Cultural Transmission and the Disease Ecology of Tuberculosis in Indigenous Communities of the Paraguayan Chaco

by

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A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved November 2014 by the
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ARIZONA STATE UNIVERSITY

December 2014

ABSTRACT

The health situation of indigenous peoples is comparable to that of the world's poorest populations, but with the additional burdens of social and cultural marginalization, geographic and cultural barriers to accessing health services, and, in some areas, appropriation of land and natural resources. Cultural transmission (the transfer of beliefs, ideas, and behaviors from one culture to another) from outsider health institutions should presumably aid in closing this health gap by transferring knowledge, practices, and infrastructure to prevent and treat disease. This study examines the biosocial construction of the disease ecology of tuberculosis (TB) in indigenous communities of the Paraguayan Chaco with varying degrees of cultural transmission from outside institutions (government, religious, and NGOs), to determine the influence of cultural transmission on local disease ecologies. Using a biocultural epidemiological framework for the analysis of human infectious disease ecology, this study employed an interdisciplinary, mixed methods approach to examine the interactions of host, pathogen, and the environment in the Paraguayan Chaco. Three case studies examining aspects of TB disease ecology in indigenous communities are presented: (1) The effective cultural transmission of biomedical knowledge to isolated communities, (2) Public health infrastructure, hygiene, and the prevalence of intestinal parasites: co-morbidities that promote the progression to active TB disease, and (3) Community-level risk factors for TB and indigenous TB burden. Findings from the case studies suggest that greater influence from outside institutions was not associated with greater adoption of biomedical knowledge of TB. The prevalence of helminthiasis was unexpectedly low, but infection with giardia was common, even in a community with cleaner water sources. Communities with a health post were more likely to report active adult TB, while communities with more education were less likely to report active pediatric TB, suggesting that healthcare access is the major determinant of TB detection. More research is needed on the role of non-indigenous community residents and other measures of acculturation or integration in TB outcomes, especially at the household level. Indigenous TB burden in the Chaco is disproportionately high, and better understanding of the mechanisms that produce higher incidence and prevalence of the disease is needed.

ACKNOWLEDGMENTS

This project was made possible with the assistance of many people. Firstly, I wish to thank the study communities for their permission to conduct the study and their enthusiastic participation. I would especially like to thank the field assistants from the study communities who worked with me the longest: Lida Centurión, Noemi Rojas, Teresita de Jesus Peralta, and Valeria Gonzalez, and their families, who helped me out of some sticky situations.

I would also like to thank the staff of the local health posts, who gave me a place to stay, included me in their daily activities, and provided me with many insights into the study communities and the challenges of providing healthcare in the Paraguayan Chaco. I greatly admire the sacrifices you make to improve health in these remote communities. And thank you for also looking after my health and well-being as the occasion arose.

I am grateful to the Boquerón and Presidente Hayes Health Regions in Paraguay, who supported the project and provided access to their medical records and staff. Special thanks to Ester Villalba de Aguero and Dr. Lucía Ibarra de Terol who opened their homes to me. Thanks also to the National Tuberculosis Program in Paraguay and the Department of Statistics for the Ministry of Public Health and Social Wellbeing.

This project would not have been possible without the logistic support and friendship of my colleagues at CEDIC (el Centro para el Desarrollo de la Investigación Científica). In particular, Dr. Celeste Vega Gomez and Dr. Miriam Rolón opened many doors for me. I greatly enjoyed my time spent at CEDIC and learned a lot from them.

I met many wonderful people through CEDIC, including the team at Paraguay Safari - Rodrigo Ayala Martínez and Johanna López, biologists Humberto Sánchez, Juan José Resquín Centurión, Julio Torres, and Diego Dorigo Cortes, and Francisco Arias and Sommers, who each provided valuable assistance to the project.

My committee members, Dr. Anne Stone, Dr. Magdalena Hurtado, Dr. Antonieta Rojas de Arias, and Dr. Dan Hruschka, have been wonderful role models and mentors. Thank you for believing in the project, and your encouragement and pragmatic advice in tough situations. I would also like to thank Dr. Antonieta Rojas de Arias and her family for welcoming me into their home and treating me like family.

This study was supported by a Dissertation Improvement Grant from the Physical Anthropology Program at the National Science Foundation (grant #1026520), a Dissertation Fieldwork Grant from the Wenner Gren Foundation (grant #8462), Sigma Xi: The Scientific Research Society, and Arizona State University's School of Human Evolution and Social Change and Graduate and Professional Student Association.

Lastly, I would like to thank my parents, who continue to support me even if they still aren't entirely sure what it is I do, and tolerated my limited contact by satellite phone in the field.

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INTRODUCTION & OVERVIEW

Statement of the Problem

Tuberculosis (TB) is curable, but it is the second leading cause of death from an infectious disease worldwide (WHO 2013a). In 2012, an estimated 8.6 million people newly developed TB and 1.3 million people died from it. This burden is not shared equally; certain groups are more at-risk of acquiring and dying from TB. TB is described as a disease of poverty, because many of the downstream effects of poverty (e.g. crowded housing, malnutrition, co-morbidities, etc.) are associated with greater exposure to TB and progression to active disease (Lönnroth et al 2009). Indigenous populations make up a disproportionate amount of the world's poor, and have the additional disadvantages of social and cultural marginalization, geographic and cultural barriers to accessing health services, and, in some cases, appropriation of land and natural resources (Stephens et al 2006).

A review by Tollefson et al (2013) showed that in most cases, where data are available, indigenous populations suffered a higher burden of TB incidence and prevalence than their non-indigenous counterparts. The caveat – "where data are available" – is important, highlighting the lack of or weakness of epidemiological surveillance for indigenous populations. Better metrics for the burden of TB in indigenous communities and risk factors explaining TB disparities are needed to improve diagnosis and treatment programs. The Tollefson et al (2013) review cited only one study of indigenous TB in Paraguay, a longitudinal study of tuberculosis among the Aché of eastern Paraguay from 1980-1999 (Hurtado et al. 2003).

The indigenous communities in western Paraguay – an ecoregion referred to as "the Chaco" - are one of two high transmission settings for TB in Paraguay, based on genetic data from TB patient isolates (Candia et al. 2007). Home to 15 indigenous ethnic groups belonging to five language families, the Chaco is a semi-arid ecosystem with limited infrastructure for housing, transportation, communication, or sanitation.

Overcoming cultural and linguistic barriers to the diagnosis and treatment of TB requires effective transmission of knowledge about TB, its causes, treatment, and prevention, as well as cultural validation of that knowledge. With better knowledge of TB, people should be better able to recognize symptoms, be more willing to seek and persist in the treatment program, and have reduced stigma towards others with the disease. This contributes significantly to the reduction of TB by decreasing the time to diagnosis and exposure of others to the disease, and preventing relapses and the development of antibiotic resistance.

Health education and health services in the Chaco are provided by institutions that are not indigenous, like the Ministry of Public Health and Social Wellbeing, the Mennonite colonies, church organizations, and NGOs, but often with the assistance of local indigenous health promoters. The isolation of the region, transportation and communication challenges, and linguistic diversity of the indigenous population must result in variable success in the cultural transmission of biomedical knowledge, and subsequently, will impact the TB disease ecologies of different communities to different degrees. This dissertation examines how different degrees of effective cultural transmission from outside institutions affect the disease ecology of TB in indigenous communities of the Paraguayan Chaco.

Anthropological Approaches to the Study of Infectious Diseases

The standard definition for the anthropology of infectious disease is the "broad area which emphasizes interactions between sociocultural, biological, and ecological variables relating to the etiology and prevalence of infectious disease" (Brown 1981: 7). Anthropological approaches to infectious disease tend to fall within four approaches: adaptationist, ecological, political-economic or ethnomedical (I use a slightly different classification system from that promulgated by Inhorn and Brown (1990).

Adaptationist approaches focus on how humans have biologically and/or culturally adapted to the pressures of infectious diseases. Studies in this area take either a microevolutionary or macroevolutionary perspective. Microevolutionary studies attempt to identify specific genotypes or cultural practices that confer immunity or resistance to infectious diseases (Inhorn and Brown 1990). The classic example of this line of research is the search for genetically determined hemoglobin abnormalities that confer resistance to malaria, such as the alleles for sickle-cell anemia (Allison 1954), glucose-6-phosphate-dehydrogenas (G6PD) deficiency, thalassemia, and hemoglobins HbC, HbE, and HbF (Livingstone 1985). Another example is May's (1960) description of how people living in the hills of Northern Vietnam are better protected from malaria than those living in the delta because they build their houses on stilts 8 to 9 ft above the flight ceiling of *Anopheles minimus*, the vector for the disease.

Macroevolutionary studies examine disease transmission in past human populations and attempt to reconstruct epidemiological patterns with historical records, bioarchaeological evidence, and ethnographic analogy (Inhorn and Brown 1990). The goals of these studies are to establish the antiquity and evolution of infectious diseases in human populations and contextualize these diseases within the physical and cultural circumstances of past populations.

In a related approach, Barrett et al (1998) combine an evolutionary and historical perspective with epidemiologic transition theory to describe three epidemiologic transitions over human history. The first epidemiologic transition is associated with the Neolithic Revolution and larger human settlements that can sustain more infectious disease transmission. The second epidemiologic transition is the shift from infectious to predominantly chronic disease mortality associated with industrialization. The third epidemiologic transition involves a resurgence of infectious disease mortality from newly emerging, re-emerging, and antibiotic resistant pathogens associated with globalization. The synthesis is an interesting exercise which highlights common themes in human-pathogen interactions over time, but the transitions described have taken place at different time scales in different places. Some societies have not undergone each of these transitions in sequence, and instead have what appear to be class stratified transitions with upper classes dying preponderantly of chronic diseases while the lower classes continue to die of infectious diseases (for example, India).

Ecological approaches to the study of infectious diseases focus on "the interaction between agent and host within a given ecosystem" (Inhorn and Brown 1990: 95). The earliest ecological studies maintained the adaptationist approach, but added a multilevel perspective and comparative studies to better understand the factors underlying the prevalence of different diseases in different populations across different environments. The first work in the area of human disease ecology is attributed to May (1958), a medical geographer who described the role of the physical and sociocultural environment in infectious disease. In May's model, the physical environment, pathogens, human hosts, and cultural practices of the human hosts are separate factors in an interactive process. Disease is defined as "the ability of the diseased tissue or individual to survive in a given environment"; making disease an expression of "temporary maladjustment between human hosts and their environment" (May 1958: 1). A number of scholars have expanded on May's insights to create more complex models of the interactions between pathogens, hosts, and the environment.

McDade's (2005) "ecologies of immune function" addresses the evolutionary and environmental determinants of host resistance to infectious disease. In addition to the forces of natural selection, the human immune system develops in response to nutritional, pathogenic, reproductive, and psychosocial factors. The immune system is designed to collect information about the surrounding disease ecology, and adjusts itself to embody the pathogenic insults it has encountered. This phenotypic plasticity allows human populations to adapt to a variety of ecological environments. Because humans actively construct their environments and our culturally mediated behaviors determine our interactions with the environment, culture is just as important an influence as ecology on the kinds of pathogenic insults that are experienced. Furthermore, with a more mature adaptationist perspective, the immune system is recognized to engage in trade-offs with other physiologically and developmentally important body systems in order to maximize fitness. However, as a human focused approach, it is difficult to include co-evolution with pathogens or environmental changes in this model.

Turshen's (1984) "political ecology of disease" departs from the biologically based ecological approaches arguing that the ultimate causes of disease are economic, social, and political. Turshen critiques the disease ecology approaches as more elaborated models of the epidemiological agent-host-environment triangle which fail to address these ultimate causes of disease. The political ecology of disease is a Marxist based approach that focuses on modes and conditions of production and changing social relations in historical (colonial) perspective. This approach has been very influential in the development of critical medical anthropology (Singer 1984).

Farmer's (2001, 2004, 2005) "structural violence" is an historically informed approach to infectious disease ecology which draws on world systems theory to show how social, economic, and political inequalities are embodied as differential risk for infection. Farmer has a twin focus, on the "ethnographically visible" experience of disease in individuals and the global forces which constrain the agency of individuals. While Farmer's arguments are convincing, unfortunately, the pathways which connect global forces to individual experience are rarely illuminated. Briggs and Mantini-Briggs (2003) use a similar approach in their study of a cholera outbreak in Venezuela, and make the pathways of structural violence more apparent in their analysis of the institutions (media and government agencies) that mediate the local and the global.

Ethnomedical approaches to the study of infectious diseases focus on culturally prescribed behavioral patterns, which can be risk factors or limiting factors for the contraction of infection, and ethnomedical beliefs concerning the etiology, symptoms, and treatment of infectious diseases. Inhorn and Brown (1990) argue that such a microsociological perspective is a necessary complement to macrosociological perspectives like human disease ecology or the political ecology of health.

Each of these approaches has strengths in its own right, but what is lacking is a theoretical integration of macro- and microlevel forces, the ultimate and proximate causes, and biological and sociocultural factors that create infectious disease patterns. Although genetic and cultural adaptations to infectious disease have both been regarded as important, they have been treated as discrete processes, as in dual inheritance theory (Cavalli-Sforza and Feldman 1981, Boyd and Richerson 1985).

The ecological approach, which is the most integrative of those listed above, remains strongly rooted in standard evolutionary theory ("the new synthesis" of natural selection and genes). Aside from McDade's (2005) treatment of the immune system, recent advances in our understanding of genetics and evolutionary processes, particularly advances in the field of evolutionary developmental biology (EvoDevo), are missing from these models (see Jablonka and Lamb 2006 for a review of recent developments in evolutionary theory).

Most of these approaches are also human-focused. While many cultural behaviors that act as selective pressures on pathogens have been identified (Hackett 1937; Livingstone 1958; May 1960; Hudson 1965; Wiesenfeld 1967; Alland 1970; and Inhorn and Brown 1990), little has been done to measure the resulting changes in the genetic diversity of pathogens. Any approach to a host-pathogen relationship should focus on both organisms; not one or the other.

Finally, while the role of humans in shaping their environment and altering their exposure to infectious disease is widely recognized (May 1958; Inhorn and Brown 1990; McDade 2005), there has been little theorizing about how this process alters the selective forces acting on humans. A recent development in evolutionary biology, niche construction theory, may be useful in this respect.

Niche Construction: A New Model for Disease Ecology

Niche construction, called "the neglected process in evolution", emphasizes the role organisms play in modifying their environment (Laland, Odling-Smee, and Feldman 2001; Day, Laland, and Odling-smee 2003; Odling-Smee, Laland, and Feldman 2003; Laland, Kendal, and Brown 2007). Niche construction is "the process whereby organisms, through their metabolism, their activities, and their choices, modify their own and/or each other's niches" (Odling-Smee, Laland, and Feldman 2003: 419).

Recognizing that niche construction can significantly modify natural selection has several implications for how we think about evolutionary processes in humans: (1) organisms are not just 'vehicles' for genes but actively modify their own and other species' environments and can thereby introduce feedback into natural selection, (2) the legacy of modified selection pressures on environments creates an ecological inheritance, and (3) niche construction does not have to result from genetic variation; niche constructing behaviors can be learned or culturally inherited (ibid). Thus, while the new synthesis of evolution by natural selection describes a process of genetic inheritance in organisms, niche construction creates a more complex model where three forms of inheritance - genetic, environmental, and cultural - interact during the evolutionary process.

Ecological inheritance refers to the inheritance of natural selection pressures in the environment which have previously been modified by niche construction (Odling-Smee 2006). Rather than the transmission of discrete replicators, ecological inheritance requires only that the changes made to the environment during the previous generation of niche constructors persist in the local environments of their descendants. The descendants are essentially inheriting the altered selection pressures created by ancestral organisms, and these ancestral organisms do not have to be related to or even the same species as the descendants.

Cultural inheritance is the transmission of cultural traits, which can be transmitted vertically (intergenerational) or horizontally (from unrelated individuals) (Cavalli-Sforza and Feldman 1981). Laland, Odling-Smee, and Myles (2010) use a definition of culture as knowledge, beliefs, values, and skills that are socially learned. Culture is packaged as particular traits (rather than as a description of a society as a whole) which allows the transmission of traits to be modeled similarly to various selective and non-selective evolutionary processes (e.g. natural selection, drift).

Inhorn and Brown close their comprehensive review of the anthropology of infectious disease with a reemphasis that "societies actively change their ecology so as to increase or decrease the risk of particular diseases" (1990: 110). McDade (2005: 501) writes: "For humans, culture and ecology are inseparable: We actively construct our environments, and culturally mediated behaviors structure our interactions with these environments." And yet the origins and maintenance of niche constructing behaviors in humans have been relatively ignored, or treated as a given in anthropological studies of infectious diseases. From an applied or interventionist perspective, niche construction is the most important element of the epidemiological triangle because it is the source of solutions for preventing and curing infectious diseases.

A Biocultural Epidemiological Framework

May (1958), the medical geographer first credited with coining the term "disease ecology", argued that in order to understand any given disease complex, one needs to understand the ecological interactions of all the factors in a disease complex. Those factors being: the host, the pathogen(s), the vector(s), and the environment. Ecology is used here in the biological sense of the term, where ecology is the study of relations between organisms, particularly communities of organisms, and to their surrounding environments both animate and inanimate. However, when one of your factors is human, the disease complex necessarily takes on both biological and sociocultural dimensions. May (1958: 30) describes how "Culture influences disease occurrence in three main ways: (1) by linking or separating challenges of the environment and host, (2) by changing the environment, and (3) by changing the host population."

Exposure to infectious diseases, disease transmission, and access to treatment are mediated by sociocultural factors at multiple levels: individual practices and beliefs, gender roles and relations, arrangement of households, patterns of subsistence, interactions and the flow of resources within social networks, as well as larger political-economic structures. Human activities create the biosocial environments ('niches') which drive host-pathogen co-evolution (Laland, Kendal, and Brown 2007). Thus, in the epidemiological triangle, the host and environment should include both biological and sociocultural factors (see Figure 1).

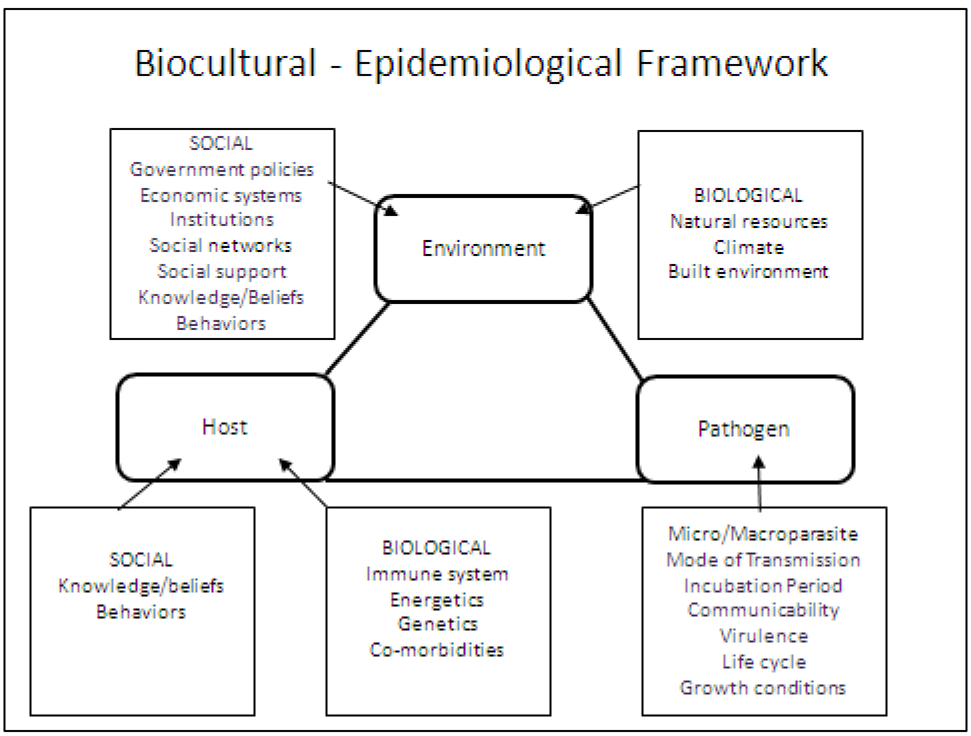

Figure 1. The biocultural – epidemiological framework

On the biological side, a human host's level of resistance or susceptibility to a pathogen is determined by several factors, including genetic makeup, energetics, state of the immune system, age, diet, and the presence of co-morbidities (McDade 2003). Genetic traits that impact infectious disease susceptibility can include alleles that directly affect the immune system, such as vitamin D receptor polymorphisms (Wilbur et al. 2007), or alleles that change interactions between pathogens and host cells they target, such as hemoglobin polymorphisms and malaria (Allison 1954, Livingstone 1985). Genetic adaptations happen at a slow pace, over generations, while phenotypic plasticity and cultural or behavioral adaptations can occur rapidly within a single lifetime.

The body relies heavily on the phenotypic plasticity of the immune system to face challenges from infectious diseases (McDade 2003). Exposure to certain kinds of pathogens, especially in early life, conditions the immune system for future challenges. In locations where populations are more exposed to macroparasites than microparasites, the immune system allocates more of its finite resources to the Th2 system than the Th1 system in anticipation of greater challenges from macroparasites (Romagnani 1996, 1997, McDade 2003, Elias et al 2001, 2006, Pedersen and Fenton 2007, Resende Co et al 2006). This better prepares the immune system to fight off macroparasite infections, but can leave the host more vulnerable to microparasite infections.

This trade-off in the allocation of resources is part of a broader conflict in the energetics of the host organism. When resources are limited, they must be divided between growth, maintenance, or reproduction of the organism (Hill and Hurtado 1996, McDade 2003). The allocation of resources to immune system capacity (rather than reproduction or growth) depends upon the available resources (nutrition), as well as age or life stage of the organism (McDade 2003). An additional concern is the presence of co-morbidities in the organism. Multiple immune system challenges create greater demands on finite resources (Pedersen and Fenton 2007). Other, non-communicable diseases can also influence the host's ability to combat disease. Diabetes, for example, can damage immune system function (Restrepo and Schlesinger 2013, Bridson et al 2014, Hodgson et al 2014).

Cultural or behavioral adaptations to infectious diseases include belief systems, behaviors, or modes of social organization that moderate exposure and interactions with pathogens. Culture is a particularly important adaptive system for humans in combating infectious diseases because the pathogens we battle evolve at a rapid pace, with viruses and bacteria passing through multiple generations in a single day. In response, humans develop medical traditions, train medical practitioners, and produce medicines to fight infectious diseases where our genes are not sufficient.

Using a cognitive definition of culture as a set of learned knowledge, beliefs, and behaviors shared by a group of people (D'Andrade 1995), culture can operate at the level of the environment or the individual host. It operates at the level of the environment because knowledge, beliefs, and behaviors are shared and learned from others; the culture of others and social networks one belongs to can alter the environment an individual lives in. However, individuals vary in the degree to which they ascribe to particular knowledge, beliefs, and behaviors, and their own specific ideas and actions have an effect on their level of exposure and susceptibility to infectious disease.

The sociocultural environment - or niche - includes beliefs, behavior, social organization, patterns of subsistence, and features of the built and sociopolitical environment that are barriers or enablers to the spread of TB. Sociocultural factors mediate exposure to infectious diseases, disease transmission, and access to treatment at multiple levels: the household, the community, the region, the nation, or internationally. Thus they can be a result of an individual hosts' own cultural group or the result of other interacting cultural groups up to a global scale, as in the case of Farmer's (2001, 2004, 2005) work on structural violence or Turshen's (1984) on the political ecology of disease. The effects of the sociocultural niche can be direct or indirect on host-pathogen interactions.

From an applied perspective, the sociocultural niche deserves a special emphasis as the source of solutions to health problems. Through "niche constructing" activities, humans can alter their environment to prevent disease and promote health. The sociocultural niche also involves medical systems of knowledge, technologies, and institutions to combat disease.

The biological environment is composed of the biotic and abiotic factors that surround the host and pathogen. Biotic factors include the wider community of organisms in the environment that the host and pathogen interact with, such as organisms that are food sources, organisms that pathogens use to transmit themselves to host organisms (vectors), or commensal organisms that protect hosts from pathogens. Abiotic factors include physical parts of the environment like climate and nutrient availability that are essential for the survival of the host or pathogen.

From the pathogen's perspective, its life cycle and growth conditions, mode of transmission, incubation period, communicability (its ability to infect others), and pathogenicity (its ability to inflict damage on the host) are important factors in determining the disease process. When the pathogen is transmitted through a vector organism or has reservoirs in another organism, the system becomes more complex, as the interactions between these organisms and the pathogen, host, and environment must also be considered.

Each of the elements in the biocultural epidemiological framework has another dimension – time depth (see Figure 2). The sociocultural environment is built through cultural inheritance, that is, cultural transmission that can be either vertical (intergenerational) and horizontal (intercultural). The biological environment is a result of environmental inheritance. Both pathogens and human hosts are subject to genetic evolution, and humans also have cultural transmission.

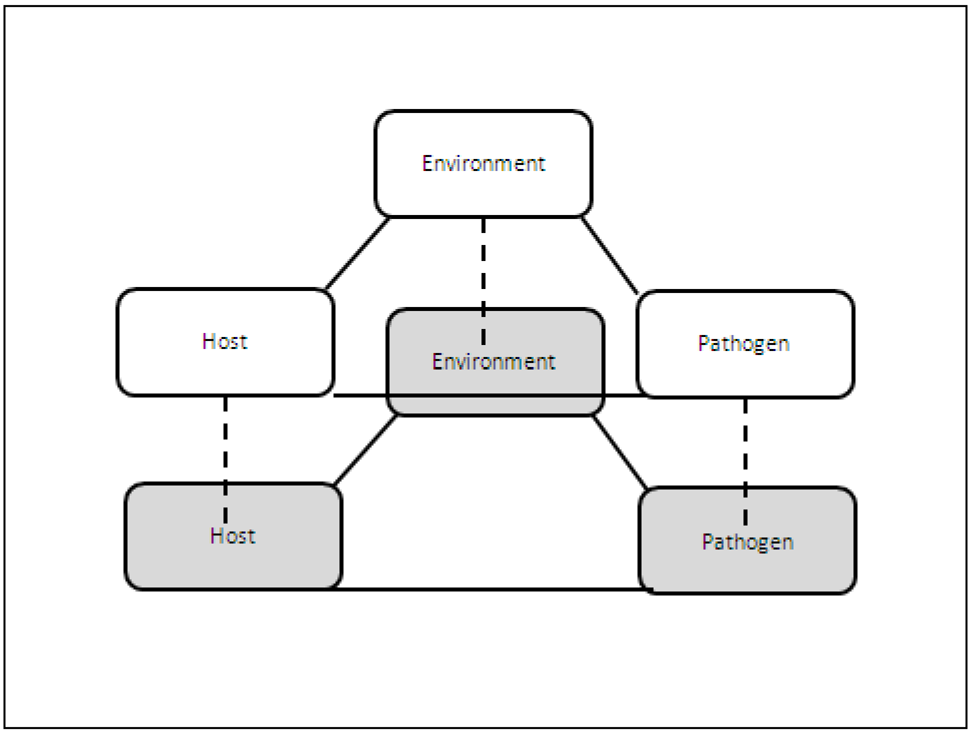

Figure 2. The biocultural-epidemiological framework with time depth

Through interactions with each other, historical processes in one element of the system are influencing the modern configurations of the others. For example, historical social policies on the use of antibiotics will influence the degree of antibiotic resistance found in modern pathogen populations. The selective pressures of pathogens on past human populations will influence the modern genetic composition of human hosts. The alterations that past human populations made to their environments will be inherited by the human populations that follow. Thus, historical processes are of considerable import to understanding modern disease ecology.

In the following sections, I outline how the disease ecology of tuberculosis falls within this framework in the context of indigenous communities of the Paraguayan Chaco.

The Disease Ecology of Tuberculosis

Tuberculosis has a long history with *Homo sapiens* and is a continued plague on modern populations. Paleopathological evidence indicates that TB has been a significant cause of death in humans for at least 5000 years (Roberts and Buikstra 2003). Tuberculosis is caused by a variety of species within the *Mycobacterium tuberculosis* complex (MTBC), including *M. bovis, M. africanum, M. microti,* and *M. canettii*, but the majority of cases are due to *M. tuberculosis* (Coberly and Chaisson 2007). An airborne disease that primarily affects the lungs, TB is spread by individuals with an active infection (i.e. people who are coughing). The bacteria are transmitted by air on tiny droplet nuclei when a person with active disease coughs, talks, sneezes, or laughs (Coberly and Chaisson 2007). TB is primarily a pulmonary affliction, but extrapulmonary cases where TB has disseminated to other parts of the body, like the spine, lymph nodes, or other internal organs, also occur (Gandy and Zumla 2003).

When the bacteria are first inhaled into the lungs, they are confronted by alveolar macrophages and engage in a war of attrition where the macrophages attempt to engulf and destroy the bacteria and the bacteria attempt to infect immature macrophage cells (Gandy and Zumla 2003). If the macrophage cells are unsuccessful, the body initiates a delayed-type hypersensitivity reaction: the bacteria release toxic chemicals that produce swellings or lesions, and the immune system surrounds the clusters of TB bacteria with a thick waxy coat to block infected tissue off from the rest of the body. After infection, the TB bacteria may remain dormant for decades (latent infection) before re-activating to cause disease (Coberly and Chaisson 2007).

The World Health Organization estimates that one third of the population worldwide is latently infected with tuberculosis (TB), but only 5-20% of those infected go on to develop active disease (WHO 2013a). The disease process for TB can therefore be thought of as a two-step process: the first being colonization with *M. tuberculosis* and the second being progression to active disease. Each step in the TB disease process has unique drivers, although some are shared. These drivers are layered over multiple levels, ranging from intrinsic host factors, household environment, community environment, and the larger political-economic environment (Table 1).

Table 1. Drivers of the tuberculosis disease process

Scale	**Colonization**	**Progression to active disease**
Host		• Genetic susceptibility • Immune suppression • Co-morbidities • Smoking/Alcohol use • Malnutrition
Environment	• Contact patterns • Crowding • Ventilation • Air quality • Delayed diagnosis • Treatment adherence • Poverty	• Food security • Air quality • Poverty

Risk factors for TB can be broken into proximate factors and upstream determinants (Lönnroth et al 2009) (see Table 1). Proximate risk factors can either (1) increase potential for exposure and infection, such as crowding, poorly ventilated housing, or high prevalence of untreated TB in the community, or (2) promote the transition from latent infection to active disease by impairing the host immune system. Major risk factors of the latter type include malnutrition, co-infections (particularly HIV), smoking, air pollution from solid fuels, alcohol abuse, and diabetes (Lönnroth et al 2009, Padmanesan et al 2013) (see Table 1). Indigenous peoples in Latin America are particularly vulnerable to TB because they are highly genetically susceptible to TB and are often immunocompromised as they fend off other neglected diseases (helminthes, HTLV, Chagas disease, etc.) (Hurtado et al 2003). For example, intestinal helminth infection is associated with reduced efficacy of BCG vaccination, active TB disease, and poor response to TB treatment (Resende Co et al 2006, Elias et al 2001, 2006).

The upstream determinants of TB are poverty and other markers of low socioeconomic status that are associated with greater exposure to the proximate risk factors for TB (Lönnroth et al 2009). The health situation of indigenous peoples is comparable to the world's poorest populations, but with the additional burdens of social and cultural marginalization, geographic and cultural barriers to accessing health services, and, in some areas, appropriation of land and natural resources (Stephens et al 2006).

TB is curable, but rising antibiotic resistance increases the rate of treatment failure and costs of TB control (Cegielski et al 2002). Members of the *M. tuberculosis* complex are relatively slow-growing bacteria (Coberly and Chaisson 2007). As most of the antibiotics used to treat TB target the cell wall formation of mycobacterial species, their effectiveness is limited by the rate at which the bacteria are dividing. Long treatment protocols are needed to ensure that the entire population of mycobacteria in the body has been eradicated. The gold-standard treatment for TB is DOTS (Directly Observed Treatment Short-Course), a standardized drug regimen administered to patients under the direct observation of healthcare workers for a minimum of 6 months (Blanc and Uplekar 2003, WHO 2008). If treatment is irregular or abandoned before completion, there is a high risk that bacteria will become antibiotic resistant.

In areas with a high burden of TB, the Bacille Calmette-Guérin (BCG) vaccine is recommended for children soon after birth (WHO 2008). The BCG vaccine, which was developed in the 1920s (Coberly and Chaisson 2007), has limited efficacy against adult forms of tuberculosis, but is protective against severe forms of pediatric TB: TB meningitis and miliary TB (WHO 2008, 2013). The efficacy of the BCG vaccine is highly variable in different populations (ranging from 0 to 80% protection); and this variation is thought to be due in part to varying degrees of exposure to environmental mycobacteria in different populations (Colditz et al 1994). Infection with intestinal helminthes, which are endemic in parts of the world, is associated with reduced BCG vaccine efficacy and may promote a Th2 bias in immune response (Elias et al 2001).

TB is fundamentally a social disease associated with poverty. The McKeown thesis (McKeown 1976) famously debunks the role of new medical technologies in the decline of TB by demonstrating that the morbidity and mortality from the disease had already undergone a substantial decline in previous decades due to improving social and economic conditions in Europe and North America. The bacillus was discovered by Robert Koch in 1882, when the standardized notification rate had already fallen by half from nearly 400 per 100,000 to 200 per 100,000 inhabitants (Gandy and Zumla 2003). When antibiotic therapy and the BCG vaccination were introduced, the standardized notification rate for TB was about one eighth of the rate 100 years earlier. Gandy and Zumla (2003) however, attribute part of the decline in TB to public health advocacy and specific public health measures, like the segregation of TB patients in workhouses, hospitals, and sanatoria, housing improvements, and the control of bovine TB (*M. bovis* can be transmitted to humans through untreated cow's milk). Regardless, it is notable that improvements in social conditions and changes in social organization - that is, changes to the sociocultural niche – were primarily responsible for the decline of the disease in Western nations.

The Paraguayan Chaco

The Gran Chaco, a semi-arid alluvial plain in the heart of South America, occupies an area about 800,000 kilometers squared (Durán Estragó 2000). One third of this area is located in western Paraguay and the rest extends into Argentina and Bolivia. Hereafter "the Chaco" is used to designate the Paraguayan portion of the ecosystem. The vegetation is adapted to a dry or semi-arid climate (Durán Estragó 2000). The most common trees are hardwoods like *quebracho colorado (Schinopsis balansae)* and *quebracho blanco (Aspidosperma quebracho-blanco)*, *algorrobo (Prosopis alba* and *P. negra)* which produce edible pods, and *palo santo (Bulnesia sarmientoi),* known for its fragrant wood *(*Durán Estragó 2000, Renshaw 2002). Other common trees include the *samu'u* (or *palo borracho*, the 'drunken tree', *Chorisia insignis*), and various palm trees and cacti. The Chaco is divided into three ecological zones, heading westward from the Paraguay River you first encounter the Lower Chaco, characterized by fields prone to flooding and isolated ponds, then the Central Chaco, characterized by dry forest, and lastly the High Chaco, characterized by cacti and thorny shrubs.

The Chaco has a tropical continental climate, with extremes of both temperature and rainfall (Renshaw 2002). Temperatures range from over 40 degrees Centigrade in the summer to below freezing in the winter months, and the Chaco is plagued by periodic droughts and flooding. The rainy season lies between November and February and the winter months are typically dry (Durán Estragó 2000). The Chaco is also known for its strong north and south winds; the former brings with it dry heat and dust storms, while the latter carries in violent storms and cooler temperatures. Rainfall is sporadic, and varies across the ecological zones. Near the Paraguay River the average annual rainfall is around 1300mm, but as you head west it decreases to about 300mm in the High Chaco (Renshaw 2002).

The Chaco is home to 15 different ethnic groups belonging to five different linguistic families (INDI 2013) (see Table 2). Traditionally, indigenous peoples of the Chaco pursued a semi-nomadic or nomadic lifestyle with a subsistence based on hunting, fishing, gathering, and some horticulture (Tomasini 1997, Renshaw 2002). Despite linguistic differences, the ethnic groups have similar social organizations and subsistence strategies (Renshaw 2002). The traditional subsistence strategies involved a gendered division of labor where women were gatherers and men were hunters of game and wild honey. The plants gathered by women include *karaguata*, *algorrobo* of various kinds, *chañar*, *tuna* (cactus fruit), *mistol*, *sachasandia*, *poroto del monte*, and others. Small animals like rabbits, *viscacha*, lizards, iguanas, and armadillos are the most frequently hunted, and often with the aid of dogs. Sometimes big game like peccaries or rheas is pursued. Local birds like pigeons and *charatas* are also hunted with sling shots. Both men and women plant crops of watermelon, corn, sweet potatoes, squash, and cassava.

Table 2. Linguistic families and ethnicities of indigenous communities in the Paraguayan Chaco (INDI 2013)

Linguistic Family	**Ethnicity**	**Number of communities in the Chaco in 2013**
Guaraní	Guaraní Ñandéva	22
	Guaraní Occidental	4
Lengua Maskoy	Angaite	32
	Enxet	16
	Guaná	1
	Lengua Enlhet Norte	3
	Lengua Enlhet Sur	24
	Sanapaná	9
	Toba Maskoy	13
Mataco	Makâ	2
	Manjui	4
	Nivaclé	44
Zamuco	Ayoreo	21
	Chamacoco Yvytoso	7
Guaicuru	Toba Qom	11

The first decades of the 20th century saw increasing contact between indigenous peoples and colonizing forces from Bolivia and Paraguay. As part of their efforts to support their land claims in the Chaco region, both countries established military bases, opened the territory to colonists, and sent missionaries to indigenous populations (Durán Estragó 2000). In 1921, the Paraguayan government allowed Mennonite colonists to settle in the Central Chaco (Durán Estragó 2000). The first successful religious missions in the Chaco were established in the early 20th century by Anglicans among the Lengua and Roman Catholics among the Nivaclé (Barbrooke Grubb 1911, 1914, Durán Estragó 2000). However, the Chaco War (1932-1935) between Paraguay and Bolivia was a major precipitating factor for the settlement of indigenous peoples in missions. Caught between the warring nations, indigenous groups chose sides or sought refuge with the missionaries (Durán Estragó 2000, Renshaw 2002). Prior to this, missionaries had difficulty convincing indigenous communities to stay in one place. In addition to their traditionally nomadic or semi-nomadic lifestyles, entire communities periodically migrated to *ingenios*, mills that processed sugarcane, in Argentina for temporary employment during the harvest season (Tomasini 1997). Indigenous peoples also migrated to tannin factories, logging camps, cattle ranches, and the Mennonite colonies in pursuit of wage labor (Renshaw 2002).

In 2002, the total population of the Chaco was 138,760, of which 42,964 (31.0%) were indigenous (DGEEC 2003). The region is sparsely populated, with less than one person per square kilometer. Today, indigenous peoples in the Chaco live mostly by subsistence agriculture and wage labor, and hunting and gathering have become supplementary to these activities (Renshaw 2002). Under intense pressures from agroindustrial development, the Paraguayan Chaco had the highest rate of deforestation in the world from 2000 to 2012 (Hansen et al 2013). The most recent data describe a high rate of poverty; 73.2% of urban and 90.3% of rural households in the Chaco had at least one Unsatisfied Basic Need (housing quality, sanitation infrastructure, access to education, or capacity for subsistence) (DGEEC 2005).

Rural communities in the Chaco are isolated due to poor transportation and communication networks. There is only one paved road, the pot-holed TransChaco highway; however the Mennonite colonies have paved some of the roads in their communities. When it rains many of the dirt roads crossing through the region become impassable, especially for heavier vehicles. In 2012, flooding caused some communities to evacuate and others were isolated for several weeks because of damage to roads and bridges. In recent years, infrastructure for electricity and cell phone towers have slowly been expanding into the more isolated parts of the Chaco, but for many isolated communities the main form of communication remains HAM radios and notices from AM radio frequencies, like Radio Pa'i Puku.

There is also limited healthcare infrastructure in the Chaco. At present, each of the three departments in the Chaco, Boquerón, Presidente Hayes, and Alto Paraguay, have their own *Región Sanitaria* (Health Region) in charge of delivering health services. Many in-patient services and diagnostic tests are limited to the few hospitals in urban areas, and these institutions refer more complicated cases to hospitals in Asunción. According to the most recent Indigenous Census, fewer than half of indigenous communities had their own health post (DGEEC 2004), and these are highly variable in the training of their staff, facilities, and equipment available. Minimally, each community should have a local indigenous health promoter, who receives training through their *Región Sanitaria*. Isolated communities receive periodic visits from teams of doctors and nurses, however the actual frequency of and quality of care provided during these visits is disputed.

During the study period, the *Regiones Sanitaria* were rolling out an initiative to decentralize primary health care and make it more accessible to remote and poor populations: *Atención Primaria a la Salud* (Primary Health Care). The program involves setting up *Unidades de Salud Familiar* (USF, Family Health Units), a health team consisting of a doctor, a licensed nurse, an auxiliary nurse, and five health promoters per every 5000 people. The team would be installed in a health center, and make regular visits to the surrounding communities (which may or may not have a health post). The implementation of the program faced several challenges in the Chaco, such as the recruitment and retention of doctors and nurses for remote and poverty stricken areas, and limited vehicles available for the medical teams to visit their surrounding health posts and transport patients and medical supplies and equipment. In 2010, the USFs covered about 20-25% of the population in the departments of Boquerón and Presidente Hayes.

Other, Non-Governmental Organizations operated by religious groups also provide healthcare services to communities in the Chaco. In 1978, the Mennonite colonies formed a cooperative organization called ASCIM (*Asociación de Servicios de Cooperación Indígena-Menonita*) to address the economic and public health problems of the indigenous communities that settled around the outskirts of the Mennonite colonies (ASCIM 2009). ASCIM provides primary health care, education, and agricultural development initiatives in the nearby communities. The *Vicariato Apostólico Pilcomayo* (VAP), which is the administrative area for much of the Roman Catholic presence in the Chaco, also engages in healthcare and educational activities (Durán Estragó 2000). The health care activities of ASCIM and VAP include providing health posts in the communities, preventive medicine, health education courses, and training indigenous health promoters and nurses. ASCIM is also involved in the provision of drinking water and housing construction, and manages a health insurance program. The services offered by ASCIM and VAP are sometimes parallel to and sometimes within the activities of the *Regiones Sanitaria.* Occasionally, other volunteers offering dental care, optometry, or other medical services will be brought into the communities by the *Regiones Sanitaria*, Mennonite colonies, VAP, or other religious groups.

Tuberculosis in the Paraguayan Chaco

In May 2010, the Ministry of Public Health and Social Wellbeing released a document titled "*Política Nacional de Salud Indígena*" (National Policy on Indigenous Health) describing the disproportionate burden of disease in the indigenous population (DGAGV 2010). The majority of indigenous peoples in Paraguay live in conditions of extreme poverty and lack access to basic sanitation. Epidemiological surveillance does not always differentiate between indigenous and non-indigenous patients, but data from the *Regiones Sanitarias* suggest that indigenous peoples suffer more from respiratory and gastrointestinal infections, malaria, parasitosis, sexually transmitted infections, malnutrition, and tuberculosis. The National Policy on Indigenous Health goes on to say:

The almost non-existent health coverage in indigenous communities has further deteriorated their living conditions. The absence of active assistance for infectious cases, poor accessibility of health centers for indigenous peoples due to geographic, economic, linguistic or cultural reasons, lack of outpatient follow-up for indigenous patients, and frequent abandonment of treatment, favors the permanence of diseases like tuberculosis in the indigenous population. (DGAGV 2010: p.15, my translation)

About 70% of the indigenous population is located in four *Regiones Sanitarias* – Amambay, Canindeyú, Presidente Hayes, and Boquerón – and these same regions account for 63 to 75% of the cases of TB in the last four years (PNCT 2011). The latter two *Regiones Sanitarias* mentioned are in the Chaco.

There is considerable genetic diversity in *M. tuberculosis* strains in Paraguay. A sample of 220 TB strains collected throughout Paraguay in 2003 were spoligotyped into 79 different patterns; 28 of which were not already part of SpolDB4, the global spoligotype database at the Pasteur Institute (Candia et al. 2007). In the sample, 33 strains were resistant to at least one drug (15%). The quantification of the diversity of TB in Paraguay further suggested that the new patterns were a result of ongoing transmission and adaptive evolution within Paraguay. Indigenous communities in the Chaco are one of two high transmission settings in Paraguay (the other being the Tacumbú jail in Asunción).

In 2004, the Chaco region had the highest TB notification rate in Paraguay, although a greater number of cases were registered in metropolitan areas (WHO 2006). The incidence of all forms of TB in the Chaco region was 204.5 per 100,000 inhabitants in 2002, 133.8 per 100,000 inhabitants in 2003, and 160.0 per 100,000 inhabitants in 2004 (Ministerio de Salud y Bienestar Social 2002, 2003, 2004). Each of these incidences is, respectively, 4.2, 2.7, and 3.3 times the national incidence in Paraguay for those years (49 cases of TB per 100,000 inhabitants from 2002-2004) (WHO 2013). These are likely underestimates because the WHO statistics are derived from the national, combined indigenous and non-indigenous, populations, rather than directly comparing indigenous with non-indigenous rates.

A decline in TB incidence in indigenous populations from 2005 to 2007 was perhaps due to insufficient case detection (Figure 3). Recent efforts to improve case detection in indigenous communities led to increased case notification rates from 2007 to 2009, and then a subsequent decrease from 2009 to 2011. In Boquerón the incidence of TB decreased from 74 cases per 100,000 in 2005 to 49 cases per 100,000 in 2011, and in Presidente Hayes the incidence of TB decreased from 57 cases in 2009 to 50 cases in 2011 (PNCT 2011). As of 2010, indigenous populations have a high treatment success rate (89%), but still have a higher level of mortality (> 5%), possibly because of delayed diagnoses (PNCT 2011). The gap between indigenous and non-indigenous TB burden remains wide, with an incidence of all forms of TB that was 10.7 times higher in the indigenous population in 2010 (Figure 3).

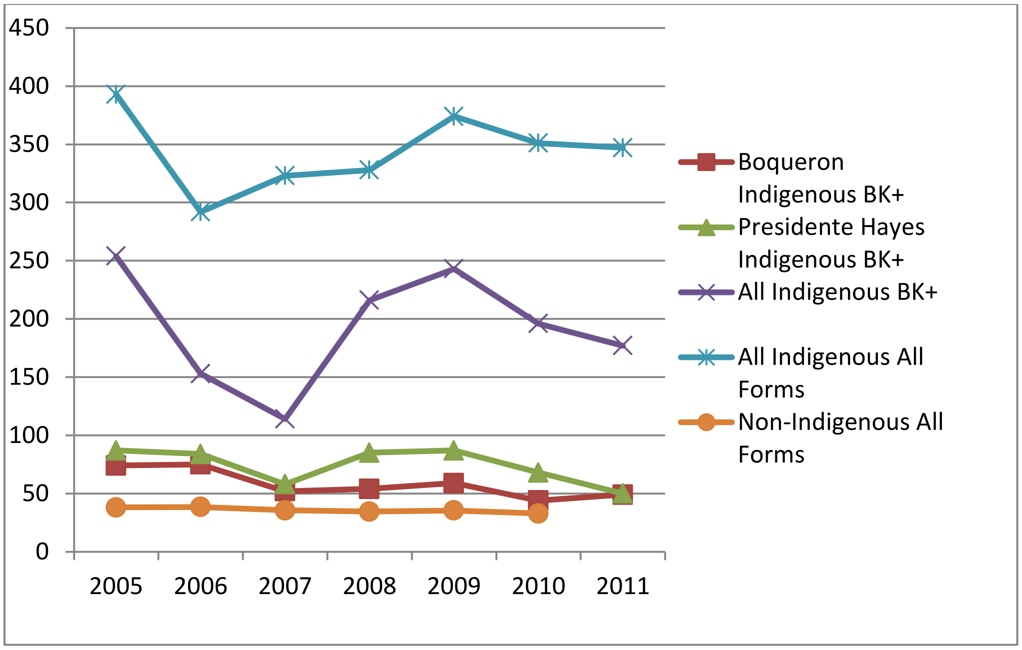

Figure 3. Incidence per 100,000 people of BK+ and all forms of tuberculosis in indigenous and non-indigenous populations in Paraguay, 2005-2011. BK+ refers to cases that sputum smear positive. Data source: PNCT 2011.

Issues with case detection and delayed diagnosis are subject to problems in healthcare access and delivery, as well as the local level of knowledge about TB. Indigenous communities with more interactions with outside institutions and greater integration into national Paraguayan society should have greater awareness of biomedical models of TB, and better public health infrastructure from both outside and local interventions. Because cough, fever, and general malaise are not symptoms unique to TB, laypersons with greater biomedical knowledge of TB will be more likely to seek diagnosis and treatment because they recognize it may not be a benign illness.

Overview of the Project

The objective of this study was to examine the role of cultural transmission from outside institutions in the disease ecology of TB in indigenous communities of the Paraguayan Chaco. To obtain a holistic view of disease ecology in the Chaco, a variety of methodologies, both qualitative and quantitative and sociocultural and biological, were employed over a period of 18 months, from September 2010 to November 2012. This section provides an overview of the complete study, and introduces the three case studies that make up the results chapters of this dissertation.

Hypotheses

The complete study used a conceptual framework of disease ecology that included the diversity of TB strains, beliefs and behaviors of the host population, various elements of the sociocultural niche, and the moderating effects of other environmental factors such as diet and pathogen load. For the purposes of this study, the sociocultural niche includes beliefs, behaviors, and features of the built and sociopolitical environment that are barriers or enablers to the spread of TB. The sociocultural niche is built through 'cultural inheritance', that is, cultural transmission that can be either vertical (intergenerational) or horizontal (intercultural). This study addresses the influence of differing levels of effective cultural transmission from outside institutions (horizontal) on disease ecologies.

When comparing indigenous communities with greater integration into national society and greater influence from outside institutions (such as Mennonite cooperatives, the Ministry of Health, missionizing churches, and NGOs) with more isolated communities, we expect to see:

Hypothesis 1: Greater awareness of biomedical models of health and disease, particularly biomedical models of TB.

Hypothesis 2: Better public health infrastructure, including health posts and hygienic facilities like wells and latrines.

Data Collected & the Biocultural Disease Ecology Framework

To test these hypotheses, the project selected communities with varying degrees of interaction with outside groups and collected data about TB knowledge [H1], the presence and quality of public health infrastructure, sanitation infrastructure, and the built environment [H2]. There are also several corollaries to these hypotheses; for example, with greater biomedical knowledge [H1] we might also expect greater adoption of health behaviors promoted in the biomedical model, like a higher frequency of hand washing and lower frequency of smoking, spitting, or sharing utensils. With greater biomedical knowledge [H1] and more public health infrastructure [H2], we might expect people to seek treatment more and earlier in the progression of disease. With better public health and sanitation infrastructure and a more hygienic built environment [H2] we might see an overall lower prevalence of disease, particularly intestinal parasites.

To isolate the effects of cultural transmission in the areas described above, it is important to control for other confounders in the overall disease ecology of TB. For example, the socioeconomic and nutritional status of participants and the demographic composition of communities and households will also have an influence on colonization and activation of TB. The diversity of data collection methods in the project controls for many of these confounding variables and allows for a more complete picture of the disease ecology of TB in the Chaco. Table 3 shows how the collected data correspond to the pathogen, host, and environment elements in the biocultural disease ecology framework presented in Figures 1 and 2. Table 4 further elaborates how some of the data gathered correspond to the major risk factors for colonization by *Mycobacterium tuberculosis* and the progression to active TB disease (a more elaborated version of Table 1). The variables that are ***bolded and***

italicized in Tables 3 and 4 will be examined in the three case study chapters that follow.

Table 3. Correspondence between data collected and the biocultural disease ecology framework

Pathogen	Host	Environment
Cheek swabs Patient records	***Biomedical knowledge*** Health related behaviors Demographics Nutrition ***Co-morbidities*** Patient records	***Biomedical knowledge*** ***Health related behaviors*** Household composition Social networks/Contact networks ***Built environment*** ***Healthcare access & infrastructure*** ***Sanitation infrastructure*** ***Socioeconomic status*** Public health policy

Table 4. Correspondence between data collected and the risk factors for colonization and activation of tuberculosis

Risk Factor	Data collected
Colonization	
Contact patterns (crowding)	Social networks, Household composition, Time allocation/Proximity observations, Demographics, ***Crowding***, Migration, Cheek swabs
Air quality/Ventilation	Ventilation in houses, Time spent outdoors, Solid fuel use
Delayed diagnosis	Health post records, Help seeking behavior, ***Health system issues***
Treatment adherence	Health post records, ***Health system issues***
Poverty	***Socioeconomic status***
Activation	
Immunocompromised	Age
Co-infections	Recent illnesses, ***Fecal sampling***
Malnutrition	24 hour dietary recall, Anthropometrics
Air quality	Smoking, Solid fuel use, Ventilation in houses

Community Selection

Most of the fieldwork was conducted in two rural Nivaclé communities, denoted by the pseudonyms Integrationville and Isolationville, chosen to represent a community with greater exposure to outside institutions and a more isolated community, respectively. Integrationville (85 households), which is home to a religious mission and is visited by a private bus line twice a week, has a history of 2-3 TB cases per year over the last decade. In contrast, Isolationville (51 households), which has more limited interaction with outside groups and is not accessible by bus, has at times had 10-15 TB cases in a single year. Both communities have health posts, but the health post in Integrationville is better staffed, in terms of professional qualifications and number of personnel, and has better equipment.

The Nivaclé communities are of particular interest because from January 2008 to June 2009, 73 of the 112 TB cases (65%) reported to the regional hospital in Mariscal occurred in Nivaclé individuals (Mariscal Regional Hospital, unpublished data). At that time, the Nivaclé were suffering from TB at higher rates than any other indigenous, mestizo, or Mennonite group in the Boquerón department.

In 2012, the project received additional funding for a second field season and two more Nivaclé communities and two Angaité communities were included in some parts of the study in addition to Integrationville and Isolationville. The new communities were added to allow for comparisons across a greater number of communities, and the Angaité communities in particular were added for cross-cultural comparisons of ethnic groups living in the same environment with similar subsistence strategies. The Angaité are reported to be one of the more highly acculturated indigenous groups in the Chaco, having lost much of their traditional language and adopted

Jopará Guaraní – a mix of Spanish and Guaraní widely spoken by Paraguayans - as their primary tongue (Renshaw 2002).

The Angaité community described in the second case study, denoted by the pseudonym Angaité-ville, is relatively near the TransChaco highway but did not have a health post or health promoter during the study period. Angaité-ville does not have involvement with ASCIM or VAP, but various NGOs have been involved in building a *pozo artesanio* (well), a chicken hatchery, and new brick housing in the community.

Research Design

Data collection can be broadly described in seven phases of research: (1) the initial health census in 2010, (2) ethnographic interviews from 2010 to 2011, (3) the household survey of 2011, (4) the household survey of 2012, (5) biological sampling, (6) time allocation observations, and (7) analysis of health records. The instruments used for the Health Census, ethnographic interviews, and surveys can be found in Appendix A.

The study employed several field assistants, mostly Nivaclé, but also some Paraguayans during the 2012 field season, to assist with data collection. Field assistants underwent training for a minimum of two days that covered the overall purpose of the project, methods for investigation, research ethics, and translation of study materials. A field assistant who spoke the local language of the study community (Nivaclé or Jopará Guaraní) was always present to assist with translation during the consent process and data collection.

(1) The Health Census

The Health Census was conducted in Isolationville and Integrationville in November and December 2010, and every household in each community was visited. The results of the census sampling are presented in Table 5. Some of the households were quite distant from the community center and were reached after an hour on foot. Conversations with community members and field assistants after the census suggest that there may be additional houses that are even farther away and were not included in the census. In most cases, a household did not participate in the census because no one was at home during the surveying period, but there were a few refusals to participate.

Table 5. Summary of Health Census sample

Community	**Households Visited**	**Households in Census (%)**	**Total Adults**	**Former TB Patients**	**Exposed to TB Patient**	**Not Exposed to TB**
Isolationville	51	44 (86.3)	170	34	79	57
Integrationville	85	73 (85.8)	271	21	73	177

The Health Census had four parts: (A) Household Characteristics, (B) Provisions, (C) Household Composition and Social Network, and (D) Health (see Appendix A). The (A) Household Characteristics portion of the census was partially based off of the data collected in Paraguay's Indigenous Census (DGEEC 2004). The materials the home was made of, the number of windows and rooms, and dimensions of the house and each room in meters were recorded. How many people were sleeping in each room was also noted. Other questions included type of garbage disposal, light source, water source, cooking fuel, latrine type, and material goods owned by the household. Respondents were also asked about their ethnicity, the number of languages they spoke, and to rate their ability in those languages as fair or good.

The (B) Provisions portion of the census was used to assess ownership of domestic animals, degree of participation in hunting, fishing, gathering, and agricultural activities and the types of resources that are exploited, and other sources of food. Respondents were asked to rate both the quantity and quality of the food consumed by their household. Because of the association between unpasteurized milk and TB, respondents were also asked about milk consumption.

In the (C) Household Composition and Social Network portion of the census, household members were asked to list the age and sex of all the people who lived in that household, their relationship to each other, their primary occupation, whether they had received the BCG vaccination, if they had ever worked with cattle, and whether they smoked. For additional social network data, respondents were asked what social groups each household member participated in and other locations they had previously lived or worked. The social groups included primary school (*escuela*), secondary school (*colegio*), traditional dancing and/or singing, the community council, dancing (*cachaca* or *chamame*), attending church, or playing sports (soccer for men and volleyball for women).

The (D) Health portion of the census noted any household members who currently or previously had TB, their date of diagnosis, date of cure, and how old they were during treatment. Respondents were then asked to list household members who had recent illnesses (in the last season), what the illness was, and what was done to treat it. Respondents were also asked, in general, who they go to for help in treating illnesses, where they got health information, and which sources of health information were trustworthy. Finally, they were asked to rate their access to health services in their community and list what they felt were the three most important health problems in their community.

The Health Census data were used to determine the sampling strategy to be used in the communities for later phases of the study and assessing the degree to which other sample data can be generalized to the community level.

(2) Ethnographic Interviews

Semi-structured ethnographic interviews were conducted with two healthcare workers, nine community members in Integrationville, and four community members in Isolationville. The demographic characteristics of the interviewees are presented in Table 6. Two lists of potential interviewees were generated based on the Health Census data: people who were currently TB patients or had previously been TB patients (TB history), and people who had not been TB patients (no TB history). An even number of men and women were randomly selected from each list. The interviews were conducted from November 2010 to May 2011.

Table 6. Demographic characteristics of interviewees

Community (# interviews)	% female	Average Age	% with individual history of TB	% with household history of TB
Integrationville (9)	56	39	56	67
Isolationville (4)	50	39	75	100
Healthcare workers (2)	--	--	--	--

The interview guide (see Appendix A) covered local beliefs about tuberculosis and the sick role, access to health care, nutrition, community history, and social networks. The interview questions about TB were based on Kleinman's explanatory model of disease (Kleinman, Eisenberg and Good 1978, Kleinman and Benson 2006) and additionally asked the interviewee to describe their own experience with TB (if they had been ill) or the experience of someone they knew who had been ill with TB. The sick role questions asked about help seeking, caregiving, and what a person can and cannot do when they are sick. The questions about access to healthcare are based on Obrist et al's (2007) framework for access to healthcare in contexts of livelihood insecurity. The nutrition questions involved a free-listing exercise for foods eaten in the community, their ingredients, and how they are prepared. Interviewees were given prompts based on time of day and particular events or occasions. The community history questions were used to establish a timeline of major events in the communities and what outsider groups had historically had interactions with the community. The social network questions were designed to discover what kinds of contact patterns existed in the community (i.e. organizations and activities that brought people together and migration to other areas).

(3) Household Survey – 2011

The Household Survey in July and August 2011 reached 94 households, 46 in Integrationville and 48 in Isolationville. The core modules of the survey that were completed by every household included a Household Composition module, a Social Network Survey module, a Vignettes module, and a Symptom Survey module (see Appendix A). Two optional modules that were randomly administered based on a coin toss were the TB Beliefs module and the 24 Hour Dietary Recall module.

For the Household Composition module, respondents were asked to list all the current occupants of the household, their mother and father, which inhabitants slept in the house the previous night and which room they slept in. For each occupant, the module also recorded whether they owned shoes or not (a risk factor for infection with hookworm) and whether they had a scar on their upper arm from the BCG vaccine (to verify earlier claims that the communities had 100% BCG vaccination coverage).

The Social Network Survey module asked participants to list 4 people who had (a) visited the house in the last week and shared food, (b) visited the house in the last week and shared maté or tereré, and (c) visited the house in the last week but did not share food or drink. For each visitor listed, the participant was asked the visitor's age, sex, and relationship to themselves (i.e. family (parent, sibling, cousin, in-law, etc.), friend, or neighbor). The research team then used that information to identify the household code the visitor belonged to.

In the Vignettes module, participants were asked a series of five randomly generated social response to illness vignettes. The vignettes were designed to determine which activities (sharing tereré, sharing food, or visiting) are allowable with different persons (with five varying degrees of closeness) when they have different illnesses (cough, vomiting, or fever). There are 45 possible combinations (3 x 5 x 3 = 45) to the vignettes.

The research team was able to visit every household in Isolationville, but due to logistic difficulties in transportation, weather, and illness in the research team, there was limited time to complete the household surveys in Integrationville. Therefore, a snowball sampling method was used to obtain as much data as possible on the members of the sampled contact network. Initial participants who came to the health post to participate in cheek swabbing, anthropometric measurements, and fecal sampling were visited in their homes to complete the survey in the weeks that followed. Once all the initial participants were contacted, visits were made to the homes of new contacts named by the initial participants in the Social Network Survey module. The process continued until data collection had to cease. This sampling strategy makes persons with biological samples the center of the network, and allows us to see the local network in which they are embedded.

The Symptom Survey module inquired if any household members were feeling ill on the day of the survey and then asked if they had any of a series of symptoms. Most of the symptoms on the list were indicators for TB or intestinal parasitosis, but there were also a couple to detect respondents who give false positive answers. The research team also took the temperatures of adult household members using a temporal artery scanning thermometer.

To incorporate official biomedical, local biomedical, and layperson models of TB, the TB Beliefs Survey was designed off of statements from published materials by the Ministry of Health and the earlier ethnographic interviews with laypersons and healthcare workers. The published materials included guidelines for healthcare workers and health education materials, like pamphlets, posters, and flip boards, to be distributed in communities. A series of statements about TB, to which a respondent could agree or disagree, were grouped by similarity of topic into causes, symptoms, treatment, prevention, and how to respond to someone with TB or how someone with TB should act. Some deliberately incorrect statements were invented to bring the expected balance of agreement and disagreement in the statements closer to 50:50. An initial pool of over 100 statements was narrowed down to 72 statements by keeping those that were mentioned most often during the interviews and eliminating those that were difficult to understand or translate into Nivaclé. One open-ended question at the end of the survey asked respondents where they learned about TB. The final survey was tested with two community members using the "think-aloud" method of cognitive interviewing (Beatty and Willis 2007) to identify any potential issues with comprehension of the statements and test for an even balance of positive and negative responses to the statements.

The 24 Hour Dietary Recall module asked participants to list all the foods they consumed the previous day. Then they are asked details about the ingredients, amounts, how the food was prepared, and its source (i.e. purchased from the store, gathered from the forest, etc.). This is sufficient information to assess the dietary intake of participants, which was of particular concern to community leaders.

(4) Household Survey – 2012

The Household Survey in October 2012 included questions from the Health Census and Household Survey from 2011. Again, sampling was restricted in Integrationville due to logistical difficulties, and only 26 households were able to participate in the sample. 51 households were surveyed in Isolationville.

The modules in the 2012 Household Survey included: Household Composition, Symptom Survey, Social Networks, Demography, Health Behaviors, TB Beliefs, Vignettes, and a 24 Hour Dietary Recall module. The Symptom Survey, Social Networks, and 24 Hour Dietary Recall modules were identical to the 2011 Survey. The Household Composition module was the same as in the 2011 Survey, but also updated any changes to the structure of the house and the rooms in which each household member slept from the 2010 Health Census, and also recorded any locations household members had traveled to in the previous year. The Demography questions updated information from the 2010 Health Census about language ability, non-indigenous household members, and material goods owned by the household. The Health Behaviors questions focused on solid fuel use, water source and treatment, hand washing, spitting, and sharing utensils. The original TB Beliefs module was cut down to just 20 questions, which represented the most variation in the 2011 responses. Instead of a randomized set of five vignettes, the 2012

Vignettes module asked respondents for their reaction to all 45 scenario combinations.

A reduced version of this survey, which did not collect identifying information, was used an additional two Nivaclé and two Angaité communities. This anonymous survey included only the Demography, Health Behaviors, TB Beliefs, and Vignettes modules from the full survey.

(5) Biological Samples: Cheek swabs, Fecal samples, & Anthropometric measurements

Cheek swabs, fecal samples, and anthropometric measurements were collected in Integrationville and Isolationville in 2011 and 2012, and an additional Angaité community in 2012. The 2011 samples were collected in July, and the 2012 samples were collected from September to November. Characteristics of the samples are displayed in Table 7.

Table 7. Characteristics of study samples, 2011-2012

Community & Year	Anthropo-metrics & cheek swabs	Fecal samples	Estimated total adult population	Total number of households	Fecal sample kit return rate	Proportion of female to male participants	Mean age (SD)
Integrationville 2011	47	46	271	85	97.9%	40:6	47.5 (±18.5)
Integrationville 2012	52	49	271	85	94.2%	44:5	49.0 (±14.9)
Isolationville 2011	97	81	170	51	83.5%	65:16	44.5 (±19.1)
Isolationville 2012	55	72	170	51	92.3%	64:8	39.1 (±14.5)
Angaite-ville 2012	32	31	Unknown	32	96.9%	18:13	42.3 (±16.0)

Initially, biological sample collection and anthropometric measurements took place at the homes of respondents during the Household Survey interviews. Unfortunately, the stadiometer began to show signs of wear after the first week of use because dust easily entered the joints during set-up and take-down. Another logistic difficulty was the availability of a field vehicle; the fecal sampling kits were too difficult to transport from house to house without reliable transport that could bring the research team reasonably close to the household. Therefore, cheek swabs, anthropometric measurements, and the distribution of fecal sampling kits were done altogether from a central location in the study community – either the health post or a school. The research team set a specific date for these activities and then went house to house to invite community members to come to the health post on that date and participate. On a few occasions the research team made a visit to a household for sample collection because a participant made a request on behalf of a family member who could not make the trip.

Cheek swabs were taken to assess exposure to *Mycobacterium tuberculosis*. DNA was extracted from the cheek swabs and quantitative PCR was used to identify SNPs (single nucleotide polymorphisms) exclusive to TB DNA. There were plans to further analyze samples positive for TB DNA for SNPs associated with particular strain types and antibiotic resistance, however only one positive sample was found over the study period.

Participants were provided with a fecal sampling kit to take home that included: a sample container with 10% formaldehyde, a pair of latex gloves, a small plastic spoon, a cardboard tray, and a Ziploc bag. Field assistants gave a demonstration of how the kit should be used to collect the fecal sample and participants were asked to return their sample as soon as possible to the health post, preferably the next day. The samples were stored in a health post fridge where possible, and I made a trip to the parasitology laboratories collaborating on the project (the lab at the Mariscal Estigarribia Regional Hospital in 2011, and the lab at the Universidad Pacifico in

2012) after waiting a few days to gather samples. Collaborating parasitologists examined the fecal samples for helminthes and enteric protozoa using concentration and flotation techniques.

Weight loss is one of the best indicators of active TB (Hurtado et al. 2003), but could also indicate another underlying medical condition or dietary deficiency. Anthropometric measurements involved recording the participant's weight without shoes a calibrated scale and measuring their height with a stadiometer. Body mass index (BMI) (weight/height^2) was calculated and, where possible, the percent change was compared over time.

(6) Time Allocation Observations

Time allocation studies are detailed observational measures of behavior, allowing researchers to describe role performance, social interactions, and activity budgets (Gross 1984). This technique has been useful in the study of health behaviors (Coreil 1991; Leatherman 1996; and Hurtado et al. 2006). Time allocation observations were conducted by Nivaclé field assistants who would observe households for 1.5 hours at a time as they went about their day. Every 10 minutes the observer would record who was present in the household, who was within 2 meter proximity of others, and what activity each individual was engaged in. The observer also kept a running tally of individuals coming to or going from the household's area and entering or leaving the house. A total of 39 households were observed in July and August 2011; 30 in Isolationville and 9 in Integrationville. Field assistants were given a schedule of randomized households that ensured observations took place at variable times of day, but no observations were done after dark.

(7) Health Records

The National Tuberculosis Program in Paraguay graciously allowed access to some of their data. And with permission from the *Regiones Sanitarias* (Regional Health Authorities), I was able to examine existing health records in the health posts in the study communities and was granted considerable leeway as a participant observer in the health regions' activities. I participated in workshops for healthcare workers, the movement of people (patients and healthcare workers) and things (medications and diagnostic samples) within the health region, and was given access to data repositories and staff. In Integrationville, I found health records that date back 25 years.

Ethical Considerations

Ethical oversight for this study was provided by the Human Subjects Institutional Review Board at Arizona State University and the Scientific Review Committee at the Fundación Moisés Bertoni in Paraguay. Permission to work in the study communities was solicited during in-person meetings with community leaders. Community leaders were presented with an overview of the study and, depending on the phase of the study, they were given a "Community Consent Form" they could sign as permission to work in the committee or they were asked to write a letter of permission for the research study. I offered to present myself and an overview of the study in a community meeting, so that community members could be made aware of the study and as a forum to answer questions about the study prior to its start. Only one community held a community meeting prior to the start of the study, but at some point community meetings were held in each community to give health education talks about TB and present preliminary results of the study.

In communities where identifying information or biological samples were requested of participants, a consent form providing an overview of the study and potential risks and benefits of participation was presented to individual participants for their signature. The consent form was written in Spanish, but audio recordings of the consent form in Spanish and Nivaclé were available for participants. A Nivaclé field assistant who was trained in research ethics was available to assist in translation and witness signatures for participants who were not literate. Multiple consent forms were used over the different phases of the study. In communities where no identifying information or biological samples were requested of participants, an informational letter providing an overview of the study and potential risks and benefits of participation was presented to individual participants. The informational letter was written in Spanish, but audio recordings in Spanish, Nivaclé, or Guaraní were available for participants.

TB is a highly stigmatized disease in some parts of the world, and while limited outright discrimination was observed during fieldwork, I was cautious to protect the privacy of current and former TB patients. Written records with the TB history of community members were coded and always kept in a locked location. The sampling strategies used in the study made an effort to include a large mix of people with and without a history of TB so that participants were blind to the TB history of other community members. The study communities are referred to by pseudonyms to further protect participants. Specifically, the main Nivaclé study communities described above are referred to as Integrationville and Isolationville, and the main Angaité study community is referred to as Angaité-ville.

The study made an effort to partner with and strengthen existing healthcare infrastructure in the study communities. Participants who were symptomatic for TB were immediately referred to their local health post for diagnosis and treatment, and participants who tested positive for intestinal parasitosis during fecal sampling were provided with free treatment through their local health post. I gave health education talks about TB and intestinal parasitosis and provided health education materials to the health posts in Integrationville and Isolationville. My close association with the health posts in Integrationville and Isolationville may have led some community members to believe that I was an employee of the local health region, but I made an effort to introduce myself as an independent investigator who was working in partnership with local healthcare workers.

Three Case Studies

The following three chapters present case studies selected from data collected in the overall project. They examine the disease ecology of TB in the Chaco through three major lines of inquiry:

(1) Does isolation affect the cultural transmission of biomedical knowledge about TB?

Learmonth (1988) stressed that in order to obtain a global view of disease "…we must add, too, the world of ideas, of the exchange of ideas, of communication and diffusion of ideas […]". Biomedical knowledge of TB by laypersons is important to promote symptom detection, treatment seeking and adherence, and reducing social stigma. To address the guiding question of this study – how horizontal cultural transmission affects TB disease ecology – we must first ask: to what degree is effective horizontal cultural transmission taking place?

Hypothesis 1 predicts that communities with greater integration with Paraguayan society will have greater awareness of biomedical models of health and disease, particularly biomedical models of TB. Using the cross-sectional 2011 TB Beliefs survey data from Integrationville and Isolationville, I compared the relative degree of adherence to biomedical models of TB in these communities, as well as the TB beliefs of local healthcare workers – the mediators in the transmission of biomedical knowledge.

(2) Is there a high prevalence of intestinal parasites in this region that could increase the risk of developing active TB?

Macroparasites stimulate the Th2 branch of the immune system at the expense of the Th1 branch, which deals with microparasites like TB. Thus, a high prevalence of enteric macroparasites like helminths and protozoa may decrease the efficacy of the BCG vaccine and promote the development of active TB (Elias 2001, 2006, Resende Co et al 2006).

Hypothesis 2 predicts that more integrated communities will have better public health infrastructure, including health posts and hygienic facilities like wells and latrines. And a corollary prediction of this hypothesis is that, in more integrated communities, there will be a decreased risk of disease from the built environment because of better infrastructure (i.e. more latrines and cleaner water sources) and the prevalence of intestinal parasites will be lower in these communities.

This paper uses cross-sectional and longitudinal data from the fecal samples and the health behavior and sanitation data from the 2011 and 2012 surveys in Isolationville, Integrationville, and Angaité-ville to examine the prevalence of intestinal parasites in indigenous communities in the Chaco and the overall hygienic environment (like sanitation infrastructure and the adoption of health behaviors like hand washing).

(3) What are the major risk factors for active TB at the community level?

The final case study uses data on TB cases in indigenous communities of the Chaco from 2002 to 2004 from the National TB Program and the most recent Indigenous Census data from 2002 (DGEEC 2004), to assess the community- level risk factors from the social and built environment. Many of the risk factors examined relate to the better public health infrastructure expected in **Hypothesis 2**, such as the presence or absence of a health post, water source, and housing quality. Other factors include remoteness and the presence of non-indigenous community members, which both influence the degree of contact with outside groups. This paper also assesses the indigenous burden of TB in the Chaco compared to non-indigenous residents, and breaks down the burden of disease by linguistic family.

CHAPTER 2

CULTURAL TRANSMISSION, ISOLATION, AND CULTURAL MODELS OF TUBERCULOSIS IN TWO NIVACLÉ COMMUNITIES

Abstract

Indigenous communities in the Paraguayan Chaco are a high transmission setting for tuberculosis (TB) in Paraguay. The successful treatment of TB is contingent on early diagnosis and sustained participation in a long and difficult treatment regimen; thus layperson knowledge of TB is important for the identification of symptoms, willingness to seek and persist in treatment, and the reduction of social stigma of TB patients. This study examines the degree to which community members endorse biomedical models of TB, and how this is related to community isolation, TB history, age, sex, and acculturation. The results suggest that endorsement of biomedical models is unrelated to any of these predictors.

Introduction

Tuberculosis (TB) is an infectious disease that primarily affects the lungs, and can result in death without proper long-term treatment. The World Health Organization estimates that one third of the world population is latently infected by the bacterium, but only about 5-20% of those infected develop active disease (WHO 2013a). The progression to active disease is precipitated by a weakened immune system, often the result of malnutrition, co-infections (like HIV/AIDS), or being very young or old. Those who develop active disease in their lungs can further spread the bacterium to others, particularly in poorly ventilated, enclosed spaces where many people share the same air. TB is characterized as a social disease because it clusters in poor communities where poor housing, crowding, malnutrition, and exposure to co-infections promote the transmission of the bacterium and development of active TB disease.

Indigenous communities in the Gran Chaco region (hereafter referred to as "the Chaco") are one of two high transmission settings for TB in Paraguay (the other being the Tacumbú jail in Asunción) (Candia et al. 2007). The Chaco is a sparsely populated, semi-arid plain of grasslands and thorny forests that extends across Western Paraguay and home to 15 indigenous ethnic groups belonging to five different linguistic families (Renshaw 2002). Historically these peoples were semi-nomadic or nomadic hunter-gatherers, fishermen, and horticulturalists, but now they are settled in communities and largely dependent on wage labor or subsistence farming. The Chaco is a precarious ecosystem, and periodic droughts and flooding cause shortages of food and water in indigenous communities. The most recent data on Unsatisfied Basic Needs (housing quality, sanitation infrastructure, access to education, or capacity for subsistence) from 2002 report 73.2% of urban and 90.3% of rural households in the Chaco region had at least one basic need unsatisfied (DGEEC 2005). From 2008 to 2009, the Chaco region had a TB incidence rate of 136.5 per 100 000 inhabitants, compared to 32.7 per 100 000 inhabitants in Eastern Paraguay (Ministerio de Salud Pública y Bienestar Social 2010).

Due to transportation and communication challenges, the Chaco is an isolated region. Aside from the paved TransChaco highway and roads within the Mennonite colonies, communities in the Chaco are connected by dirt roads that become impassible in the rain. Communities can be cut off from contact for several weeks during flooding. Electricity and cell phone service are slowly penetrating into the more remote parts of the Chaco. Remote villages communicate with the outside world through HAM radios, and information about what is going on in other parts of the world mostly filters in through AM radio stations like Radio Pa'i Puku. The isolation of indigenous communities limits access to healthcare and opportunities for health education. Slightly less than half (45.2%) of indigenous communities in the Chaco have their own health post (DGEEC 2004), and these vary considerably in terms of facilities and staffing.

The successful treatment of TB is contingent on early diagnosis and sustained participation in a difficult treatment regimen that lasts a minimum of six months; thus the general public's knowledge of TB is important for several reasons:

(1) The ability to identify symptoms.

The early symptoms of pulmonary TB (cough, fatigue, night sweats, and weight loss) are often confused with other respiratory disorders and extrapulmonary TB (an infection localized outside the lungs, in the bones or soft tissue) is difficult to diagnose (Storla, Yimer, and Bjune 2008, Rubel and Garro 1992). Public health programs in Paraguay urge citizens to go to their local health post to do a sputum test for TB if they have sustained a cough for two weeks and it is not improving.

(2) Willingness to seek treatment and persistence in the treatment program.

New patients are enrolled in a DOTS (Directly Observed Treatment Short-course) program, which minimally requires six months of daily pills taken under the direction of a healthcare worker (Munro et al 2007). The DOTS treatment programs are intensive and can be difficult to adhere to because they require a significant investment of time, the costs or indirect costs of treatment (for example, travel to and from clinics, or patients may be unable to work and support their families during treatment), patients may face social stigma, and the antibiotics have unpleasant side effects (Storla, Yimer, and Bjune 2008, Munro et al 2007, Rubel and Garro 1992).

Once patients feel relief from their symptoms, they may fail to see the value in continuing the treatment regimen and stop taking the pills before completing the regimen (Kaona et al 2004). Patients who relapse after incomplete treatment regimens are likely to have antibiotic resistant strains of TB (Munro et al 2007, Rubel and Garro 1992). Resistant cases of TB require DOTS treatment for one year or longer and patients may have to take second or third line anti-TB drugs, which are more expensive and have worse side effects.

(3) The social acceptance of TB patients.

Social stigma, stemming from fear of contagion or suspicion of a fault in character associated with the disease, can cause TB patients to be socially excluded in their communities (Cramm et al 2010, Munro et al 2007, Kaona et al 2004, Rubel and Garro 1992). TB sufferers may become unwilling to seek diagnosis or treatment because they are fearful of identification with the disease and social exclusion. Where strong social stigma exists, TB patients who are unable to look after themselves or their families may be left without caregiving or other social supports in the community.

This study draws from a cognitive anthropology approach to culture as a set of beliefs and behaviors learned and shared within a group of people (D'Andrade 1995, Romney et al 1996). This approach has spawned a series of analytical techniques designed to assess the degree to which cultural beliefs are shared within and across communities (for example: Romney, Weller, Batchelder 1986, Romney, Batchelder, and Weller 1987, Weller and Baer 2002, Weller 2007, Hruschka et al 2008, Mueller and Veinott 2008, Batchelder and Anders 2012, Anders and Batchelder 2012, Oravescz, Vandekerckhove and Batchelder 2014, Oravecz, Anders and Batchelder 2013, Oravecz, Faust and Batchelder 2014). Cultural models can shift over time and through cultural transmission - the adoption of new beliefs or behaviors through exposure to another cultural model. The goal of health education activities is to encourage the incorporation of biomedical beliefs and practices into layperson models of health and disease.

The official biomedical model of TB in Paraguay can be considered the published guidelines for healthcare workers and health education materials prepared for distribution by the Ministry of Health. As the transmission of information is not expected to have perfect fidelity, we can expect local healthcare workers to vary in their adherence to the official model of TB. Further to this, during health education activities, laypersons will adopt the model presented by local healthcare workers to variable extents. Factors influencing how laypersons adopt biomedical beliefs may include their community of residence (degree of isolation) and personal experience with TB, as well as age, sex, and degree of acculturation to national society (for example, Kaona et al 2004, Punchak et al 2013, Rubel and Moore 2001). Each of these factors is related to the degree of exposure an individual might have to biomedical models and to various competing models for TB, through access to information and personal experience. Thus, one can expect an official biomedical model, a local biomedical model, and various layperson models of TB.

This study addresses the effective cultural transmission of official communications from the Ministry of Health on local biomedical and layperson models of tuberculosis in two Nivaclé communities with differing degrees of isolation. It examines differences between the biomedical and community models, as well as influences from past experience with TB, age, sex, and degree of acculturation. It asks: How well is biomedical knowledge transmitting to isolated communities? And what are the best predictors of adherence to biomedical beliefs?

Methods

Oversight for this study was provided by the Arizona State University Office of Research Compliance and Assurance in the United States and the Fundación Moisés-Bertoni Scientific Review Committee in Paraguay.

Study communities

Data collected by the Boquerón Health Region show that from January 2008 to June 2009, 73 of the 112 TB cases (65%) reported to the regional hospital in Mariscal Estigarribia occurred in Nivaclé individuals (Mariscal Estigarribia Regional Hospital, unpublished data). Two Nivaclé communities, denoted by the pseudonyms Integrationville and Isolationville, were chosen to represent a community with greater exposure to outside institutions and a more isolated community, respectively. Integrationville (85 households), which is home to a church mission and is visited by a private bus line twice a week, has a history of 2-3 TB cases per year over the last decade. In contrast, Isolationville (51 households), which has more limited interaction with outside groups and is not accessible by bus, has at times had 10-15 TB cases in a single year. Both communities have health posts, but the health post in Integrationville is much better staffed, in terms of professional qualifications and number of personnel, and has much better equipment.

Survey design

To incorporate official biomedical, local biomedical, and layperson models of TB, the TB Beliefs Survey was designed based on a series of 15 semi-structured interviews conducted with laypersons and healthcare workers in Integrationville and Isolationville from November 2010 to May 2011, as well as materials published by the Ministry of Health. Interview questions about TB were based on Kleinman's explanatory model of disease (Kleinman, Eisenberg and Good 1978, Kleinman and Benson 2006) and additionally asked the interviewee to describe their own experience with TB (if they had been ill) or the experience of someone they knew who had been ill with TB. Two lists of potential interviewees were generated based on census data from November 2010: people who were currently TB patients or had previously been TB patients (TB history), and people who had not been TB patients (no TB history). An even number of men and women were randomly selected from each list. The researcher and a Nivaclé field assistant trained in interview techniques conducted the interview in the language of the interviewee's preference, directly with the researcher in Spanish or in Nivaclé with translation assistance from the field assistant. See Table 8 for the demographic characteristics of the interviewees.

Table 8. Demographic characteristics of interviewees

Community (# interviews)	% female	Average Age	% with individual history of TB	% with household history of TB
Integrationville (9)	56	39	56	67
Isolationville (4)	50	39	75	100
Healthcare workers (2)	--	--	--	--

Published materials from the Ministry of Health included guidelines for healthcare workers and health education materials to be distributed in communities. The latter were in the form of pamphlets, posters, and flip boards.

A series of statements about TB, to which a respondent could agree or disagree, were drawn from the interview transcripts and materials published by the Ministry of Health. The statements were grouped by similarity of topic into causes, symptoms, treatment, prevention, and how to respond to someone with TB or how someone with TB should act. Some deliberately incorrect statements were invented to bring the expected balance of agreement and disagreement in the statements closer to

50:50. An initial pool of over 100 statements was narrowed down to 72 statements (see Appendix A) by keeping those that were mentioned most often during the interviews and eliminating those that were difficult to understand or translate into Nivaclé.

Of the final 72 statements on the TB Beliefs Survey, a subset of 38 statements could be verified by the official biomedical model (documents published by the Ministry of Health) and 34 were statements unique to the interviews that could not be verified. One final open-ended question on the survey asked respondents where they learned about TB, and each survey collected the age and sex of respondents. The survey was translated and back-translated between Spanish and Nivaclé three times by a pair of Nivaclé field assistants before a satisfactory wording of the statements was reached. The final survey was tested with two community members using the "think-aloud" method of cognitive interviewing (Beatty and Willis 2007) to identify any potential issues with comprehension of the statements and test for an even balance of positive and negative responses to the statements.

Data collection

The TB Beliefs Survey was a module of a larger survey that attempted to reach every household in Integrationville and Isolationville in July and August 2011. The TB Beliefs module was alternated with another survey module; during the household survey the researchers flipped a coin to determine which of the modules they would administer. The research team visited all occupied households in Isolationville, but unanticipated logistic difficulties in the field made it impossible to sample every household in Integrationville. In Integrationville the researchers used a respondent-driven sampling strategy that was guided by a Social Network Elicitation module on the household survey – thus there may be some bias in that many of the houses surveyed had a social connection to another. The statements were read aloud to respondents in the language of their preference (Spanish or Nivaclé). Often, if more than one adult was present they would jointly respond to the survey. On the rare occasion when they disagreed on the response to a statement, the response given by the person who was recorded as the primary respondent to the household survey was accepted. See Table 9 for the characteristics of the TB Belief Survey sample. The research team also surveyed four local healthcare workers in Integrationville and Isolationville to represent the Local Biomedical model of TB. The healthcare worker interviewees were encouraged to elaborate on why they agreed or disagreed with a statement on the survey.

Three measures of acculturation from census data collected in November 2010 could be matched to the households that participated in the TB Beliefs Survey: language skill, migration, and non-indigenous household members. During the census, participants were asked what languages they spoke and to rate their skill level in each language as fair or good. Typically there was a progression in the acquisition of languages from Nivaclé, then Spanish, and then Guaraní. Respondents were assigned a language score by adding 1 point for every language spoken well and 0.5 points for every language spoken fair. Migration was sorted into respondents who had not left their community, respondents who had a household member travel to work on a cattle ranch, and respondents who had a household member travel to an urban area in the last year. If a household member had traveled to both a ranch and urban area in the last year they were scored under the urban area category. The final variable was scored as the presence or absence of a non-indigenous household member (a spouse who married into the community). The acculturation measures were not available for six households (two in Isolationville and four in Integrationville) who did not participate in the census.

Data cleaning

Sometimes, rather than agreeing or disagreeing, a respondent would say "I don't know" to a statement. The research team would encourage them to guess, but in many cases respondents were reluctant to do so. Most imputation procedures would randomize these missing values with 50:50 odds (Weller 2007), however, Nivaclé respondents were noted to have a predilection for agreeing with statements that fall within the realm of the possible, no matter that they might be improbable. For example, when musing on the statement "People with tuberculosis have spots on their skin", a respondent commented that he knew one man who had TB and also had spots on his skin; thus this may in fact be a symptom of TB even though this is the only case he is aware of. In order to account for the missing values without distorting underlying trends in responses, a matrix of responses for each community was passed through a function in R statistical software (version 2.15.2) (R Core Team 2014) that randomly replaced the missing values with weighting based on the proportion of agreement and disagreement observed in other responses to the same statement. The proportion of responses that were "I don't know" and had to be imputed were 3.47% in the Integrationville data set and 5.02% in the Isolationville data set. Two of the respondents from Isolationville responded "Yes" to all of the 72 statements on the TB Beliefs Survey, and on the subset of 38 published statements, ten respondents from Isolationville and two respondents from Integrationville responded "Yes" to all of the statements. These surveys were removed from further analysis. Demographic details of these excluded surveys are included in Table 9.

Analysis

Within and between group agreement

Responses to the statements in the TB Beliefs Survey were entered into a profile matrix with rows of respondents and columns of their answers to each of the 72 statements (1 = agree, 0 = disagree). Then, using the Bayesian Cultural Consensus Toolbox (BCCT version 2) (Oravecz, Vandekerckhove, and Batchelder 2014), parameters for a cultural consensus model with dichotomous data, a homogenous degree of difficulty in the statements, and heterogeneous guessing bias and competency (how well respondents agree with one another) in respondents were estimated using a Bayesian framework. A Bayesian approach is advantageous over other analytical methods because it allows the relaxation of assumptions about the heterogeneity of competence, guessing bias, and item difficulty (Karabatos and Batchelder 2003).

To assess the degree of within and between group agreement in the layperson models of TB, Bayesian cultural consensus parameter estimations were performed on all 56 of the layperson respondents combined, and on laypersons grouped by community (26 from Isolationville and 30 from Integrationville) and TB history (27 with a history of TB and 29 with no history of TB). For each estimation, the Markov Chain Monte Carlo (MCMC) sampler was set to the default 1000 samples for adaptation, 1000 iterations for the final posterior samples, and six chains. Because the responses had very high proportions of ‘yes’ answers (see Table 9), a thinning procedure, where only every k^{th} sample is retained, was used in each estimation to ensure adequate representation of the posterior density in the sample and keep the level of autocorrelation below 0.3. The k value was set to 7 for Integrationville, 26 for Isolationville, 5 for TB history, 32 for no TB history, and 14 for all the respondents together.

To assess the degree to which respondents draw from a single cultural model, the ratio of the first and second eigenvalues of a covariance matrix of the informants' responses was examined (Hruschka et al 2008). As a rough guideline, if the eigenvalue ratio is less than three, the single culture assumption is most likely violated. BCCT calculates the eigenvalue ratio from the raw data, and then conducts a posterior predictive check of the one underlying culture assumption, to assess whether the raw data eigenvalue ratio falls within the 95% posterior predictive distribution of simulated values (Batchelder and Anders 2012).

The between group agreement for the layperson models can be calculated algebraically by weighting the subgroup agreements by the proportion of observations they contribute to the total, and subtracting this from the agreement level for all respondents (Weller and Baer 2002). The average competence of respondents (one of the values returned by BCCT) squared is equal to the average Pearson correlation coefficient for that group – which is interpreted as the degree of shared knowledge within that group.

Model fit was assessed using the Bayesian p-value and Deviance Information Criterion (DIC) returned by BCCT. The Bayesian p-value represents the global fit of the CCT model to the data (Karabatsos and Batchelder 2003). Low p-values (< 0.05) indicate a poor fit of the current data, under the assumption that the model is correct. The DIC evaluates the relative goodness-of-fit of the model in terms of complexity (applying penalties for higher numbers of parameters) and deviance (Karabatsos and Batchelder 2003). A lower DIC value is preferred.

Correlation between biomedical and layperson answer keys for TB

Answer keys – the culturally correct responses for each statement – were calculated for the healthcare workers (Local Biomedical model, n = 4), each community (Isolationville, n = 26 and Integrationville, n = 30), and each TB history grouping (TB history, n = 27 and no TB history, n = 29) by averaging the responses to each statement across all the respondents in that grouping. Rather than using the modal responses (which would code as 0 or 1, representing the substance of the general response), using the average responses (ranging from 0 to 1) better preserves the salience of different statements for the respondents.

An answer key for the Official Biomedical model was assembled from the information given in published materials from the Ministry of Health. As only 38 of the 72 statements in the TB Beliefs Survey were drawn from published materials, the Official Biomedical answer key does not extend to the other 34 statements that were drawn from interviews with laypersons and local healthcare workers.

To compare how well each grouping compared with each other, as in, how closely their answer keys approximated each other, we examined correlations between each of their answer keys using R statistical software (version 3.1.1) (R Core Team 2014). The comparison was made at two levels: (1) the Official Biomedical, Local Biomedical, Isolationville, Integrationville, TB history, and no TB history answer keys were compared for the set of 38 published statements, and (2) all the models except for the Official Biomedical model were compared for the complete set of 72 statements about TB.

Statement comparisons

To determine whether the responses to particular statements were different across the models, subgroup differences in their proportion of "yes" responses to each statement were tested (Hruschka et al 2008). For the 72 statements, a Bonferroni-corrected Fisher's exact test was used to compare (1) Isolationville and Integrationville, and (2) TB history and no TB history (adjusted alpha = 0.05 / (72 x 2) = 0.0003472). The Local Biomedical model was compared to the community and TB history subgroups with a Bonferroni-corrected binomial test of proportions, to indicate where statements in the four layperson models were significantly different from the proportion expected in the Local Biomedical model (adjusted alpha = 0.05 / (72 x 4) = 0.0001736).

Given the high overall proportion of "yes" responses in the layperson models, which make up 89% or more of the responses in the layperson models (see Table 9), there is not much variation for assessing agreement. The high proportion of "yes" responses, which may be more representative of high guessing bias in the layperson models than actual knowledge, may lead to falsely inflated levels of agreement with the biomedical models on "yes" responses. Thus, to set a strict criterion for agreement, significant agreement across models is limited here to instances of universal agreement – where all respondents gave the same response to a statement – using the original responses before the "I don't know" answers were imputed.

To compare statements across the Local Biomedical and Official Biomedical models, the answer keys were placed side by side and examined for divergence. In addition, statements where the local healthcare workers were undecided (50:50) in their mean response were examined in light of statements made during their interviews.

Regression analysis

The degree to which individual respondents draw from the biomedical model was determined by calculating the correlation between their response pattern and the Local Biomedical answer key for the full 72 statements. To determine which factors best accounted for biomedical knowledge, linear multiple regression was performed with individual correlations to the biomedical model as the dependent variable, and age, presence of a male (0 = all female, 1 = male present), TB history (0 = no history of TB, 1 = TB history), and three acculturation measures as independent variables. Acculturation was represented by language skill (a scale that starts at 1 and increases in increments of 0.5), having a non-indigenous household member (0 = all indigenous, 1 = at least one non-indigenous household member), and migration in the last year (0 = stayed in the community, 1 = traveled to a cattle ranch, 2 = traveled to an urban area). This procedure was repeated for individual correlations with the Local Biomedical model on the 34 statements drawn from interviews, and the Local and Official Biomedical models on the 38 statements drawn from published materials. The models were examined for multicollinearity and goodness-of-fit.

Statistical hypotheses for regression analysis

One would expect that with greater isolation there would be decreased biomedical knowledge in the community; therefore residence in Integrationville should predict better biomedical knowledge than residence in Isolationville. Women are generally more involved in caregiving, and thus we would expect them to have greater biomedical knowledge than men. Younger adults have typically had more educational opportunities, and should have greater biomedical knowledge than their seniors. And finally, greater acculturation, in terms of greater language ability and migration for wage labor to the cattle ranches and urban centers, should be associated with greater adoption of biomedical knowledge. Significant results for the regression analysis were based on an alpha of 0.05.

Results

Survey sample characteristics are presented in Table 9. The respondents from Isolationville were, on average, a little older than the respondents from Integrationville, had more men present at the interviews, and had a higher rate of TB history in the household, but none of these differences are statistically significant ($p > 0.05$). The only significant difference between the discarded “All Yes” and remaining surveys, for the complete 72 statements and 38 published statements only, was that a greater proportion of the discarded surveys were from Isolationville ($p < 0.01$).

The proportion of ‘yes’ answers in the answer keys is very high for all the layperson models (>89% for all subsets, see Table 9), which means that the models may be skewed by limited variance across statements and respondents. The proportion of ‘yes’ answers is 60% in the Local Biomedical answer key and 45% in the Official Biomedical answer key.

Comparison of biomedical models

When comparing the subset of 38 statements that can be verified in Ministry of Health documents, the correlation between the answer keys for the Official and Local Biomedical models is only 0.68 (see Table 10). Most of the difference between the Official and Local Biomedical answer keys is caused by nine statements where the healthcare workers were split evenly between agreeing and disagreeing (see Table 11). Three undecided statements are related to maintaining a hygienic environment in the household, which may support general health though they are not activities specific to preventing tuberculosis. Four undecided statements are related to TB symptoms, which might be expected, considering the variable presentation of the disease. Although, since cases of extrapulmonary TB are not unusual in these communities, it is surprising that the statement "All people with tuberculosis have a cough" was divided in opinion. The other three symptoms that were undecided by the healthcare workers: head pain, lack of will to eat, and sputum quantity, were described in line with the healthcare workers' personal experiences with TB patients in the communities, and would likely not interfere with diagnosis.

Table 9. TB Belief Survey sample characteristics

Grouping	n	Mean age	% male present	% household TB history	% 'Yes' responses
Healthcare workers	4	--	--	--	63
72 statement analysis					
Integrationville	30	40.9	6.7	40.0	91
Isolationville	26	45.2	19.2	57.7	89
Both communities	56	42.9	12.5	48.2	90
TB history	27	44.0	6.9	100	91
No TB history	29	41.7	18.5	0	89
38 statement analysis					
Integrationville	28	41.5	7.1	42.9	90
Isolationville	20	44.0	25.0	55.0	92
Both communities	48	42.5	14.6	47.9	91
TB history	23	40.0	21.7	100	92
No TB history	25	44.9	8.0	0	90
Discarded "All Yes" surveys					
72 statements (all Isolationville)	4	45.5	50.0	25.0	100
38 statements (10 Isolationville, 2 Integrationville)	12	45.2	16.7	41.7	100

Table 10. Correlations between the Official Biomedical Model, Local Biomedical Model, and Layperson answer keys for tuberculosis (TB) in Nivaclé communities on 38 published statements

	OFFICIAL BIOMEDICAL	LOCAL BIOMEDICAL	INTEGRATION-VILLE	ISOLATION-VILLE	NO TB HISTORY	TB HISTORY
OFFICIAL BIOMEDICAL	1	--	--	--	--	--
LOCAL BIOMEDICAL (n = 4)	0.68	1	--	--	--	--
INTEGRATIONVILLE (n = 28)	0.03	0.29	1	--	--	--
ISOLATIONVILLE (n = 20)	0.23	0.55	0.51	1	--	--
NO TB HISTORY (n = 24)	0.13	0.39	0.97	0.66	1	--
TB HISTORY (n = 24)	0.06	0.41	0.92	0.78	0.92	1

Table 11. Undecided statements in the Local Biomedical answer key

Category	**Official Biomedical Answer Key**	**Statement**
Symptom	True	People with tuberculosis have head pain.
Symptom	True	People with tuberculosis have no will to eat.
Symptom	False	People with tuberculosis don't have much sputum.
Symptom	False	All people with tuberculosis have a cough.
Cause	False	Tuberculosis is caught from garbage.
Cause	True	Tuberculosis is caught from talking to a person who has the illness.
Cause	False	Tuberculosis is caught from a dirty house.
Prevention	False	Tuberculosis can be prevented by using dishes that are washed well.
Sick role	False	A person with tuberculosis should not share drinks.

There was only one statement where the modal response of healthcare workers disagreed with the official biomedical model: “You can share tereré with people who have tuberculosis.” Tereré and maté are the cold and hot versions of a communal herbal drink that is shared from the same cup and straw in social settings. Sharing tereré and maté is important to the social fabric in Paraguay; it can be shared among family, friends, or even with strangers. In the study communities, tereré or maté were consumed throughout the day – morning, noon, and evening. The official position of the Ministry of Health is that tereré and maté can be shared with TB patients without risk of infection, but only one healthcare worker out of four agreed that the drink could be shared. Research has shown that TB can be transferred from inanimate objects (fomites) (Kramer, Schwebke, and Kampf 2006, Agerton et al 1997), and the contact of multiple mouths with the same drinking straw would support that kind of transmission. However, if the TB patient is receiving adequate treatment, they should no longer be infective (Dye and Williams 2010). It is interesting that the statement "A person with tuberculosis should not share drinks" was undecided (50:50) by the healthcare workers, but the explicit mention of tereré in the statement caused three of the four healthcare workers to disagree with sharing.

Sources of knowledge about TB

Respondents from Isolationville reported a greater diversity of sources of information about TB than those in Integrationville (see Table 12). Most respondents in Integrationville reported 'school' as the source of their knowledge of TB, while the most popular answer in Isolationville was a 'healthcare worker' for more than half of respondents. During the study period, health classes in the local high schools were taught once a week by one of the healthcare workers; thus there may be no distinction between learning about TB from healthcare workers or in schools. Respondents who learned about TB through 'media' described watching an informational video about TB while working in the Mennonite colonies and hearing an ad on the radio. The 'healthcare worker training' cited by respondents in Isolationville was typically a midwifery course (there are several *parteras empíricas* in both communities), although a few retired or partially trained health promoters also made up the sample. Interestingly, only respondents from Isolationville considered ‘observing or knowing a TB patient’ to be a source of knowledge about TB.

Table 12. Sources of knowledge about tuberculosis

Community	Healthcare Workers	School	Media	Healthcare worker training	Observed a tuberculosis patient
Isolationville	58.1%	16.1%	3.2%	19.4%	9.7%
Integrationville	30.0%	80.0%	--	--	--

Comparison of layperson models

The eigenvalue ratios of the layperson models are all less than 3 and violate the single culture assumption, except for the Isolationville and Integrationville subsets (Table 13). The average competence of respondents is low across the board except for Integrationville, and the wide 95% confidence intervals for all the subgroups suggest that respondents are drawing from multiple cultural models of TB (Table 13). The between group agreement for Isolationville and Integrationville was calculated to be 0.05, and the between group agreement between those with and without a TB history was calculated to be 0.17. In accordance with the high proportion of ‘yes’ answers, the mean guessing bias for each subset was very high, ranging from 0.82 in the no TB history subset to 0.90 in the TB history subset (Table 13).

Table 13. Measures of within group agreement for the full 72 question survey

Group	Eigenvalue ratio	Posterior Probability Check	Average competence (95% CI)	Average Pearson correlation coefficient	Mean Guessing Bias (95% CI)
Both communities (n = 56)	1.73	fail	0.43 (0.18-0.73)	0.18	0.88 (0.56-0.98)
Isolationville (n = 26)	5.35	pass	0.41 (0.07-0.79)	0.17	0.86 (0.49-0.98)
Integrationville (n = 30)	8.59	pass	0.65 (0.21-0.94)	0.42	0.79 (0.33-0.98)
TB history (n = 27)	1.89	fail	0.39 (0.15-0.57)	0.15	0.90 (0.62-0.98)
No TB history (n = 29)	1.80	fail	0.47 (0.17-0.88)	0.22	0.82 (0.41-0.98)

To what extent does community membership affect biomedical knowledge?

The community answer keys correlate poorly with the Official Biomedical model and somewhat better with the Local Biomedical model (see Table 10). In both cases, Isolationville has more in common with the biomedical models. When comparing the full 72 statements in the TB Beliefs survey, the answer key for Isolationville has a much stronger correlation with the Local Biomedical model than Integrationville (see Table 14).

To what extent does TB history affect biomedical knowledge?

Answer keys for respondents with and without TB history correlate poorly with the Official Biomedical model and somewhat better with the Local Biomedical model (see Table 10). Notably, the answer key for respondents without TB history correlates highly with the answer key for Integrationville, and the answer key for respondents with TB history correlates highly with the answer key for Isolationville. Since 15 of 26 respondents (57.7%) in Isolationville and 12 of 30 respondents (40.0%) in Integrationville had a TB history, this relationship is not surprising. When comparing the full 72 statements of the TB Beliefs Survey, the answer keys for the respondents with and without TB history draw on the Local Biomedical model approximately equally; they perform less well than the answer key from Isolationville, but much better than the answer key for Integrationville (see Table 14).

Table 14. Correlations between Local Biomedical Model and Layperson answer keys for tuberculosis (TB) in Nivaclé communities on 72 statements drawn from interviews and official documents

	LOCAL BIOMEDICAL	INTEGRATION-VILLE	ISOLATION-VILLE	NO TB HISTORY	TB HISTORY
LOCAL BIOMEDICAL (n = 4)	1	--	--	--	--
INTEGRATIONVILLE (n = 30)	0.23	1	--	--	--
ISOLATIONVILLE (n = 26)	0.60	0.40	1	--	--
NO TB HISTORY (n = 29)	0.47	0.90	0.73	1	--
TB HISTORY (n = 27)	0.45	0.82	0.83	0.93	1

What factors best account for better knowledge of the biomedical models?

The results of adjusted linear multiple regression models for individual correlation with (1) the full 72 statements of the Local Biomedical model, (2) only the 34 unofficial statements of the Local Biomedical model, (3) only the 38 official statements of the Local Biomedical model, and (4) only the 38 official statements of the Official Biomedical model are shown in Table 16. Neither of the models examining adherence to the official Ministry of Health statements on TB, either agreement with local healthcare workers or agreement with the official answers, was significant ($p > 0.05$). None of the factors investigated here are significant predictors for adoption of the official biomedical model.

Table 15. Regression analysis sample characteristics

Grouping	n	Mean age	% male present	% Isolation-ville	% household TB history	Mean language skill	% non-indigenous household member	% migration to cattle ranches	% migration to urban areas
72 Statements (Interview & Published)	50	42.4	14.0	48.0	54.0	2.0	6.0	20.0	58.0
34 Statements (Interview only)	47	42.4	14.9	46.9	53.2	2.0	6.4	17.0	61.7
38 Statements (Published only)	39	42.2	18.0	46.1	51.3	2.0	7.7	23.1	48.7

Table 16. Linear regression models for biomedical knowledge of tuberculosis, NS = Non-significant with alpha set at 0.05, aR^2 = Adjusted R^2

Predictor Variables	**Local Biomedical 72 Interview & Published Statements**		**Local Biomedical 34 Interview Statements Only**		**Local Biomedical 38 Published Statements Only**		**Official Biomedical 38 Published Statements Only**	
	ß	**p-value**	**ß**	**p-value**	**ß**	**p-value**	**ß**	**p-value**
Community	-0.08	NS	**-0.20**	**<0.05**	0.04	NS	-0.08	NS
Tuberculosis history	-0.01	NS	-0.02	NS	-0.00	NS	-0.02	NS
Mean age	0.00	NS	0.00	NS	0.00	NS	-0.00	NS
Male present	0.10	NS	0.09	NS	0.05	NS	0.00	NS
Non-indigenous	-0.04	NS	0.06	NS	-0.03	NS	0.01	NS
Language skills	**-0.10**	**<0.05**	-0.13	NS	0.00	NS	0.02	NS
Migration - Ranches	**-0.16**	**<0.05**	-0.16	NS	0.02	NS	0.03	NS
Migration - Urban	-0.03	NS	-0.09	NS	0.03	NS	0.01	NS
	aR^2: 0.333 df = 41 p = **0.001***		aR^2: 0.398 df = 38 p = **0.000***		aR^2: -0.195 df = 30 p = 0.983		aR^2: -0.149 df = 30 p = 0.921	

The model for the full collection of 72 statements from official sources and interviews with laypersons and healthcare workers had two significant predictors: language skills and migration to cattle ranches (when compared with households staying in the community) were associated with decreased Local Biomedical agreement ($p < 0.05$). When the 34 statements that were not part official documents are modeled separately, only community membership is a significant predictor of correlation with the Local Biomedical model of TB ($p < 0.05$), and those in Integrationville agreed less with the Local Biomedical model of TB when compared to Isolationville.

Statement comparisons between layperson and biomedical models

Perhaps the most interesting result of comparing the responses to individual statements is the ten statements that are universally agreed upon by biomedical and layperson models (see Table 17). These statements are arguably the most important items within the model and would give a layperson the minimum required knowledge for symptom identification, causation, diagnosis, and treatment of TB. Three of the universally agreed upon statements are not found in published materials, but reflect local wisdom about susceptibility to TB – that those who smoke are at greater risk of developing TB – and TB treatment - that patients recover faster with rest and by eating honey. Honey is an important traditional food with high nutritious value (in addition to antibiotic properties), which is locally recommended for increasing the body weight of TB patients who are thin and have difficulty eating.

Table 17. Universally agreed upon statements about tuberculosis in biomedical and layperson models

Official Biomedical model	**Category**	**Statement**
Yes	Symptom	People with tuberculosis cough.
Yes	Symptom	People with tuberculosis are very thin.
Yes	Cause	Tuberculosis is caught from a microbe.
No	Cause	People who smoke are attacked more by tuberculosis.
Yes	Diagnosis	A person who coughs for a long time must do the analysis for tuberculosis.
Yes	Treatment	If you do not complete your treatment well, the tuberculosis can return.
No	Treatment	A person with tuberculosis must rest.
Yes	Treatment	A person with tuberculosis must take vitamins.
No	Treatment	A person with tuberculosis must eat honey.
Yes	Treatment	Tuberculosis is curable.

Statements about the other three major TB symptoms - fever, chest pain, and night sweats – were each only one "I don't know" response away from universal agreement. The statement "Tuberculosis can be prevented," was only two "I don't know" responses away from universal agreement. One additional unofficial statement drawn from the interviews was also two "I don't know" responses away from universal agreement: "People who don't look after their health are attacked more by tuberculosis," indicating that some degree of personal responsibility is attached to developing the disease.

Bonferroni-corrected binomial tests of proportion revealed significant differences on 25 statements between the Isolationville and Local Biomedical models, and 32 statements between the Integrationville and Local Biomedical models ($p < 0.0001736$, Bonferroni-corrected). The areas where Integrationville had more significant differences than Isolationville in relation to the Local Biomedical model tended to be statements about the prevention of TB and the way a person with TB should act and be interacted with. In general, respondents from Integrationville were less likely to agree with the specific methods suggested for preventing TB, and more likely to support the separation of TB patients from others.

Statement comparisons across layperson models

Only four statements were significantly different in the Bonferroni-corrected Fisher's exact tests between the community models. Isolationville respondents were more likely to agree with the statements "Tuberculosis can be prevented by using dishes that are washed well," and "Tuberculosis can be prevented by a vaccine," than Integrationville respondents ($p < 0.003472$, Bonferroni-corrected) (Table 18). Integrationville respondents were more likely to agree with the statements "There are traditional remedies for tuberculosis," and "Tuberculosis can be cured with traditional remedies," than Isolationville respondents ($p < 0.003472$, Bonferroni-corrected) (Table 18). None of the statements were significantly different between the models of respondents with and without a history of TB ($p > 0.003472$, Bonferroni-corrected).

Table 18. Percent of layperson agreement with statements that are significantly different across community models of tuberculosis, Bonferroni-corrected alpha = 0.003472

Statement	Isolationville % agreement	Integrationville % agreement
Tuberculosis can be prevented by using dishes that are washed well.	96.2	26.7
Tuberculosis can be prevented by a vaccine.	88.5	30.0
There are traditional remedies for tuberculosis.	23.1	86.7
Tuberculosis can be cured with traditional remedies.	34.6	90.0

Discussion

As expected, the effective of transmission of the biomedical model of TB is imperfect for local healthcare workers and laypersons in the study communities. Overall, the TB model of local healthcare workers is strongly correlated with the official biomedical model, but lies halfway between the official and layperson models of TB. In the areas where the local healthcare workers are undecided, the promotion of general hygiene is not a bad thing, though it may not specifically prevent TB, but the confusion about symptoms of TB may be cause for some concern.

The singular statement where local healthcare workers disagreed with the official biomedical model related to sharing tereré with TB patients. The belief that maté or tereré should not be shared with TB patients is not unique to these communities and appears to be of some long standing; Renshaw (2002) describes a community meeting where the chief informs residents that they should not be sharing tereré with community members who had recently been diagnosed with TB. The official stance that maté and tereré can be shared with TB patients who are in treatment may be an attempt to ameliorate social stigma and social exclusion of people with the disease.

In spite of greater isolation, Isolationville reported both a greater diversity of sources of information about TB and had more in common with biomedical models of TB than Integrationville; which suggests that isolation is not an obstacle to access to information and health education in this case. The non-significant difference between the TB models of people who had a history of TB and those who did not suggests that the greater TB knowledge in Isolationville cannot be attributed to a greater number of respondents with a history of TB. However, because Isolationville has historically been a high incidence community, the community as a whole may have received additional attention in efforts for health education. Several respondents in Isolationville mentioned a non-local healthcare worker, who previously made periodic visits to the community in relation to the National TB Program, as a source of information about TB. It might be that this extra attention is responsible for better adoption of the biomedical model in Isolationville.

Although the correlations between the layperson answer keys and the Official Biomedical answer key were very low, an analysis by the individual statements suggests that the layperson models are at least in universal agreement with 12 of the most important statements needed for symptom detection, diagnosis, and treatment of TB. Thus, while there are many differences between the layperson and biomedical models, there is agreement on the most practical aspects. How well actual behaviors, like treatment seeking and adherence, correlate with TB knowledge is another matter. A particular concern, based on the high proportion of 'yes' answers, would be a layperson perspective that nearly anything could be true about TB, which could lead to limited differentiation between "fact" and "rumor".

The answer keys for the layperson models correlated somewhat better with the Local Biomedical answer key than the Official Biomedical answer key, which supports the role of local healthcare workers as intermediaries between official and local understandings of disease. Familiarity with local customs, like the importance of honey in the diet, is a great aid for the promotion of treatment adherence, and familiarity with the local presentation of disease, like increased susceptibility of smokers to TB, is a great aid in diagnosis and prevention. Although smoking was not listed as a risk factor for TB in any of the health education materials examined, it is in fact a recognized risk factor in the biomedical literature (Bates et al 2007; Lin, Ezzati, and Murray 2007).

The statement "Tuberculosis can be prevented," was nearly universally agreed upon by the layperson and biomedical models, but the areas where Integrationville diverged significantly more from the biomedical model than Isolationville was in the specific statements about how to prevent TB and how TB patients should act and be interacted with. In combination with another statement with nearly universal agreement: "People who don't look after their health are attacked more by tuberculosis," the placement of personal responsibility on preventing the disease, yet disagreement with the specific methods suggested for preventing TB and agreement with the separation of TB patients from others in Integrationville suggests a degree of social exclusion and/or social stigma for TB patients in that community. Two of the interviewees who were former TB patients stated that community members had not been nice when they were in treatment for TB, but would not elaborate on how others had been unkind.

Aside from methods of prevention, the community models also significantly disagreed on statements about the use of traditional remedies. Respondents in

Integrationville were more likely to believe that there were traditional remedies for TB and that these could cure TB. More information is needed about what traditional remedies are being used for TB and whether these might interfere with the biomedical treatment regimen. Respondents in Isolationville, on the other hand, were adamant that only the pills given at the health post were capable of curing TB.

None of the variables under investigation (age, sex, community of residence, TB history, language ability, or migration) were significant predictors of individual adherence to the Official Biomedical model of TB, but this is not unexpected, considering the overall very low level of adherence to the Official Biomedical model. It is possible that, because of the low variance in layperson models (due to the high proportion of 'yes' responses), there are no reliable between-individual differences in adherence to the biomedical model, and that can explain the lack of any individual level effects on adherence.

Language ability and migration to cattle ranches were associated with significantly lower agreement with the overall Local Biomedical model of TB, which is a bit surprising, since one might expect better language ability to improve understanding of biomedical communications that are mostly delivered in Spanish, rather than Nivaclé. Residing in Integrationville was associated with significantly lower agreement with the Local Biomedical model on the subset of statements that came from interviews. This last finding is surprising, considering a greater number of layperson interviews were conducted in Integrationville (n = 9) than Isolationville (n = 4).

The respondents may not be entirely representative of the study communities. There was an innate bias to the sampling strategy used in that female respondents were most likely to be at home – many men (and also single mothers) work at wage labor outside the community and return periodically. However, the sample is representative of the general day-to-day composition of the communities. Another concern in the sampling strategy was the Social Network Elicitation driven recruitment in Integrationville. While the goal was to reach every household in the community, instead, the subset of households that were surveyed mostly have some social connection to other households, and thus may not be representative of the community as a whole. Also, in light of the high proportion of 'yes' responses and propensity of Nivaclé respondents to agree with statements that may be possible, though improbable, an alternative survey technique like free listing might be a better choice for subsequent surveys.

Conclusions

Access to biomedical information and health education is not limited by the isolation of these Nivaclé communities, and although there are significant differences between the biomedical and layperson models of TB, the most practical aspects of the biomedical model are agreed upon in terms of symptom identification, diagnosis, and treatment. The differences between the study communities may be a result of more intensive intervention from the National TB Program in Isolationville, as a high TB incidence community. None of the variables examined here were able to predict individual adherence to the Official Biomedical model; but better linguistic ability and migration to cattle ranches significantly predicted a lack of adherence to the Local Biomedical model. These results should be interpreted with some caution, as there was limited variation in layperson responses and a high bias towards 'yes' responses. How well the health behaviors of community members related to their models of TB is an area for further inquiry, however this kind of cognitive analysis is useful for identifying problem areas in the transmission of essential biomedical knowledge and improving health education materials and strategies.

CHAPTER 3

INTESTINAL PARASITE BURDEN IN INDIGENOUS COMMUNITIES OF THE PARAGUAYAN CHACO

Abstract

Introduction

This cross-sectional study examines the risk factors for and prevalence of helminthes and protozoan parasites in three rural, indigenous communities of the Paraguayan Chaco, where the current prevalence and distribution of intestinal parasites is unknown.

Methods

In 2011, 134 stool samples were collected from adults in two remote Nivaclé communities. In 2012, the same Nivaclé communities were re-sampled along with an Angaité community from another part of the Chaco, and a total of 152 stool samples were collected. Stool samples were collected in 10% formalin and refrigerated after arriving at the laboratory. Concentration and flotation methods were used to examine the samples for helminthes and protozoa. Health risk factor surveys at different time points in 2011 and 2012 collected information about household water source, water treatment, hygiene, latrine type and condition, and number and type of domestic animals in the study communities.

Results

No helminthes were detected in the 2011 Nivaclé samples or 2012 Angaité samples. Fewer than 5% of Nivaclé samples in 2012 had helminthiasis. In 2011, *Giardia lamblia* was detected in 13.0% and 21.0% of samples in the less and more isolated Nivaclé communities, respectively. In 2012, the prevalence of *Giardia lamblia* decreased to 4.0% and 15.3% in the less and more isolated Nivaclé communities,

and was 32.3% in the Angaité community despite better water infrastructure. The significantly lower use of soap during handwashing in the Angaité community may account for this finding.

Conclusions

The prevalence of soil-transmitted helminthiasis in the three study communities was extremely low compared to other South American indigenous groups and prediction models, while giardiasis was high. These findings suggest more research is needed into the seasonality and demographic spread of infection in this region.

Introduction

Globally, indigenous peoples are disproportionately affected by neglected tropical diseases (NTDs) (Gracey and King 2009, King, Smith and Gracey 2009, Hotez 2014). Many indigenous peoples live in poverty, have poor housing and sanitation, and/or lack access to healthcare (Gracey and King 2009, King, Smith, and Gracey 2009). In addition, studies of indigenous populations of the Americas have shown that cultural change and environmental degradation augment the prevalence of parasitic infections (Wirsing 1985, Confalonieri, Ferreira, and Araujo 1991, Fitton 2000). Precarious living conditions put indigenous peoples at greater risk of NTDs, and enteric helminth and protozoan infections are among the most prevalent (Hotez 2014).

While rarely deadly, enteric helminth and protozoan pathogens can have severe effects on child growth and development, nutritional status, cognitive function, and work capacity (Heelan and Ingersoll 2000, Muller 2002, Thompson and Smith 2011, Huang and White 2006, Wright 2012). The estimated DALYs (disability-adjusted life years) for ascariasis, trichuriasis, and hookworm disease in the Americas are 60, 73, and 20, respectively (WHO 2010); however these may not accurately reflect the severity of disease or an individual's quality of life, particularly in areas where polyparasitism is common (Conteh, Engels, and Molyneux 2010, Raso et al 2004). Polyparasitism by enteric protozoans is common in the developing world, but its clinical significance is poorly understood (Thompson and Smith 2011). In addition to causing poor health, NTDs place a substantial social and psychological burden on their sufferers (Hotez et al 2009, Hotez 2008, Weiss 2008), and cause a loss of productivity for individuals, households, communities, and national economies (Conteh, Engels, and Molyneux 2010, Hotez et al 2009).

This study examines the prevalence of enteric parasites in indigenous communities of the Paraguayan Chaco, specifically: the soil-transmitted helminthes, *Giardia lamblia*, *Cryptosporidium* species, and *Blastocystis hominis*. Soil-transmitted helminths are a group of nematodes with similar epidemiological characteristics, which include *Ascaris lumbricoides*, *Trichuris trichiura*, the hookworm species (*Acylostoma duodenale* and *Necator americanus*, indistinguishable in microscopic examination), and *Strongyloides stercoralis* (Heelan and Ingersoll 2000, Muller 2002). An infected person sheds eggs in their feces, and a susceptible person can become infected by ingesting contaminated food or soil, or through direct skin contact with contaminated soil in the case of hookworms or *Strongyloides stercoralis* (Muller 2002).

The enteric protozoan pathogens examined here are all zoonotic diseases, with reservoirs in domestic animals like dogs and cattle, as well as wild animals (Thompson and Smith 2011). Infection with *Giardia lamblia*, *Cryptosporidium* species, and *Blastocystis hominis* is promoted by opportunities for fecal-oral transmission of cysts in food, water, soil, and direct contact with an infected person or animal (Thompson and Smith 2011, Wright 2012, Huang and White 2006).

Giardia causes mild to severe cases of diarrhea and malabsorption. Patients with severe symptoms experience malabsorption of fat, xylose, and vitamin B12 with high stool weights, and nausea contributes to anorexia and weight loss. Cryptosporidiosis typically causes a small bowel infection with mild, watery diarrhea for 5.5 days, but prolonged diarrhea may result in immunocompromised patients – for example, those co-infected with AIDS or immune deficiencies resulting from malnutrition. Giardiasis and cryptosporidiosis are most common and most severe among children and infection declines with age through acquired immunity or reduced exposure (Wright 2012, Huang and White 2006).

The pathogenicity of *Blastocystis hominis* remains controversial, but it is at the very least a marker for exposure to fecal contamination (Boorom et al 2008; Clark et al 2013). *Blastocystis* is most often associated with chronic infections and prevalence increases with age (Boorom et al 2008). It may be that some strains are more pathogenic than others, as is the case with *Giardia* (ibid).

The transmission of helminthes and enteric protozoan parasites is dependent on the built environment and human behavior. Because the transmission cycles of these organisms are mediated by the contamination of the environment with fecal material, factors that moderate contact with infectious material, like migration, animal husbandry, housing construction and placement, water source, defecation practices and latrine construction, sanitary behaviors, shoe use, and overcrowding are important in determining the pattern of disease (Gamboa et al 2003, Gamboa et al 1995). The risk of infection with enteric protozoan parasites is higher in rural environments, probably due to increased opportunities for transmission in areas with poor sanitation and increased contact with domestic and wild animal reservoirs of infection (Thompson and Smith 2011). In addition, previous research has found the distribution of soil-transmitted helminths to be correlated with social and economic disparities (Holland et al 1988, Confalonieri, Ferreira, and Araujo 1991, Chernela and Thatcher 1989, Fitton 2000, Lawrence et al. 1980, and Schwaner and Dixon 1974).

Only a few studies of intestinal parasite prevalence have been conducted in the Paraguayan Chaco, most of these focusing on animals other than humans, and the studies on indigenous communities in Paraguay are very dated (see Soper 1927). Soper (1927) reported nearly universal hookworm infection, save for one child that was a year old, in a sample of 71 Lengua indians. More than half of the hookworm cases (59%) had *Necator americanus;* however all had *Ancylostoma duodenale,* which accounted for 93% of the hookworms found. The high ratio of *Ancylostoma* : *Necator* in the Lengua (13:1) appeared to be decreasing with increasing contact with outside groups, and was in stark contrast to the ratio found in Paraguayans east of the Paraguay river (1:14). All the individuals sampled were infected with *Enterobius vermicularis* (pinworm), however no infections with *Ascaris lumbricoides* or *Trichuris trichiura* were found (ibid). In more recent years, two studies of children in the Chaco region of Argentina found 69.8% prevalence of *Ancylostoma* species and 14.5% prevalence of *Giardia* species in 106 fecal samples (Taranto et al 2000), and >10.0% prevalence of *Giardia* species (Molina et al 2011).

In the Paraguayan Chaco, fecal analysis is only available to hospital inpatients, and diagnoses of parasitism are based on symptomatology. Therefore, most of the population in the Chaco, which is largely rural, remains undiagnosed and untreated, unless a healthcare worker diagnoses them on suspicion of having helminthiasis or giardia. Within the last ten years, public schools have also begun a de-worming program that regularly provides de-worming medications to children enrolled in the school. In the past, medical teams who periodically visited remote indigenous communities are reported to have given antiparasitosis drugs out with most consultations, regardless of the medical complaint.

Chammartin et al (2013) conducted a geostatistical meta-analysis of reports of soil-transmitted helminth infection in South America to assess the geographical distribution of infection risk with Bayesian models. They estimated the risk of infection in Paraguay to be 8.3% (95% CI: 5.3-15.5) for *Ascaris lumbricoides*, 7.1% (95% CI: 2.6-21.4) for *Trichuris trichiura*, and 18.3% (95% CI: 12.1-28.0) for hookworm (Chammartin et al 2013). In the maps of infection risk provided (Chammartin et al 2013: p. 511-513), the risk for *Trichuris trichiura* and hookworm appears somewhat higher in the Chaco than in the eastern part of Paraguay. However, these estimates are based on reports of parasite prevalences from outside the Paraguayan Chaco.

The objective of this study is to examine the actual prevalence of intestinal parasites in two remote Nivaclé communities (Integrationville and Isolationville) and an additional Angaité community (Angaité–ville) that is nearer to the TransChaco highway, as well as risk factors for infection in these communities.

Methods

The communities involved in this study were part of a bigger project on the disease ecology of tuberculosis in the Paraguayan Chaco, and their names have been anonymized to protect research participants. The two main study communities, Integrationville and Isolationville, belong to the Nivaclé ethnic group. Integrationville (85 households) is home to a church mission and visited by a private bus line twice a week, and thus is more integrated with national society than Isolationville (51 households) which is not accessible by bus. An Angaité community, Angaité-ville, was added during the second year of the study. The Angaité are considered one of the more acculturated indigenous ethnic groups in the Chaco, having lost much of their traditional language and adopted Jopará Guaraní – a mix of Guaraní and Spanish spoken widely in Paraguay – as their primary language (Renshaw 2002). This community is also located relatively close to the TransChaco highway, the only paved road running through the Paraguayan Chaco. All three communities are considered to fall within the Central Chaco ecoregion.

In July and August 2011, a cross-sectional study of the Nivaclé communities collected 134 stool samples from adults age 18 and over (47 from Integrationville and 87 from Isolationville). From September to November 2012, the same Nivaclé communities were re-sampled along with the Angaité community. A total of 152 stool samples were collected in 2012 (49 from Integrationville, 72 from Isolationville, and 31 from Angaité-ville).

Community members were invited to the local health post or school where an oral presentation of the study consent form and a demonstration of how to use the fecal sample collection kit were given in Spanish and the local language (Nivaclé or Jopará

Guaraní). Fecal sample collection kits were distributed to participants along with a small gift for participating and they were asked to return their samples to the collection point the following day. The fecal sampling kits included: a sample container with 10% formalin, a pair of latex gloves, a small plastic spoon, a cardboard tray, and a Ziploc bag.

The samples were stored in a health post fridge where possible, and transported to the parasitology laboratories within three days. In 2011 the samples were analyzed at the Boquerón Regional Laboratory in Mariscal Estigarribia and in 2012 the samples were analyzed at the Universidad Pacifico in Asunción. Both laboratories were a day's drive from the remotest collection sites. Concentration and flotation methods were used to examine the samples for helminthes - *Ascaris lumbricoides*, *Strongyloides stercoralis*, and hookworm - and protozoa – *Giardia lamblia*, *Cryptosporidium* species, and *Blastocystis hominis*. Participants who tested positive for parasites in their fecal samples were provided treatment free of charge in collaboration with local healthcare workers.

Surveys on health risk factors conducted in November and December 2010 and October 2012 collected information about household water source, water treatment, hand washing practices, latrine type and condition, number and type of domestic animals, flooring and house construction materials, and shoe ownership. The surveys in Isolationville and Integrationville were part of a larger study of infectious disease ecology in those communities, while the survey in Angaité-ville was in an anonymous, reduced format. In 2010, 44 households in Isolationville (86.3%) and 73 households in Integrationville (85.8%) were surveyed. In 2012, 51 households in Isolationville (100%), 26 households in Integrationville (30.6%), and 36 households in Angaité-ville (percent coverage unknown) were surveyed. This study was approved by community leaders, the Institutional Review Board at Arizona State University, and the Scientific Review Committee at the Fundación Moisés Bertoni in Paraguay.

Results

Characteristics of the fecal sample participants are displayed in Table 19. The sample kit return rate was very high for all communities (>83.5%) (Table 19). There is a strong bias towards female participants, especially in the Nivaclé communities (Table 19). The men in these communities often travel for wage labor, and women are more likely to be at home in Isolationville and Integrationville. There was also a tendency in these two communities, especially Isolationville, for men to wait until all the women present had received medical services first. As the wait could be quite long, some men would leave before their turn to take care of other business.

Table 19. Characteristics of study samples, 2011-2012

Community & Year	Ethnic group	Number of participants	Estimated total adult population	Total number of households*	Mean people per household	Sample kit return rate	Proportion of female to male participants	Mean age (SD)
Integrationville 2011	Nivaclé	46	271	85	8.4	97.9%	40:6	47.5 (±18.5)
Integrationville 2012	Nivaclé	49	271	85	10.0	94.2%	44:5	49.0 (±14.9)
Isolationville 2011	Nivaclé	81	170	51	8.4	83.5%	65:16	44.5 (±19.1)
Isolationville 2012	Nivaclé	72	170	51	8.3	92.3%	64:8	39.1 (±14.5)
Angaité-ville 2012	Angaité	31	Unknown	32	6.4	96.9%	18:13	42.3 (±16.0)

*Number of households was estimated from the 2010 survey for the Nivaclé communities and the 2002 Indigenous Census (DGEEC 2004) for the Angaité community

In 2011, contrary to expectations, no cases of helminthiasis were detected in the study communities (Table 20). Of the 81 samples analyzed from Isolationville, 23.5% had at least one known pathogen (*Ascaris lumbricoides, Strongyloides stercoralis, Giardia lamblia*, or *Cryptosporidium* species) present. Of the 46 samples analyzed from Integrationville, 13.0% had at least one known pathogen present. Neither community had multiple known pathogens in a single sample. *Giardia lamblia* was detected in 21.0% of samples in Isolationville and 13.0% of samples in Integrationville (Table 20). *Blastocystis hominis* (which is not counted as a 'known pathogen' in this study, but is included as a marker of fecal contamination) was detected in 29.6% of samples from Isolationville and 28.2% of samples from Integrationville (Table 20).

Table 20. Number of fecal samples from study communities with intestinal parasites

Community & Year	*Ascaris lumbricoides*	*Strongyloides stercoralis*	*Giardia lamblia*	*Blastocystis hominis*	*Cryptosporidium* species
Isolationville 2011 (n=81)	0 (0.0%)	0 (0.0%)	17 (21.0%)	24 (29.6%)	2 (2.5%)
Integrationville 2011 (n=46)	0 (0.0%)	0 (0.0%)	6 (13.0%)	13 (28.3%)	0 (0.0%)
Isolationville 2012 (n=72)	3 (4.2%)	1 (1.4%)	11 (15.3%)	26 (36.1%)	3 (4.2%)
Integrationville 2012 (n=49)	1 (2.0%)	0 (0.0%)	2 (4.0%)	28 (57.1%)	1 (2.0%)
Angaite-ville 2012 (n=31)	0 (0.0%)	0 (0.0%)	10 (32.3%)	22 (71.0%)	0 (0.0%)

In 2012, 4 cases of helminthiasis were detected, 1 in Integrationville and 3 in Isolationville. The prevalence of *Giardia lamblia* was 4.1% in Integrationville, 15.2% in Isolationville, and 32.3% in Angaité-ville (Table 20). The prevalences of *Blastocystis hominis* were even higher than the previous year, with a prevalence of 36.1% in Isolationville, 57.1% in Integrationville, and 71.0% in Angaité-ville (Table

20). Overall, 23.6% of the samples from Isolationville, 8.2% of the samples from Integrationville, and 32.3% of the samples from Angaité-ville had at least one known pathogen. There was only one case of polyparasitism in 2012; a woman in Isolationville who was positive for both *Ascaris lumbricoides* and *Strongyloides stercoralis*.

Of the 56 participants who gave fecal samples both years, 23.2% in 2011 and 21.4% in 2012 were positive for at least one known pathogen. Five of the thirteen (38.5%) participants to receive treatment the first year were re-infected the second year, although three of these five were re-infected with a different pathogen.

The three study communities had similar environmental risk profiles. Domestic animals, like dogs, cats, chickens, goats, and others, were ubiquitous in the three communities and had free range. Fecal material from animals was observed throughout the communities. Latrine construction was similar across communities and nearly all households had latrines; only one did not use a latrine in Integrationville. Shoe ownership was also nearly universal among adults in all three communities, although children were less likely to have shoes. There were three women in Isolationville who participated in 2011 and did not have shoes; one was positive for *Giardia lamblia*.

Many of the houses in Isolationville and some of the houses in Integrationville and Angaité-ville have tanks to collect rainwater from the roofs of their houses. Participants in Isolationville and Integrationville preferred to use rainwater when it was available, but during droughts and heat waves they often run out and have to use water from the *tajamars* (open water collection pits) shared by the community.

The water use data for 2011 were actually collected in December 2010, near the height of the dry season, so it is likely that the high percentage of households using the *tajamar* that year (90% in Isolationville and 100% in Integrationville, see Table 21) is due to a lack of rainwater. These data were collected several months prior to the fecal sample collection and analysis, and thus are not representative of the water usage at the time. The water use data for 2012 were collected in October 2012, a couple of months earlier in the dry season, and closer to the actual date of fecal sample collection.

Table 21. Risk factor variables in study communities, 2011-2012

Community & Year	Primary water source by percent of households:			Average number of times handwashing per day:		Percent of households with earthen floors
	tajamar (open water pit)	rainwater	*pozo artesanio* (well)	**with soap**	**without soap**	
Integrationville 2011	100%	0%	0%	--	--	87.7%
Integrationville 2012	57.7%	42.3%	0%	3.4	0.5	87.7%
Isolationville 2011	90%	10%	0%	--	--	11.1%
Isolationville 2012	47.1%	52.9%	0%	3.1	0.1	11.1%
Angaite-ville 2012	0%	2.8%	97.2%	1.6	1.6	100%

Based on the survey data from 2012, every household using a *tajamar* as a primary water source filters the water through fabric before consuming it, except for two households in Integrationville. One of these uses chemical treatment and the other filters the water through a cactus. Six of the households surveyed in 2012 had rainwater tanks without covers; the five in the Nivaclé communities filtered or used chemical treatment on this water before consuming it, but the one Angaité household did not. In Isolationville 25 households were using covered rainwater tanks; about one third of these households drank this water without treatment, and the other two thirds filtered it before consumption. Eight households in Integrationville were using covered rainwater tanks; two of these (25%) drank the water untreated and the other six (75%) filtered the water before consumption. All but the one household with an uncovered rainwater tank in the Angaité-ville used the *pozo artesanio* (well). Only 20% of these households treated the well-water before drinking it, most drank it without treatment.

There was no significant variation between the three communities in their estimates of the number of times per day they wash their hands ($F=2.08$, $p=0.13$), but Angaité respondents were significantly less likely than Nivaclé respondents to report using soap when washing their hands ($F=17.62$, $p<0.01$) (Table 21). During the survey, several Angaité respondents remarked that the soap they were using was actually shampoo, which suggests that it may not be a lack of will to wash with soap but a scarcity of soap in the community that leads to less hand washing with soap.

The other major difference between communities is the percent of households with earthen floors (Table 21). Having a brick floor in the house is generally associated with persons of higher socioeconomic status in these indigenous communities; however, the Paraguayan government has implemented a housing program in recent years that builds free brick homes in indigenous communities to improve their living conditions. Isolationville was one of the beneficiaries of the program, thus they have a low percentage of households with earthen floors (those who did not receive one of the government houses, or moved to another part of the community and built their home after the housing program). Most of the people with government houses kept their older homes with earthen floors as kitchens, and some family members continue to sleep in the older homes. Most of the households in Integrationville and Angaité-ville have earthen floors.

Discussion

The low prevalence of helminthiasis found in this study is unusual among South American indigenous groups (Hurtado et al 2005, Hotez et al 2008). In particular, the absence of hookworm (*A. duodenale* and *N. americanus*) is striking, in comparison with Soper's (1927) findings and a follow-up study conducted by Labiano-Abello et al (1999) in Itagua, Paraguay. Soper (1927) hypothesized that the nearly universal levels of *A. duodenale* in the Lengua of the Chaco were the typical, indigenous pattern of hookworm infection, and that the *N. americanus* found east of the Paraguay River would gradually replace *A. duodenale* with increasing contact. Labiano-Abello et al (1999) found that 59% of the individuals they tested in Itagua were infected with hookworm, and that *A. duodenale* has persisted in eastern Paraguay, although *N. americanus* continues to be the predominant pathogen.

The prevalences of enteric parasites reported here are likely underestimates of disease burden. Fecal sampling protocols generally recommend that fecal samples be collected over multiple days to account for considerable variation in eggs counts in stool over five day periods, or even within the same stool (Hall 1981). In this study, sample collection was limited to one day to ensure that samples could be transported to the laboratory for analysis within seven days of their fixation with formalin. A prolonged sampling would undoubtedly reveal higher infection rates. In addition, the fecal sampling occurred during the dry season, when infection with Cryptosporidium oocysts is less common (Huang and White 2006) and helminth transmission rates tend to vary by season (temperature and precipitation) (Chammartin et al 2013). There are greater logistic challenges to sampling during the wet season, but that would give a more accurate picture of enteric parasite prevalence.

In addition to sampling issues, the low prevalence of helminthiasis may be partly explained by the mass deparasitization programs in primary schools and the practice of blanket distribution of anti-helminthic drugs during past medical rounds. Studies typically show variation in parasite infection over the demographic structure of the community (Anderson et al 2013). A more representative sampling of men, women, and children in a follow-up study would reveal whether children are the main reservoir of infection in the community, or if helminthes have been successfully eliminated from them through the school deparasitization programs.

The estimated prevalences of soil-transmitted helminth infections by Chammartin et al (2013) is based largely on the environmental determinants of different regions in Latin America, such as soil and climate characteristics, and has no input on the host factors involved in infection. Innate biological immunity of indigenous populations to enteric pathogens is relatively unknown (Confalonieri, Ferreira, and Araujo 1991). Social and behavioral factors that determine the prevalence and level of infection are closely tied to traditional cultural practices as well as the processes of acculturation and cultural change. Confalonieri, Ferreira, and Araujo (1991) name several acculturation factors that influence the occurrence of intestinal helminth infections in indigenous peoples: disruption of geographic isolation, sedentism and increase in population density, changes in housing pattern and environment, changes in patterns of individual and environmental hygiene, social stress and malnutrition, introduction of modern medicine, and genetic changes. Each of these factors will occur to variable degrees in different populations.

Although rainwater harvesting is expected to produce a safer water source than a *tajamar*, some studies have found high rates of contamination with bacterial and protozoan pathogens in harvested rainwater (Dobrowsky et al 2014). The contaminants are presumed to be from bird feces, insects, mammals, reptiles, and other debris on roof surfaces that are flushed into the rainwater tanks from the gutters. Thus respondents using rainwater without treatment for drinking may be at increased risk of infection with Giardia or Cryptosporidium.

The high prevalence of *Giardia lamblia* in Angaité-ville was surprising because their primary water source is a *pozo artesanio* (well), while the Nivaclé communities rely more heavily on the *tajamars*, which are open to contamination. The significantly lower use of soap in handwashing in Angaité–ville may account for this finding. Because the overall rates of handwashing are similar across all three communities, providing greater accessibility to soap in Angaité-ville would probably be sufficient intervention.

This study is the first report of intestinal parasite prevalence in the Paraguayan Chaco in over 80 years, and opens up several avenues for future investigation. Of particular importance is multi-day sampling and better demographic representation of children and men in subsequent fecal analyses, and an investigation of individual and household level risk factors for infection with intestinal parasites. The relative absence of enteric pathogens in these communities is just as interesting as their high prevalence in other indigenous communities. Other future research plans include direct testing of soil and water sources for parasites, measuring the effectiveness of local filtration methods in removing parasites, and investigation of seasonal variation in parasite loads and the impact of climate change.

Conclusions

The prevalence of helminthiasis is lower than expected in indigenous communities of the Paraguayan Chaco, while the prevalences of *Giardia lamblia* and *Blastocystis hominis* are quite high. The Angaité community had a higher prevalence of *Giardia lamblia* than the Nivaclé communities despite better sanitation infrastructure, and this may be explained by significantly lower use of soap while handwashing. Better demographic representation and multi-day samples are needed to better assess the prevalence of enteric pathogens in these communities. Further research is needed on individual and household level risk factors for enteric pathogens, their seasonality in the Chaco, and the effectiveness of local water treatment practices.

CHAPTER 4

COMMUNITY-LEVEL RISK FACTORS FOR TUBERCULOSIS IN INDIGENOUS COMMUNITIES OF THE PARAGUAYAN CHACO, A CROSS-SECTIONAL STUDY FROM 2002-2004

Abstract

Background

Indigenous populations are generally reported to suffer greater tuberculosis (TB) disease burden. The objective of this study was to examine community-level risk factors for active TB in indigenous communities of the Paraguayan Chaco.

Methods

Ecological associations between cases of active adult and pediatric TB reported from 2002-2004 and community characteristics were examined by negative binomial and Poisson GLM regression, respectively.

Results

In the Chaco, active TB prevalence in indigenous peoples was eight times greater than the non-indigenous population. Communities with a health post were more than twice as likely to report active adult TB (RR = 2.07, CI [1.14-3.83], $p < 0.05$). Each additional average year of education in the community was associated with nearly 50% less likelihood of reporting active pediatric TB (RR = 0.53, CI [0.38-0.73], $p < 0.001$). Although non-significant, the presence of non-indigenous community members had a strong protective association in both the adult (RR = 0.56, CI [0.30-1.03], $p = 0.06$) and pediatric models (RR = 0.64, CI [0.34-1.14], $p = 0.14$).

Conclusions

The burden of TB in these communities falls within the mid-range of other indigenous groups worldwide. These results reinforce the importance of improving upstream social determinants of health for TB control and focusing on vulnerable populations.

Introduction

A review of published data on TB disease burden in indigenous populations worldwide found that, in most cases, indigenous populations have higher rates of active TB disease than non-indigenous populations (Tollefson et al. 2013). Risk factors for TB can be broken into proximate factors and upstream determinants (Lönnroth et al. 2009). Proximate risk factors can either (1) increase potential for exposure and infection, such as crowding, poorly ventilated housing, or high prevalence of untreated TB in the community, or (2) promote the transition from latent infection to active disease by impairing the host immune system. Major risk factors of the latter type include malnutrition, co-infections (particularly HIV), smoking, air pollution from solid fuels, alcohol abuse, and diabetes (Lönnroth et al. 2009, Padmanesan et al. 2013). The upstream determinants of TB are poverty and other markers of low socioeconomic status that are associated with greater exposure to the proximate risk factors for TB (Lönnroth et al. 2009). The health situation of indigenous peoples is comparable to the world's poorest populations, but with the additional burdens of social and cultural marginalization, geographic and cultural barriers to accessing health services, and, in some areas, appropriation of land and natural resources (Stephens et al. 2006).

The Chaco is a semi-arid ecosystem that extends west from the Paraguay River and makes up approximately 60% of Paraguay's territory. In 2002, the Chaco had a total estimated population of 138,760, of which 42,964 (31.0%) were indigenous

(DGEEC 2003). The region is sparsely populated with less than 1 person per square kilometer. The Chaco is home to 13 indigenous ethnic groups belonging to five linguistic families, but these communities share similar social organizations and subsistence practices (Renshaw 2002). Periodic droughts and flooding lead to shortages of food and water in indigenous communities and there is a high rate of poverty; in 2002, 73.2% of urban and 90.3% of rural households in the Chaco had at least one Unsatisfied Basic Need (housing quality, sanitation infrastructure, access to education, or capacity for subsistence) (DGEEC 2005).

This paper investigates the community-level risk factors for active tuberculosis disease in indigenous communities of the Paraguayan Chaco, using the most recent census data for these communities and prevalence data from the National Tuberculosis Program from 2002-2004. The paper presents separate models of adult and pediatric TB, in recognition that the clinical presentation and progression of TB differs across childhood and adulthood. The number of pediatric TB cases typically indicates recent community transmission and thus the effectiveness of TB control programs (Marais 2011). In addition, the TB burden of Chacoan indigenous communities is compared with the non-indigenous population in the Chaco, and with other indigenous groups worldwide.

Methods

Tuberculosis control program

The Tuberculosis Control Program in Paraguay was implementing the DOTS (Directly Observed Therapy – Short Course) treatment strategy from 2002-2004 and had limited coverage (OPS 2007). In 2002, 10% of the population lived in a DOTS area (WHO 2002), and by 2004 the program had expanded to 27% of the Paraguayan population (OPS 2007). The case detection rate for TB in all forms was relatively regular in Paraguay from 1995 and 2004 (WHO 2006); but there was an increase in smear positive cases of pulmonary TB between 2003 and 2004 that could be attributed to increased detection activities.

Data sources

A comprehensive database of indigenous communities and their characteristics in the departments of Boquerón, Presidente Hayes, and Alto Paraguay was compiled from the 2002 *Atlas of Indigenous Communities in Paraguay* (DGEEC 2004). The data for the *Atlas*, a compendium of demographic and socioeconomic information about ethnic groups and communities, were collected during the 2002 National Indigenous Census of Population and Households in Paraguay. Population sizes of the communities were broken into population under 15 years and population 15 years and older to divide the pediatric and adult populations of each community.

Variables from the *Atlas* were chosen based on how well they operationalized potential risk factors for TB (see Table 22). Crowding was measured as the average number of people per household in the community. Distance from the capital of the department (in hundreds of kilometers) was used as a proxy for remoteness of the community. Remoteness represents the degree of isolation of a community as well as potential difficulty in accessing healthcare and other infrastructure. The presence or absence of a health post in the community is a measure of local healthcare access, and as the health posts are charged with reporting TB cases to the National TB Program, they also correspond to a greater likelihood of detection (detection bias). The potential for co-infections, particularly of the gastrointestinal form, was included as the percentage of community members whose primary water source is surface water.

Multiple variables were included as measures of socioeconomic status (SES). These included the percentage of community members engaged in wage labor (nearly the inverse of those engaged in subsistence activities), and the percentage of households of a permanent construction type (generally, brick walls and a metal roof, described as *casa* in the *Atlas*) divided by ten for ease of interpretation (DGEEC 2004). Level of education was operationalized by the average years of study of adult community members. Whether or not the community owns their own land is also indicative of SES, as well as the infrastructure available to the community. The presence or absence of non-indigenous community members was included in the model as a marker of the degree of acculturation and social integration with general Paraguayan society, and is another potential proxy for SES.

The National TB Program and Department of Statistics for the Ministry of Public Health and Social Wellbeing in Paraguay provided data on the locations and ages of all cases of active tuberculosis reported to them by health posts from 2002 to 2004. From this database, 532 cases of active tuberculosis in the 105 Chacoan communities identified as indigenous by the *Atlas* were extracted for analysis. Most TB cases were reported at the community level, but when TB cases were reported for a subdivision (*aldea)* of a community the subdivision was treated as an independent community. For these cases the population of the independently reported subdivision was subtracted from the community totals. The reported TB cases were sorted into six age groups: < 1 year, 1-4 years, 5-14 years, 15-19 years, 20-49 years, and 50 or more years. No further demographic information was available.

Data cleaning

In some instances, the names of the communities reported in the National TB Program data were not easy to connect with the names given in the *Atlas* because a community is known by multiple names or there were multiple communities with similar names. Most of these problems could be resolved when the location and primary ethnic group of the community were further investigated in the INDI database (INDI 2013), but a few were resolved due to the authors' firsthand knowledge of the communities. One community was excluded from the analysis due to missing data.

Statistical analysis

All statistical analyses used R software, version 2.15.2 (R Core Team 2012). Correlations between the predictor variables were examined for potential collinearity, and variation across linguistic families and departments was investigated. Ecological associations between pediatric and adult cases of TB from 2002-2004 and community characteristics were examined by Poisson GLM regression and negative binomial GLM regression, respectively, to account for overdispersion in the adult model. The model for multivariate analysis included nine main variables extracted from the *Atlas* and an offset for population (see Table 22). Unadjusted and adjusted risk ratios were calculated from the regression coefficients for each variable in univariate and multivariate models. Odds ratios, which would be more appropriate to a cross-sectional study, should be approximately equal to the risk ratios under the rare disease assumption (Davies, Crombie and Tavakoli 1998).

Ethics approval for this study was provided by the Institutional Review Board at Arizona State University.

Results

The prevalence of tuberculosis cases from 2002-2004 and demographic characteristics of the three departments and five linguistic families in the Chaco are presented in Table 22. The indigenous population in the Chaco is concentrated in the Central Chaco, near the Mennonite colonies, and Lower Chaco; as shown by the greater number of communities located in the Boquerón and Presidente Hayes departments. The majority of the indigenous population belongs to either the Lengua Maskoy or Mataco Mataguayo linguistic families. Communities ranged in size from 23 to 3888 individuals.

Table 22. Descriptive statistics for TB cases and demographics of indigenous communities of the Chaco by department and linguistic family, 2002-2004

	TB cases 2002-2004			**Prevalance of active TB cases per 100,000 inhabitants per year**	**Total population (<15 yrs:≥15yrs)**	**Number of communities**
	<15 yrs	**≥ 15 yrs**	**All**			
Department						
Boquerón	18	147	165	278	19807 (7997:11810)	49
Presidente Hayes	79	263	342	587	19409 (8200:11209)	39
Alto Paraguay	6	19	25	263	3166 (1444:1722)	17
Linguistic Family						
Lengua Maskoy	51	246	297	518	19130 (7683:11447)	52 (5 ethnic groups)
Guaicuru	7	31	38	888	1427 (682:745)	4 (1 ethnic group)
Guaraní	1	20	21	157	4469 (1915:2554)	8 (2 ethnic groups)
Mataco Mataguayo	39	122	161	384	13972 (5900:8072)	27 (3 ethnic groups)
Zamuco	5	10	15	148	3384 (1461:1923)	14 (2 ethnic groups)
Total	**103**	**429**	**532**	**418**	**42382**	**105**

The active TB prevalence in indigenous peoples in the Chaco (418 TB cases per 100,000 per year) is eight times greater than the non-indigenous population in the Chaco (52 TB cases per 100,000 per year) (Figure 4). When the linguistic families are analyzed separately, they range from 2.8 times the non-indigenous prevalence in the Zamuco to 17.1 times the non-indigenous prevalence in the Guaicuru. When comparing the prevalence of TB for indigenous groups of the Chaco to other indigenous groups worldwide, they fall into the middle range (see Tollefson et al. 2013). When restricting the comparison to Latin America, the prevalence of TB for indigenous groups in the Chaco is on the lower end, but two of the high prevalence studies (among the Yanomami (Sousa et al. 1997) and Panara (Baruzzi et al. 2001) were conducted several years earlier (Figure 4).

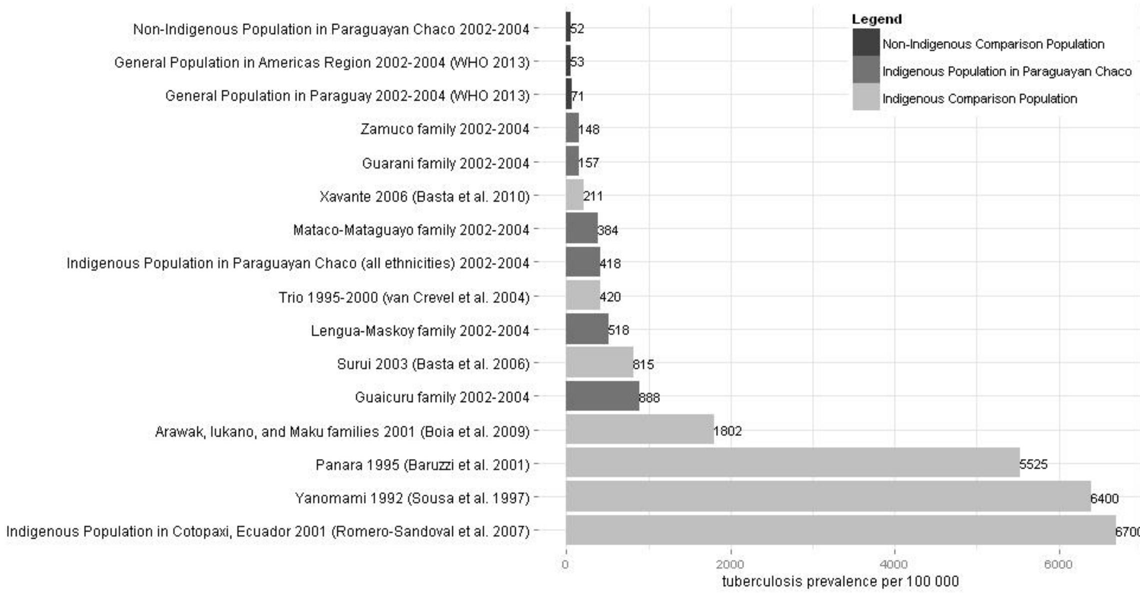

Figure 4. Comparison of tuberculosis prevalence in indigenous populations of the Paraguayan Chaco to non-indigenous populations and other Latin American indigenous peoples. Latin American data were sourced through the Tollefson et al. (2013) meta-analysis; original source articles are listed next to the population and year of data collection.

Descriptive statistics for the predictor variables are presented in Table 23. Indigenous communities in the Chaco are generally remote; an average of 236km away from their department capital. On average, these communities had 5.72 (± 1.21) people per household and 2.03 (±0.91) years of education. There was large variation in the percentages of permanent houses, surface water usage, and participation in wage labor. Slightly less than half of the communities had their own health post (45.2%), and most owned their own land (62.5%). Non-indigenous community members were present in 28.8% of communities.

Table 23. Description of variables selected from the 2002 Atlas of Indigenous Communities in Paraguay (DGEEC 2004)

Continuous Variables	**Description**	**Mean and standard deviation**
Crowding	Average number of people per household	5.72 ± 1.21
Education	Average number of years of study	2.03 ± 0.91
House type	Percentage of community members who have permanent houses, divided by 10	4.67 ± 3.24
Remoteness	Distance from the department capital in hundreds of kilometers	2.36 ± 1.49
Surface water usage	Percentage of community members who use a *tajamar* or surface water as a primary water source	58.08 ± 43.08
Wage labor	Percentage of community members engaged in wage labor	43.41 ± 27.39
Binary Variables	**Description**	**Proportions (Yes : No)**
Health post	Does the community have a health-post? (yes/no)	47 (45.2%) : 57 (54.8%)
Land ownership	Does the community own its land? (yes/no)	65 (62.5%) : 39 (37.5%)
Non-indigenous	Are there non-indigenous community members? (yes/no)	30 (28.8%) : 74 (71.2%)

In the negative binomial adult model, having a health post was the only significant association with active TB, while the presence of non-indigenous community members was nearly significant (see Table 24). Holding all else constant, communities with a health post were more than twice as likely to report adult TB (RR = 2.07, CI [1.14-3.83], $p < 0.05$). Communities with non-indigenous community members had 44% less risk for adult TB (RR = 0.56, CI [0.30-1.03], $p = 0.06$). Years of study and house type were associated with minor risk reduction for active TB, but had wide confidence intervals. Crowding, land ownership, and remoteness were associated with minor risk increases for active TB, but had wide confidence intervals. Neither wage labor nor water source was associated with active TB.

Table 24. Models of associations between community characteristics and number of adult and pediatric TB cases in indigenous communities of the Chaco from 2002-2004, offset by population

Variable	**Negative binomial ADULT MODEL**			**Poisson PEDIATRIC MODEL**		
	Unadjusted Risk Ratio (95% CI)	Adjusted Risk Ratio (95% CI)	Adjusted p value	Unadjusted Risk Ratio (95% CI)	Adjusted Risk Ratio (95% CI)	Adjusted p value
Crowding	1.06 (0.87-1.28)	1.11 (0.90-1.37)	0.34	0.86 (0.69-1.06)	0.84 (0.65-1.08)	0.19
Health post	1.49 (0.91-2.45)	**2.07 (1.14-3.83)**	**0.02**	0.81 (0.52-1.31)	1.15 (0.63-2.19)	0.65
House Type	0.94 (0.86-1.01)	0.95 (0.87-1.04)	0.24	0.94 (0.87-1.02)	0.99 (0.91-1.08)	0.84
Land Ownership	1.57 (0.93-2.63)	1.15 (0.63-2.11)	0.63	1.07 (0.65-1.86)	1.00 (0.55-1.88)	1.00
Non-Indigenous	0.80 (0.48-1.36)	0.56 (0.30-1.03)	0.06	0.49 (0.29-0.81)	0.64 (0.34-1.14)	0.14
Remoteness	1.11 (0.95-1.30)	1.06 (0.88-1.27)	0.53	1.20 (1.06-1.37)	1.03 (0.87-1.22)	0.72
Wage Labor	0.99 (0.98-1.00)	1.00 (0.99-1.01)	0.95	0.99 (0.98-1.01)	1.00 (0.99-1.02)	0.44
Water Source	1.00 (1.00-1.01)	1.00 (1.00-1.01)	0.52	1.01 (1.00-1.01)	1.00 (1.00-1.01)	0.17
Years of Study	0.88 (0.66-1.17)	0.88 (0.64-1.21)	0.41	0.50 (0.39-0.65)	**0.53 (0.38-0.73)**	**<0.001**
Model fit	Theta =1.19, AIC = 420.27 Residual deviance 104.79 on 94 df Goodness-of-fit test for Poisson assumption $\chi2= 104.79$ *P* = 0.21			AIC = 219.52 Residual deviance 106.71 on 94 df Goodness-of-fit test for Poisson assumption $\chi2= 106.71$ *P* = 0.17		

In the Poisson pediatric model, years of study was the only significant predictor of active TB (see Table 24). Holding all else constant, each year increase in the average years of education in the community was associated with nearly 50% less likelihood of reporting pediatric TB (RR = 0.53, CI [0.38-0.73], $p < 0.001$). Communities with non-indigenous community members had 36% less risk for pediatric TB (RR = 0.64, CI [0.34-1.14], $p = 0.14$). Contrary to expectations, increased crowding was associated with a minor reduction in risk for active TB, but this result is non-significant. Having a health post was associated with a minor increased risk of active TB, but the confidence interval was large. House type, land ownership, remoteness, wage labor, and water source appeared to have a neutral or no association with active TB. The goodness-of-fit statistics indicate that both models fit the data well (P = 0.21 and P = 0.17, respectively, for the adult and pediatric models).

Discussion

In the adult model, the presence of a health post in the community was associated with increased risk of active TB disease (see Table 24). TB cases are more likely to be detected where there is a constant healthcare worker presence, and this may explain the strong association. Also, sometimes people from outlying communities move to communities with health posts to receive care and may live with relatives in the community while they complete treatment. Alternatively, health posts may have been built in these communities because they historically reported a higher prevalence of TB.

Interestingly, the presence of non-indigenous community members had a strong protective association against TB in both models, although the effect is only nearly significant in the adult model (see Table 24). Acculturation and social integration are reported to have variable effects on health in indigenous societies (Montenegro and Stephens 2006, Young 1994, Wirsing 1985). While the association is protective in this case, a longitudinal study of two Ache communities in Eastern Paraguay found that the more acculturated community had higher risk of active TB disease and positive PPD results (Hurtado et al. 2003). The non-indigenous community members may be aid-workers or missionaries who work to improve healthcare, or Paraguayans who have married into indigenous communities. Anecdotally, households with non-indigenous community members in the Chaco tend to have better housing and greater material wealth; thus non-indigenous community composition may also be a proxy for SES. It could also be that people from communities with fewer TB cases are more likely to marry a non-indigenous person.

In the pediatric model, the average years of education in the community was associated with increased reporting of pediatric TB cases (see Table 24). Higher education levels may increase the ability of community members to identify TB symptoms as well as overcome language barriers and navigate the healthcare system, and in this way may support the effectiveness of TB control programs. Higher education levels may also improve access to better paying jobs and economic security, and therefore be an indicator of reduced exposure to the proximate risk factors for TB.

The choice of predictor variables for this analysis was limited by the data available in the *Atlas*. The analysis could be improved with a better measure of material wealth, and data on other reported risk factors for TB that were not available, such as the prevalence of smoking, alcohol abuse, and diabetes, the use of solid fuels, and food security in Chacoan communities.

The TB burden in indigenous communities of the Chaco region fits well within the range of variation in indigenous TB burden worldwide and further supports evidence that indigenous peoples generally suffer greater disease burden than non-indigenous (Tollefson et al. 2013).

Conclusions

While the national incidence and prevalence of TB in Paraguay is not very high when compared globally, the indigenous population in the Chaco suffers TB incidences and prevalences comparable to high-burden countries. TB prevention and control efforts are probably better served by focusing on specific at-risk subpopulations – like the indigenous – rather than national statistics that dilute the scale of the problem in these communities. The data support significant associations between healthcare access and active TB disease in adults, and education and active TB in children. These findings suggest that the action plan put forth by Lönnroth et al. (2009) is appropriate here: a focus on vulnerable populations, public health systems strengthening, and interventions tailored to upstream social determinants. This study provides initial clues for the disparity in active TB prevalence between indigenous and non-indigenous populations in the Chaco, but better surveillance data are needed on known risk factors for TB.

CHAPTER 5

OVERALL DISCUSSION & CONCLUSIONS

The three case studies presented in this dissertation approach the disease ecology of TB in different ways. Chapter two is a microsociological examination of how the biomedical model of TB is being adopted in two indigenous communities with different degrees of interaction with outsiders. Chapter three investigates the prevalence of intestinal parasites, an important co-infection in the progression to active TB disease, and sanitation infrastructure in three indigenous communities in the Central Chaco. Chapter four analyzes the risk for active TB throughout indigenous communities in the Chaco using variables from the National Indigenous Census of 2002 in Paraguay as proxies for TB risk factors. Each of these case studies contributes to answering the two hypotheses proposed by the overall project.

Hypothesis 1: When comparing indigenous communities with greater integration into national society and greater influence from outside institutions with more isolated communities, we expect to see greater awareness of biomedical models of health and disease, particularly biomedical models of TB.

The comparison of Isolationville and Integrationville in Chapter Two demonstrated that greater distance from urban centers, decreased accessibility of transportation and communication, and less interaction with outside groups did not inhibit the adoption of the biomedical model of TB in Isolationville. In fact, residents of Isolationville reported a greater diversity of sources of information about TB, and agreed more with the biomedical model of TB than Integrationville. In addition, measures of acculturation, such as greater language ability and migration for wage labor to cattle ranches or urban centers, were not significantly associated with an individual’s agreement with the biomedical model of TB. Rather, greater language ability and migration to cattle ranches were actually significantly associated with lower agreement with the biomedical model of TB held by local healthcare workers.

These lines of evidence suggest that Hypothesis one is incorrect; greater integration with national society or contact with outside groups does not lead to greater awareness of biomedical models of TB. It could be, however, that there is simply not enough variation within the sample of laypersons from Isolationville and Integrationville to detect any significant associations in adherence to the biomedical model. Also, because the sampling period was cut short in Integrationville, the responses from that community may not be representative of the community as a whole.

The comparison of layperson models of TB with both the local biomedical and national biomedical models of TB gives a microlevel perspective of the process of cultural transmission, and reveals which aspects of the biomedical model are being adopted and the degree of fidelity. Laypersons in both Isolationville and Integrationville agreed with the biomedical model in the most practical aspects in terms of symptom identification, diagnosis, and treatment. Interestingly, the biomedical model of TB held by local healthcare workers, who are the main source of information about TB in the study communities, lay about halfway between the layperson and national biomedical models of TB.

Hypothesis 2: When comparing indigenous communities with greater integration into national society and greater influence from outside institutions with more isolated communities, we expect to find better public health infrastructure, including health posts and hygienic facilities like wells and latrines.

The quantity and quality of public health and sanitation infrastructure seems rather arbitrary, and perhaps depends most on which outside groups are involved in the community. As I mentioned in the introduction, Integrationville has a large and well-staffed health post even though it is much farther away from the TransChaco highway and urban centers than Angaité-ville, and Angaité-ville has no health post. This might be related to how long the relationships between the outside groups and the indigenous community have existed, since the Angaité community is younger than both Isolationville and Integrationville. Integrationville, as the site of a religious mission, must also have more sustained interaction with outsiders than Isolationville or Angaité-ville since the missionaries reside in the community. Or, it may be that the type of assistance offered by the outside groups has less of a health emphasis in Angaité-ville.

Chapter Four's analysis of community-level risk factors for active TB demonstrates the importance of public health infrastructure in the indigenous communities of the Chaco. Communities with a health post were more than twice as likely to report active adult TB (RR = 2.07, CI [1.13-3.83], $p < 0.05$). This phenomenon has three potential explanations. Firstly, it may be detection bias, since the health posts are charged with reporting TB cases to the National TB Program and cases are more likely to be spotted when healthcare workers are around to detect them. Secondly, it may be that the construction of health posts has been more of a priority in communities with a historically high incidence of TB. Lastly, it may be a result of TB patients moving into a community with a health post to seek treatment.

Another interesting finding from Chapter Four was the strong protective association of non-indigenous community members, whose presence indicates a greater degree of integration with national Paraguayan society, with active TB. The protective association was strong in both the adult (RR = 0.56, CI [0.30-1.03], $p = 0.06$) and pediatric models (RR = 0.64, CI [0.34-1.14], $p = 0.14$), although non-significant for both. These non-indigenous residents could be NGO workers or missionaries, like those in Integrationville, or they may be Paraguayan spouses who have married into indigenous communities.

Education, which is also a potential indicator of acculturation or integration with national society, was the only significant association with active pediatric TB. Each additional average year of education in the community was associated with nearly 50% less likelihood of reporting active pediatric TB (RR = 0.53, CI [0.38-0.73], $p < 0.001$). Greater education should better enable parents to overcome cultural and linguistic barriers to getting health care for their children, and it may also provide a better socioeconomic status for the family.

The main drawback of using the pre-existing data from the Indigenous Health Census and the National TB Program is the limitation of the variables collected. Data on risk factors that are specific to TB, like the prevalence of co-morbidities like diabetes, smoking, or alcohol abuse, the use of solid fuels, and food security, or a better measure of socioeconomic status would improve the model. The data from the National TB Program did not allow for disaggregation by sex, and had pre-determined age categories. This approach still identified important avenues for future investigation at the household and individual level.

Besides the health posts, in Chapter Three we see that the sanitation infrastructure in the three communities is nearly identical for latrines, but variable for water sources and housing materials. Latrine construction was similar across the communities; nearly all households used latrines except for one in Integrationville. Angaité-ville had a *pozo artesanio* (well) for clean drinking water, which is the ideal water source. The Nivaclé communities had a water use strategy that prioritized using the cleaner water source – rainwater – first, and then the *tajamar* when driven by necessity. The primary water source used by households varied over the year, depending on rainfall. Isolationville had better infrastructure to collect rainwater from household rooftops because these pipes and tanks were included with the brick houses recently constructed by the government. These brick houses are also the reason for fewer earthen floors in the households in Isolationville, whereas most of the households in Integrationville and Angaité-ville have earthen floors.

A corollary prediction of having better sanitation infrastructure is that intestinal parasites should have decreased prevalence, but as chapter three demonstrates, behavior also plays a large role in the transmission of infectious disease. While respondents from all three communities reported washing their hands a similar number of times per day, the residents of Angaité-ville used soap only about half as often ($p < 0.05$). This may be why, in spite of having a *pozo artesanio* for clean drinking water, Angaité-ville had the highest prevalence of giardia. Many of the respondents in Angaité-ville who did use soap to wash their hands mentioned that they were actually using shampoo as a soap substitute. This suggests that soap may simply not be accessible in the community, and the residents of Angaité-ville would use it if it was available; in which case this may be an outcome of poverty rather than behavior.

The results of the three case studies also provide some interesting insights into the overall disease ecology of TB in the Paraguayan Chaco. In the introduction, I mentioned that the incidence of all forms of TB was 10.7 times higher in the indigenous population compared to the non-indigenous population in 2010. This gap probably increased in recent years since data from Chapter Four reveal that, in a high transmission setting like the Chaco, back in 2002 the active TB prevalence in the indigenous population was eight times greater than in the non-indigenous population.

The relative lack of helminthiasis found in the three study communities of chapter three is an unexpected finding. The prevalence of helminthes may have been underestimated by the single-day fecal sampling or season of sampling, but it remains surprising in light of the high prevalence of helminthiasis in other indigenous communities. A sample with better demographic representation, particularly a sample that includes children, who play in the dirt and are less likely to own shoes, might reveal more demographic structure to the prevalence of infection. Although in Soper's (1927) original study among the Lengua, it was the adults who had the highest prevalence of hookworm.

One of the main challenges of research in human infectious disease ecology is the great number of confounding variables that must be controlled for to isolate a particular relationship. This task is easier when working in a region where some data are already known, but the Chaco has limited published health research or even health statistics. Add to this the remoteness of the communities, difficulties in transportation and communication, and the vagaries of climate, and it becomes extremely difficult to accurately sample across time and space in these communities. For example, the collection of survey data and biological data might be separated by months because rains or flooding cuts off road access to the study communities, and the correlation between these two data sets may no longer be relevant. The best strategy was to collect the greatest amount of data possible within the shortest time span, using a large team of field assistants.

Each of the case studies revealed new avenues for future work, and several of the data sets collected for the overall project await analysis. Among these, two lines of inquiry are particularly interesting: the relative adoption of health behaviors, and household-level risk factors for TB.

One of the corollary predictions of Hypothesis one is that with greater biomedical knowledge, we expect a greater adoption of health behaviors promoted in the biomedical model, such as a higher frequency of health protective behaviors like hand washing and a lower frequency of risky behaviors like smoking, spitting, or sharing utensils. Several data sets include measures of health behaviors, including the health behavior survey, vignette questions, and time allocation observations. Help seeking behavior and treatment adherence can also be ascertained through the health records from the health posts. To assess whether health beliefs match health behaviors, a participant's corresponding behaviors can be compared with their responses to the TB Beliefs survey.

The investigations of community-level risk factors for TB in chapters three and four provide a macro perspective of the disease pattern, but household-level risk factors for TB will provide a better perspective on the mechanics of the disease process. As a rural, sparsely populated region, the household is probably the main site of TB transmission in the Chaco, because the household is where people come together in crowded, enclosed spaces to sleep at night. In combination with the census and survey data, the association between prospective cases of TB recorded over the study period and household-level risk factors will be investigated. The social networks data and time allocation observations will be analyzed for changes in household composition and contact patterns. The social networks data can also be related to the health beliefs and behaviors data sets, and using health post data on respiratory illnesses, a general model of respiratory disease transmission could be built.

Conclusions:

To summarize the contribution of these three case studies to evaluating the overall project hypotheses: (H1) greater integration into national society and greater influence from outside institutions is not associated with greater adoption of biomedical knowledge of TB; and (H2) both measures of greater integration into national society and public health infrastructure were associated with active TB, but the presence of public health infrastructure may or may not be a result of greater integration with national society or contact with outside groups. More research is needed on the role of non-indigenous community residents and other measures of acculturation or integration in TB outcomes, as well as the histories and policies that led to the establishment of public health infrastructure in different communities (i.e. why do some communities have health posts and not others). Indigenous TB burden in the Chaco is disproportionately high, and better understanding of the mechanisms that produce higher incidence and prevalence of the disease is needed. Future work includes investigations on household-level risk factors for TB and associations between health beliefs and health behaviors.

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APPENDIX A

DATA COLLECTION INSTRUMENTS

HEALTH CENSUS

Código

CENSO DE SALUD - COMUNIDADES

Fecha y hora de censo: _______________

A. DATOS DE LA VIVIENDA

1. *¿Qué tipo de vivienda es?*
- ☐ Rancho
- ☐ Casa
- ☐ Temporal
- ☐ Galpón

2. *¿Qué material predomina en las paredes exteriores?*
- ☐ Ladrillo
- ☐ Madera
- ☐ Adobe
- ☐ Adobe con paja
- ☐ Tronco de palma
- ☐ Cartón, hule, o madera de embalaje
- ☐ No tiene pared
- ☐ Otro

3. *¿Qué material predomina en el piso?*
- ☐ Tierra
- ☐ Ladrillo
- ☐ Cemento
- ☐ Otro

4. *¿Qué material predomina en el techo?*
- ☐ Teja
- ☐ Paja
- ☐ Chapa de zinc
- ☐ Tablilla de madera
- ☐ Tronco de palma
- ☐ Cartón, hule, madera de embalaje
- ☐ Otro

5. ¿Cuántas ventanas tiene su casa?

____

6. ¿Cuántas piezas tiene su casa?

____

Medidas de esta casa
Largo ________
Ancho ________

Medidas de cada pieza
Largo ________
Ancho ________
☐ Se usan para dormir
Cuántas personas:______

Largo ________
Ancho ________
☐ Se usan para dormir
Cuántas personas:______

Largo ________
Ancho ________
☐ Se usan para dormir
Cuántas personas:______

Largo ________
Ancho ________
☐ Se usan para dormir
Cuántas personas:______

7. ¿Cómo elimina habitualmente la basura?
- ☐ La quema
- ☐ La recoge el camión o carrito de basura
- ☐ La tira en el patio, baldío, zanja o calle
- ☐ La tira en la chacra
- ☐ La tira al tajamar
- ☐ La entierra o tira en pozos
- ☐ Otro

8. ¿Qué tipó de luz usa usted?
Puede dar más que una respuesta.
- ☐ Fogón
- ☐ Velas
- ☐ Fuego a leña
- ☐ Linterna
- ☐ Generador

Código

9. ¿De dónde proviene principalmente el agua que utiliza en la casa?
- ☐ Tajamar
- ☐ Agua de lluvia: tanque sin tapa
- ☐ Agua de lluvia: tanque con tapa
- ☐ Pozo
- ☐ Otra fuente

10. El agua llega a la casa a través de...
- ☐ canilla dentro de la casa
- ☐ canilla afuera de la casa
- ☐ canilla pública
- ☐ vecino
- ☐ aguatero
- ☐ otros medios

11. ¿De dónde proviene el agua que utiliza para beber?

____

12. Para cocinar usa principalmente...
- ☐ leña
- ☐ gas
- ☐ carbón
- ☐ generador
- ☐ otro
- ☐ ninguno, no cocina

13. ¿Hace fuego dentro de la casa en la cocina?
- ☐ Si
- ☐ No

14. ¿Hace fuego dentro de la casa en la pieza?
- ☐ Si
- ☐ No

15. ¿Tiene letrina?
- ☐ Si
- ☐ No

16. ¿Qué tipo de letrina tiene la casa?
- ☐ Letrina de madera
- ☐ Letrina de plástico-cartón
- ☐ Pozo
- ☐ No tiene ninguno de estos tipos

17. La letrina se desagüa en...
- ☐ un hoyo o pozo
- ☐ un pozo ciego
- ☐ otro

18. Esta casa tiene...

Marca todos los que aplican.
- ☐ televisor
- ☐ heladera/refrigerador
- ☐ celular
- ☐ radio/grabadora
- ☐ máquina de coser
- ☐ automóvil o camioneta
- ☐ moto
- ☐ bicicleta
- ☐ hacha
- ☐ machete
- ☐ pala
- ☐ lima
- ☐ azada
- ☐ arado
- ☐ molino
- ☐ mortero
- ☐ trampa
- ☐ lanza/fija
- ☐ red de pesca
- ☐ arco/flecha
- ☐ telar
- ☐ carro/carreta
- ☐ canoa
- ☐ motosierra
- ☐ revólver/escopeta
- ☐ generador
- ☐ no tiene ninguno de estos bienes

19. ¿Qué idiomas habla usted?

____

____

____

____

20. ¿Cuál es su origen étnico?

____

Código

B. PROVISTA

1. ¿Qué animales domésticos tienen?
Marca todos los que aplican y la cantidad de cada tipo de animal.
- ☐ Caballos: ____
- ☐ Mulas/burros: ____
- ☐ Pollos: ____
- ☐ Patos: ____
- ☐ Loros: ____
- ☐ Vacas: ____
- ☐ Ovejas: ____
- ☐ Cabras: ____
- ☐ Cerdos: ____
- ☐ Perros: ____
- ☐ Gatos: ____
- ☐ Otro: ______________________
- ☐ No tiene animales

2. ¿Las personas de esta casa practican la cacería o pesca? ☐ Sí ☐ No

¿Qué cazan o pescan?
Ejemplos: Carpincho, Quiiquincho, Cerdo silvestre, León, Venadu, Mborebi, Conejo, Lagarto, Otros

____

____

3. ¿Las personas de esta casa recolectan alimentos del bosque, del campo u otros lugares? ☐ Sí ☐ No

¿Qué recolectan?
Ejemplos: Poroto del monte, Algarrobo, Tuna, Miel silvestre, Chañar, C'waitsi, Ninívá, Ajôyej, Otros

____

____

4. ¿Cultivó una chacra el año pasado?
☐ Sí ☐ No

¿Qué cultivó?
Ejemplos: Sésamo, Batata, Zapallo, Sandia, Maíz, Melón, Poroto, Calabasa, Otros

____

____

Destino del cultivo es...
☐ Venta ☐ Venta y consumo ☐ Consumo

5. ¿Dónde (más) consigue la provista?
Puede dar más de una respuesta.
- ☐ Almacén en la comunidad
- ☐ Almacén de estancia
- ☐ Emergencia
- ☐ Políticos
- ☐ Macetero
- ☐ Merienda escolar
- ☐ Otro: ______________

6. Generalmente, ¿cómo paga la provista?
- ☐ Al contado
- ☐ Fiado/crédito
- ☐ A cambio de trabajo
- ☐ Trueque
- ☐ Otra forma
- ☐ Gratis

7. ¿De dónde viene la leche que toma?
Puede dar más de una respuesta.
- ☐ Directamente de la vaca
- ☐ Comprarlo
- ☐ Leche de la gobernación
- ☐ Leche de la programa de escuela
- ☐ No toma leche

Si bebe la leche que viene directamente de la vaca, ¿bebe la leche sin hervir?
- ☐ Sí
- ☐ No

8. En su opinión, en general la cantidad de comida que comen los miembros de su casa es…
- ☐ mucho.
- ☐ suficiente.
- ☐ poco.
- ☐ muy poco.

9. En su opinión, en general la calidad de comida que comen los miembros de su casa es…
- ☐ muy bueno.
- ☐ bueno.
- ☐ malo.
- ☐ muy malo.

Código

C. LISTADO DE PERSONAS QUE PASARON LA NOCHE EN LA CASA Y RED SOCIAL

Por cada persona que pasa la noche en la casa, conteste las siguientes preguntas y completa la tabla siguiente:

A. ¿Qué edad tiene?

B. ¿Es varón o mujer?

C. ¿Cuál es su relación o parentesco con usted?

D. Si trabaja o trabajaba antes, ¿Cuál es o era su ocupación principal en el trabajo? Especifique la tarea.
Ejemplos: Artesano, Agricultor, Troperos de estancia, Limpiador de patios, Técnico agropecuario, Pescador, Cazador, Albañil, Docente, Promotor de salud

E. ¿Trabaja o trabajaba antes con vacas?

F. ¿Ha recibió la vacuna BCG?
Puede contestar (A) *Si,* (B) *No,* (C) *Ha recibió una vacuna, pero no se dé que* o (D) *No se*

G. ¿Esta persona fuma?

H. ¿Participa esta persona en organizaciones o grupos que se reúnen regularmente?
Ejemplos: escuelas, colegios, iglesias, reuniones de comunidad, equipos de deportes

I. ¿Alguna vez esta persona ha vivido o trabajado en una comunidad diferente de donde usted vive ahora? Indica donde.

Notas:

Código

C. LISTADO DE PERSONAS QUE PASARON LA NOCHE EN LA CASA Y RED SOCIAL (TABLA)

Persona #	A. Edad	B. Varón o mujer (V/M)	C. Relación o parentesco con usted	D. Ocupación principal en el trabajo	E. ¿Con vacas? (S/N)	F. ¿Vacunación BCG? (A/B/C/D)	G. ¿Fuma? (S/N)	H. Organización #1	H. Organización #2	H. Organización #3	H. Organización #4	H. Organización #5	I. Si ha vivido o trabajado en una comunidad diferente, indica donde:
1													
2													
3													
4													
5													
6													
7													
8													
9													
10													
11													
12													

Código	

D. DATOS DE SALUD

1. ¿Hay en esta casa alguna persona que tenga tuberculosis o que haya tenido tuberculosis en el pasado?

- ☐ Sí
- ☐ No

Numero de *Parte C del Censo*	Tiempo de TB (*fecha de diagnostico, fecha de cura, cuantos años tuvo la persona*)
#	
#	
#	
#	
#	

2. ¿En la temporada pasada, cuántos enfermos hubo entre los miembros de esta casa? ¿Cómo se trataron? *Lista la enfermedad, persona que se enfermó, y como fue tratado.*

Numero de *Parte C del Censo*	Enfermedad	Como fue tratado
#	1	
#	2	
#	3	
#	4	
#	5	
#	6	
#	7	

3. ¿Cuando un miembro de esta casa se enferma, a quién acuden en busca de ayuda para tratar la enfermedad?

Puede dar más de una repuesta.

- ☐ Un miembro de la casa
- ☐ Líder religioso/Chamán
- ☐ Anciano
- ☐ Promotor de salud
- ☐ Doctor o enfermera
- ☐ Partera empírica
- ☐ Macetero
- ☐ Otras personas: ______________________

Código [ ]

4. ¿Dónde obtiene información sobre la salud?
Puede dar más de una repuesta.
- ☐ Un miembro de la casa
- ☐ Líder religioso/Chamán
- ☐ Anciano
- ☐ Promotor de salud
- ☐ Doctor o enfermera
- ☐ Partera empírica
- ☐ Macatero
- ☐ Líder de la comunidad
- ☐ Radio
- ☐ Folletos
- ☐ Otras: ____________________

5. ¿En su opinión, qué fuentes de información sobre la salud son confiables?
Puede dar más de una repuesta.
- ☐ Un miembro de la casa
- ☐ Líder religioso/Chamán
- ☐ Anciano
- ☐ Promotor de salud
- ☐ Doctor o enfermera
- ☐ Partera empírica
- ☐ Macatero
- ☐ Líder de la comunidad
- ☐ Radio
- ☐ Folletos
- ☐ Otras: ____________________

6. En su opinión, el acceso a los servicios de salud en su comunidad es…
Solo una repuesta.
- ☐ muy bueno.
- ☐ bueno.
- ☐ malo.
- ☐ muy malo.

7. En su opinión, ¿cuáles son las problemas de salud más importantes en su comunidad?
Lista 3 por favor.

____
____
____
____
____
____
____

¡Muchas gracias por participar en nuestro censo!

INTERVIEW GUIDE

Tuberculosis

1. Are there other names for tuberculosis?
2. What do you think causes tuberculosis? (When you had tuberculosis, why do you think it started when it did?)
3. What does tuberculosis do to you? What is its mechanism? How does it work? Please list all of the tuberculosis symptoms that you can think of.
4. How severe is tuberculosis? Will it have a short or long course?
5. What problems does tuberculosis cause for people?
6. What do you fear most about tuberculosis?
7. What kind of treatment should be given for tuberculosis? (What did you do to treat your tuberculosis?)
8. What are the most important results you can receive from treatment?
9. What do you fear most about the treatment for tuberculosis?
10. Is tuberculosis a problem in your community?
11. Are there people who are more at risk of tuberculosis than others?
12. How are people with tuberculosis viewed in your community? How do people in your community act towards people with tuberculosis?
13. (Tell me about your experience with tuberculosis.) Do you know anyone (else) who had tuberculosis? Tell me about their experience.

Sick Role

1. When someone in this community is sick, where do they go for help?
2. What kinds of problems or illnesses do they seek help for?
3. Who looks after sick people in your community? (Feeding them, transporting them to the hospital, buying medication, making sure they take their medication, etc.)
4. What does a person do when they are sick? (Do they stay at home? continue going to work? continue going to church? etc.)

Access to Health Care

1. Who can treat illnesses in this community?
2. When are they available to help?
3. How can they help? What do they do to help?
4. How much does it cost to get their help? Are there other costs for seeking help (like transportation, lost time and income, unofficial charges)?
5. How far do you have to travel to receive help? How do you travel there? How long is the trip?
6. Are you satisfied with the health care in your community? Are there enough sources of help? Are the sources of help of good quality?
7. What are the major health problems in your community? Is the community receiving help with these problems?
8. Do you feel welcomed and cared for when you seek treatment? Do you trust the (doctor/nurse/macetero/etc.)? Do you feel you get enough information about your illness and its treatment?

Nutrition

1. I want to make a list of all the typical foods that people eat in this community. I'd like you to think of all the different foods that people eat in a day. Please list as many (breakfast/lunch/merienda/dinner/snack) foods that you can think of.
2. *For each of the foods listed:* What are the ingredients used to make this food? How do you make it?

Community history

1. I would like to learn more about the history of the community. When was the community founded?
2. Starting from when the community was founded and up until today, what were the major events that happened in the community? What year/month was this?
3. When was the (road/school/church/etc.) built?
4. What encounters has this community had with outsider groups? (Missionaries, Mennonites, government officials, health care providers, foreigners, other indigenous peoples, ranchers, mestizos.)
5. Has there ever been a time when there was not enough food in the community? What year/month was this?
6. Has there ever been a time when the food in the community was not of good quality? What year/month was this?
7. Has there ever been a time when there were lots of illnesses in the community? What year/month was this?

Social Network

1. I'm interested in how much time people spend together in this community. I'd like you to think of all the different occasions where people come together. Please list as many organizations or groups that regularly have meetings that you can think of. (Schools, churches, community meetings, sports teams, etc.)
2. *For each organization/group:* Where do they meet? How often do they meet? How many people go to the meeting?
3. Do people in this community do any traveling? Who? Where do they go? Why do they go there? How do they get there?

Código

COMPOSICION DE CASA

Quiero saber quienes son sus parientes.

¿Quien dormía en esta casa ayer? ¿En que pieza se duermen? ¿Quien tiene zapatos o zapatillas? ¿Quien tiene una cicatriz de la vacuna BCG?

Nombre y apellido	Edad/ Sexo	**Madre** Nombre y apellido	**Padre** Nombre y apellido	**DUE**	**PZA**	**ZAP**	**BCG**	**CON**	**HEC**	**MEJ**	**CC**	**RS**	**ALI**

XO = X duermen aca, O otro lugar, **PZ =** # de pieza, **ZAP =** X tiene zapatos, O no tiene, **BCG =** X tiene, O no tiene

COMPLETO (X) o NO (O): CON (consentimiento), HEC (heces), MEJ (mejilla), CC (consenso cultural), RS (red social), ALI (alimentos)

Código

ENCUESTA DE SINTOMAS

¿Quien es en casa ahora?

Edad/Sexo												
Temperatura (C)												

¿Como están ustedes hoy? ¿Alguien es enferma?

Síntoma							**Descripción/Notas**
Tos	( )	( )	( )	( )	( )	( )	¿Estetoscopio, C/ catarro?
Resfriado	( )	( )	( )	( )	( )	( )	
Fiebre	( )	( )	( )	( )	( )	( )	¿Mañana, Tarde, Noche?
Dolor de estomago	( )	( )	( )	( )	( )	( )	
Dolor de cabeza	( )	( )	( )	( )	( )	( )	
Dolor de espalda	( )	( )	( )	( )	( )	( )	
Dolor de pecho	( )	( )	( )	( )	( )	( )	
Sudor en la noche	( )	( )	( )	( )	( )	( )	
Choocho	( )	( )	( )	( )	( )	( )	
No ganas de comer	( )	( )	( )	( )	( )	( )	
No tiene fuerza	( )	( )	( )	( )	( )	( )	
Le pica la colita	( )	( )	( )	( )	( )	( )	
No puede dormir	( )	( )	( )	( )	( )	( )	
Manchas en la piel	( )	( )	( )	( )	( )	( )	¿Blanca?
Diarrea	( )	( )	( )	( )	( )	( )	
Vomito	( )	( )	( )	( )	( )	( )	
Dificultad respirar	( )	( )	( )	( )	( )	( )	

ANTROPOMETRICA

Edad/Sexo								
Altura 1								
Altura 2								
Peso 1								
Peso 2								
Circum. de brazo1								
Circum. de brazo 2								
Pliegue de brazo 1								
Pliegue de brazo 2								
Ancho de codo 1								
Ancho de codo 2								
Edad/Sexo								
Altura 1								
Altura 2								
Peso 1								
Peso 2								
Circum. de brazo1								
Circum. de brazo 2								
Pliegue de brazo 1								
Pliegue de brazo 2								
Ancho de codo 1								
Ancho de codo 2								

Código

REDES SOCIALES - INDIVIDUO

ID-Participante: _______________

Por favor, lista 4 personas que **no viven** en esta casa que:

Comparte comida con usted en la semana pasada	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			
Comparte tereré con usted en la semana pasada	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			
Visita su casa en la semana pasada (sin compartir comida o tereré)	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			

¿Si su ___(A)___ tiene ___(B)___, usted ___(C)___?

A1 pareja	B1 tos	C1 compartirá su comida con el/ella del mismo plato?	#	Si / No
A2 padre o madre	B2 fiebre	C2 compartirá su tereré con el/ella?	#	Si / No
A3 hermano o hermana	B3 vomito	C3 estará cerca con el/ella?	#	Si / No
A4 primo o prima			#	Si / No
A5 amigo o amiga			#	Si / No

1. ¿Usted usa jabón? ( ) No ( ) Si → ¿Que marca? _____________
   ¿Para que usa?

____

2. ¿Usted usa agua del tajamar? ( ) No ( ) Si → ¿Para que? _____________
   ¿Se usa con un tratamiento, por ejemplo hierve o agrega químicos?

____

Codigo

ENCUESTA DE LA TUBERCULOSIS

Esta es una lista de frases sobre la tuberculosis. Por cada frase por favor indicar si usted esta de acuerdo o no con la oración, responda Si o No. No hay buenas o malas respuestas, estamos interesados en su opinión. Si no esta seguro, por favor denos su mejor conjetura.

		Si/No
1	Personas con tuberculosis tienen fiebre.	
2	Personas con tuberculosis tienen dolor de pecho.	
3	Personas con tuberculosis tienen frío, mismo en el calor.	
4	Personas con tuberculosis tienen diarrea.	
5	Personas con tuberculosis tienen dolor de espalda.	
6	Personas con tuberculosis tienen tos.	
7	Personas con tuberculosis tienen dolor de cabeza.	
8	Personas con tuberculosis tienen vomito.	
9	Personas con tuberculosis tienen muchos resfriados.	
10	Personas con tuberculosis tienen manchas en la piel.	
11	Personas con tuberculosis no tienen ganas de comer.	
12	Personas con tuberculosis son muy flacas.	
13	Personas con tuberculosis no tienen fuerza.	
14	Personas con tuberculosis sudan mucho en la noche.	
15	Personas con tuberculosis no tienen mucho catarro.	
16	Personas con tuberculosis duermen muy poco.	
17	Personas con tuberculosis no pueden trabajar.	
18	Personas con tuberculosis no pueden ir a la iglesia.	
19	Personas con tuberculosis no quieren oler la comida.	
20	Todas las personas que tienen tuberculosis tienen tos.	
21	La tuberculosis puede salir de cualquier parte de su cuerpo.	
22	Una persona no puede morir de la tuberculosis.	
23	La tuberculosis no es grave.	
24	La tuberculosis es una enfermedad muy rápida.	
25	La tuberculosis sale solamente en los pulmones.	
26	Todos pueden enfermar de tuberculosis.	
27	La tuberculosis es una enfermedad de corta duración.	
28	La tuberculosis se contagia de basura.	
29	La tuberculosis se contagia de hablar con una persona que tiene la enfermedad.	
30	La tuberculosis se contagia de una casa sucia.	
31	La tuberculosis se contagia de persona a persona.	
32	La tuberculosis se contagia de leche de vacas.	
33	La tuberculosis se contagia del aire.	
34	La tuberculosis se contagia de agua sucio.	
35	La tuberculosis viene de un microbio.	

Código

ENCUESTA DE ALIMENTOS 24 HORAS ANTES – INFO BASICA

ID-Participante: ___________
Sexo: ( ) Hombre ( ) Mujer
Edad: ______

( ) Embarazada ( ) Mamando ( ) Adulto no embarazada/mamando

Fecha de hoy _______________ (día/mes/año)

Fecha de ayer _______________ (día/mes/año)

¿Ayer fue un día "normal"?: ( ) Si ( ) No ( ) Enfermo ( ) Otro (especifica): _______________

¿Usted toma vitaminas o minerales?: ( ) Si ( ) No
En caso de si, especifica: Nombre de la marca: ________________ Frecuencia de consumo: ______________

Durante una semana normal, ¿cuanta bebida alcohólica toma usted? ________________

1. Entrevistador, por favor lee al participante:

"Por favor, recuerde que usted como ayer, ____________________ (*escribe que día de la semana*), desde cuando usted despertado con lo mas detalles posibles."

COMPLETA LA TABLA AL REVERSO. USA TODOS LOS PAGINAS QUE TE NECESITA.

2. Pregunta:
» Que ingredientes fueron usado (incluyendo la marca),
» Cantidad de ingredientes,
» Como la comida fue preparado (Ex. frita, hervido),
» De donde viene los alimentos
  (*$* - comprado, *m* – plantes o animales del monte, *d* – producido (huerta o animales domesticas)
» Cuanto se comió. *UTILICE EL PLATO Y TAZA PARA MOSTRAR.*

3. Seguimiento: grasa, aceite, agua, sal, azúcar, bebidas (mate, tereré, alcohol), picar algo (chiclet, caramelo, algarrobo)

4. Revista: Lee la lista al participante. ¿El participante recuerde otros alimentos o bebidas?

Código

ENCUESTA DE ALIMENTOS 24 HORAS ANTES – TABLA ID-PARTICIPANTE: ___________ PAGINA # ________

Tiempo del dia	Nombre de alimento	Ingredientes	Forma de cocinar	Fuente *$/m/d*	Cantidad consumido	Comentarios

CODIGO

COMPOSICION DE CASA

¿Quien vive en esta casa? Queremos saber quiénes son sus parientes: ¿Quiénes son sus padres? ¿Quién dormía en esta casa ayer? ¿En qué pieza se duermen? ¿Usted ha viajado afuera de esta comunidad en el año pasado?

CODIGO	Nombre y apellido	Edad/ Sexo	Madre Nombre y apellido	Padre Nombre y apellido	DUE	PZA	TRA
	1						
	2						
	3						
	4						
	5						
	6						
	7						
	8						
	9						
	10						
	11						
	12						
	13						
	14						
	15						
	16						
	17						
	18						

DUE = X duermen aca, O otro lugar, **PZA** = # de pieza, **TRA** = X viajado fuera de la comunidad en el año pasado, O = no viajado

Lugares de viaje en el año pasado (codigo):

Medidas de esta casa
Largo ________
Ancho ________
de ventanas _____
de piezas _____

Medidas de cada pieza
Largo ________
Ancho ________
☐ Se usan para dormir
de personas: _____

Largo ________
Ancho ________
☐ Se usan para dormir
de personas: _____

Largo ________
Ancho ________
☐ Se usan para dormir
de personas: _____

Largo ________
Ancho ________
☐ Se usan para dormir
de personas: _____

Materiales de esta casa
Paredes exteriores:
☐ Ladrillo ☐ Madera
☐ Troncos de palma
☐ Adobe ☐ Otro
____
Piso: ☐ Tierra ☐ Otro
____
Techo: ☐ Zinc ☐ Otro
____

ENCUESTA DE SINTOMAS/REDES SOCIALES

¿Quien es en casa ahora?

Edad/Sexo												
Temperatura (C)												

¿Como están ustedes hoy? ¿Alguien es enferma?

Síntoma							**Descripción/Notas**
Tos							¿Estetoscopio, C/ catarro?
Resfriado							
Fiebre							¿Mañana, Tarde, Noche?
Dolor de estomago							
Dolor de cabeza							
Dolor de espalda							
Dolor de pecho							
Sudor en la noche							
Choocho							
No ganas de comer							
No tiene fuerza							
Le pica la colita							
No puede dormir							
Manchas en la piel							¿Blanca?
Diarrea							
Vomito							
Dificultad respirar							

Por favor, lista 4 personas que **no viven** en esta casa que:

Comparte comida con usted en la semana pasada	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			
Comparte tereré con usted en la semana pasada	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			
Visita su casa en la semana pasada (sin compartir comida o tereré)	#	Edad/ Sexo	Relación	HH-ID
	1			
	2			
	3			
	4			

DEMOGRAPHIA Y COMPORTAMIENTOS Y CONOCIMIENTO

Código

1. ¿Qué idiomas habla usted?
¿ Habla bien o poco?
_______________ ☐ bien ☐ poco
_______________ ☐ bien ☐ poco
_______________ ☐ bien ☐ poco

2. ¿Cuántas personas en esta casa no son [*nombre de la etnia local*]? ___________

3. Esta casa tiene...
Marca todos los que aplican.

☐ televisor	☐ heladera/refrigerador
☐ celular	☐ radio/grabadora
☐ moto	☐ bicicleta
☐ hacha	☐ machete
☐ pala	☐ lima
☐ azada	☐ arado
☐ molino	☐ mortero
☐ trampa	☐ lanza/fija
☐ red de pesca	☐ arco/flecha
☐ telar	☐ carro/carreta
☐ motosierra	☐ revólver/escopeta
☐ generador	☐ automóvil o camioneta

☐ no tiene ninguno de estos bienes

1. En las últimas 24 horas, ¿cuántos fuegos con leña hizo usted?
Dentro de la casa ____ Cerca ____ Lejos ___

2. En las últimas 24 horas, ¿de dónde proviene principalmente el agua que bebió?
☐ Tajamar (# ______)
☐ Agua de lluvia: tanque sin tapa
☐ Agua de lluvia: tanque con tapa
☐ Otra fuente

3. En las últimas 24 horas, ¿cuántas veces usted trató el agua antes de beber?
Veces tratadas _____ Veces no tratadas _____

Tipo de tratamiento: ________________________

4. En las últimas 24 horas, ¿cuántas veces usted lavó sus manos?
Con jabón ____ Sin jabón ____

5. En las últimas 24 horas, ¿cuántas veces usted escupió sobre el piso? ____

6. En las últimas 24 horas, ¿cuántas veces usted compartió cubiertos con otras personas? _____

CONOCIMIENTO DE TUBERCULOSIS ACUERDO/NO

1	Todas las personas que tienen tuberculosis tienen tos.	
2	Personas con tuberculosis tienen diarrea.	
3	Personas con tuberculosis tienen vomito.	
4	Personas con tuberculosis tienen manchas en la piel.	
5	Personas con tuberculosis no quieren oler la comida.	
6	La tuberculosis se contagia de una casa sucia.	
7	La tuberculosis se contagia de persona a persona.	
8	La tuberculosis se contagia de leche de vacas.	
9	La tuberculosis se contagia de agua sucio.	
10	La tuberculosis viene cuando hay algo malo con su alma.	
11	La tuberculosis ataca mas a personas que no tienen abrigos.	
12	Se puede prevenir la tuberculosis por usar cubiertos bien lavados.	
13	Se puede prevenir la tuberculosis con una vacuna.	
14	Se puede prevenir la tuberculosis por comer frutas y verduras.	
15	Personas con tuberculosis pueden ir a la iglesia.	
16	Se puede visitar una persona con tuberculosis dentro de su pieza.	
17	Se puede compartir tereré con personas que tienen tuberculosis.	
18	Hay remedios tradicionales para la tuberculosis.	
19	Se puede curar personas con la tuberculosis muy avanzada o grave.	
20	Se puede curar la tuberculosis con remedios tradicionales.	

Código

ESCENARIOS

¿Si su ___(A)___ tiene ___(B)___, usted ___(C)___?

1	PAREJA	TOS	compartirá su comida con el/ella del mismo plato?	SI / NO	1
2			compartirá su tereré con el/ella?	SI / NO	2
3			estará cerca con el/ella?	SI / NO	3
4		FIEBRE	compartirá su comida con el/ella del mismo plato?	SI / NO	4
5			compartirá su tereré con el/ella?	SI / NO	5
6			estará cerca con el/ella?	SI / NO	6
7		VOMITO	compartirá su comida con el/ella del mismo plato?	SI / NO	7
8			compartirá su tereré con el/ella?	SI / NO	8
9			estará cerca con el/ella?	SI / NO	9
10	PADRE O MADRE	TOS	compartirá su comida con el/ella del mismo plato?	SI / NO	10
11			compartirá su tereré con el/ella?	SI / NO	11
12			estará cerca con el/ella?	SI / NO	12
13		FIEBRE	compartirá su comida con el/ella del mismo plato?	SI / NO	13
14			compartirá su tereré con el/ella?	SI / NO	14
15			estará cerca con el/ella?	SI / NO	15
16		VOMITO	compartirá su comida con el/ella del mismo plato?	SI / NO	16
17			compartirá su tereré con el/ella?	SI / NO	17
18			estará cerca con el/ella?	SI / NO	18
19	HERMANO O HERMANA	TOS	compartirá su comida con el/ella del mismo plato?	SI / NO	19
20			compartirá su tereré con el/ella?	SI / NO	20
21			estará cerca con el/ella?	SI / NO	21
22		FIEBRE	compartirá su comida con el/ella del mismo plato?	SI / NO	22
23			compartirá su tereré con el/ella?	SI / NO	23
24			estará cerca con el/ella?	SI / NO	24
25		VOMITO	compartirá su comida con el/ella del mismo plato?	SI / NO	25
26			compartirá su tereré con el/ella?	SI / NO	26
27			estará cerca con el/ella?	SI / NO	27
28	PRIMO O PRIMA	TOS	compartirá su comida con el/ella del mismo plato?	SI / NO	28
29			compartirá su tereré con el/ella?	SI / NO	29
30			estará cerca con el/ella?	SI / NO	30
31		FIEBRE	compartirá su comida con el/ella del mismo plato?	SI / NO	31
32			compartirá su tereré con el/ella?	SI / NO	32
33			estará cerca con el/ella?	SI / NO	33
34		VOMITO	compartirá su comida con el/ella del mismo plato?	SI / NO	34
35			compartirá su tereré con el/ella?	SI / NO	35
36			estará cerca con el/ella?	SI / NO	36
37	AMIGO O AMIGA	TOS	compartirá su comida con el/ella del mismo plato?	SI / NO	37
38			compartirá su tereré con el/ella?	SI / NO	38
39			estará cerca con el/ella?	SI / NO	39
40		FIEBRE	compartirá su comida con el/ella del mismo plato?	SI / NO	40
41			compartirá su tereré con el/ella?	SI / NO	41
42			estará cerca con el/ella?	SI / NO	42
43		VOMITO	compartirá su comida con el/ella del mismo plato?	SI / NO	43
44			compartirá su tereré con el/ella?	SI / NO	44
45			estará cerca con el/ella?	SI / NO	45

ENCUESTA DE ALIMENTOS 24 HORAS ANTES – INFO BASICA

Código

ID-Participante: ___________
Sexo: ( ) Hombre ( ) Mujer
Edad: ______
( ) Embarazada ( ) Mamando ( ) Adulto no embarazada/mamando

Fecha de hoy _______________ (día/mes/año)
Fecha de ayer _______________ (día/mes/año)

¿Ayer fue un día "normal"?: ( ) Si ( ) No ( ) Enfermo ( ) Otro (especifica): _______________

¿Usted toma vitaminas o minerales?: ( ) Si ( ) No
En caso de si, especifica: Nombre de la marca: ________________ Frecuencia de consumo: ______________

Durante una semana normal, ¿cuantos bebidas alcohólicas tome usted? ________________

1. Entrevistador, por favor lee al participante:
"Por favor, recuerde que usted como ayer, ____________________ (*escribe que día de la semana*),
desde cuando usted despertado con lo mas detalles posibles."

COMPLETA LA TABLA AL REVERSO. USA TODOS LOS PAGINAS QUE TE NECESITA.

2. Pregunta:
» Que ingredientes fueron usado (incluyendo la marca),
» Cantidad de ingredientes,
» Como la comida fue preparado (Ex. frita, hervido),
» De donde viene los alimentos
  (*$* - comprado, *m* – plantes o animales del monte, *d* – producido (huerta o animales domesticas)
» Cuanto se comió. *UTILICE EL PLATO Y TAZA PARA MOSTRAR.*

3. Seguimiento: grasa, aceite, agua, sal, azúcar, bebidas (mate, tereré, alcohol), picar algo (chiclet, caramelo, algarrobo)

4. Revista: Lee la lista al participante. ¿El participante recuerde otros alimentos o bebidas?

Código

ENCUESTA DE ALIMENTOS 24 HORAS ANTES – TABLA ID-PARTICIPANTE: ____________ PAGINA #______

Tiempo del dia	Nombre de alimento	Ingredientes	Forma de cocinar	Fuente *$/m/d*	Cantidad consumido	Comentarios