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Disease Prevalence and Politics- A Study of Chagas Disease in Bolivia

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Cover Page Footnote

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Abstract

Reducing disease prevalence within South America is critical for reaching global health goals and increasing life expectancy of vulnerable populations. Chagas disease, often referred to as the "the New HIV/AIDS of the Americas," is a prevalent cause of disability and death within Bolivia (Hotez et al. 1). The Plurinational State of Bolivia, a large South American nation-state, is a crucial player in promoting global health outcomes. However, intra-state political turmoil and historical tensions often affect its healthcare systems, which in turn affect individual health outcomes. This paper traces these connections within the Bolivian healthcare system—first by identifying political and cultural factors within Bolivia which contribute to the lack of access to healthcare among indigenous citizens, then by understanding factors of Chagas disease which disproportionally affect indigenous citizens, and finally, applying these factors to a proposed solution which includes actions by domestic and international bodies.

Keywords: Chagas Disease, Human Rights, Indigenous Rights, Social Determinates of Heath, Bolivia

Disease Prevalence and Politics: A Study of Chagas Disease in Bolivia

The increased prevalence of disease within communities leads to negative impacts for individuals, countries, and the international community. Negative symptoms of diseases in an individual may lead to negative impacts at a larger scale – while individuals may struggle to survive while dealing with chronic disease, large numbers of individuals struggling with a disease may have great impacts on a national economic ecosystem. Furthermore, increased mortality and disease prevalence may have a large impact on the sustainability of a local community. The ability of an individual to maintain a healthful standard of living is crucial to ensuring fair representation in government, strong community and familial bonds, and an individual's own wellbeing. As a human right, healthcare and the prevention of disease stand at the forefront of the fight for wellbeing. However, historically disenfranchised individuals oftentimes face social barriers to entry into a healthcare system that focuses on serving the majority. Such is the case with indigenous individuals within the Plurinational State of Bolivia. Despite attempts to create a universal healthcare system designed to serve all individuals within Bolivia, the healthcare system created in 2013 by *La Ley de Prestaciones Servicios de Salud Integral* (The Law of Integral Health Services) fails to serve all individuals as required by the Bolivian Constitution – particularly, the historically disenfranchised indigenous population. One such case is seen in Chagas disease, or "the New HIV/AIDS of the Americas" (Hotez et al. 1). While Chagas disease is preventable, Bolivia's indigenous population oftentimes lacks the resources to prevent Chagas and may not be able to afford treatments or related costs in accessing treatment after diagnosis.

The nation-state of Bolivia was founded in 1825, after it was freed from Spanish colonization (CIA World Factbook). Conditions under colonization were harsh. According to

María Eugenia Choque-Quispe and Marcia Stephenson, “The conquerors, obsessed with gold and silver, raped, kidnapped, and defiled, bringing dishonor to [indigenous Bolivian] women” (12). Violent acts such as these were done in order to establish a power dynamic between the colonized (indigenous populations) and colonizer (Spaniards).

While power dynamics exist between Bolivians of indigenous origins and those of Spanish origin, with people of Spanish origin holding a higher social status than those of indigenous origin, there was a further power dynamic in regards to gender identity and perception. Choque-Quispe and Stephenson claim that indigenous men were often forced into marriages with Spanish women, who would then force them to take on her name; thus “the indigenous male was [made] subordinate to the Spanish female” (13). This memory of persecution over their culture frames the indigenous perspective of their struggles today (Canessa 202). According to Felipe Arocena, the aftereffects of colonialism in Bolivia led to indigenous individuals being “segregated and marginalized, sometimes used as forced labour (sic), sometimes kept apart in pseudo-evangelized ‘Pueblos de indios’… national identity did not include indigenous populations nor their rights” (pp. 11-12).

Unequal power dynamics between men and women within indigenous communities in relation to gender roles continue as well and are perceived to be a direct result of colonization efforts by some indigenous individuals. According to Anders Burman, indigenous women who are activists who attempt to speak about their concerns in community meetings are often faced with disapproval, not because of their perceived abilities or lack thereof; rather, disapproval arises because of “male dominance, which [indigenous individuals], in turn, almost unanimously relate to [Spanish] colonialism” (73). These power dynamics, between men and women and between indigenous and non-indigenous individuals, continue today, which have seriously impacted their experiences within the healthcare field.

The experience of individuals with Chagas disease depends on their societal social standing, economic means, and individual identity. Those with better financial means oftentimes do not consider Chagas disease a threat to their wellbeing. According to Ventura-Garcia et al., “Socially and economically favored groups [such as individuals who identify as male and/or individuals who are not indigenous] do not often consider the possibility of infection [of Chagas disease as a threat]” (5). However, indigenous individuals often see Chagas disease as a threat to economic sustainability and living, as medical issues caused by Chagas disease often limit a person’s economic solvency, their economic future, and affect their ability to live their daily life. Because of these issues and cultural norms surrounding disease, “disease causation [is] explained in personalistic terms, or as violation of taboos or social norms” (Ventura-Garcia et al. 4), which makes discussion between indigenous individuals and medical personnel much more difficult. While the perception of Chagas disease by medical professionals is largely influenced by their experiences with the disease, the perception of Chagas disease by indigenous individuals is largely dependent on the history and perception of the disease by their local community (Ventura-Garcia et al. 4). Due to this, any policy created to solve Chagas disease must account for country, departmental, regional, and local differences in understanding, and medical professionals must understand their local communities and the preconceptions (and perhaps, misconceptions) their patients have of the disease.

According to some, the legal and social status of indigenous individuals noticeably improved with the 2005 election of Bolivia’s first indigenous president, Evo Morales. According to author Felipe Arocena, Morales established himself as a “defender of the peasants who live growing coca leaves," standing up for them against the United States (which has been accused of imperialism due to its policies during the "War on Drugs" that deeply affected the Bolivian coca industry) within his 2005 campaign (13). While President Morales continues to aim to increase rights for those who are historically disenfranchised, issues around healthcare and welfare for indigenous Bolivians persist and largely remain unaddressed.

Morales has also declared water security a human right promised by the Bolivian constitution, as water insecurity within Bolivia is prevalent (Water Security in Bolivia's Constitutional Reform). As Bolivia is a presidential republic, the President holds much power in guiding public policy, including reforms. However, tensions continue within Bolivian politics, particularly between the ruling MAS party and other, less dominant parties. In order to gather public support for reform, President Morales and the MAS party often spend much of their time working to centralize the party, which has led to political contention, particularly surrounding reforms within healthcare (Kohl & Brensnhan 11). These healthcare reforms have specifically focused on integrating indigenous medicine alongside Western medical practices, as indigenous cultural traditions have been historically neglected due to colonialism (Kohl & Brensnhan 15).

While healthcare in Bolivia has improved dramatically in the last few decades, the prevalence of disease continues to be a pressing concern of the Bolivian government, international organizations, and Bolivians alike. In fact, healthcare and wellbeing are seen as human rights among Bolivians, as result of the Morales administration's stance towards healthcare. Ideally, in accordance with the 2013 Bolivian law establishing the Bolivian healthcare system, healthcare should be provided to individuals within select groups, such as individuals over the age of 60, children under the age of five, and women of reproductive age. Despite programs such as *El Seguro Universal Materno Infantil* [SUMI], which covers maternity and infant care, and *El Seguro Salud Para el Adulto Mayor* [SSPAM], which covers care for individuals over age 60, significant gaps exist for those who are not within those two categories. This law and these programs do not meet the requirements of the Bolivian constitution, which states that access to healthcare for all citizens is a human right that shall be provided to all Bolivians. Another issue with the law is found within domestic political conflict. There has been significant political tension regarding the integration of traditional, indigenous medicine into the current healthcare system. According to Kohl and Brensnhan, “The Vice Ministry (of Bolivia) is intent not only on creating a national system of traditional medicine but also on ensuring that it has the same status as Western (bio-) medicine” with the goal of decolonization (15). In addition, it does not address international agreements, such as those found within the United Nations 2030 Sustainable Development Goals, which state that each nation pledges to “achieve universal health coverage and access to quality health care” by 2030 (Transforming Our World 11).

Beyond the inability for Bolivians to receive universal healthcare in accordance with the Bolivian constitution and the United Nations 2030 Sustainable Development Goals, there is an inequality between access to healthcare for indigenous individuals and non-indigenous individuals. According to the United States of America’s Congressional Research Service, “[maternal and neonatal medical care] are much worse in indigenous and rural communities, due to a continued lack of access to sanitation and health services” (Ribando Seelke 5). While some departments, such as the department of Tarija, implement department-run, universal healthcare plans, not all Bolivians are covered, only residents within that department (Child Family Health International). While governments, such as that of United States of America, have in the past given significant aid to Bolivia for the purposes of reducing the rates of infectious diseases, the acceptance of this aid has been reduced dramatically, likely due to President Morales' political goal of decolonization (Ribando Seelke 11).

Other issues in the Bolivian healthcare system, such as a lack of adequate salary, high turnover among employees, and a lack of basic medical care led to a reduced capacity to treat patients with medical issues within Bolivia's healthcare system. According to the Special Program for Research and Training in Tropical Diseases of the World Health Organization, "The current salary system does not provide performance incentives or incentives to work in underserved areas" (4). Understandably, because there is a lack of incentives to work in underserved areas, rural areas often have a lower ability to access medical care. This lack of access is exacerbated by the shifting medical system in Bolivia, one where most of the resources allocated by the Bolivian government towards medical care have gone towards tertiary healthcare and not towards primary care. This reduces the services available to those who need preventative care, especially in rural areas (Special Program for Research and Training in Tropical Diseases 4). These issues all contribute to the inequitable distribution of medical staff, therefore causing a lack of medical care in the rural areas. As many indigenous individuals reside in rural communities, they oftentimes lack access to Western medicine. Because of this, many indigenous individuals rely on traditional medicine, oftentimes found outside of the state-run medical system, as access to medical clinics and hospitals may be limited or perceived by some as not as useful. Such is the case in treating Chagas disease in Bolivia.

Chagas disease is one of the most prevalent and dangerous diseases in Bolivia. According to a study within the Public Library of Science, "With approximately 10 million people living with Chagas disease, this condition is one of the most common NTDs [Neglected Tropical Diseases] affecting the bottom 100 million in the region, a prevalence exceeded only by hookworm and other soil-transmitted helminth infections" (Hotez et al. 1). Chagas can transfer through birth, blood, organ transplantation, or uncooked food with feces from infected bugs (Center for Disease Control). Within the context of Bolivia, these methods of transmission make the disease extremely difficult to control. Since many Bolivians do not have the finances to afford insect nets or other preventative bug treatments, poor, rural and indigenous populations in particular may not be able to afford bug nets, so are often infected at higher rates. According to the Pan American Health Organization, "living in poorly constructed housing – particularly in rural and suburban areas – having limited resources, residing in areas of poverty that are socially or economically unstable or have high rates of migration, and belonging to groups linked to seasonal farm work and crop harvests are among the main risk factors for the disease" (Pan American Health Organization). Because of these risk factors, it makes sense that those who are poor or live in rural areas are more likely to be susceptible to the disease, and are less likely to be able to seek even primary medical treatment in their areas of residence. Additionally, as the distribution of the ability to receive state-subsidized healthcare is uneven, those who do not receive healthcare under the 2013 healthcare law are unlikely to have access to expensive medication, transportation for treatment, or preventative measures for Chagas disease.

Chronic Chagas disease is extremely dangerous. Even in its acute phase, organ damage is common, including damage to the "the heart, gastrointestinal tract…, and central nervous system" (Marin-Neto et al. 1). In its chronic forms, Chagas can cause Chagasic cardiomyopathy, which can induce "cardiac arrhythmias, heart failure, and risk of sudden death from ventricular fibrillation or tachycardia or thromboembolic events" (Hotez et al. 1). While the global yearly deaths currently attributed to Chagas total 12,500, this is likely an underestimation, as not all who die from Chagas disease, nor all those who die from complications, will be properly identified as victims upon their death (Doctors Without Borders Access Campaign 2013). Furthermore, Chagas is incurable – the disease is in the bloodstream for life, and future damage to the immune system can cause more intense symptoms (CDC). Despite this, many do not receive treatment for the disease, as it is inordinately expensive. According to Hotez et al., "the expected cost of treatment per patient year is $1,028 (USD), with lifetime costs averaging $11,619 (USD) per patient" (1). As the Gross National Income per person was $6,714 United States Dollars (Human Development Report, United Nations Development Program), it becomes economically unfeasible for most individuals without health coverage provided by the government to receive treatment while maintaining the needs of themselves and/or a family. While prevention is the most useful way to fight the disease, many Bolivians do not have the ability to afford such measures, including sleeping under a bug net covered in insecticide, and/or using insecticides or insect repellents within the place or residence. This puts Bolivians in a dilemma – poor Bolivians cannot afford expensive medications that treat Chagas disease, but cannot afford the preventative measures either. In addition, indigenous Bolivians also face significantly increased risk simply because of the "diversity of languages spoken by ethnic groups in addition to the conditions of extreme poverty in which they live" (International Federation of Pharmaceutical Manufacturers & Associations para. 3). This may make it difficult to receive medical advice within their native language and medical advice which is feasible to apply to their lives. Because up to 30-40% of indigenous children under 15 in rural areas are infected with the disease and may not receive proper treatment (Special Program for Research and Training in Tropical Diseases para. 3), many children may face medical barriers to attending school, which would improve their economic future, leading to reoccurring poverty.

Because of the many reasons indigenous individuals may not have access or trust in the Bolivian medical system, some indigenous individuals use a technique called *tranquilidad* (or a practice of remaining calm) in order to prevent serious complications of the disease. According to a study by anthropological researcher Collin Forsyth, 10 out of 20 individuals with Chagas disease interviewed stated that they used *tranquilidad* to deal with their diagnosis and subsequent symptoms (3). Participants described “the need to be calm (*tranquilo*) not only for one’s emotional wellbeing, but to lessen the effects of CD” (3).While many Bolivians understand that medical care would help with their disease, medical care is inaccessible; in order to deal with their diagnosis and its symptoms, this system of self-management can lead to an acceptance of the disease by patients (Forsyth 9). With less than 1% of individuals diagnosed having formalized, biomedical treatment, many use other techniques in order to create a sense of control and acceptance of the disease (Forsyth 7). Despite a universal medical system, access to medical care is still limited in Tarija for citizens who live in rural areas of the department. For other Bolivians outside of the universal medical system found in Tarija, medical care may be virtually unaffordable or inaccessible.

When understanding the prevalence of Chagas disease within Bolivia, it is first important to understand the barriers to treatment – namely, the lack of availability of healthcare workers, the lack of multilingual healthcare workers, and the lack of affordability of medical treatment. These barriers often prevent Bolivians, especially those of indigenous, poor, or rural backgrounds, from receiving much needed medical treatment. These social determinants of health must first be addressed before Chagas disease is eliminated in Bolivia. In order to combat Chagas disease, the nation-state of Bolivia must make medical care more affordable and accessible to all individuals, not just those residing in the city or those who fall into the bounds of the current Bolivian healthcare law.

While the factors preventing indigenous, poor, and rural Bolivians from receiving adequate healthcare may appear to be a lack of governmental control in the healthcare system, the roots of the issue reach back much further – to the disenfranchisement of indigenous individuals due to colonialism and its aftereffects. While the election of President Morales in 2005 and the reformatting of the Bolivian constitution may have been a step towards proper healthcare, as evidenced by decreased disease levels overall within the Bolivian Healthcare System, it can be seen that indigenous, rural and poor Bolivians continue to face significant barriers to accessing healthcare in the case of Chagas disease (Institute for Health Metrics and Evaluation). Any work to prevent Chagas disease and treat existing cases within indigenous communities should be done in a culturally appropriate context, focusing on identifying local medical staff who are likely to know how to approach members of their own communities in treating the disease in a local-specific context. According to Ventura Garcia et al., “People are not merely recipients of information and, although social groups handle Chagas-related knowledge and meanings based on their sociocultural worldviews, … [categorization of individuals are not] closed and pure” (5). As each individual’s understanding of Chagas disease is different, and highly influenced by their background, international and domestic aid towards prevention and treatment of Chagas disease would be best used in contexts where local staff may maintain control and where supplies are allocated as requested by those staff.

In order to best solve the Chagas crisis, the international community should band together with permission from domestic governmental bodies to provide international aid in the ways it is allowed and encouraged by local medical staff, targeting issues identified in localized contexts.

As the indigenous population of Bolivia makes up a large proportion of the population, independent, extra-state actors must practice an understanding of the history of colonization, as well as be willing to work with, instead of against, the ruling MAS party's agenda (Bernstein 232). As Chagas disease continues to rise, it is the responsibility of nation-states to band together in order to provide the most medically effective healthcare for all global citizens. As Chagas disease is understood by local communities differently than other communities, and doctors (while facing some barriers) are more likely than interstate or intrastate actors to understand the complexities and unique needs of each patient, Chagas disease would best be treated by empowering local staff over temporary staff from international organizations, interstate or intrastate actors, and temporary relief workers. International discussions and agreements, such as the 2030 U.N. Sustainable Development Goals, emphasize the reduction of disease on a global scale, as well as an increase in access to critical healthcare for all individuals. In order to best meet both domestic and international goals for the treatment of disease, as well as provide healthcare to all citizens including those who are disenfranchised such as the indigenous population within Bolivia, local medical staff must be allowed to act to treat patients in localized contexts, using supplies given by others.

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