography on weakness among monolingual Spanish indigenous communities in Peru, anthropologist K. Oths also observed the effects of household stress and hardship among women (Oths 1999:301). She argues that *"debilidad* can be viewed as a result of the embodiment of life's accumulated hardships" (1999:308). This observations contributes to an embodied understanding of health and illness among the Aymara that is linked to broader processes of political and economic transformation. Contrary to Pedrero's account, K. Oths brings up an important question on the sociocentric understanding of the self. In a similar line, M. Tapias (2006) discusses the effects of structural adjustments in interpretation of illness among the Aymara in rural Bolivia. According to M. Tapias, the economic instability of the neoliberal period affected the emotional responses to distress among market-and-working-class women in Bolivia. Tapias affirms: "women's bodies thus become the vectors for both transient and enduring ailments and debility in their children" (2006:400). In her research she shows that Aymara women consider two particular emotions (rage and sorrow) as potential cause of ill health. For Tapias, these emotions are connected to changes in the labor and displacement. Moreover, Tapias shows that in this context of social suffering, most illnesses are expressed in terms of debilidad. She explains this by demonstrating that *debilidad* is in fact also a social marker:

> One additional factor must be taken into account in trying to understand the salience of discourses of *debilidad*. *Debilidad* is a social marker. When a person was pointed out to me as *débil*, there was an implicit understanding that this person suffered and had a hard life, was let down, neglected, or mistreated (often unfairly into the eyes of the sufferer) by family, community members, or life. When an infant was pointed out as *débil*, however, it marked a mother's past suffering. A such, she might not be as harshly criticized for her inability to adequately address her child's ailment and susceptibility (2006:410)

Tapias contribute to unravel the meanings of illness beyond the classic ethnomedical definition. There are further significances of illness in terms of the social construction of pain and the place of illness in mediating what is accepted. The connections between discomfort, inequality, and emotions are important for learning about the Aymara experience of illness in terms of a sociocentric orientation of the self (Hallowell 1955). Current ways of organizing the political within the Aymara communities (urban and rural) show that on the one hand they actively engage with an indigenous view on the body and illness. They have also integrated more contemporary elements to that framework (as exemplified by the figure of the kharisiri as a medical doctor). On the other hand, as Oths and Tapias demonstrate, there is a connection between ill health and the experience of inequality and social suffering. Tapias also argues that emotions such as sorrow and rage were part of the illness experience in the context of structural adjustments during the neoliberal period. Another example of the salience of these connections in relation to political transformation in the Bolivian context is the work on performances of political contestation among the mestizo-elites in the Bolivian lowlands (Santa Cruz), where N. Fabricant and N. Postero analyze political performances of contestation in relation to discourses of emotion. They draw from Taylor's idea of "repertoires of embodied memory" (Taylor in Fabricant and Postero 2013) to sustain that current political performances of contestation in Bolivia are linked to discourses of race and violence, they affirm that in the context of political struggle "bodies become texts for remembering, for displaying a particular political statement, or even reinventing a historical narrative" that is expressed by emotions (2013, 197). This case study brings up an important aspect of political idioms and practices as grounded in historical constructions of race, class, and gender. Can we further extent these arguments to the understanding of tuberculosis as embodiment of structural violence in the border between Bolivia and Chile?

5. Illness and emotions

Within social anthropology, culture and nature tend to appear as two discrete categories. Anthropologists also often described "culture" as a circumscribed whole that contains ideas and practices, which are thereby naturalized through the ethnographic text. Nature, despite its overarching presence in everything that is human, remained a separate field beyond anthropology's focus of study. Anthropology has tend to study the transformations of nature and biology, solely, in relation to human intervention.

French anthropologist Philippe Descola has debated this problem, developing a theoretical discussion on what he calls the “anthropology of nature.” According to him, the cornerstone of anthropology should not be a bounded concept of society or “culture,” but localized systems of interrelations where the anthropologist could observe the connections between the spheres of culture/society and nature. This, he argues, requires a “genuine symbolic ecological” approach (Descola 1992: 124). In this chapter I follow Descola’s question, examining the problem of “socialization of nature” and “naturalization of the social world” by interrogating the relationship between tuberculosis and emotions within the Aymara body - mountain paradigm. I look at tuberculosis as a natural/biological reality that resides in the cultural realm of the Aymara. In this chapter I draw from psychological anthropology perspectives on ethnopsychologies to argue that emotions craft the framing of tuberculosis through the connections of the individual’s feelings of pain and the explanatory models of illness (Kleinman 1980).

5.1.*Kuliratawa* (I feel angry)

“Me hace renegar” (it makes me bitter/angry/sad) is one of the most common phrases one can hear when walking through busy and crowded La Paz streets. Among the Aymara in Bolivia, *renegar* conveys frustration, bitterness, and also a mix of sad-

ness and indignation. It is an expression that people use when talking about disappointment and frustration due to failure in business, differences with friends or family, and also illness. In Spanish, renegar is associated with denial and despise. It is also a historical word used as an expression to deny or act against God. In Chile, the latter is a more contemporary way of talking about abandonment of the catholic church. That is also the use of renegar in the Chilean altiplano, where the Aymaras speak of *rabia* or *enojo* when they feel frustrated and angry. At the same time, being healthy is related to being happy (alegre), after the question of what is health? Don Carlos, a man in his thirties in La Paz said: “To be happy, just to be tranquilo (mellow), I am humilde (translate)…that I can tell you.” (La Paz)

From an embodied perspective on illness, both M. Tapias (2006) and K. Oths (1999) consider that the experience of illness is related to everyday struggles with economic hardship and social suffering. M. Tapias argues that emotions are important within the experience because expressing emotions is a way of acting in the world:

> [M]y research demonstrates that emotions must be understood as aspects of sociality and social relations rather than as natural internal biological states. people are not passive receptors of the dictates of social power (…) As people interact with others in their social milieu, emotions guide and prepare subjects for social action and enable an expression of agency, even if that agency initially entails not outwardly expressing emotions or taking action at all (2006:403).

This argument restates M. Rosaldo’s view on emotions as “embodied thoughts” (1984:143) that are intertwined with notions of the person and of society itself. In her ethnographic account of emotions among the Ilongots, M. Rosaldo argues that:

> That affects, whatever their similarities, are no more similar than the societies in which we live; that ways of life and images of the self (the absence, in the Ilongot case, of an interior space in which the self might nurture an unconscious rage) decide what our emotions can be like in shaping stories of their likely cause and consequence. Elongate discourse about "anger" overlaps with, yet its different from our own. The same thing can be said about the things Ilongots feel. Or stated otherwise, the life of feeling is an aspect of the social world in which its terms are found (1984:145).

In the case of the Aymara, emotions are part of a broader meaning making process where expressing or not expressing emotions may affect health. For example, tuberculosis gets people who are renegones (bitter/sad). Expressing that sadness affects their role within the community and their ability to share (*compartir*). If we consider the sociocentric orientation of the self among the Aymara, expressing sadness (lläqui) is dangerous, while at the same time "accumulating" that sadness can be dangerous too because it may be channeled in other ways. As Tapias argues:

> when a particular social context proved inappropriate for expression, a person might "hold in" their emotions, an act perceived as harmful to the body. The damage, however, did not always manifest itself in the bodies of the individuals experiencing the emotions. In pregnant and lactating women, the harm could be passed on to infants. In each situation the effects on health are different (2006:405)

Among the Aymara, the experience of illness is related to the individual and the social dimensions of everyday life. A person's well being depends on quotidian experiences, such as those at home, in the field, etc. TB is associated to the *sonqo* (heart), where thoughts and emotions are located. Hence, any emotional distress may be a cause for illness. An Aymara old man said about tuberculosis: “Sadness, something like that. That is [katxaruña] when tuberculosis [gets] you *(te agarra)*. Not so much contagion” (Patacamaya). In Andean Spanish, *“agarrar”* also means “to be frightened” (*asustado*). The idea behind *golpe*, or a strike is also related to the notion of being agarrado by the earth, by the wind, by a place (like shadow places in Sajama), it is when one losses the *ajau*, the animo, understood as energy and morale. And, once that happens, people can fall into great sadness. The following quotes illustrate this point:

> P: If someone in our family “gets” tuberculosis, what should we do?
> R1: You need to cheer [him/her] up. See into [him/her], so that [he/she] doesn’t worry anymore.
> R2: We need to talk to him so he is not sad…If tuberculosis he has, they [other people] will attack him…
> R3: We say: “jilata (brother), don’t worry, you will get out of this”

There is a riveting connection between illness, emotions, and the social. On the one hand, illness is explained as a result of experience of lläqui, which is a rupture or break in the flow of strength (ch’ama). On the other hand, this break provokes a second disconnect between the self and others. While the Aymara rely on the yatiri and the performance of rituals for restoring the spiritual disconnect, the social reinstating of the sick is a responsibility of the family, friends, and of the sick person. The sociocentric orientation of self towards *compartir* (sharing) is an important aspect of the healing process and of the ajau/animu/ch’ama balance. At the same time, emotions such as happiness and sadness/bitterness are part of the health/illness conundrum. In this sense, lläqui is of particular importance, as it shows the continuity between the human and non-human components of the Aymara world-view.

Anthropologist C. A. Lutz's views emotions as social constructions that are grounded in cultural contexts and social interaction and performed in the everyday life. Lutz asserts that Western concepts on emotions are grounded in two major ideas: discourses on human nature and mind/body dualisms. These two ideas make our conception of emotion particularly ambivalent and difficult to define. Hence, she argues that it is necessary to deconstruct the concept of emotion considering both its cultural and biological dimensions (1988:4).[38] For Lutz, there is a tendency in the West to consider emotions as a physical reality that can be translated from one culture to the other through the use of language. Consequently, by *essentializing* emotions, anthropology has neglected the experiential dimension of emotions and the ideological practices that shape them. Rather than looking at emotions only as pure discourse, anthropology should examine emotions as subjective experience as well. Lutz's approach shows us that emotions are relative to cultural and social structures, as well as personal orientations and experiences. The subjective dimension of emotion is in dialogue with the material reality of culture. Thus, emotions take the form of

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[38] "After deconstruction, emotion retains a value as a way of talking about the intensely meaningful as that is culturally defined, socially enacted, and personally articulated (…) and that it retains value as a way of orienting us toward things that matter rather than things that simply make sense" (1988:5).

discourses that orient people's actions and responses to their "natural" environment. Culture is carried to the domain of nature through the assumption that emotions are "natural", as if they were a constitutive part of human nature. As C. Lutz (1988) points out in her work "Unnatural Emotions", however, this limited view on emotions has impeded anthropologist's ability to fully understand how others "feel" the world. I take Lutz' argument to sustain the idea about emotions and illness as two 'universally different' notions involved in the therapeutic process. As M. Rosalso and C. Lutz show, emotions are culturally produced, and they are learned through socialization processes, which also differ from one society to another. Furthermore, as Lutz (1990) describes, these processes are closely related to language acquisition. Thus, the context of learning varies depending on the social relations involved, which implies that an individual navigates through several layers of mediation depending on their status within the social structure.

This last aspect of emotions is further discussed by J. Jenkins (1994) in examination of the concepts of emotions, culture, and psychopathology, where she affirms that to understand the connections between culture and emotions it is important to look at the indigenous ethnopsychologies. She affirms that ethnopsychologies include: "the constitution of the self; indigenous categories and vocabularies of emotion; the predominance of particular emotions within societies; the interrelations of various emotions; identifications of those situations in which emotions are said to occur; and ethnophysiological accounts of bodily experience of emotions" (Jenkins 1994: 100). Her analysis of the connections between emotions, psychopathology, and culture bring up relevant theoretical concerns on intersubjective processes, social definitions of the normal and the pathological, and the affective dimension of illness experience. In view of these important connections, in the following section I explore these questions: How are illness and emotions mirroring the Aymara ways of understanding the human and non-human experience of the natural world? What is the link between ill health and *renegar* showing us? The connection between illness and emotions is more than a cause-effect relationship where one gets sick because of sadness, or one is sad because of illness. In the dissertation I am proposing that the experience of tuberculosis among the Aymara is related to issues of structural violence such as institutional racism and precarious living conditions due to neoliberal reforms. However, as this chapter shows, emotions are vital in the configuration of the Aymara as a socially oriented self. Another riddle shows this important aspect of the community in the life of the Aymara:

> What is it? What is it?
> There is a person with a thousand hands, eyes, heads.
> Nobody can defeat this person.
> What is it? (Albó and Layme 1992: 203)

In the Andean context, the community transcends the physical landscape, forming as I discussed at the beginning of the chapter an embodied territorial narrative. At the same time, maintaining the community as a complete whole it is a challenge because of the multiple possibilities for conflict, like those of the Sajama and

Parinacota mountains. In this chapter I am proposing that the body-mountain paradigm and the emotions connected to ideals of health and definitions of illness are related to broader sociopolitical structures that set the conditions for the everyday struggles that the Aymara face. In this sense, the Aymara in the border share a particular way of interpreting and expressing discontent (or frustration), sadness, and happiness (“tranquilo, normal”) that form what J. Jenkins defines as political ethos:

> By political ethos, I mean the culturally standardized organization of feeling and sentiment pertaining to the social domains of power and interest (Jenkins 1991: 140)

This concept is helpful in revealing further layers of meaning of the illness experience and the role of emotions in the context of state intervention, political changes, and Aymara territorial narratives. The political dimension of emotions in terms of resistance or contestation to structural inequalities in Chile, such as those presented by Fabricant and Postero (2013) or Tapias (2006) for the Bolivian case, is something that requires more ethnographic data. In view of the painful and still un-resolved legacies of the dictatorship (Han 2012) and the state violence towards the indigenous peoples in Chile (Richards 2013), is of particular relevance to know more about the state construction of affect and political ethos as described by J. Jenkins (1991) for the Salvadorean refugees .

6. Conclusions

The discussions presented above show that illness and emotions are related to the social world, which is inhabited by humans and non-humans entities. The connection between a disturbance of “living well” (suma qamaña) and emotions is clear within the Aymara illness semantic network, where usuña (illness) is a consequence and source for emotional distress (lläqui, ñanqha). The works of Oths and Tapias shows how Aymara, particularly vulnerable women, embody the suffering that comes from everyday struggles by feeling debilidad (weakness), which is associated with lack of sources of energy (breath, blood, and fat). Thus, I see emotions and tuberculosis (illness) as two related elements that orient culturally grounded ideas and practices within society. I consider illness as social experiences that constitute spaces of negotiation of social reality. It is in that process that emotions become so relevant, because they mediate the configurations of what is socially accepted, influencing not only the framing of disease but also the whole therapeutic process - including ideas about recovery.

Figure 29. Yatiris performing a ritual for the celebration of the Plurinational state in La Paz (2013). Photograph by Paula F. Saravia.

CHAPTER 5

FROM SUFFERING TO CITIZENSHIP

Chapter Summary

This chapter discusses the double bind of illness looking at tuberculosis as a chronic illness experience that can be at the same time a mechanism of inclusion and exclusion (exclusion through isolation and stigma and inclusion through medicalization). The sufferer becomes a patient that navigates within new biomedical and biotechnological discourses in a political context where he or she are agents in healing. By interpreting the medical categories derived from their illness, TB patients engage with state policies in different ways. Thus, I suggests that this illness sets the grounds for a form of an emerging form citizenship that is "biologically" based, transforming sufferers/patients into biocitizens.

1. POLITICAL FRAMINGS OF HEALING AND INDIGENOUS BODIES

Driving from Chiapa to Jaiña, in the Chilean altiplano, we encountered a woman who was looking after her fields. She was an elderly woman, and very kindly started to talk to us about her life in the Quebrada de Chiapa, under the tutelage of Tata Jachura (apu). "I had a childhood without school, without a doctor" she affirmed with a bit of sadness in her voice. Unlike today, at that time the Chilean state had not yet installed the elementary school or the health post in that corner of the highlands. She felt very happy about having education and healthcare in her small village, where nowadays, a few younger Bolivian families work the land and take care of the animals. It struck me how vivid her memories were, and how she made state intervention a key element in the history of the community and in her own life. This encounter showed me the many layers of state intervention in the highlands, and how deep state institutions have influenced the life of the people living there. Even in a place like Jaiña. How have state institutions influenced people's everyday life in these lonely and apparently isolated villages if not by education and healthcare? The role of these two state institutions in Bolivia, however, is felt very differently by the Aymara. When talking to Aymaras in Bolivia they do not mention the state at all, but they do talk about state institutions in terms of government or the military. However, during my years visiting the area I noted that there has been a slight change now that there is an indigenous president in power. The presence of the Bolivian state in the highlands is more and more visible through new healthcare centers built by the stater (not only the foreign aid). For example in Sajama there is a new medical posts with an ambulance, and this did not exist in 2009 when I first visited. Unlike the Aymaras from Chile who consistently link their memories to the Chilean-state, in Pisiga Bolívar, people frame the past in terms of memories of indigenous movements and the emergence of "*sindicatos*." These divergent sedimented memories (Bourdieu and Waqant 1992) illustrate the importance of considering a geographically specific historical perspective, and looking at current biopolitical frameworks as embedded in earlier configurations of the nation state in both countries, which I argue, gives rise to particular citizenship regimes (Postero 2007). In this dissertation I emphasize the sociohistorical background for the experience of illness as well as the institutional mechanisms that influence the experience of suffering and pain. In chapter 1 I examined the sedimented nature of current biopolitical frameworks in Bolivia and Chile, showing that while in Chile there was a strong process of Chilenization of the Aymara indigenous communities, in Bolivia the biopolitical framework emerges mostly during the liberal period (1890s -1920s) and after the Chaco war (1932-1935). In this chapter I will retake that discussion from the perspective of the sufferers-patients and their view on these issues.

Figure 30. Map of the Bolivia-Chile border and its terrain, showing the town of Jaiña (red) and the other research field sites (yellow stars). Source: google maps.

2. CITIZENSHIP

A crucial aspect of my research is the way(s) in which nation-states incorporate modernity projects, and the relations between said projects and governance. What are the interplays between ideas of modernity and other social constructions such as race and indigeneity?

It is precisely from this discussion that I propose to explore the role of race and illness as sites of modern ideas of the state and the nation by looking at both social constructions as a site of citizenship. Through which dynamics do modern states deal with difference? What kind of subject is produced under these regimes of citizenship?

2.1 Classical Theories of Citizenship

The seminal work of T.H. Marshall shows that liberal democratic citizenship is a framework that validates social inequality. Examining the history of rights in Europe, he identified three forms of rights: the civil (rights necessary for individual freedom), the political (the right to participate in the exercise of political power), and the social (a broad aspect of rights that range from economic welfare to the right to a fulfilling life). Marshall considers citizenship to be dynamic, evolving across the past three centuries according to the development of modern nation-states. For him the three elements are intertwined and have evolved in different phases. Civil rights were the first to be achieved and the social the latest. Thus, Marshall argues that social equality is a final phase to be achieved, once the modern state develops institutions to distribute rights to all, granting them citizenship. According to Marshall, the relationship between citizenship, state institutions, and social equality/inequality is key for understanding social differentiation precisely because of the social structures that are formed around those institutions, and the access – lack of it – to rights that would allow the subject to fully exercise citizenship and participate in the project of modernity. In other words, those who are not integrated into the state are excluded from becoming a modern subject.

An interesting perspective that targets this issue of citizenship and modernity is that of anthropologist J. Holston, who underlines the role of the state as the grantor of citizenship while accentuating spaces that subjects create for negotiating the distribution of rights. Thus, Holston defines of citizenship as the way in which the state distributes rights and obligations according to difference (2008). For him, citizenship constitutes a key aspect of modernity insofar it establishes social structures for belonging to the nation state: "[c]itizenship, rather than subjectship, kinship, or cultship, has defined the prerogatives and encumbrances of that membership, and the nation-state, rather than the neighborhood, village, city, or region, established its scope" (2008:21). Moreover, Holston's argument gives great importance to the nation state as a space where relationships are being created and sanctioned. Thus, for him citizenship is "challenging" because it is a fundament of modernity, while at the same time it is a framework that is constantly questioning the "modern" political order. If we think about this argument in terms of Foucault's conception of modernity as "embodied awareness of our time" [add ref], we can link citizenship as legitimating the modern political order, and the necessary subjects who embody the politics of inclusion and exclusion that are based on difference.

In addition to the traditional view on citizenship, with an emphasis on the distribution of rights by modern nation-state and its institution (and the formation of modern nation-states in Latin America, for example), there are other perspectives that discuss citizenship in the context of global – an local -cultural movements, ethnic recognition, and the actualization of racial imaginaries through cultural "revitalization." By looking at phenomena like migration and transnational circuits, these perspectives demonstrate that present forms of citizenship are closely related to cultural identities within national societies, and even beyond the limits of the nation-state.

2.2. Cultural Citizenship

Anthropologist R. Rosaldo has elaborated on the forms of cultural citizenship in the context of multiculturalism in Latin America. In his view, citizenship implies both "the right to be different and the right to belong in a participatory way" (1994: 402). In analyzing the resistance to changes in education in the US during the early

1990s, he presents a critique to the nineteenth century narrow and static conception of citizenship that he calls “doctrine of sameness” (1994:403). For him, instead of a national status granted by the state (Mashall 1950), citizenship should be thought of a positional experience that is linked to social status, class, race, as well as gender. According to his view, our conceptions of citizenship depend on our social position and cultural background. Different from approaches, like Holston, Rosaldo discusses citizenship in terms of meanings and practices, where the subject is active in interpreting his or her context. Furthermore, cultural identities turn into political practices by the actualization of meanings of citizenship in the everyday life. What I find interesting about Rosaldo’s argument is his focus on the importance of social change and agency for the exercise of rights. The nation-state’s social exclusion can catalyze social forms and political transformations, turning historical social exclusion into participatory practices. A good example of this process is Bolivia’s political reorganization over the last decades, which have resulted in the election of Evo Morales as the first indigenous president.

Yet, considering Rosaldo’s idea of a spectrum of citizenship without looking at structural violence could be misleading. Although agency is an important aspect of the politics of exclusion, it is also true that there are certain conditions that allow for structural changes, such as those of Bolivia and others that limit state power. Cultural struggles are always political struggles, and it is precisely in the cultural terrain where the citizenship process is articulated. In analyzing citizenship as discursive practices, K. Abowitz and Jarnish (2006) underline Rosaldo's contribution's in terms of his critique to the "assimilation fallacy" (2006: 670). Precisely, cultural citizenship addresses the problem of identity within national societies, which tend to result in assimilation (or the notion of a "melting pot"). Numerous contradictions emerge from the "melting pot" framework, including practices that undermine cultural diversity and recognition. Thus, cultural citizenship, "speaks a language of rights and agency" (ibid) within the context of political liberal discourses that favor individual rights over cultural forms. In looking at the contradictions of demands for membership and participatory belonging to the national society on the one hand, and liberalism on the other, we are confronted with the question of how these dynamics are embodied within national societies and how is it that citizens push cultural boundaries. Rosaldo's analysis of cultural citizenship within the United States presents the problem of the meanings of the right to belong and to be different within social dynamics of political exclusion in a multicultural context. Yet, despite his "de-essencialization" of citizenship, it is not clear how cultural forms of belonging overcome structural conditions of segregation and exclusion, or legal limits for social action. How is agency expressed in the political struggles for recognition of difference?

A good complement to Rosaldo's perspective is that of C. Hale and his discussion of citizenship in a neoliberal multicultural context. Anthropologist C. Hale elaborates on the question of the political economy of multiculturalism in Latin America.

According to him, the politics of cultural recognition have become stronger in Latin America, displacing the traditional project of assimilation, or *mestizaje* (2005). In discussing about the conditions of this political process, Hale analyzes neoliberalism in Latin America, particularly its transformation from what he calls its original meaning into a full-fledge political project (2005:12). He asserts that neoliberalism accepts cultural recognition as a way of governing, as long as those recognized subjects are not a threat to state form of capitalism (2005). His argument is a critique of the dominant global policy-making of multilateral institutions and their programs (2002). Moreover, Hale underlines the political implications of neoliberalism in sustaining social policies that promote the recognition of certain cultural rights – neoliberal multiculturalism - while limiting indigenous right movements, a paradox that turns into a menace for the status quo (2002). His concept of "*Indio permitido*" (permitted Indian) captures the paradox: a subject who is allowed to belong, but limited in terms of challenging structural order.

Through his ethnographies in Guatemala, Hale contributes to a critical analysis of the conditions for cultural recognition and to the limitations and possibilities for indigenous rights movements within the neoliberal state. Besides acknowledging the problems behind political change in Guatemala – and Latin America – Hale discusses the ambivalent aspect of racial differentiation. Like Larson and Rosaldo, Hale affirms that racial categories are positional categories that are embedded in existing social relations that turn race and cultural identity into very flexible social constructions, constrained by the current neoliberal project. Nevertheless, as shown by L. Green (1999) and D. Nelson (2009), when these categories are enacted they can be violent and not flexible.

His analysis on the indigenous movements in Guatemala shows that multiculturalism is a tool for the perpetuation of the carefully delimited cultural rights. Hence, multiculturalism is not a menace for the status quo but for the advancement of social movements themselves. However, Hale's view on Guatemala cannot be generalized to the rest of Latin America. Ethnographic research shows that although neoliberal reforms are a strong force in shaping indigenous movements, there are historical and cultural dynamics that contest the neoliberal trend. In her ethnography about indigenous movements in Bolivia, anthropologist Nancy Postero describes a rather different outcome of multicultural policies in the context of neoliberal reforms. Acknowledging the Bolivian case as different, in her book "Now we are citizens," Postero argues that state led multiculturalism, with an emphasis of recognition of indigenous peoples as poor and excluded, triggered political action towards social change. Bolivian political organization and the historical role of sindicatos helped to shape this widely implemented model. So, instead of constraining indigenous movements, state's legal reforms like "Law of Popular Participation" *(ley de participación popular)* encouraged local indigenous movements:

> The 1994 reforms, particularly the LLP, were intended to further disrupt the power of unions, as modernizing elites sought to dismantle this corporatist system of politics (…) Particularly during the economic cri-

> sis of the 1990s, the state could no longer continue to take direct actions to meet demands of popular sectors. By breaking the power of the clientelist system, the hope was to make political and economic decisions more rational and effective, rather than to continue the costly and often corrupt expenditures needed to silence vocal political actors (Laserna 2002: 27 in Postero 2007:138).

The actual enactment of the LLP articulated novel meanings of political practice among the indigenous peoples in Bolivia, changes that transcended the political arena and were put into practice in people's everyday life, as a way of being in the "neoliberal" world. Postero carefully discusses the process by which the LLP logic permeated the relationship between the indigenous peoples and the state, but most importantly, it changed the ways each subject presented him or herself to the rest of the community:

> When the LLP was enacted in 1994, there was a substantial amount of fanfare about the revolutionary changes it presented. As the government began to enact the law, there was a recurrent buzz about the "pluri-multi" nature of the country and the extension of participatory Indians (…) Instead of seeing the state as the source of resources and making *reclamos* (demands) against it, now indigenous people would see themselves as citizens, with rights and obligations: "We want fewer inhabitants and more citizens (...)" (2007: 138-139)

Hence, the process did not rely exclusively on the state and the local governments, but also on the production of a particular subject who would engage responsively in the multicultural dynamics:

> (…) by learning "techniques of the self" – such personal skills as rational participation, effective money management, and most important, "responsibilization" – Indian leaders prepared for the exercise of citizenship in multicultural Bolivia (2007:218).

Municipalities and local organizations are important within Postero's argument. The LLP presented municipalities as a space for the development of local leadership, but instead, they "became the site of expanded patronage, clientelism, and corruption" (Postero 2007:217). As a consequence, indigenous and popular sectors opted to employ conflictive mobilizations to bring their demands to the table "[f]rustrated, these people turned back to the tried-and-true model of conflictive mobilizations. They also undertook a new strategy of forming their own political parties" (ibid). Unexpectedly, indigenous entered the electoral politics demanding rights rather than class or race demands (Postero 2007:222). Citizenship, Postero asserts, is "a discourse that orders society"; her conceptualization of citizenship goes beyond the politics of recognition to a political and social articulation that connects both the politics of belonging and the contest over political culture, that has been questioned in Bolivia through new forms of social activism (2007:223).

Postero's perspective is interesting because it draws our attention away from the mere conditions of exclusion, towards culturally grounded strategies for political change. This perspective is fruitful for understanding the processes of transformation of political structures as it considers the production of subjectivities that relate to citizenship by the creation of transformative political subjects. If citizenship refers to both politics of contestation and belonging, there is room for agency. From there, the question then is not about the state integrating or not difference, but about the subjectivities that are produced around belonging and the possibilities of accept the terms of belonging or not. Going back to the issue of indigenous rights and the struggle for recognition, Postero concludes that the "formal granting of citizenship rights did not a guarantee inclusion of participation" (2007:224); nevertheless, despite, indigenous peoples contested the existing structures of exclusion – including racism – and *resignifying* political belonging. Like Hale and Rosaldo, Postero also looks at citizenship as a discourse in the context of multiculturalism in neoliberal Latin America.

2.3. Flexible Citizenship

A different perspective on the complexities of citizenship within the neoliberal context is that of A. Ong (2010, 2006, 2004), who examines changes in citizenship within the United States, considering identity politics and transnational capitalism as catalysts of new meanings of citizenship. She considers the question of how particular geographies of economic flow make possible the emergence of meaningful mechanisms for social mobility across national borders. Thus, by looking at high technology industry she develops the concept of "flexible citizenship", defining it as "[t]he assemblage of transnational practices for gaining access to different global sites as well as the versatile mobilizations of business, legal, and social assets that facilities a high degree of mobility" (2004: 57). According to her, current economic dynamics characterized by flexible accumulation, on time production, transnational capital flow, interconnects social constructions of race, cultural identities, and citizenship resulting in processes of relative positioning. The fact that the subject's positions are contingent on the shifts in global economic conditions (and not the other way around), favor a particular form of citizenship, one that is based on transborder stratification. Hence, when talking about latitudes of citizenship, Ong describes the influence of transnational networks of capital in the configuration of citizenship in the U.S. This configurations take place in the context of a moral economy where the value of the individual is his or her capacity to work. Thus, she turns back to the problem of race and multicultural citizenship, adding to this dynamics technology and transnational capital as key elements for political integration of foreign laborers to the American society. In other words, the right to be different is conditioned by the participation on the flows of transnational capitalism and technology. In the end, Ong is alluding to a kind of citizenship that is conditioned by economic flows and transnational labor rather than other important sites for political status such as race, gender, or as O'Neill argues, religious practices.

What are the discourses of a race-tech based citizenship? Ong alludes to socially constructed racial categories that are supported by technology (genetics, for example). She only develops this relationship in her work on "Mutations in citizenship" (2006) where she builds on the idea of biotechnology and the transformative aspect of citizenship. Yet, focusing on social mobility through economic integration is part of the problem. What is underneath flexible citizenship? What is the meaning of those dynamics? Although Ong elaborates on transnational networks of capital, she is not taking into account the limits of a "flexible" kind of citizenship: if it is based on market integration, what is then the possibility of expanding those rights and turn them into political participation? How are those forms of citizenship produced and how is it that they become legitimate?

Race and biotechnology, particularly the use of genetic data for governing, seem to be part of the problem of contemporary political integration (Ong 2010). Although, as we have seen, race is considered to be a social construct, there are still biological aspects of race that are not totally clear: how is it that illness is connected to race? In part, the answer is that science has gained power in legitimizing difference even though this is only a discursive practice: inequality is based on a discourse of biological differences rather than material conditions of living. Furthermore, in Ong's view, structural violence is not part of the process of unequal distribution of rights. She relies on globalization and global stratification as an appropriate avenue for social integration, instead of tackling the structural conditions of inequality – that precisely underline the emergence of the global - that occur in the new spaces of sociality – or *biosociability* as mentioned by Ong.

In my view, biomedicine and science are legitimate discourses for explaining conditions of inequality and social exclusion. Both discourses have become "regimes of truth," where the individual needs to be responsible for his or her abilities – or disabilities – as well as for their social integration to the market economy. In view of Foucault's discussion of the modern forms of objectification and subject-making within modern states, biomedicine has been, and it is *the* discourse that legitimates contemporary regimes of power. Instead of being a mere product of the social order, biomedicine and biotechnology have become the sociosymbolic basis of current sociopolitical structures.

In view of these transformations, current analysis of citizenship considers science – particularly medicine and genetics – to be the basis of global sociopolitical structures that overshadow traditional forms of citizenship (nationality, for example) including what some have called "hyphenated citizenship" (D. Stasiulis 2006; Gusfield 1996). Hyphenated forms of citizenship imply fragmenting – and even overlapping – senses of belongings such as gender or age, social status.

In this chapter I am proposing the emergence of intricate relationships between current notions of race, modernity and a particular form of citizenship that is scientifically and medically based, namely: biocitizenship. From my perspective, it is biopolitics that gives meaningful content to the political structures put in motion by neoliberal governmentality. Inherent to modernity, biopolitics and biocitizenship have produced a subject that relates to the state in terms of the "politics of life itself" (N. Rose). In other words, biopolitics and biological citizenship it is not "new" to modernity, it has been in fact "the" modern regime all along. I will now illustrate this argument by analyzing three different approaches to biological citizenship.

3. CITIZENSHIP THROUGH A MEDICAL LENS

3.1 From sufferers to citizens

Part of the critiques to a hyphenated citizenship paradigm targets the argument of compartmentalizing society and its results: a limited – and conditioned – citizenship. As I discussed above, Ong's argument about flexible citizenship is related to embodied economic changes (transnational flows of capital), sociocultural changes (gender and age roles), and also to mixture of technology and science (biotechnology and pharmaceuticals). As a result, citizenship becomes a demand that is closer to market integration rather than political inclusion or the constitution of a political subject; a process that occurs within liberal states and neoliberal governmentality, where rights are conditioned by flows of capital and labor, for example. In other words, the individual – the potential citizen – needs to claim his or her rights from a very particular position in conditions of inequality, or where inequality is the rule rather than the exception. Furthermore, a resourceful potential global citizen, who is able to be accepted within the interstices facilitated by globalization, contradicts some of the main tenets of modernity: the principle of establishing relationships with the state that translate into a set of universal rights. Hence, instead of the state, it is the individual who needs to manage his or her own risk. In a later work, Ong argues that biomedicine, particularly biotechnology validates this flexibility by producing political relationships grounded in scientific logics about the body and the nation. Thus, according to her, health claims are an example of how "diverse actors invoke not territorialized notions of citizenship, but new claims – postnational, flexible, technological, cyber-based, and biological – as grounds for resources, entitlements, and protections" (2006:504). Within this framework, biological citizenship is an example of the contemporary tension between neoliberalism and human rights, for a successful market driven economy where flexible citizenship is performed, requires a moral economy inspired by deterritorialized human rights look after risky individuals, or those individuals who are not able to embody a flexible citizenship.

Following the same line of thought, N. Rose suggests that in view of the importance of risk and the displacement of risk responsibility from the state to the individual, contemporary biopolitics are in fact risk politics (2001: 3). His concerns are the strategies and practices that come from state-sponsored biopolitics, and the consequences of those strategies in terms of subject and nation making processes:

> Today, however, the rationale of political interest in the health of the population is no longer framed in terms of consequences of unfitness of the population as an organic whole for struggle between nations. Instead it is posed in economic terms – the cost of ill-health in terms of days lost from work or rising insurance contributions – or moral terms – the imperative to reduce inequalities in health (2001: 5)

For Rose, "advanced liberal" frameworks are orienting changes in the role of the state from a distributor of welfare to the governing of risk. Therefore, the state needs to design programs to prevent, identify, and manage different levels of risk (2001: 7). As a result, there is an increasing feeling of uncertainty among the population because of the probability of being identified as a risky individual, or potential patient. This approach integrates risk into the debate on citizenship as a way to understand contemporary political processes where politics target what he calls "vital processes" (birth and death, for example) using tools that are medically grounded. The health of the population is not the main responsibility of the state; on the contrary, it is the role of the individual to manage the risk of being unhealthy using those tools given to him or her by the state. In Rose's words: "[E]very citizen must now become an active partner in the drive for health, accepting their responsibility for securing their own well-being" (2001:6). Thus, risk is key in current configurations of citizenship and their articulations to the state. In his view, risk "denotes a family of ways of thinking and acting, involving calculations about probable futures in the present followed by interventions into the present in order to control that potential future" (2001:7). As a reaction to these logics, new collective strategies to manage risk have emerged. Opposite to previous "modern" responses, strategies are not administered by the state but by part of the "community": medical associations, pharmaceutical laboratories, religious organizations, etc. All of these discourses grounded in a specific medical scientific knowledge, especially genetics. In addition, for the politics of risk to be effective, the individual must be part of a political structure that is "pastoral." Here, like O'Neill, Rose builds on Foucault's definition of pastoral power,[39] highlighting the shared aspect of this particular subject making process. In other words, the welfare of the "flock" – or in this case the risky subjects – is embedded in political structures of care led by new pastorates linked to the field of scientific medicine instead of the state:

> [this contemporary pastoral power] takes place in a plural and contested field traversed by the codes pronounced by ethics committees and professional associations, by the empirical findings generated by researchers, the attitudes and criteria used by employers and insurers, the tests developed and promoted by psychologists and biotech companies, the advice offered by self-help organizations, and even, one might add, the critical perspectives contributed by religious organizations and sociological critics. Crucially, this pastoral power does not concern itself with the flock as a whole. (2001:9)

It is important then, to ask what happens with those individuals who are not part of the community of sufferers? What happens with those who are excluded from these dynamics? By relating these questions to the current notions of health and "healthy bodies", Rose argues that current biopolitical frameworks imply a change in they ways in which subjects embody politics. The challenge then is to question traditional perspectives on biopolitics and governmentality in view of the problem of defining the very essential site of politics: life itself.

Although this is a very convincing argument, it only accounts for those individuals who are already part of the system, that is, those whose lives are targeted by

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[39] Foucault develops the conception of pastoral power to emphasize the bridge between the symbolic and the materialization of different forms of power among subjects outside the state. Pastoral power is therefore a form of government, of conducting others that operates under the logic of the pastor leading the welfare of the "flock." For further theorizing of this subject, see Foucault's article "the subject and power" in *Critical Inquiry* 8(4): 775-95, 1982.

state policies or whose conduct is regulated by governmentalities. Rose does not consider those outside the state's government. This is the topic of a global parallel paradigm: humanitarianism. Precisely, G. Agamben's (1998) work on the modern forms of power and the role of humanitarianism in legitimizing what he calls "bare life." Agamben's framework underlines the differences between the sovereign (one who stands within and out of the law, as he dictates states of exception) and the *homo sacer* – life that is included only because of its exclusion from political life -. Grounded in the Greek's distinction between "zöe" from "bio," the *homo sacer* is the one who is set apart, one who can be killed but not sacrificed. Agamben's work on refugees and concentration camps illuminate his argument on modern biopolitics and humanitarianism.

Building on Agamben's and Foucault's work, anthropologist Myriam Ticktin presents a discussion on how biological citizenship is embedded in both neoliberal structures and human rights discourse. Her work is a good response to Rose and Nolan's idea on biocitizenship as well as Agamben's notion of bare life. In her article: "Where Ethics and Politics Meet: The Violence of Humanitarianism in France" (2006), Ticktin analyzes emergent biopolitical practices that are grounded in the problem of political recognition within a system of humanitarian governance based on the belief of the universality of (biological) life in contemporary France. In her ethnography, she describes the process by which *sans papiers* ("those without papers") can become part of the polis. She calls this "the paradox of being a sufferer or a citizen" (2006:40). She argues that the new ethical configurations based on humanitarianism are problematic because they produce contradictory subject positions where one needs to trade his or her biological integrity in exchange for political recognition: "being sick is what is required to be a political subject" (2006:42). For Ticktin, the paradoxes of contemporary immigration policies based on humanitarianism in France are closely related to historical transnational regimes of capital and labor that shape the flows and transits of people in a postcolonial Europe.

Like Rose, Ticktin focuses on the contradictions of regimes of citizenship that rely on biological categories of political belonging. As O'Neill and Rose, she builds on the works of Foucault on governmentality and biopolitics, demonstrating the importance of current definitions of population for the articulation of political structures. Because the French state guarantees the right of "illegals" to stay depending on health conditions, the doctors and nurses become the 'gatekeepers' of citizenship, as they are the ones who authorize the permits. By drawing from Agamben's work, she extends the argument of biological citizenship showing how, in addition to scientific biomedical categories, notions of bare life mediate the relationship between the individual and the state. Her focus is on the question of the sovereign power of the state in defining what constitutes humanity, and who can belong or not to the polis.

Her critique on humanitarianism instead of a regime of rights as the ground of political inclusion brings up questions about the limitations of biological citizenship in the context of neoliberal governmentality. At the end of her paper she questions how functional for this model is the existence of *homo sacer* (those who can be killed and not sacrificed) insisting in the role of humanitarianism in reproducing structures of inequality where the suffering body is the legitimate vehicle for political action.

3.2. Sanitary citizenship and unsanitary subjects

Cholera has been a major public health issue for the last centuries (Herring and Swedlund 2010; Porter 1996; Rosenberg 1992). Furthermore, nineteenth century English hygienic movement was built around the problem of cholera and the challenges of building healthy industrial cities by promoting social as well as environmental sanitation (Rosenberg). Thus cholera and sanitation have been closely related within the public health arena. Briggs and Mantini-Briggs' 2003 study, "Stories in Time of Cholera" is an account of the cholera epidemic of the early 1990s in Venezuela, which started amongst the Warao indigenous communities (the Mariusans) in Delta Amacuro region. This ethnography constitutes a significant political and medical analysis of the epidemic, showing 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. In this case power relations that define the role of the state and the communities – whether they were affected or not by the disease - were framing the epidemic. Briggs and Mantini-Briggs organize their argument around two intertwined theoretical concepts: race and citizenship. They state that these categories are pillars for the social construction of the epidemic in Venezuela, and they demonstrate these by discussing the perspectives of both the Mariusans affected by cholera and the population living in the cities - state authorities for example -. The authors observed that race was a key category for the notion of citizenship and political participation in Venezuela. An example of this is the state's approach towards the Warao living in the Delta before the epidemic.

> From the perspective of the residents of Tucupita, Mariusa is just plain off the map. Not only is it 'inaccessible', it is the home of the most 'isolated' and 'uncivilized' of the 'Warao' (…) Few government officials would even consider making the trip. Persistent requests by Mariusans over decades for a clinic, a school, a water tank, and polling places have fallen on deaf ears (2003: 59).

The cholera epidemic of the 1990s changed the status of the Mariusans from isolated indigenous communities to a target of public health. This change had to do more with the risk they represented for the rest of the country rather than a shared new conception about the role of the indigenous people in the national context. The potential expansion of the epidemic from the Warao communities to the rest of Venezuela threatened the 'modern' and hygienic national identity. Cholera was associated with premoderns ways of life that the indigenous shared. Cholera is also associated with poverty and race; nevertheless, instead of being considered vulnerable communities, indigenous communities were blamed and pointed at as responsible for the epidemic:

> The disease became an "indigenous problem", closely aligned with an entire population, at the same time it was individualized - that is, tied to the attitudes and behaviors of the specific people it infected. These narratives were created largely by public health officials and disseminated widely by the media (…) Having identified indígenas or, more specifically, "the Warao", as responsible for the transmission of the disease,

> the stories detailed how cultural beliefs and practices transformed individual bodies into natural bearers of the disease" (2003:9)

In addition, by blaming the indigenous peoples of the Delta for the cholera stroke, the national society took no responsibility for taking care of the situation. Briggs and Mantini-Briggs argue that this was due to the relationship people have towards medicine, public health, and hygiene and the way the state determines their status as citizens (2003: 10). In this context, Briggs and Mantini-Briggs suggest the notions of "sanitary citizenship" and "unsanitary subjects" as an important theoretical construction for understanding the relationship between the people and the state in the context of the epidemic

> Representing the public also helped draw attention away from the process through which cholera stories portrayed Venezuelans. 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).

From this point of view, political society (the government, parliament, political parties, public health officials, etc.) decides beforehand who can exercise social and political rights and who does not by generating categories about citizenship. The "sanitary citizen" is the one who is integrated into the modern medical understanding and follows the medical advice of the public health institutions; while the "unsanitary subject" is that person who is not integrated into the public health system, and thus does not follow medical advice, or refuses to do so. According to the authors, representations about the Warao peoples as unsanitary subjects brought into those communities the stigma of carrying cholera.

Briggs and Mantini-Briggs show the imbricate relationship between modern hygienic notions and the building of a state apparatus, which establishes power structures that determine people's status within society. Epidemics are not the elements that cause these distinctions, but they are a space where inequalities are crystallized. "Stories in the time of cholera" demonstrate that there are severe differences that are produced and reproduced by well-established social mechanisms. As a consequence, the state does not take responsibility for the health of the population as a whole, but protects certain people and leaves others out. What is interesting about this perspective is that it is grounded in ethnographic data that shows how inequalities are based on institutionalized racial profiling, and not by mere social constructions or race representations.

At the same time, the ethnographic portrayal of dynamics of citizenship in the context of a cholera epidemic/pandemic is a good example of the role of illness as triggering political processes. They show that the definitions of who is included are a prerogative of the state and its institutions. In other words, their theoretical contribution of the distinction between sanitary citizen and unsanitary subject originates from the state perspective. Thus, even though they describe some of the strategies the Warao developed for approaching the state, it is not the main dimension of their argument. Are there other ways of political change that epidemics trigger, in terms of citizenship? What are the possibilities of the unsanitary subjects in contesting their situation of exclusion from the state? How does the state draw the line between healthy and unhealthy?

From this work we learn that race is the site for constructions of politics of difference. A study that complements “stories in the time of cholera” is Nayan Shah’s historical study “Contagious divides: epidemics and race in San Francisco’s Chinatown” (2001), which focuses on epidemics within the nineteenth and early twentieth urban context. In this case the “unsanitary subjects” were part of the everyday life of the city, not isolated like the Waraos. For this reason Shah talks about “Chinatown as the laboratory of infection” (2001:1) where race-based systems of inclusion/exclusion operated. In his view, “race is better understood as a social and political category that persists because it offers a seemingly ‘natural’ observable difference to explain social inequality and domination” (2001:5). According to him, public health has been a political project; key for the state to accomplish the modern tenet of control and discipline of healthy and hygienic populations. Thus, Shah discusses citizenship within the framework of modern political structures and liberalism. In doing so he develops the notion of citizen-subject as a “combination of political status of liberal democracy within the social practices of modern disciplinary institutions” (2001:7).

3.3. Biological citizenship

A good case for showing how citizenship can be built up from biological conditions and illness - that are not exactly epidemics- is the work of American anthropologist Adryana Petryna “Life Exposed: biological citizenship after Chernobyl” (2002). This is a historical-anthropological account of what has been named as the “technogenic catastrophe” of Chernobyl, in the context of Ukraine’s capitalist transition. Here, Petryna analyzes the political effects and consequences of the 1986 radioactive accident in relation to the sociopolitical history of this community. Petryna engaged in 18 months ethnography and in archival work – particularly scientific reports and medical records – to write a “micro history” of Chernobyl’s experience.

Her research aims at understanding how individuals relate – and adapt - to a state in transition (former member of the Soviet Union to independent market economy oriented Ukraine), and how they “create” or “use” a medicalized citizenship discourse as a survival strategy in a context of risk and uncertainty. She traces the role of the state and its technical intervention during and after the accident in configuring a biopolitical framework where people navigate and build their own agency via-avis the disaster. Furthermore, she identifies mechanisms for political inclusion in what she defines as the political economy of claims around radiation illness, and the role of health care policies in creating a "language" of citizenship that brings the individual experience and the state politics together.

Her approach takes into account several medical anthropological perspectives, such as critical medical anthropology (N. Scheper-Hughes), meaning-centered medical anthropology (Kleinman, Good, Del-Vecchio Good), and a social suffering perspective (Das). Petryna also includes Foucault's theorization on biopolitics, and Rabinow's biosocial framework to ask about the new connections between biology and identity, and how these connections generate an illness-based form of citizenship (2002:14). She argues that suffering transcends individual experience, becoming a central element in the social organization of the victims for accessing state welfare and health care delivery. In the second part of her argument, she pays attention to the ways suffering is socially constructed within a biotechnical space, where science and biotechnologies are appropriated by the different social actors involved in the management of risk, health, and disease. [40] A decisive mechanism for the social construction of "accepted" suffering has been the state policies that target Chernobyl population. As a consequence, Chernobyl's population is stratified according to categories of

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[40] This particular engagement towards biotechnology for the constitution of the "ill-self" is what we see for example in the use of x-rays by tuberculosis patients in order to commit to the social role of being sick. M.J. Del Vecchio Good defines this as the "technological embrace" (2001).

suffering establish by a “scientific” method to rank the victims from 1 – ARS disabled person - to 4 - sufferer (2002: 84).

Petryna also argues that suffering also contributes to the social making of what the state defines at “population at risk” (2002:15). In a perverse way, the state distributes resources according to the categories of suffering, which results in a social system where “being healthy means being left alone by the state, exposed to the market and without social support” (2002:85). Hence, within this model, the risk of the population defined according to a medical categorization that “protects” the ill in such a way that healthy need to become ill – at risk – to be part of the system. This is an important aspect of her argument, because here she questions the established public health’s notion of population based on ethnographic evidence that shows the flexibility and arbitrariness of these parameters.

Finally, she states that the dynamics underneath the process of medicalization of citizenship in Ukraine originated new power structures, new political spaces where Chernobyl citizens fight for their rights of political recognition and integration to the welfare system. She refers to this process as the constitution of a new “Chernobyl self”, where illness acts as counter-politics to current Ukraine neoliberal governmentality. As a consequence, citizens need to learn a biomedical language that defines the good-Chernobyl-citizen, “exploiting” their illness and putting their well being at risk. She defines this kind of participation as “biological citizenship”, which allows subjects to establish a social and political membership that is dependent on the sick role.

In her words “this results in a population that claims injury” in order to be part of Ukraine’ nation-building process.

When describing the political movements based on biocitizenship, she talks about another concept that I found interesting if we related to J. Holston’s notion of insurgent citizenship: the clinical insurgent identity of the active biocitizen that participate in the Chernobyl funds. At the same time, the idea of biological citizenship – like in the Holston’s case – raises the question of the configurations of citizenship under the neoliberal/open market oriented economy paradigm. An illustration of this problem could be the dilemma public health officials have in managing health care delivery when – like in the case of tuberculosis patients – there is no political organization or discourse that links them as a “community of sufferers.”[41]

Are these new forms of citizenship an outcome of the sufferer’s agency or, on the contrary, is this a social form that is functional to this particular governmentality?

4. POLITICS OF TB DIAGNOSIS

As I demonstrated in chapter 3, the experience of tuberculosis among Aymara patients is complex because it implies a reconfiguration of the ways in which individuals deal with an infectious chronic illness associated to social categories of race, class, and gender. The experience of Eva and MM in Bolivia, presented in chapter 3,

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[41] Both, PAHO representative and the director of the TB program in Bolivia refer to this issue as problematic. They mentioned the organizations of HIV-Aids patients as an example of good organization and citizenship towards health care access.

show us the complexities of overcoming a diagnosis and becoming a TB patient. In the case of Eva, developing strong allergies extended her treatment to more than two years, which in a violent way forced her to learn about the treatment and motivated her to help others. Eva's commitment to improving other patients's lives and other "RAFA"[42] patients has also influenced the work of doctor Morales and other TB doctors in Bolivia. Eva is one of the funding figures of Aspacont (Asociación de Pacientes con Tuberculosis), and sees this organization as a window of opportunities for integrating - and "keeping" - TB patients committed to treatment. She said: "For many [patients] TB is a curse (*una maldición*)." In a way, Eva explains, in addition to the painful symptoms of the illness itself, the diagnosis may destroy the infected person, making them afraid of the treatment and uncertain about the future. From the point of view of the providers, the feeling of sadness or bitterness that the diagnosis brings up poses a threat to the possibilities of healing. This is where people like Eva from Aspacont become important. One of the main goals of the organization is to provide information to the recently diagnosed patients, so they can learn about the treatment and that they can heal if they follow the doctor's instructions and engage with the treatment. Sofía, a young female TB doctor working in the prison system in La Paz said to me:

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[42] Patients suffering from Adverse Reactions to Anti-tuberculosis pharmaceuticals (RAFA in Spanish). See chapter 3 for more information.

> When they give you the diagnosis, we all get scared. But…I mean…at the end of the day, like I am telling you, the program [PNCTB] has publicized that this is free, that there won't be any charge, and that it is better that he/she bear…this, that this will help them not to lose their families. I mean, the idea is to get to them through their families: take this, you will be alright. If you don't take it, you will die, you will leave your family alone. Now, for instance, inside the prison we apply the same method: 'if you don't take the treatment, you die…think about your family'…that is how we hold (the patients)…yes, they do get sad, but they know there is a treatment. (Sofía Salas, MD. La Paz)

Medical providers are quick in bringing up family ties and social connections in their strategy to recruit the sufferer and turn him or her into a compliant patient. Thus, most of the TB campaigns aim to create awareness of TB as a problem and adherence to treatment as the solution. In the campaigns the messages emphasize that TB has a cure ("*la tuberculosis se cura*") focus on the collective responsibility of the patients in being aware of the threat of TB and of the medical providers in detecting this illness by performing the required tests *(baciloscopías*) and re-enforcing patient's compliance with the treatment (see figure). By conveying the notion of the anti-tuberculosis fight the campaigns are also promoting a sense of community responsibility towards this illness.

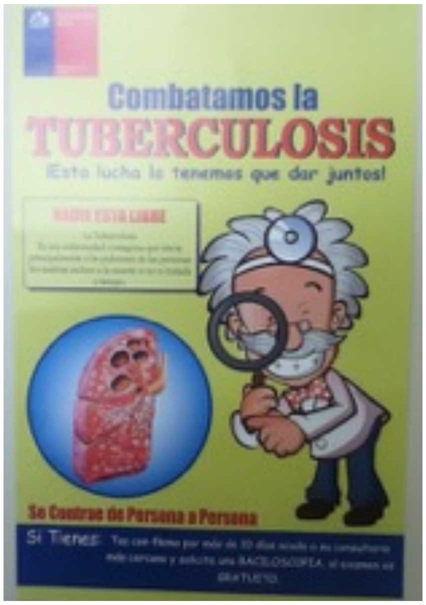

Figure 31. An anti-tuberculosis campaign poster in Chile with the message "let's fight tuberculosis. We have to fight this together, no one is safe." Alto Hospicio, Dec. 2012. Photograph by P. Saravia.

I recall a conversation I had in 2009 with an expert from the Pan-American Health Organization (PAHO) in La Paz. In that opportunity, Dr. Blanco talked to me about the problems of implementing anti-tuberculosis health programs in Bolivia and Chile, and how the differences between these countries facilitated certain strategies. When I asked about the organization of TB patients the conversation took an interesting turn. He said:

> This is my personal opinion, not the PAHO's opinion. But, I think this organization is something artificial, created just to get resources. It is an organization based on the conjuncture [of being ill], with an artificial leadership. The persons [in charge] are cured but they remain in the organization representing the "new sick persons." They were forced to organize.

It is a common practice within the development projects promoted by NGO work and by the state in Latin America to organize groups of interests. In the neoliberal strategies for social and economic development, creating this groups is part of the des-centralization of the state as well as a way to enforce community responsibility over welfare and economic progress. In my work in implementing development programs in rural Chile I witnessed this process. Most of the groups are formed to consolidate productive clusters among small producers, which are officially registered as *"asociaciones productivas."* I agree with Dr. Blanco in that these kind of association may be artificial in nature and that their orientation is mainly economic. However, in the case of illness-related associations I do not quite agree. I have also worked with *asociaciones* of diabetes and obesity patients in urban under-served communities in Santiago. These associations usually begin as part of "self-improvement" strategies within the healthcare centers. It is true that the associations may be promoted by an external agent (medical provider, NGOs, for example) but after a while sharing common experiences and problems, these groups of patients developed a collective identity. Medical anthropologist C. Han also describes a group of mental health patients in La Pincoya (Chile), who were part of a clinical trial. C. Han argues that the group grew from both an ethos of experiment and pre-existing relational modes of self:

> The group was a mixture of affect, identification, allegiances, and interventions. Formerly "an experimental" group in the strict sense (…) the group had become a new test site for the formation of an affective community that employed "depression" as a proxy for multiple conditions that women struggled with in their everyday lives. Depression as an experience was reworked in a way that could articulate the interconnections between domestic troubles, debts, insecurity, unemployment, and scarcity (2012:183)

The case analyzed by C. Han shows the relevance of understanding these associations in context. If these organizations tend to be neoliberal in origin, like in the case of Chile, that does not take away the fact that in contexts of precarity and exclusion taking advantage of a space of biosociality (Rabinow 2008) like this becomes a valuable opportunity for accessing more resources but most importantly for crafting meaning and connecting with others who share the same experience. That said, considering Dr. Blanco's appreciation of the Bolivian association of TB patients, I think that he is missing an pivotal aspect of the political culture that marks a difference between the situation of associations in Bolivia and Chile: the social value of organizing. In Bolivia, beyond the neoliberal decentralization and risk management, we find a multiplicity of symbolic repertoires of mobilizing where discourses, rituals, and collective performances have long influenced social movements and indigenous organizations (movimientos sociales).   While in Chile the Concertación governments focus on low intensity political participation, in Bolivia there was a development of social movements that resulted in the election of Evo and a Constituent Assembly. Hence, looking at Aspacont as an artificial organization with artificial leadership is overlooking the historic grounds of the whole process.

In the following section I will discuss the role of Aspacont as a mediator between the patients and the biomedical framework as well as its goal on creating awareness of tuberculosis at the national level.

4.1. Diagnosis and emerging political categories

Among other things, Eva visits new patients (*"pacientitos"*) at the hospital of thorax to "translate" the diagnosis to a more comprehensible language. Eva said that one of the hardest parts of the illness is when the *pacientito* receives an incomprehensible diagnosis. She also described to me the different categories of "TB patients," and how important it is for the new patients to be involved in the organization. Membership starts, she said, by the moment of diagnosis. When I asked her about more details of the recruitment proces she was very surprised by the question and took a moment to answer: "once diagnosed with TB, one automatically becomes a member of Aspacont. It is *automático* (automatic). Every diagnosed patient is a member, although not all of them are active in the organization" (La Paz February 2013). However, she mentions that because of the characteristics of the treatment, "RAFITAS" are those who participate the most, as it is crucial for them to know about their medications and possibilities of accessing healthcare services. She then explained in detail to me the different categories of patients:

> Sensitive patient or new case. Those are the patients that have received a recent diagnosis. *En ahí* (from there on) new cases, those are pulmonary or extra-pulmonary patients. Then there are the RAFA patients, TB-RAFA, and they are those who could be pulmonary or extra-pulmonary also, those are the patients who develop a reaction to the anti-tuberculosis medicines. Then there are the MDRs patients, TB multidrug resistant. We know them as MDR. And they too are pulmonary and some extra-pulmonary. But for the most part they have to do lots of study to catalog an extra-pulmonary MDR. The TB pediatric patients, the children. I can tell you that there has been RAFA among children too. In La Paz I saw two blind kids. One was 8 years old and the other only ten, with an anti-tuberculosis treatment. The pediatrics is the same, they can be pulmonary or extra-pulmonary.
>
> And the patients with co-infection. En aquí (here) I am forgetting to tell you that there are also the relapsing patients, those previously treated. Before all knew the *pacientitos*. Since 2004 or 2006 we have seen others. Then the RAFAs appeared. These *normales* [regular RAFAs]. Since 1998 there were RAFAs but then the MDRs and RAFAs have entered the cohort. And now since last year, 2011, there have been the XMDRs patients [inaudible] since the 2011-2012 *gestión* (administration) the list is growing, I just hope it does get bigger. Because there is leishmaniasis and tuberculosis [cases] together! We had a case or two already here in La Paz.

In several occasions Eva commented on her own case as a RAFA patient. Over the years she learned about this illness and also about the bacteria or “los bastoncitos” (the little walking sticks) as she calls them. One day she was trying to explain to me why her case was so rare, but I could not get what she was saying, it was something about genetics. So, she decided that it was best to make a drawing (figure 32).

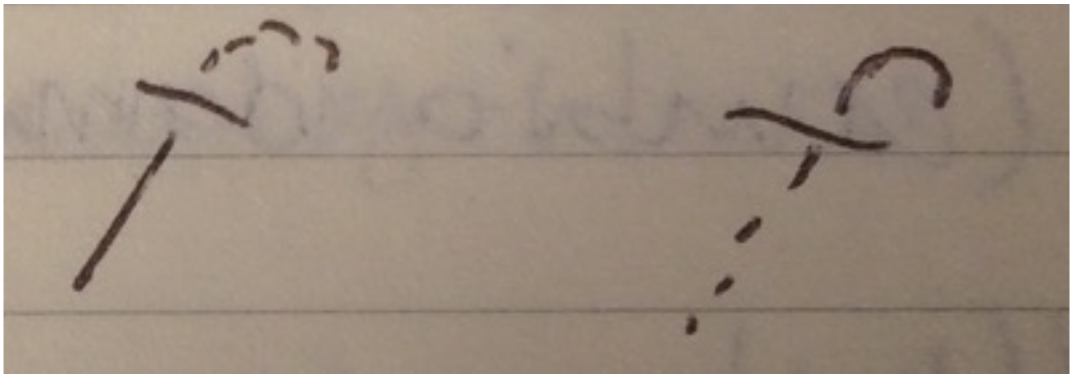

Figure 32. Drawing of the differences between a sensitive tuberculosis strain and a non-sensitive or resistant strain, by E. Limache (Aspacont).

Later that day Dr. Camacho from the bacteriological institute in La Paz explained to me the differences between a dysgonic and a eugonic strain of mycobacterium tuberculosis, which were related to the growth of the culture within a period of time. Whether Eva's description was accurate or not, the fact that it is important to her shows that the diagnosis and treatment of tuberculosis strongly influenced her own identity. This reminded me of T. Mann's "Magic Mountain" and the attachment that sanatoria patient had to the x-rays as a way of configuring their lifeworld as patients/ sufferers. What other biological markers make a difference in experiencing the TB illness and treatment?

4.2 The treatment

I have discussed the subjective dimensions of the anti-tuberculosis medications (chapter 3 of this dissertation). A subsequent discussion is the political dimension of the medications in the context of biological citizenship.

Medical providers in both Bolivia and Chile are concerned about the patient's compliance. At the same time, they are aware of the social conditions of the patients and the place of medications within the larger context of dealing with illness and health. There is much to learn about the use of pharmaceuticals in both countries, particularly in relation to self-medication. Distribution and access to pharmaceuticals are different in Bolivia and Chile. Yet, in both countries anti-tuberculosis medication can be only distributed by public medical centers.

In the opinion of Bolivian medical providers, the current regulation of antibiotics is a problem. According to medical doctors, there are several consequences of the widespread practice of accessing drugs by consulting with the pharmacist or a neighbor, friend to relative. On the contrary, buying antibiotics or psychopharmaceuticals without prescription is not allowed in Chile, although recent increment of online trade of these drugs is challenges these legal norms. The regulation for distribution of medications in Bolivia applies to the private and the public sector of course. Private pharmacies are not authorize to sell anti-tuberculosis medications, although some still do (Lambert et al 2004).

In Bolivia, medical doctors told me that one of the most dangerous consequence, besides creating resistance to these strong antibiotics, is that patients delay their visits to the clinic. As in the rest of Latin America, in Bolivia and Chile individuals are likely to seek care at local pharmacies. Dr. Sofía Salas said:

> P: What about the patient who said "I have been coughing but I have taken antibiotics"…those antibiotics, who gives those to the patient? A medical doctor?
>
> SS: Here most [of the people] self-medicate. They go to the pharmacy and say "you know, I have cough for two days"… "ah ok, amoxicillin 1gr". For example, we had *aymarista* [Aymara] person in Obrajes: "yes, so I will check on you"… "no, amoxicillin 1gr, amoxicillin 1gr"[the Aymara person said] a lady with *pollera*! From the countryside, who doesn't even know much Spanish, that she would know about amoxicillin is…ahh [angry] what have they done to her? They self-medicate, same for their children: cotrimoxazole, cotrimoxazole!"

Virginia Plaza, a medical provider and a patient in Coroico, corroborates the medical doctors's observations on self-medication:

> Yes. I was coughing. I didn't realize…I …for instance, in Tarija I coughed but I injected myself terbocyl and I was ok. But here [in Coroico] that didn't happen (to me) and I continued…they injected me but it didn't work. But I didn't realize, it never crossed my mind that it could be tuberculosis (V. Plaza, Coroico 2011)

From the point of view of the medical doctors, the patient should be a "good citizen" (buen ciudadano) by attending the medical center and completing the prescribed treatment. It was very interesting for me to hear about citizenship in Chile, where the systems operates without strong citizenship participation. However, in the medical field, citizenship is important. In chapter 1 of the dissertation I discussed the categories of *"extranjero chilenizado"* (Chileanized foreigner) and *extranjero* (foreigner). In addition to this, the categories of "Aymara natural" and "Aymara urbanizado" help to understand the mechanism that allows an excluded indigenous (Aymara natural) cross over to the included (more tolerated) and compliant urban indigenous. As noted by a medical provider in Iquique:

> It is hard to control the natural aymaras in the rural areas, but also in the cities. When they are in their campos they don't follow the treatment, they feel ok and they discharge themselves…when they come to the cities they live in places that are unhealthy. The aymaras urbanizados know that they need to come to the healthcare centers, they still have their herbs and medicines, but they know about us.

Eva explained how these medical categories connected to particular ways of participating in the organization in Bolivia. Membership in this kind of associations depends on the patient's capacities of participating. First, in Aspacont, member volunteer to do the work of connecting new patients with the organization and providing counsel and support, especially during the first months of the treatment. Second, the organization helps PNCTB to coordinate activities at the local level (information sessions, presentations, distribution of materials, etc.). Eva also made a drawing to explain to me the structure of the association as compared to PNCTB (figure 33). She said that during the last administration (*gestión*) they were working on getting more funding from the global TB fund (Stop TB program). The national program (PNCTB) endorses the association, and every time we met Eva was proudly wearing a blue jacket with Aspacont written in the back.

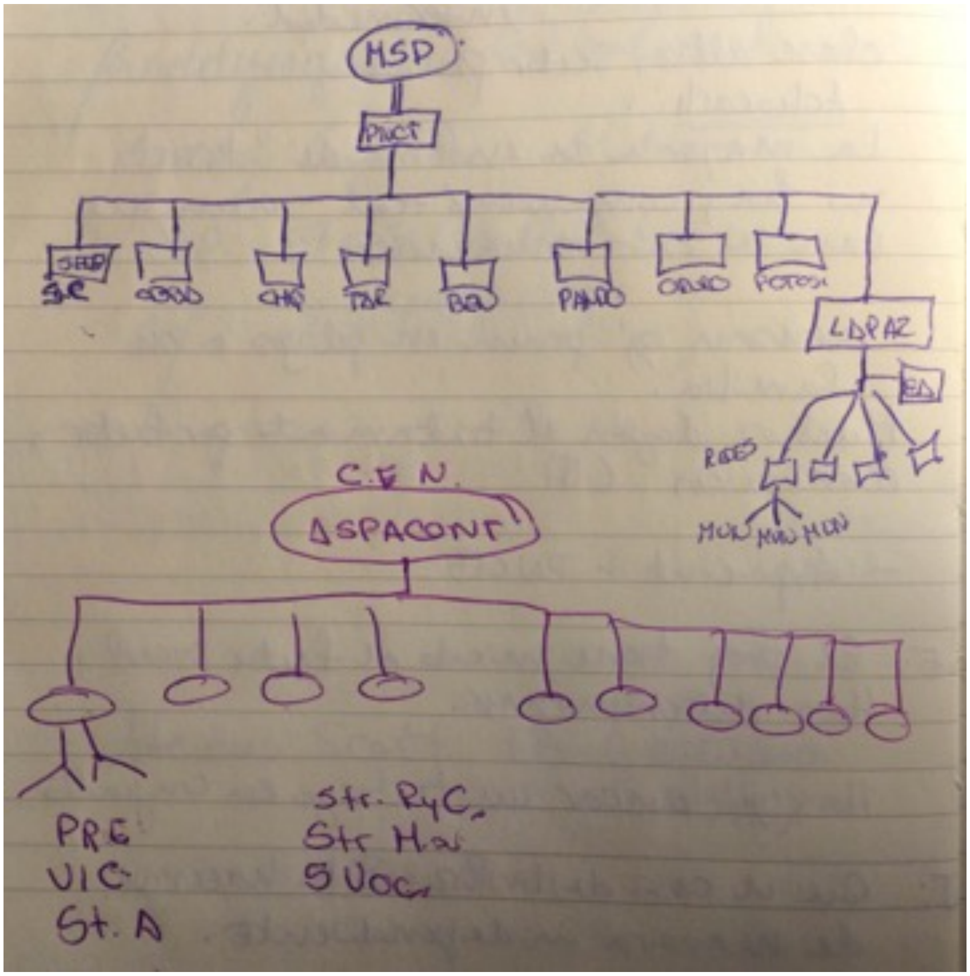

Figure 33 . Drawing of the structure of Aspacont as compared with the PNCTB in Bolivia. By E. Limache (La Paz 2013)

Another important milestone for Aspacont was when patients participated in a study that compiled the testimonies of "real" patients in a DVD (Rivera et al 2008). According to Eva, these initiatives are helpful in showing the experience of the "invisible" TB-RAFA patients to the rest of the society, "we can make people understand that it is not only about not taking the pills…we suffer from the treatment as well."

4.3. Engaging human pharmakons?

A patient who is diagnosed needs to start taking the pills promptly, which means that the compliant patient – already stigmatized and socially excluded – starts to live a pharmaceutically mediated exclusion from the world. Medical anthropologist J. Bielh defines this excluded subject as a "human pharmakon" (2010). In his research on psycho-pharmaceuticals in Brazil, Bielh shows how a pharmacological therapy is the crystallization of deep mechanisms of exclusion that push the sufferer to the margins of the "normal healthy world." I find the concept of human pharmakon an important contribution for deepening our knowledge about the liminal subjective position of the medicalized sufferer and her or his inclusion via pharmaceutical drugs. The sufferer/patient enters a a liminal position between the included, entitled political member/citizen of society and the bare life/excluded subjects as those described by Agamben (1998) and Butler (2009). At the same time, from the point of view of the state, a non-compliant patient is viewed as irresponsible and guilty for putting society at risk. One way or another they feel excluded, so their only possibility is choosing an exclusion that they can administer. The patient's "non-compliance" with DOTs does not mean that there is rejection of pharmaceuticals. On the contrary, in both Bolivia and Chile, self-medication is an extended medical practice. What is the way out for Aymara tuberculosis patients?

Their engagement or non-engagement with antituberculosis drugs is part of a larger "idiom" of suffering embedded in Bolivia, where pharmaceuticals are just one of the potential means of healing. The meanings of antituberculosis medications transcends the mere TB diagnosis because by taking the medications the patients are intervening in their bodies in very painful ways. Aymara patients find themselves struggling with precarious conditions of existence "living" in a weak body.

On the one hand, following the treatment results in the possibility of healing, as well as being "acknowledged" as a good medicalized citizen. On the other hand, becoming a TB patients renders visible their health condition and opens the possibility of stigma, which excludes them from meaningful social spaces such as religious festivities, community leadership in the cargo system, etc. Medicalization results in potential biological citizenship while non-engagement may provoke isolation and the impossibility of *compartir* with their families and communities.

In Chile, where compliance with TB treatment is higher than Bolivia, there are other conditions for political participation. Recently,patients and families formed an association for demanding the universal access of pharmaceutical drugs for cancer treatment and other illnesses that require long-term intake of expensive medications (not covered by the public system). Ricarte Soto, an influential journalist working on the national television who suffered from cancer, led a massive campaign that finally (and only in 2014 after his death) resulted in a presidential decree to guarantee access to these expensive medications ("ley Ricarte Soto").

I argue that in the process of engaging in such a long and harsh therapeutic process, the sufferers/patients learn about their vulnerabilities and strengths, and cope with their illness accordingly. In Bolivia, where the political organization is a legitimate political practice for negotiating with the state, tuberculosis patients undergo a process of becoming potential human pharmakons who are aware of the social consequences of the social stigma of TB. On the other hand, non-engagement translates into a rupture with the state, which implies blame or shame for putting his or her community at risk.

4.4. Illness and citizenship: A double bind?

The different categories of TB patients resemble what happens in other contexts with people suffering from other illnesses, such as aforementioned cases of leprosy patients in Brazil (White 2009) or Chernobyl victims in Ukraine (Petryna 2002). In those cases, besides initial ideas of illness being a "curse", with time it becomes a mechanism for political inclusion and risk management in contexts where individuals may have “limited” political involvement, or “full” exercise of rights. I am inspired by by G. Bateson’s the elaboration of the concept of the double-bind (1972) in the context of schizophrenia and J. Cattelino (2010), who looks at the dilemmas of collective governance and economic power posed as a double-bind among the Seminole tribe in Florida. I am extending this concept to illness and citizenship to understand the experience of concomitant mechanisms of political inclusion (medicalization) and exclusion (isolation and stigma) that set the grounds for a form of citizenship that is “biologically” based. In her work, A. Petryna also 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 legitimizes structures of social inequalities that are consequences of both the radioactive accident and of the economic transformation (and crisis) in Ukraine. Extending her argument to the case of TB sufferers/patients in Bolivia and Chile, 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 on indigenous bodies through medical institutions, which turn to be the link to the political arena.

These concepts are connected to medicalization, and, as I argue, are also linked to 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 during its neoliberal period, 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 of 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 in time. Indeed, these conditions turns out to be an illness in 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 offer integration through medicalization, but rather exclusion through pathologizing the unhygienic other, the "unhygienic Indian". The "unhygienic indians", however, developed their own strategies and framing of TB, to think about this terrible illness.

5. CONCLUSIONS

In this chapter I have argued that medicine and medical institutions articulate and reproduce modern forms of citizenship in Bolivia and Chile. This particular articulation has been evident since the early republics, as they tried to legitimize political orders and structures of domination based on racial distinctions, which heavily relied on modern notions of hygiene. Thus, the incorporation of modern hygiene's tenets contributed to the crystallization of social constructions of race that shaped the distribution of rights and obligations according to racial difference. However, I showed that current anthropological work is contesting this traditional view on citizenship, which is anchored in the state as the grantor of rights and entitlements. Rather, I suggest the importance of looking at culture, religion, and indigenous rights as elements that tension state power. The work of Holston, Hale, and Postero are particularly relevant for comprehending political transformations in neoliberal Chile and "postmulticultural" Bolivia. In addition, the discussion of new forms of citizenship within neoliberal and transnational frameworks (flexible citizenship) shows that there is an intricate relationship of race, modernity, and a scientifically and medically based form of citizenship: biocitizenship. By considering theoretical and ethnographic works in Latin America (Briggs and Mantini-Briggs 2003) as well as in Europe (Ticktin 2006, Petryna 2002, Rose 2001), I have concluded that biopolitics and biopower are not "recent" forms of power. On the contrary, as stated by Foucault, biopolitics has nurtured with meaning modern states' political projects and structures. From my perspective, biopolitical frameworks have also given meaning to current neoliberal governmentalities that orient a biologically-based relationship between the subject and the state.

CONCLUSIONS

This comparative qualitative multi-sited study examined the experience of tuberculosis among the Aymara on the border between Bolivia and Chile and the links between the illness experience of tuberculosis and the two biopolitical frameworks that are implemented by both states. In this dissertation I show the intricate ways in which Aymara people across national borders deal with issues of health and illness; and the Aymara illness semantic network in connection to institutional biomedical practices and the Aymara medical system.

I analyzed current state framings of tuberculosis and the big difference between the prevalence of TB in these two countries by looking at the national anti-tuberculosis programs and the sociocultural and political mechanisms that shape the everyday life of indigenous peoples in each country. I found that on each side of the border, the Aymara struggle with issues of precarity in particular ways. In Chile, where they face economic instability and political exclusion, they are highly medicalized. As the non-indigenous Chilean population, they are subjects of state biodiscipline and follow the treatments inscribed in both the biomedical and Aymara indigenous medical systems. In Bolivia, where the state is going through a "postneoliberal" moment (Postero 2013, 2007), there are structural constraints that prevent the medical providers from fully delivering healthcare to Aymara communities. At the same time, the Aymara resist the state medical intervention by adapting the anti-tuberculosis treatment to their own ways of life (having a day of *descanso*, for example).

A second important conclusion from this research is that despite the conspicuous differences in integrating the Aymara indigenous medicine into the state healthcare system, in both countries there is a multicultural framework inspired by neoliberal policies that promotes indigenous medical practices as a symbolic acknowledgement of ethnic difference without fully integrating said medical systems into the state structure that controls policy-making. Both countries supposedly base their interventions on the Andean principle of *suma qamaña* (to live well). The significance of this principle, however, is different in both countries: while in Bolivia it is part of the new constitution, in Chile it is limited to the intercultural healthcare programs promoted in the "Aymara" regions of Parinacota and Tarapacá. Nevertheless, even in Bolivia, where there is a Vice Ministry of Intercultural and Traditional Medicine, indigenous healers are not included in decision-making processes. Furthermore, as I discussed in chapter 2, vice minister A. Camaqui, who is an Aymara healer himself, has maintained a fairly neutral approach instead of a more critical position to interculturality. In this sense, his intercultural program is similar to the one that is implemented in Chile. R. Bautista (2010) and B. Johnson (2013, 2010) referred to these intercultural interventions as shortcomings to the decolonization agenda in Bolivia. In their view, the fact that these programs are not aiming at more profound changes of the content of medical practices show some of the limitations of Morales' "*proceso de cambio*."

Hence, while in both countries we observe multiple efforts for integrating indigenous medicines as a way to improve healthcare access to indigenous communities, the structure and the organization of medical practices promoted by allopathic medicine (or biomedicine) limit the possibilities medical providers have to integrate the necessary changes for delivering intercultural healthcare.

Thirdly, this dissertation also demonstrates the difficulties that the anti-tuberculosis treatment itself presents to the patients, whose engagement with DOTs is precarious. It is precarious not only because the material conditions for engaging with the treatment are scarce, but also because tuberculosis presents challenges to the social life of the Aymara patients. When suffering tuberculosis, the Aymara patients feel physical discomfort and pain (continuos cough, fever, loss of appetite, loss weight, and weakness) and lläqui (deep sadness/bitterness) that they interpret as a rupture with their social world. Instead, the Western perspective on tuberculosis sees these experiences as symptoms that the treatment will remedy. Hence, while the anti-tuberculosis treatment promoted by the biomedical system threatens the possibilities of participating in the life of the community (*compartir*), the Aymara medical practices restore the community relations. Thus, alongside precarious engagements we find contested compliances. This is particularly true in Bolivia, where Aymara TB patients/sufferers who follow the medication intake tend to negotiate their own terms. Previous studies on "non-adherence" or "non-compliance" among Aymara indigenous peoples have failed to account for the *agentic* dimension of the illness experience. Contrary to those studies, this re search considers both subjective meaning-making processes and structural conditions that influence illness outcomes. The dissertation is about the nuanced strategies that Aymara TB sufferers develop to deal with tuberculosis in their own terms, and abandonment of tuberculosis treatment is only a small part of that.

In the dissertation I have shown how Aymara patients contest the treatment by integrating the indigenous categories of suma qamaña to the everyday struggles for achieving prosperity and health for themselves and their families. The Aymaras refer to this as *"salir adelante"* (to come through). My analysis of tuberculosis among the Aymara demonstrates the political dimension of the medicalization process and its relevance in understanding the embodiment of structural inequalities that transcend national borders.

Lastly, in this research I examined the particular associations that the Aymara make between the individual illness experience, emotional well-being, and indigenous identity. I discussed the Aymara illness semantic network, where tuberculosis is connected to an embodied conception of space and time. For the Aymara, Tuberculosis is thus a symptom of a deeper disconnect between the self and the environment that needs to be repaired and healed. This is a comparative ethnographic account of the subjective experience of this illness across the border, and the ways in which illness constitutes a transformation of the self, which is mediated by medications intake.

My work contributes to the literatures on the subjective experience of illness and biopolitics by discussing the problem of tuberculosis and race from three different theoretical anthropological fields of study: political, medical, and psychological anthropology. My research connects contemporary illness experience among the Aymara with historically grounded political processes such as the consolidation of public health apparatuses in Bolivia and Chile. In this sense, I consider medical encounters as spaces of convergence between the state and the indigenous sufferers/patients/citizens, where the medical providers reproduce state projects that convey national identities and racial categories. Hence, my research also contributes to current debates on racialization processes and emerging forms of citizenship in Bolivia and Chile. This dissertation also contributes to the debate on interculturality and the possibilities and limitations of the intercultural health approach. Current policy making could benefit from the ethnographic evidence presented in the dissertation and the questions that emerge from the analysis.

While conducting this long-term project I learned about the importance of language - particularly language ideologies - in understanding subjective processes and notions of the self in indigenous and non-indigenous contexts. Indeed, I consider that not being fluent in the Aymara language was a limitation for this research. Knowing more Aymara would be beneficial, even for my work with Aymara who are Spanish monolingual.

A second limitation was the impossibility to know more about the experience of the Aymara in Peru. I visited Lima, Cuzco, and Tacna, but I could not learn in depth about the framings of tuberculosis there, or the Aymara medical practices in Peru.

Finally, my own nationality limited the initial rapport with indigenous and non-indigenous people in Bolivia. It took a long time to gain people's trust and show them that I was not an evil Chilean spy. What made things even more difficult for me in the field was that I was a student of an American university. These two aspects of my background added layers of distrust. Bearing in mind the multi-sited research strategy, this was a crucial limitation.

This research opens potential veins of study, which I will develop as part of my post-doctoral work in Chile. My postdoctoral research will expand my current research on the experience of tuberculosis (TB) among the Aymara in both countries by studying the organic relationship between precarity, forms of racism, and difficulties in accessing and delivering health care in transnational indigenous contexts. My research questions are: Do Aymara living in Bolivia and Chile experience illness differently? If so, what are the institutional mechanisms that condition these different illness experiences among the Aymara? What are the discourses and medical practices in each country that sustain such structures? I propose to answer these questions by conducting a multi-sited ethnography of medical encounters in urban and rural indigenous contexts in the regions of Oruro-La Paz (Bolivia) and Arica-Parinacota/Santiago (Chile).

It is important to conduct more research about the subjective experience of infectious diseases and its implications for social change. Applied medical anthropologists have advanced in developing strategies for improving healthcare access and helping patient to continue their treatment. However, these studies tend to maintain a body/mind dualism, which leads them to overlook the embodied experiences of illness and the connection between the experience of infectious diseases and deeper psychological processes.

This dissertation opens up new anthropological discussions on how study the experience of illness and the embodiment of race and inequality among transborder communities. Further research on these topics could help to understand more about the meanings of illness and the experience of being human.

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