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The Ethnomedical Context of Tuberculosis in a Northern Ecuadorian Province

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ABSTRACT

Background. Tuberculosis (TB) prevention and control remains a major global public health challenge. Ecuador has among the highest estimated population prevalence rates for TB, TB-mortality, and multidrug resistant TB in the Americas (WHO, 2007; PAHO, 2004). However, with the exception of one prior study of a high-risk group of suspected cases and household contacts referred for TB testing (Armijos et al., 2008), very little is known about the disease and treatment knowledge, beliefs, attitudes, and practices of Ecuadorian groups and the various socio-cultural and other factors (e.g., rurality, education, gender, disease experience) that shape these. The improved understanding of such factors that may influence health-seeking behavior is of potential value to the Ecuadorian National TB Control Program. This information can be used to shape culturally appropriate messages regarding TB prevention, diagnosis, treatment and follow-up which can make the program and its services more relevant to the competing needs, demands, and priorities of the population.

Study Aims. The study investigated the ethnomedical context of TB in two predominantly mestizo rural and peri-urban groups residing in the same Ecuadorian province (Pichincha). It specifically examined reported subject knowledge, beliefs, and perceptions about TB symptoms, severity, causation, transmissibility, and treatment. It also investigated their reported beliefs, attitudes, and perceptions about the impact of TB on usual lifestyle and role functioning. In addition, it examined reported subject perceptions regarding TB-associated stigma. The study explored the perspectives and priorities of subjects regarding the Ecuadorian national TB control program and its services. It was hypothesized was that rural residents would have less knowledge and more misperceptions about the disease and its treatment compared to those

living in a peri-urban setting due to their reduced access to health care, lower education, and reduced experience with the disease. It was also hypothesized that these factors would make rural residents more likely to associate a higher degree of stigma with TB.

Methods. The data were collected during a 6-month period (1999-2000) in two rural Ecuadorian (Malchingui; n=150) and peri-urban (Chillogallo; n= 126) communities. Potential subjects were included in the data analysis if they were $\geq$ 15 years, had no conditions that would impede their ability to adequately understand and respond to questions, and did not have another household member participating in the study. The data were collected by structured questionnaire during face-to-face interviews with subjects. Subjects first answered a closed-ended question (yes/no) followed by an open-ended question on the same topic. This strategy allowed subjects to explain their answers in their own words and permitted further probing by interviewers. Subject qualitative responses to open-ended questions were subsequently grouped into categories using content analysis which produced general categories or "themes". Quantitive data were analyzed using descriptive, bivariate, and multivariate statistical techniques.

Results. Although many subjects reported being acquainted with the disease and some of its characteristics, they also held a number of common misconceptions and/or lacked key pieces of knowledge which could adversely affect early diagnosis, prompt treatment, and treatment adherence. Education, age, gender, and prior disease experience were the most consistent predictors of reported subject knowledge, beliefs, perceptions, and attitudes. The influence of residence site (rural vs. peri-urban) was less evident. The subjects also associated TB with a number of adverse consequences for the lifestyle, role functioning, and social relationships of the

TB sufferer. In addition to internal stigma, most subjects linked TB with significant social stigma, regardless of the degree of kinship.

Conclusions and Recommendations. The results underscore the need for improving TB education and promotion efforts in rural and peri-urban communities. They confirm that TB is a highly stigmatized disease. Many persons are afraid of contracting TB and strongly desire formal educational opportunities to learn more about its prevention and control. The study findings can be used by the Ecuadorian National TB Control Program to develop population-specific health promotion and education interventions aimed at decreasing stigma, improving disease prevention, and faciliating early diagnosis, prompt treatment, and treatment adherence.

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BACKGROUND AND SIGNIFICANCE

Overview of Tuberculosis

Tuberculosis (TB) is an infectious disease caused by different species of the bacillus, *Mycobacterium*. The mycobacterium complex includes *M. tuberculosis*, *M. bovis, M. avium and M. microti,* among others. While all of these species can cause tuberculosis, *M. tuberculosis* is the single most frequent cause of human disease. Most tuberculosis affects the lungs but infection also can be disseminated through the blood and lymphatic systems to other parts of the body such as the central nervous system, kidneys, and vertebral spine. Extra-pulmonary tuberculosis is less common than pulmonary tuberculosis (PAHO, 2004), affecting spine, bone, peripheral joints, gastrointestinal, liver, adrenal gland, upper respiratory tract, female genital tract, male genital tract, renal and urinary tract (WHO, 2004).

Tuberculosis appears to be a very ancient disease. It has been present throughout prehistory and history according to the evidence from genetic studies, archeological findings, and historical written records. Genetic evidence suggests that the *Mycobacterium* bacillus evolved more than 150 million years ago (Daniel, 2006). Archeological evidence of tuberculosis has been found in both the Old and New Worlds. For example, *M. tuberculosis* DNA has been recovered in the mummified tissues of Egyptian mummies (Daniel, 2006). Other archeological evidence suggests the disease was already present in the Americas prior to the arrival of the first European explorers (Daniel, 2006). Recent genetic and fossil evidence now strongly suggests that *M. bovis* appears to have migrated from humans to cattle. This evolutionary leap jump long occurred prior to the domestication of cattle by humans more than 113,000 years ago and by extension infers

that *M. tuberculosis* is a much older human pathogen than what was once thought (Gibbons, 2008).

Mycobacterium tuberculosis is reported to be the pathogen responsible for the highest number of deaths in human populations that is produced by a single microbial pathogen. Tuberculosis is contacted through exposure to the bacillus. Persons with active TB spread the disease to others through aerosolized droplets. This occurs when an infected person coughs, sneezes, or sings. Repeated or prolonged exposure is usually required for a person to contract the disease (PAHO, 2004). It has been estimated that one untreated TB patient can infect 10-15 persons by year (WHO, 2005). Some of the most frequent symptoms of pulmonary TB include fatigue, fever, night sweats, anorexia and weight loss. More advanced TB cases often present with additional symptoms such as persistent coughing, thoracic pain, and bloody sputum (PAHO, 2004). Most healthy persons who become infected with *Mycobacterium tuberculosis* do not develop active disease because their immune system keeps the bacterium under control (PAHO, 2004). People with latent TB usually have a positive skin test but they usually cannot infect others (CDC, 2005).

Risk factors associated with TB are those associated with reduced immuno-competence such as very young or old age, malnutrition, another co-infection (e.g., HIV), or other factors (e.g., physical stress, substance abuse). Persons who previously received incomplete or inadequate antibiotic treatment for TB also are at high risk developing the disease again or relapse (CDC, 2005).

The recommended gold standard diagnostic tool for TB is the Acid-Fast Bacillus (ABF) sputum smear techniques (WHO, 2007).This laboratory technique involves obtaining a sputum sample from a person with suspected TB. It is then smeared on a glass slide and stained with an

acid-fast stain. The slides are examined using light microscopy in order to determine whether the bacilli are present or absent (WHO, 2007).

First line treatment for TB consists of the daily administration of four antibiotic drugs, i.e., rifampicina, isoniazida, etambutol, and pirazinamida (NOM-006-SSA2, 1993) for approximately 2 months (intensive phase) followed by administration of rifampicina and isoniazida (sustained phase) for an additional 4 months (NOM-006-SSA2, 1993). The TB-treatment strategy recommended by international health authorities (CDC, 2007; WHO, 2007; IUATLD, 2000) is Directly Observed Therapy (DOTS). It requires that medication is taken while the health care provider confirms by direct observation that the patient has swallowed the required drug dose (Kaona et al., 2004). The DOTs approach is recommended because the major determinant of a successful treatment outcome is patient adherence to the prescribed drug regimen. Non-adherence can lead to inadequate treatment which can result in relapse, continued transmission, and the development of drug resistance.

The WHO has recently recommends DOTS Plus for major objective of DOTS-Plus is controlling MDR-TB, to prevent development and spread of MDR-TB. The DOTS-Plus is a management approach that consists of the basic elements of the DOTS strategy plus the administration of second-line antibiotics (WHO, 2004). The implementation of DOTS-Plus is recommended for areas characterized by high levels of MDR-TB in order to reduce the risk of an epidemic occurring. The WHO/IUATLD Global Project on Drug Resistance Surveillance has identified an increasing prevalence of drug resistant and multidrug resistant TB (MDR-TB) among new cases in Latin America, Europe, Africa, and Asia (WHO, 2007).

Drug resistance occurs when the bacillus becomes resistant to one of the first line antibiotic drugs used to treat TB. Multidrug-resistant TB occurs when the bacillus becomes

resistant to at least two of the basic TB drugs, isoniazid and rifampicin, the two most powerful anti-TB drugs (WHO, 2007). Drug resistance is usually caused by improper use of antibiotics in the chemotherapy of drug-susceptible TB patients. This may result from the sub-optimal or erroneous administration of antibiotics by healthcare workers or failure to ensure that patients complete the whole treatment. Drug-resistance is much more common in areas characterized by poor TB control programs (WHO, 2007). Drug-susceptible TB can be cured within six months, while forms of drug-resistant TB need an extensive chemotherapy for up to two years with drugs which have more side effects (WHO, 2007).

Global Public Health Significance of Tuberculosis

The World Health Organization (WHO) has designated tuberculosis (TB) as a global health emergency (WHO, 2007). Despite the wide availability of sensitive detection methods and effective antibiotic treatment, TB remains one of the most common and deadly infectious diseases found in the world. One third of the world's population is estimated to be infected with *Mycobacterium tuberculosis* and this reservoir of latency has a 2-23% lifetime risk of developing active disease (Shimono et al., 2003). Tuberculosis is still responsible for the largest number of deaths in the world from a single infectious cause (Emili et al., 2001). In 2005, the disease was estimated to contribute to 4,400 deaths/day around the globe or about 1.6 million deaths/year (WHO, 2007). Ninety-eight percent of all global TB mortality occurs in developing countries (PAHO, 2004).

Tuberculosis in Ecuador

Tuberculosis is regarded as a serious public health threat to the Americas region. Recent Pan American Health Organization (PAHO) estimates indicate that 352,000 persosn annually in

the Americas are affected by TB and 50,000 persons die from it (PAHO, 2007). Although the total number of reported cases in the region has remained relatively stable during the previous decade, large differences exists in estimated prevalence rates among Latin American countries. This geographic variation in the prevalence of MDR-TB was recently documented by the Global Tuberculosis Drug Resistant Surveillance Project (PAHO, 2007). Findings from a preliminary random sample survey of resistance carried out in 1986-1990 revealed that Ecuador, Haiti and the Dominican Republic had the highest rates of drug resistance in the Americas region (PAHO, 2007). For that reason, PAHO placed Ecuador on its priority list for needing improved TB control.

Recent population prevalence data confirms that Ecuador has among the highest estimated population prevalence (202/100,000 inhabitants) and incidence rates for TB (131/100,000 inhabitants), TB-mortality (27/100,000 inhabitants) and multidrug resistant TB (MDR-TB) reported in the Americas (WHO, 2007; PAHO, 2005). In Ecuador, TB is a notifiable disease and by law, all cases must be reported to the *Ministerio de Salud Publica* (Ministry of Public Health). However, actual prevalence and incidence is probably much higher than these estimates indicate since these data are collected by the Ministry using passive rather than active surveillance techniques. A recent point survey carried out in a rural indigenous community in the Ecuadorian highland also documented an estimated prevalence of TB that was several orders of magnitude higher than that reported by the government (Romero et al., 2007). Ecuadorian immigrants to the U.S. (CDC, 2005) and Europe (Codecasa et al., 1999; Iñigo et al., 2006), also reported to be at high risk for developing TB and MDR-TB. Another study conducted in two Ecuadorian hospitals in a rural and an urban area of the country concluded that 24% of the patients who had

never been treated were resistant to one or more drugs (primary resistance) and 42% of the patients who had had prior treatment had secondary resistance (Mertz et al., 2000).

Health-Seeking Behavior

Prior studies have identified a number of structural, group, and individual factors that influence diagnostic delay, treatment adherence, and treatment outcomes. Some of the most consistently reported structural factors include poverty (Jackson et al., 2006; Cambanis et al., 2005; Needham et al., 1998; Farmer et al., 1991), gender inequities (Liefooghe et al., 1997), racial/ethnic disparities (Liefooghe et al., 1997; Baldwin et al., 2004; Macq et al., 2005), access to health care (Needham et al., 1998; Kamolratanakul et al., 1999), and poor educational opportunities (Farmer et al., 1991; Baldwin et al., 2004). However, group and individual level factors also are important. For example, explanatory models or culturally based explanations of illness and health have well known influences on the health seeking behaviors of individuals (Liefooghe et al., 1997; Jaramillo, 1998; Coreil et al., 2004; Rubel and Garo, 1992). These include knowledge, beliefs, and perceptions about the cause of a disease, its signs and symptoms, severity, transmission, options for treatment, and prognosis (Liefooghe et al., 1997; Jaramillo 1998; Coreil et al., 2004; Rubel and Garo, 1992).

Individuals also are influenced by what members of their social network tell them about a disease and its treatment (Rubel and Garo, 1992; Baldwin et al., 2004) their conceptions about how disease and treatment affect role functioning (Liefooghe et al., 1997; Eastwood & Hill, 2004), how they personally experience symptoms, whether there is any stigma surrounding a disease (Liefooghe et al., 1997; Kelly, 1999; Macq et al., 2005; Jaramillo, 1998), patient roles within a health care system, social network and the larger society (Liefooghe et al., 1997;

Jaramillo, 1998; Kelly, 1999; Marra et al., 2004). Other aspects that have been identified as the major causes of poor utilization of primary health care services are lack of geographical accessibility, cultural beliefs, low maternal literacy levels, and large family size (Shaikh and Hatcher, 2005). Health-seeking behavior can vary by location (i.e., rural vs. urban). This factor can have a significant impact on affect health care cost, quality, and access (Thompson, 2002).

Tuberculosis-associated internalized and social stigma is common across many societies. Both types of stigma can adversely affect care seeking behavior and influence patient disclosure about their TB status to family, friends, co-workers, and employers (CDC, 2007; Johansson et al., 1996). Kelly (1999) found that almost TB patients perceived themselves as disease vectors. Many feel less respected by others due to their diagnosis (Yamada et al., 1999; Johansson et al., 1996). Tuberculosis patients who experience discrimination at the hands of relatives, friends, and other social network members are less is likely to engage in positive health seeking behaviors which in turn, impedes disease control in the population (Irani et al., 2007). Kelly (1999) has reported that almost all TB patients felt that their family and friends avoided or shunned them. Patients responded to these attitudes by isolating themselves and becoming even more secretive about their illness (Kelly, 1999). The social stigma attached to TB may have a greater impact on women than men (Hoa et al., 2004).

The health-seeking behavior of persons is influenced by their health and disease knowledge, beliefs, attitudes, and perceptions. These can influence prevention behaviors, the timing of diagnosis and treatment, patient understanding of the diagnosis and treatment, treatment initiation, treatment adherence, and interactions with health care providers. What people know or perceive about TB even when they are not yet affected is an important determinant of their future health seeking behavior (Auer et al., 2000). The better educated and

persons who are knowledgeable about TB prior to diagnosis are more likely to have better outcomes (Wandwalo and Morkve, 2000). When people lack of knowledge about TB, they are more likely to consider alternatives other than conventional medicine for their care (Alvarez et al., 2000).

Comparisons with other Ecuadorian groups are made difficult by the lack of published studies on the topic. The sole exception is a recent study by Armijos and associates (2008) which focused on a high risk group of TB patients and/or household contacts undergoing testing for the disease at an urban Ministry of Public Health facility. Although most of the 212 subjects were familiar with TB and some of its characteristics and treatment aspects, many also held misconceptions or lacked key knowledge which could adversely affect early diagnosis and treatment and adherence to treatment, and thereby allow the disease to spread. Subject education was the single most important predictor of knowledge, beliefs, perceptions, and attitudes followed by gender, age, and prior disease experience. The subjects linked TB to multiple adverse health, economic, psychological, and social consequences, including stigma. In this study, none of the subjects had yet been definitively diagnosed at the time of interview yet many reported experiencing strong internalized and social stigma. Social stigmatization in this at-risk group was inversely associated with degree of kinship. Only a few individuals reported that they had informed their friends/co-workers or employers due to fear of social stigma, isolation and potential job loss (Armijos et al., 2008). In the Ecuador study education was the most consistent predictor of TB knowledge, beliefs, attitudes, and perceptions (Armijos et al., 2008). Although informative, the study was restricted to very high risk urban adults so it is unclear whether these results can be generalized to lower risk groups, persons living in non-urban settings, and other age groups.

STUDY OBJECTIVES & HYPOTHESIS

The study investigated the ethnomedical context of TB in two predominantly mestizo rural and peri-urban groups residing in the same Ecuadorian province (Pichincha). It specifically examined reported subject knowledge, beliefs, and perceptions about TB symptoms, severity, causation, transmissibility, and treatment. It also investigated their reported beliefs, attitudes, and perceptions about the impact of TB on usual lifestyle and role functioning. In addition, it examined reported subject perceptions regarding TB-associated stigma. The study explored the perspectives and priorities of subjects regarding the Ecuadorian national TB control program and its services. It was hypothesized was that rural residents would have less knowledge and more misperceptions about the disease and its treatment compared to those living in a peri-urban setting due to their reduced access to health care, lower education, and reduced experience with the disease. It was also hypothesized that these factors would make rural residents more likely to associate a higher degree of stigma with TB.

METHODS AND MATERIALS

Description of the Study Population

The Republic of Ecuador is a small but diverse South American country of 13.5 million inhabitants situated between the countries of Colombia on the northern border and Peru on the southern (Figure 1). The major export crops of this Andean nation include bananas, shrimp, flowers, and petroleum. The predominant ethnic group in the country is mestizo (i.e., persons of Spanish-Quechua descent). Persons of mestizo ethnicity constitute about 60-70% of the population. Quechua speakers and other indigenous groups comprise about 25-30% of the Ecuadorian population while those of African descent account for 6-10% (PAHO, 2005; CIA, 2006). Nearly one-third (30.2%) of the Ecuadorian population is under the age of 16 years (CIA, 2006; USAID 2006). The population averages only 7.3 years of formal schooling; 9% of adults are illiterate. Almost half of Ecuador's adolescents do not attend school (PAHO, 2005).

Similar to many of its other Andean neighbors, Ecuador has serious economic challenges. The country began going through an especially severe economic crisis starting in the mid-1990s. By 1999, the country's economic situation had deteriorated so much that the gross national product decreased by 7.3% (CIA, 2006). This crisis served to further increase the already large social and economic disparities in the country. For example, 19% of the urban population lived in poverty in 1995 but by 1999, the prevalence had risen to 42%. During the same time period, the prevalence of rural poverty rose from 56% to 77% (PAHO, 2005; CIA, 2006). The results of the most recent national economic survey indicated that in 2004, over half of the entire population lived in poverty (41.5%) or extreme poverty (9.7%) (INEC, 2004). The current annual rate of inflation is around 7.9% .*Per capita* income also has not increased in the last

decade. Gross *per capita* national income has remained low, only ~$1,830 US dollars per year (PAHO, 2005). Unemployment rates have remained in excess of 10% with underemployment staying close to 50% during the past several years. Ecuador's total estimated external debt as of 2004 represents almost six-tenths (57%) of its gross domestic product while debt service (estimated as a percentage of export product earnings) is around 22.1%. The country's economic problems are illustrated by its mandatory monthly debt service payments which are more than four times than what it expends on basic social services for its population (USAID, 2005).

The continuing economic crisis has resulted in an increased rate of internal migration by rural inhabitants to the capital city, Quito, other large urban areas, and the Ecuadorian Amazon. Urbanites now constitute 64% of the population. It is estimated that 6.3% of the population migrates internally each year, the majority of these (65%) are $\leq$ 30 years of age (USAID, 2005). The economic crisis also has resulted in a large external migration movement. Specifically, more than 600,000 Ecuadorians emigrated to the U.S. and Europe from 2000 to 2001. It is estimated that in excess of two million Ecuadorians or about 20% of the population now have emigrated to U.S., Spain, or other European countries (e.g., Italy) in search of work (US State Department, 2005).

Eight million Ecuadorians or 59% of the population does not have access to basic health services. Ninety-one percent of poor women, adolescents and children lack access to preventative health care. Ecuador's annual population growth rate is 2.1%. It has a high infant (30/1,000) (ENDEMAIN 99) and maternal mortality rate (77.8/100,000 live newborns) (PAHO, 2005). The prevalence of child chronic under-nutrition and infectious diseases is also high (e.g., tuberculosis, malaria, HIV/AIDS, other STD's). Population access to safe water and sanitation in Ecuador is reported to be more problematic than in Peru and Bolivia (USAID, 2005). Only

40% of Ecuadorian households have access to running water (40%) or sewage systems (44%). In addition, modern health care facilities are limited among urban and rural poor populations (PAHO, 2005; USAID, 2006; CIA, 2006).

Ecuador is currently undergoing an epidemiologic transition from one where most morbidity and mortality is caused by infectious illnesses to one where both infectious (TB, pneumonia, gastrointestinal illnesses) and chronic diseases (e.g., cardiovascular disease, diabetes, cancer) associated with overweight/obesity, environmental pollution, and other factors are responsible for the burden of disease. There also is the increasing problem of HIV/AIDS and co-infection with other infectious illnesses (e.g., TB, leishmaniasis). The most recent figures available from the Ecuadorian Ministry of Public Health (2006) indicate that the principal cause of mortality for the population was from heart disease (3.1/10,000 inhabitants) which accounted for 7.3% of all deaths. Other major causes of mortality were pneumonia (2.3/10,000), cardiovascular disease (2.3/10,000), diabetes (2.1/10,000), and violence (1.8/10,000).

Study Design and Research Site

The survey design study was carried out to describe and compare the knowledge, attitudes, and practices about TB symptoms, severity, causation, transmissibility, and treatment of urban versus rural residents. The data were collected during a six month period from 1999-2000 in two study sites in two cantons (counties) within Pichincha Province in northern Ecuador. As Figure 2 shows, the rural site, Malchingui, is located in Canton Mejia and the other in periurban neighborhood (Chillogallo) in the capital city of Quito (Canton Quito).

Subject Selection

Potential subjects were excluded if they were a minor under the age of 18 years, had a condition that impeded their ability to adequately understand and respond to questions, or if another member of their family already was a study participant. None of the prospective subjects declined to participate. The TB status of subjects was still undetermined at the time of the interview. The study was approved by the INHLIP administration and the research ethics committee of the medical school of the Universidad Central del Ecuador. All subjects went through the informed consent process prior to enrollment.

Data Collection

Survey Questionnaire

The face-to-face interviews used a structured questionnaire consisting of a closed-ended question followed by an open-ended question on the same topic. This strategy allowed further probing by the interviewer and for the subjects to explain their answers using their own words. The first part of the questionnaire elicited information about the sociodemographic, ecological, and living conditions of each household in the study. The data gathered included questions about subject age, sex, ethnicity, education, marital status, family size and composition, occupation, migration history, and living condition. In addition, the questionnaire collected data on the reported knowledge, beliefs, and perceptions of subjects regarding their familiarity with TB and its symptoms, causes, severity, transmissibility, treatment and follow-up. In addition, it collected information on subject beliefs, attitudes, and perceptions about the impact of TB on lifestyle, role functioning (i.e., a person's ability to perform designated roles at work, home, and in society),

and stigma. The final section of the questionnaire explored subject perspectives and priorities for the national TB control program.

Data Analysis

The data were entered into the SPSS database management and statistical analysis system (SPSS, Chicago, IL; version 14.0). Descriptive numerical data were reported as means $\pm$ standard deviations and categorical data described as % (n) or % (nl sample size) where only a subset of the study sample was used. The bivariate analyses assessed differences between proportions using contingency table analysis with corrected X^2 or Fisher's exact test. Mean between-group differences were analyzed by Students' t-test or one-way analysis of variance. The multivariate analyses employed the use of multiple logistic regression to analyze between-group differences while controlling for potential confounders (e.g., rurality, education, age, gender, previous TB experience).

RESULTS

Subject Characteristics

The sociodemographic and other characteristics of the 276 Ecuadorian subjects surveyed in the are shown in Table 1. All but a small minority (3%) of the subjects self-identified as mestizos (i.e., mixed Spanish-Quechua Indian ancestry). Slightly more than half lived outside of the capital city, Quito, in a rural area of Pichincha Province. In excess of one-half of the subjects were female, aged 30 years and older, and poorly educated. Close to 65% reported living in a legal or consensual marital union in a household that averaged close to five family members. Only 51% reported having received the minimum two BCG vaccination doses required by Ecuadorian law at birth and age six years. One-fifth indicated that they had not ever received any BCG vaccination. Twelve percent reported that they had prior TB experience by virtue of the fact that either they and/or an immediate family member had been previously diagnosed with the disease. Twenty subjects (12.4%) were identified with a positive PPD (> 10 mm) suggesting possible active or latent TB.

Sources of TB Familiarity

Most of the study subjects who had prior familiarity with TB, locally known as "ice pick lung" (*pulmon picado*) or "consumption" (*tisis*) indicated that they had first learned about it through casual conversation/ gossip (37%), prior personal and/or familial disease experience (39.5%), mass media sources such as newspapers, magazines, or radio (12.3%), from health care personnel (7.4%), or during school health education lessons (2.5%). Age and prior TB experience were the only two variables identified as associated with the reported TB familiarity

of subjects. Specifically, a greater proportion of subjects aged $\leq$ 40 years (20.5%; 25/122) compared to their older counterparts (36.4%; 56/154) reported prior familiarity with the disease (X^2 =7.6; P= 0.006). Likewise, more subjects having prior TB experience than those without such experience noted that they were already familiar with the disease (100%; 32/32 vs. 20.6%; 49/238; X^2= 81; P< 0.0001). Gender was the sole factor identified as associated with the reported initial source of subject familiarity with TB. A greater proportion of women (47%; 24/51) compared to men (20%; 6/30) reported first learning about TB through casual conversation/gossip rather than another source (X^2= 4.8; P= 0.028).

Disease Severity

A majority of the subjects in the study indicated that they were able to rank the severity of TB disease compared to other illnesses. Although some ranked TB as being no more severe than the common cold (20.9%; 48/230), most ranked it as being equally severe as other potentially life-threatening illnesses such as pneumonia (38.7%; 89/230), cancer (31.7%; 73/230), diabetes (10.9%, 25/230), or heart attack (2.1%; 5/230).

Fewer of the subjects who reported prior experience with TB (3.3%, 1/30) equated the disease with the common cold (24.1%, 47/195) compared to those without such experience (Fishers's P= 0.007). In addition, a reduced proportion of rural residents (15.3%; 18/230) compared to urbanites (26.9%; 30/230) ranked TB as similar to the common cold (X^2= 4.0; P=0.047). The results of the multiple logistic regression analysis confirmed that even after covariate control, both prior disease experience (Wald statistic= 4.3; P= 0.037) and site of residence (Wald statistic= 4.2; P= 0.040) retained their associations with subject response. Subject age, gender,

ethnicity, education and the other characteristics measured did not predict any of the subject responses regarding disease severity.

Disease Causation

Relatively few subjects (43.8%; 121/276) reported being able to identify the cause of TB disease and many identified multiple causes. A greater proportion of subjects with $\geq$ 10 years of education (50.4%; 70/139) than those with less schooling (36.2%; 46/127) reported that they could identify at least one cause for TB (X^2= 4.8; P=0.028). Subjects who indicated being familiar with the cause(s) of TB reported an average of 1.6 $\pm$ 0.84 different ones. Males identified a slightly higher average number of TB causes compared to their female counterparts (1.8 $\pm$ 1.0 vs. 1.5 $\pm$ 0.7 causes; t=2.0; P=0.047).

The single most frequently mentioned disease cause by study subjects who said that they had any idea was a poor diet that weakens the body (25.6%; 31/121). Other causes identified by subjects were germs acquired from a person with TB (18.2%; 22/121), exposure to cold ambient temperatures (18.2%; 22/121), being a careless (18.2%; 22/121) or dirty person (17.4%), performing excessive physical labor (9.1%; 11/121), being in a generally weakened state (8.3%; 10/121), breathing dirty air (9.9%; 12/121) and consuming dirty water or food (6.6%; 8/121). Less frequently mentioned reasons were having close contact with animals (4.1%; 5/121), heredity (1.7%; 2/121), and lack of regular health care (5%; 6/121).

A greater proportion of persons with $\geq$ 10 years of education (31.3%; 5/16) compared to less well-educated subjects (6%; 6/100) indicated believing that TB is caused by coming into contact with the germs of a person with TB (X^2= 7.5; P=0.006). More subjects aged $\geq$ 40 years (13.7%; 10/73) than those under age of 40 years (0%; 0/48) identified weakness as responsible

for TB (Fisher's 2-tailed P= 0.006). None of the other subject characteristics predicted the causes identified for TB among those who said that they knew.

TB Signs and Symptoms

Fewer than one-half (40.6%, 112/276 of the study subjects reported that they could identify at least one characteristic sign and/or symptom and 49.4% (164/276) said that they did not know or were unsure. The sole predictor identified for whether or not a subject reported that they could identify at least one characteristic disease sign or symptoms was prior TB experience. An increased proportion of subjects with prior experience (84.4%; 27/32) than those without such experience (35.7%; 85/238) were able to identify at least one characteristic TB sign or symptom (X^2= 25.5; P< 0.0001). Subject gender, age, education, ethnicity, residence and the other factors measured in the study were not significant predictors.

Of the 112 subjects who said they knew, each identified an average of 1.94 $\pm$ 0.88 symptoms each. The major symptoms they identified in order of frequency were generalized body weakness (49.1%, 55/112), unexplained weight loss (31.3%, 35/112), persistent cough (17%; 19/112), pallor (14.3%; 16/112), loss of appetite (12.5%; 14/112), alterations in behavior such as irritability and rudeness (12.5%, 14/112), bloody cough (4.5%; 5/112), generalized body pain (4.5%, 5/112), and faintness (0.9%; 1/112).

Persons with prior TB experience (37%; 10/27) were more likely than those without such experience (10.6%; 9/85) to report a persistent cough as characteristic of the disease (X^2= 8.4; P= 0.003). Women (57.7%; 41/71) were more likely than men (34.1%; 14/41) to identify pain as characteristic of TB disease (X^2= 25.5; P< 0.0001). However, age, education, ethnicity, residence

and other characteristics were not associated with the specific TB sign and symptoms reported by the study subjects.

Disease Signs and Symptom Experience

In order to understand how common respiratory and other signs and symptoms are in the population that may resemble those of TB, the subjects were questioned as to whether they had experienced any of these in the recent past. If such signs and symptoms occur frequently, this could potentially cause confusion and delay treatment-seeking by members of the population. Many subjects reported that they themselves had previously suffered from some of the signs and symptoms used in the clinical screening of TB. These included persistent cough (68.8%; 190/276), dry cough (29.3%; 81/276), wet cough (51.1%; 141/276), bloody cough (10.1%; 28/276), unintended appetite loss (36.2%; 100/276) or weight loss (37.7%; 104/276), severe fatigue (61.2%; 169/276), fevers (24.3%; 67/276), night sweats (19.6%; 54/276) or chest pain (33.7%; 93/276).

The bivariate analyses indicated a decreased proportion of rural (18%; 27/150) compared to peri-urban residents (32%; 40/125) reported having experienced high fevers (X^2= 6.5; P = 0.011). A higher proportion of subjects with $\leq$ 6 years of schooling (27%; 34/126) compared to those who were better educated (14.4%; 20/139) reported having experienced night sweats (X^2= 7.7; P = 0.017). More women (40.6%; 71/175) than men reported (22%; 22/100) having experienced past chest pain (X^2= 9.0; P= 0.003).

Female subjects (43.4%; 76/175) were more likely than their male counterparts (28%; 28/100) to report having previously experienced unexplained weight loss (X^2= 5.8; P= 0.016). Subjects who had only $\leq$ 6 years of education (73%; 92/126) were more likely than those with

more years of formal schooling (49.6%; 69/139) to report severe fatigue (X^2= 14.2; P < 0.0001). Subjects aged $\geq$ 41 years (71.9%; 82/114) also were more likely than their younger counterparts (54%; 87/161) to report experiencing severe fatigue (X^2= 8.3; P= 0.004). In addition, a greater proportion of women (66.9%; 117/175) compared to men (52%; 52/100) reported experiencing fatigue (X^2= 5.3; P= 0.021). However, the results of the multiple logistic regression model confirmed the previously identified contribution of low education (Wald statistic= 6.8; P= 0.009) but those of female gender (Wald statistic= 3.5; P=0.06) and older age (Wald statistic= 1.6; P=0.21) were no longer significant and were dropped from the model.

More women (44.8%; 78/174) than men (22%; 22/100) reported experiencing unexplained appetite loss (X^2= 13.3; P < 0.0001). A greater proportion of subjects with $\leq$ 6 years of schooling (47.6%; 60/126) compared to those with more education (24.6%; 34/138) reported experiencing unexplained appetite loss (X^2= 14.2; P < 0.0001). The results of the multiple logistic regression analysis confirmed the previously identified association of female gender (Wald statistic= 8.9; P= 0.003) and poor education (Wald statistic= 12.2; P < 0.0001) with appetite loss.

Disease Transmissibility and Perceived Risk

Sixty-two percent (62%; 170/276) of the subjects reported believing that TB is a transmissible disease, 10.2% (28/276) said that it is not and 28% (77/276) indicated that they didn't know or were unsure. The only predictor of the correct response that TB is transmissible was prior disease experience. Specifically, subjects with TB disease experience were more likely to report than those without such experience to agree that TB is transmissible (90.6%; 29/32 vs. 58.6%; 139/237; χ^2 = 11; P = 0.001). However, gender, age, ethnicity, education, and place of

residence, and the other measured characteristics measured were not associated with subject responses.

Slightly more than one-third of the subjects (39.1%; 59/151) who said they knew how TB is transmitted correctly identified direct exposure to airborne particles transmitted by a person with TB coughing or sneezing. The other major risk factors erroneously identified by subjects included contact with discarded TB patient sputum and urine (17.2%; 26/151), contact with their fomites (33.8%; 51/151) through sharing eating and drinking utensils, towels, blankets, bedding, and clothing, casual contact with a TB patient (19.9%; 30/151) or close/intimate contact (9.9%; 15/151). None of the subject characteristics such as prior TB experience, education, age, gender, marital status, residence site, and ethnicity predicted subject responses on this question.

The study subjects also were questioned about which age and gender groups, if any, they believed were at higher risk for developing TB disease. They also were asked to explain why they believed what they did. Slightly fewer than one-fifth (19.6%; 54/276) reported that they were unsure about the answer to this question and 8.7% (24/276) responded that neither age nor gender affected TB risk. The age groups reported to be at great risk for developing the disease by the others were young children (50.4%; 139/276) and the elderly (47.8%; 132/276) followed by adolescents (33.5%; 74/276) and adults (25.7%; 71/276). The gender groups identified by subjects as at increased risk for TB were girls (17.8%; 49/276) vs. boys (18.5%; 51/276); female (14.9%; 41/276) vs. male adolescents (13%; 36/276), and adult females (23.9%; 66/276) vs. adult males (19.9%; 55/276).

Table 2 displays the different rationales provided by subjects to explain why they believed that age, and to a lesser extent, gender, influences a person's risk for developing TB disease. The most frequently mentioned single factor was that the inherent biological state, usually extremes

of age (young and old) or female gender makes persons generally "weaker" or more susceptible for developing infectious illnesses. Some subjects specified that young children or females are more "delicate" and thus more defenseless against strong illnesses such as TB. The main explanation given by subjects for the increased risk for adolescents was behavioral places them at risk such a hanging around with bad companions in bad places or being constantly on the go with friends which wears down their resistance. The other major reasons given were having a poor diet/nutrition, excessive physical exertion/work, exposure to cold or wet, living in a dirty environment and the lack of vaccination. Some also mentioned that adult and adolescent males have a tendency to indulge in "vices" such as sex and drinking which causes them to be weaker.

Psychosocial Consequences

Almost two-thirds (60.5%; 167/276) of subjects linked TB disease with adverse psychosocial consequences, 12% (33/276) said that there were no such effects, and 27.5% (76/276) said that they didn't know or were unsure. The specific effects noted by those subjects who said that TB had a psychosocial impact were feeling stigmatized (28.9%; 46/159), uneasy due to lifestyle interruptions (39%; 62/159), mental suffering in the form of fear, anxiety, and depression over having a dangerous disease, not getting better and dying (28.9%; 46/159), and emotional changes engendered by the constant physical pain and suffering (11.9%; 19/159). A slightly greater proportion of non-mestizos (66.7%; 2/3) than mestizos (10.9%;17/156) identified the latter as a psychosocial consequence of TB disease (Fisher's 2-tailed P=0.038) although the number was small. None of the other subject characteristics included in the study were found to predict subject responses.

Lifestyle Changes

Seventy percent of the study subjects (192/276) agreed that the usual lifestyle of individuals who develop TB undergoes significant alterations, 5.4% (15/276) said that it does not, and 25% (69/276) said that they did not know or were unsure. Most (97.4%; 187/192) of the subjects who responded that TB alters a person's usual lifestyle said that they could explain why this occurs. Close to one-sixth (14.4%; 28/187) reported that this is to due to the physical (e.g., fatigue, weakness, malaise) or psychological/emotional symptoms (e.g., irritability, anger, anxiety) caused by the disease iteself. One-third (32.6%; 61/187) reported that one's lifestyle is changed because of the physical and social isolation imposed by the patients themselves or others to reduce the chance of passing on the disease. Twenty eight percent (52/187) said that it occurs because of the need to reduce one's activity in order to get better and decrease the chance that the disease will worsen. It was also reported that TB treatment-seeking also has an impact on lifestyle (18.2%; 34/187) and 8% (15/187) that having TB causes one to significantly alter their diet to cope with the disease.

Role Functioning

Outside Employment

A majority of study subjects (71.4%; 197/276) indicated that the role functioning of persons of persons who contract TB is adversely affected with respect to outside employment, 14.1% (39/276) said that it is not, and 14.5% (40/276) said that they did not know or were unsure. Neither gender, education, age, ethnicity, residence, TB experience nor any of the other measured subject characteristics predicted the response of subjects regarding whether or not TB has an adverse impact of outside employment role functioning.

One of the most frequently stated reasons for decreased ability to function on the job was that because of the extreme fatigue caused by the disease, a person would have reduced physical strength and would require frequent rest (53.9%; 104/193). Other reasons reported by subjects were that one's work would be adversely affected because of TB's psychological impact such as depression, anxiety, and fear (10.4%; 22/193), the person would be too ill to go into work (17.6%; 34/193) or they would feel too much physical pain to carry out work tasks (2.1%; 4/163). In addition, some of the responses alluded to the patient would be afraid of passing the disease on to others at the workplace (9.3%; 18/193), their work would suffer because of the need to stay on a special diet (0.5%; 1/193), they would suffer too much social rejection and stigma to be able to function properly (11.4%; 22/193) or working would make their symptoms worse so they would have to leave their jobs (4.7%; 9/193).

Domestic Tasks

When questioned about the potential adverse effect of TB on domestic role functioning, 65.5% (180/276) of the study subjects stated that it has an adverse impact, 19.9% (55/276) said that it does not, and 14.9% (41/276) said that they did not know or were uncertain. A greater proportion of subjects aged $\leq$ 40 years (65.1%; 69/106) compared to older subjects (86%; 111/129) responded that TB has a significant adverse effect on domestic role functioning (X^2= 13.3; P < 0.0001). Conversely, rural residents (83.9%; 115/137) were more likely to respond than urbanites (66.3%; 65/98) that TB adversely effects domestic role functioning (X^2= 9.9; P= 0.003).

School

When the question was asked about the impact, if any, on the role functioning of children and adolescents at school, 66.7% (184/276) said that it did, 18.8% (52/276) said that it did not,

and 14.5% (40/276) replied that they did not know or were unsure. Thirty-four percent (61/179) explained that the physical fatigue or adverse psychological effects (20.7%; 37/179) caused by TB would make students unable to study or pay attention in class. Other reasons given were that the physical pain caused by TB disease makes it impossible to study or attend school (2.2%; 4/179), fear of passing the illness on to schoolmates (6.7%; 12/179), the need to maintain a special dietary regime doesn't permit kids to attend class (1.1%; 2/179), rejection and stigma from schoolmates at school (1.1%; 2/179) or studying and attending class would worsen illness and increase recovery time (3.4%; 6/179). None of the subject predictors measured in the study such as gender, education, age, ethnicity, residence, marital status, and prior disease experience was associated with subject responses with respect to student role functioning.

TB & Stigma

Social Stigma

As a way to better understand the social stigma associated with TB in the study population and triangulate their concepts on disease causation and transmissibility, the subjects were asked about whether changes would occur in the behavior of their social network members toward them if they were told they had the disease. As Table 2 indicates, depending on the type of social network member, from 35-48.3% said that changes would occur, 15-25% said that the behavior would remain the same, and 29-53% said that they were unsure whether these people would change their behavior toward them or that the question wasn't applicable them (e.g., they have no spouse/partner or children).

Almost all of the changes described were negative. The reasons given by subjects fell into several major categories and were more or less the same for all five social groups. The major

explanation given was social rejection and isolation due to fear of getting a dangerous disease (61.9-69.7%). Other reasons given were that others would treat the TB sufferer like damaged goods because he/she was no longer healthy and or wasn't getting better fast enough (15.8-20.2%), a loss of love and trust since persons who get TB got it because they were irresponsible or careless (8.2-9.3%) or they would act tired, irritated, or angry about having to care for the patient (2.6-6.1%). In contrast, fewer than 5% said that positive changes would occur. The reason that they gave were that they would take care of them much better and give them more love and support (1.6-3.6%).

Stigma Attitudes.

Attitudes about TB-associated social stigma were explored further by posing three open-ended hypothetical scenarios to the subjects.

Scenario 1. In the first scenario, the subjects were asked what they would do if they were the owner of a business and discovered that one of their employees had TB disease. Twenty-one of the 276 (7.6%) study subjects reported that they did not know or were unsure about what action they might take if they discovered that one of their current employees had active TB disease. Three-fourths of the 255 subjects who responded had generally positive answers about what they would do. For example, 69.8% (178/255) said that they would let the individual remain in their employment and assist them in getting treatment. The remainder reported that they would do nothing (2.7%; 7/255), offer them economic help (2%; 5/255), offer them advice on their disease or treatment (1.2%; 3/255) or worry a lot about their employee 0.4%; 1/255). However, one-quarter reported that they would immediately fire the employee (24.7%; 63/255).

The bivariate analysis results revealed that subjects over the age of 40 years than those under the age of 40 years (58.1% vs. 78%; $\chi^2 = 10.7$; P = 0.001) to report that they would be inclined to assist an employee with TB to find treatment. This was also the case for subjects with only ≤ 6 years (59.5%; 69/116) compared to those with > 6 years (79.4%; 104/131) of formal schooling ($\chi^2 = 10.7$; P= 0.001). The results of the multivariate analysis revealed that low formal education (Wald statistic= 4.5; P=0.033) retained its previously identified association with the response that the subject would help the employee find treatment. However, the contribution of older age became less strong and was dropped from the model (Wald statistic= 3.5; P=0.052).

Other bivariate analyses were conducted to examine the factors associated with subject reports that they would fire an employee with TB. They revealed that more women (29.8%; 48/161) than men (16%; 15/94) said that they would be likely to fire an employee with TB ($\chi^2 = 5.4$; P= 0.020). Likewise, more subjects who were aged ≥ 41 years compared to younger subjects said that they would be more inclined to fire an employee ($\chi^2 = 16$; P< 0.0001). A greater proportion of subjects with ≤ 6 years of formal schooling (35.3%; 41/116) than others (15.3; 20/131) were also more likely to report the same ($\chi^2 = 12.3$; P= 0.001). Likewise, more subjects with prior TB experience (43.3%; 13/30) compared to those without (22.7%; 50/220) indicated that they would fire an employee who had TB ($\chi^2 = 4.9$; P= 0.027). Two of the variables, age (Wald statistic= 8.1; P=0.004), and gender (Wald statistic= 6.1; P=0.023), retained their associations with the subject response but the previously identified contributions of the other two variables, education (Wald statistic= 2.8; P=0.096) and TB experience (Wald statistic= 3.1; P=0.08) were no longer evident and were eliminated from the final model.

Scenario 2. In the second hypothetical scenario, the subjects were asked if they would hire a person with TB to work as a maid inside their home, slightly more than one quarter (26.4 %; 73/276) said that they were unsure what they would do in such a situation. The two principal reasons given by the others who said that they knew what they would do was that they would not hire them as they would be fearful the person would pass the disease on to them or their family (77.8%; 158/203) or because TB's debilitating effects would make the prospective employee unfit for work (21.7%; 44/203). Another reason (0.5%; 1/203) given was that the time required for treatment seeking would interfere with the employee's duties or they just didn't want a person with such a stigmatized disease as an employee (0.5%; 1/203). Age, gender, education, prior experience with TB, site of residence, and the other measured characteristics did not predict subject responses on this question.

Scenario 3. In the third scenario, subjects were asked what their own employer would do if he/she discovered that they had TB. Nearly half (46%; 127/276) said that they did not know or the question was not applicable to them. However, among those who had at least one answer, the most frequent response was that their employer would fire them immediately (72.5%; 108/149) or treat them adversely (3.4%; 5/149). In contrast, nearly one-fifth of the responses were that that their employer would assist them in finding treatment (18.8%; 28/149) or would exhibit a positive attitude towards them (3.4%; 5/149). More women (81.9%; 77/94) than men (56.4%; 31/55) hypothesized that their boss would dismiss them from their job ($\chi^2 = 11.1$, P= 0.001). In contrast, more men (32.7%; 18/55) compared to women (10.5%; 10/94) said that their employer would assist them in finding treatment ($\chi^2 = 9.7$; P= 0.002). None of the other characteristics measured in the study predicted this or the subject responses concerning this question.

TB Treatment

Treatment Requirements

Most study subjects (89.5%; 247/276) responded in the affirmative that persons who have TB need treatment, 1.4% (4/276) said that they do not, and 9.1% (25/276) replied that they did not know or were unsure if treatment is required. When asked to further explain, a preponderance (97.2%; 240/ 247) of those who responded that treatment is needed said that they could give a least one reason why this is so. The single most common explanation (65%; 156/240) provided by subjects was that medical treatment is the only way that a TB patient can get better and be cured. The other major explanations were that treatment is the only way that the disease can be prevented from getting worse and the patient dying (20.8%; 50/240) or preventing disease spread to other people (18.3%; 44/240). Several subjects also mentioned that treatment is the only way to stop the pain caused by TB (1.3%; 2/240) or that the only type of treatment that would be effective is that obtained from a TB specialist (1.7%; 4/240).

Treatment Methods

Very few subjects reported that they could identify the specific methods used for treating TB (3.6%; 10/276). The others indicated that they did not know (76.8%; 212/276) or that they were unsure (19.6%; 54/276). Antibiotics accounted for only 5/23 treatments they mentioned. The others that they described were non-antibiotic prescription or over-the-counter remedies (47.8%;11/23) such as cough syrup, vitamins, antispasmodics or “natural” remedies (30.4%; 7/23) such as dark beer, aromatic eucalyptus and other herbs or herb mixtures with honey.

Length of TB Treatment

When subjects were questioned if they knew how TB treatment takes to complete, most (62.3%; 176/276) said that that they did not know and 19.2% (53/276) reported that it is variable

and one person reported that it lasts the rest of a person's life (0.4%; 1/276), and other 50 subjects a specified length of time < 3 months (5.1%;14/276), 4-6 months (5.4%; 15/276), 7-12 months (3.6%; 10/276),and ≥24 months (3.6% 11/276). Most reported (99%) that strict treatment adherence is necessary. They explained that this is the only way to ensure that the disease is completely cured

Need for Post-Treatment Follow-up

When asked whether some type of post-treatment follow-up is required, 88% (243/276) said that it is necessary, 2.4% (6/276) said that it is not, and 9.8% (27/276) said that they did not know or were unsure. The three major reasons given by those who thought post-treatment follow-up to be necessary was to determine whether or not the person was cured or if they still had the disease (57.6%; 136/236), so that they don't get infected again (25%; 59/236), or it is needed to finish curing the person (14.4%; 34/236).

TB Treatment Facilities

The subjects were asked hypothetically as to where they themselves would go if they suspected that they had TB. The three major sources from which they said that they would seek assistance were a private physician (37%; 101/277), government public health clinic (31.5%; 87/276) or government hospital facility (26.4%; 72/276). Some subjects also mentioned that they would seek help from family and friends (3.3%; 9/276) or a local pharmacy (1.4%; 4/276).

Treatment Barriers

The subjects were ask to identify any potential barriers that they viewed for getting TB treatment. Nearly three-quarters reported that they did not know or were unsure (74.6%;

206/276). Of those that said they knew of at least one barrier, the most frequent responses they gave were poor service by employees including rudeness, misinformation, or mistreatment (15.7%; 11/70), high cost of treatment (21.4%; 15/70), long travel distance (14.3%; 10/70), time (28.6%; 20/70), feel too tired to seek treatment (2.9%; 2/70), too many different doctors (5.7%; 4/70), poor diagnostic or treatment quality (14.3%; 10/70).

The bivariate analyses indicated that a greater proportion of women (32.5%; 13/40) compared to men (6.7%; 2/30) identified high treatment cost as a treatment barrier (χ^2= 5.3; P= 0.021). Persons with ≤ 6 years of education (37.9%; 11/29) were more likely than those with more years of schooling (10%; 4/40) to report the same (χ^2= 6.3; P= 0.013). The multiple logistic regression analysis results confirmed the previously identified contribution of sex (Wald statistic= 4.0; P= 0.045) and low education (Wald statistic= 4.5; P= 0.035). None of the other subject characteristics were associated with subject response.

National TB Program

Only a small minority (18.2%; 35/276) of subjects indicated that they had ever heard of the Ecuadorian National TB Program. When asked to explain what type of help they would be likely to receive from the program if they were a TB patient, the most common response was that they did not know (42.8%; 118/276). Of the subjects who said that they could identify at least one type of help that they would receive, 31.8% (88/276) said they would get treatment, 8% (22/276) said that they would get diagnosis, 5.4% (15/276) would get economic help, 15.9% said TB information, 1.8% (5/276) psychological counseling/assistance, 4% (11/276) prevention in the form of vaccination or evading contagion, food or vitamins (0.8%; 2/276).

DISCUSSION

Improving TB prevention and control continues to be a major global public health challenge including in high risk countries in the Americas region and elsewhere. Ecuador is characterized by an elevated population prevalence of TB (WHO, 2007; PAHO, 2004), drug-resistant TB and multi-drug resistant TB (WHO, 2007; PAHO, 2004). However, with the exception of a single study of a high risk urban group of suspected TB patients and their household contacts (Armijos et al., 2008), very little is known about TB-related knowledge, beliefs, perceptions, and attitudes of Ecuadorian groups and the various socio-cultural and other factors that shape these. The improved understanding of factors that influence health-seeking behavior has potential value for the Ecuadorian National TB Control Program. This information can be used to shape culturally appropriate messages regarding TB prevention, diagnosis, treatment and follow-up which can make the program and its services more relevant to the competing needs, demands, and priorities of the Ecuadorian population.

One of the major findings from this study were that even though some subjects were acquainted with some of the characteristics of TB, they also held a number of common misconceptions and/or lacked key pieces of knowledge about the disease and its treatment which could adversely affect early diagnosis, prompt treatment, and treatment adherence. Another major finding was that the most consistent predictors of reported TB knowledge, beliefs, perceptions, and attitudes were subject educational attainment, age, gender, and as would be expected, prior experience with the disease. The impact of geographical residence (i.e., rural vs. peri-urban) was less evident.

Prior authors have reported that, in some populations, one of the most common reason for delaying seeking care is that people do not consider TB symptoms to be serious (Sarmiento et al., 2006; Van der Werf et al., 2006). In our study, nearly one person in four who said that they were able to rank TB severity indicated believing that it is no more severe than the common cold. A person's perception about the severity of TB and their interpretation of symptoms is often the impetus for health seeking (Rubel and Garro, 1992). This is important because prior studies indicate that there often is considerable delay between when symptoms first start and the initiation of medical treatment among pulmonary TB patients (Pronyk et al., 2001; Nnoaham et al., 2006; Katamba et al., 2005).

Another noteworthy finding was that only 40% of the study subjects reported that they were able to identify at least one characteristic sign and/or symptom of TB and that for most of these; it was because they had prior direct experience with the disease. This is an important point because delays in diagnosis and treatment are increased when people confuse the initial symptoms of TB with those of a common cold (Liefooghe et al., 1997). In addition, if the prevalence of other TB-like signs and symptoms occur frequently in a population, this could potentially lead cause confusion and delay treatment-seeking by members of the population. Our study results indicated that indeed, many of these were common including persistent cough (68.8%), bloody cough (10.1%), unintended appetite loss (36.2%) or weight loss (37.7%), severe fatigue (61.2%), fevers (24.3%), night sweats (19.6%) and chest pain (33.7%). These results underscore the need for education about early disease recognition.

One of the cornerstones of TB control in populations is prevention. This requires a basic understanding of what causes the disease and how its transmission occurs. In the current study, many subjects seemed to recognize that TB is contagious but differed how it is transmitted (e.g.,

body secretions, fomites, dirt, and contaminated air). They also offered different theories, some overlapping, to explain its cause. As has been previously reported for TB (Armijos et al., 2008) and other infectious illnesses (Weigel and Armijos, 2001; Pedersen and Coloma, 1983), disease causation among Ecuadorian groups often combines elements of germ theory, 16th century humoral medicine, locally evolved beliefs, and personal and familial explanations. Many of the explanations the study subjects offered to explain the cause of TB revolved around the notion of an imbalance in the body such as that precipitated by a disparity in dietary intake or physical activity or that related to sudden changes in body temperature hot-cold (humoral) which "weaken" the body and increase a person's susceptibilty to catching a disease. Others included exposure to certain types of "dirty" pollutants which lead directly to TB development. Many of these explations are similar to those reported for other groups in Mexico (Alvarez et al., 2000) or in nearby Colombia (Jaramillo, 1998) and Peru (Baldwin et al., 2004). Only one-fifth of the explanations identified "germs" as responsible; most of these appeared to believe that simple, one-time exposure to a TB germ caused a person to develop full-blown disease.

The limited knowledge about disease transmission is underscored by the fact that only 21% of the subjects correctly identified direct exposure to airborne particles transmitted by a person with TB coughing or sneezing. Instead, most reported that TB is transmitted through discarded patient sputum and urine, contact with their fomites (i.e., eating utensils, towels, blankets, bedding, and clothing) or through casual contact. Belief in fomite transmission of TB is commonplace throughout Latin America (Armijos et al., 2008; Jaramillo, 1998; Baldwin et al., 2004; Alvarez et al., 2000), Hispanics in the U.S. (Poss, 1998), and Asia (Hoa et al., 2003; Long et al., 2001; Portero et al., 2002). The widespread belief that persons with TB and their

fomites easily pass TB to others appears to be one of the major factors contributing to the high degree of social stigma linked with this disease.

Our study findings highlight the very significant social, psychological, and economic consequences imposed upon persons with TB, their families, and the larger society. Tuberculosis is a disease that often changes how a person feels about themselves (internalized stigma), how they are treated by others (social stigma), and the nature of their social relationships (Heather et al., 2007; Kelly, 1999; Zhang et al., 2007). The results of the current study confirm those reported by Armijos and associates (2008) indicating that TB is a highly stigmatized disease in Ecuadorian society. They also are consistent with other published studies conducted in diverse global location that linked TB with a variety of adverse psychological and emotional consequences. These include feelings of uneasiness, isolation (Kelly, 1999; Yamada et al., 1999; Corona et al., 2000; Armijos et al., 2008), fear (Nnoaham et al., 2006; Kelly, 1999), anxiety, feeling depressed over having a dangerous, life-threatening disease, and emotional changes due to the constant physical pain and suffering (Johansson et al., 1996; Rajeswari et al., 2005). Patients with TB often feel less respected by others and feel that people avoided or shunned them (Johansson et al., 1996; Kelly, 1999). In fact, our study results suggested that many persons blame the TB patient for being careless in getting the disease or not healing fast enough.

Both internalized and social stigma associated with TB are reported to contribute to the delay of patients in seeking out treatment as well as the abandonment of any treatment started (Liefooghe et al., 1997; Auer et al., 2000; Johansson et al., 1996; Rubel and Garro, 1992). For that reason, it has been recommended that there should be a strong focus on reducing TB-associated stigma along with other activities when developing TB educational programs (Rubel and Garro, 1992).

Some authors have reported that the degree of perceived social stigmatization linked with TB in patients is inversely correlated with the degree of kinship (Armijos et al., 2008; Liefooghe et. al., 1997) while others found little differences. The Ecuadorian subjects in our study suggested that no matter the degree of kinship, individuals would treat persons with TB more negatively because of the fear of catching the disease or resentment including that related to having to care for the ill individual, the fact that they were so careless as to catch the disease in the first place, or because they would take too long to heal. Very few subjects conceptualized that the members of their social network would be more supportive toward.

Tuberculosis was also rightfully perceived of as having adverse economic consequences, specific and general, by the study subjects. One of the concerns was the potential loss of paid employment due to the stigma associated with the disease and the fear of contagion by employers. Another was that the debilitating impact of the disease on the body, especially fatigue and loss of physical strength, coupled with time and money needed to seek treatment adversely affect the ability of TB sufferers to work at an outside job and as appropriate, perform in school or carry out household duties. These have important potential ramifications implications for TB control as out-of-pocket medical expenses for treatment and income reductions in poor households caused by under-employment or loss of employment have been linked with delayed disease diagnosis and antibiotic treatment adherence (Kamolratanakul et al., 1999; Needham et al., 1998).

Similar to that recently reported by Armijos and associates (2008) for their high-risk urban Ecuadorian group, most of our study subjects reported first learning about TB only after they or close kin experienced the disease or through causal conversation and gossip. Only a few had first heard about in a newspaper, magazine, or on the radio, during school health education lessons or

from medical personnel. None identified the public health ministry or mass media public service announcements as a source. In addition to the specific suggestions offered by subjects for improving the national TB control, suggests that the national TB control program, the larger public health service, and other health providers may be missing opportunities for educating the public.

There are various complementary strategies that could be used to facilitate this goal. One of the most effective strategies for achieving widespread dissemination of health messages is through coordinated mass media use. The Ecuadorian Ministry of Public Health, Pan American Health Organization, and other national and international health agencies have enjoyed significant success using social marketing techniques delivered through national mass media campaigns ranging including but not limited to iodized salt to combat iodine deficiency disorders, breastfeeding and contraceptive promotion, and HIV/AIDS prevention (Raczynski et al., 1999; Hornick, 2002; UNICEF, 2007; Favin and Griffiths, 1992; Georgetown University/USAID, 2008). As Armijos and colleagues (2008) have suggested, the use of entertaining animated characters from respected sources (e.g., "*Maximo the Toucan*") and respected community leaders could be used to inform the public about TB and its treatment, reduce stigma, and address many of the frequent concerns noted in this and the only other published study on the topic for Ecuador (Armijos et al., 2008). Other complementary strategies could be to reinforce TB education messages from mass campaigns and other sources messages using multimedia onto health care provider visits or during mass health screening and vaccination campaigns for other conditions. Other possible health education venues include churches, daycare and school sites, local neighborhood and professional associations, employment sites, and health fairs.

The potential strengths and limitations of this mixed methods study should be taken into account when interpreting its results. The study strengths were that the sample was population- rather than clinic/hospital-based and included individuals from different geographical, gender, age, educational, TB experience and other backgrounds. The Ecuadorian study team was carefully trained in the use of the survey questionnaire and was closely supervised in the field during the data collection by a senior, experienced investigator (RXA). Another strength was the use of open-ended questions which allowed respondents to answer in their own words. The qualitative response coding was performed by a trained bilingual anthropologist (MMW) with two decades of experience working on similar studies in the same study population.

Some of the potential limitations of the study include the use of non-random sampling method and a relatively small sample size of 276 subjects which could have introduced sampling error or other forms of bias. Convenience sampling always require additional caution in result interpretation and generalization to other populations. Individual experiences may differ for those having different TB risk profiles, for those with different age, education, income, and other sociodemographic characteristics. Likewise, persons with different disease experience and health care access may be different. Additional research employing the use of larger sample sizes should be undertaken in the same groups as well as indigenous, Afro-Ecuadorian and other mestizo groups in other parts of the country for the purpose of relocating the results and generalizing the study findings.

The results of this study strongly underscore the need for improving TB education and promotion efforts in rural and peri-urban communities. They confirm that TB is a highly stigmatized disease. Many persons are afraid of contracting TB and strongly desire formal

educational opportunities to learn more about its prevention and control. The study findings can be used by the Ecuadorian National TB Control Program to develop population-specific health promotion and education interventions aimed at decreasing stigma, improving disease prevention, and faciliating early diagnosis, prompt treatment, and treatment adherence.

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Table 1. Subject Sociodemographic and Other Characteristics (n = 276)

Subject Characteristic	Malchingui rural site (n=150	Chillogallo peri-urban site (n=126)	X^2 or t-test	P-value
Ethnicity: Mestizo	147 (98.0)	121 (96.0)	0.37	0.54
Gender: female	87 (58.0)	88 (69.8)	3.64	0.06
Marital status: Legal/consensual union	93 (62.8)	84 (66.7)	0.29	0.59
Education: $\leq$ 5 yrs	79 (54.9)	48 (39.3)	5.77	0.016
6-9 yrs.	52 (36.1)	58 (47.5)	3.10	0.078
$\geq$10 yrs.	13 (9.0)	16 (13.1)	0.75	0.39
Mean family size	4.6 $\pm$ 2.0	5.3 $\pm$ 2.3	2.77	0.006
Mean age (yrs)	44.1 $\pm$ 22.1	34.3 $\pm$ 17.7	3.98	<0.0001
Age: < 20 yrs	28 (18.7)	35 (27.8)	2.73	0.10
21-30 yrs	26 (17.3)	32 (25.4)	2.22	0.14
31-40 yrs	20 (13.3)	20 (15.9)	0.18	0.67
> 41 yrs	76 (50.7)	39 (30.1)	10.2	0.001
Prior TB experience	21 (14.2)	11 (9.0)	1.25	0.26
BCG history: No dose	29 (23.2)	17 (16.2)	1.34	0.25
Partial dose	27 (21.6)	39 (37.1)	6.00	0.014
Complete dose	68 (54.4)	49 (46.7)	1.10	0.30
Current PPD (mm)	4.5 $\pm$ 4.4	4.6 $\pm$ 4.3	0.39	0.97
Current positive PPD (> 10 mm)	16 (12.8)	4 (11.1)	0.00	1.00

* Mixed Spanish-Quechua; Note: Some percentage totals may not equal 100% because of rounding.

Table 2. Explanations given by Subjects for Perceived Age and Gender Differences in TB Risk

Subject Responses	No. (%) of responses
Age Categories	
Children (124 responses)	
Young age makes them more vulnerable/weaker/delicate	62 (50.0)
Play behavior exposes to dirty environment/dirty companions	31 (25.0)
Poor diet/nutrition	13 (10.5)
Poor personal hygiene	8 (6.5)
Incompletely vaccinated	7 (5.6)
More exposure to wet/cold/wind	3 (2.4)
Teenagers (49)	
Age makes them more vulnerable/weaker/delicate	16 (32.7)
Behavior (run wild, roam around)	17 (34.7)
Poor diet/nutrition	4 (8.2)
Vices (alcohol, tobacco, sex)	4 (8.2)
Excessive physical work	4 (8.2)
More exposure to wet/cold/wind	2 (4.1)
Poor personal hygiene	2 (4.1)
Adults (43 responses)	
Behavior (run wild, roam around)	17 (39.5)
More vulnerable/weaker	12 (27.9)
Excessive physical work	7 (16.3)
Poor diet/nutrition	6 (14.0)
Vices	1 (2.3)
Elderly (121 responses)	
Weaker/more delicate due to age	101 (83.5)
Poor diet/nutrition	10 (8.3)
More exposure to cold/wet/wind	3 (2.5)
Excessive work/physical exertion	4 (3.3)
Often wander away from home/get lost	3 (2.5)
Gender Categories	
Boys (51 responses)	
Young age makes them more vulnerable/weaker/delicate	23 (45.1)
Play behavior exposes to dirty environment/companions	12 (23.5)
Poor diet/nutrition	6 (11.8)
Poor personal hygiene	4 (7.8)
Incompletely vaccinated	3 (5.9)
More exposure to wet/cold/wind	2 (4.0)

Table 2 (continued). Explanations given by Subjects for Perceived Age and Gender Differences in TB Risk

Subject Responses	No. (%) of responses
Girls (49 responses)	
Young age makes them more vulnerable/weaker/delicate	29 (59.2)
Play behavior exposes to dirty environment/dirty companions	9 (18.4)
Poor diet/nutrition	4 (8.2)
Poor personal hygiene	3 (6.1)
More exposure to wet/cold/wind	2 (4.1)
Incompletely vaccinated	2 (4.1)
Male Adolescents (36 responses)	
Bad companions/bad lifestyle/careless	16 (44.4)
Age makes them more vulnerable/weaker	9 (25.0)
Poor diet/nutrition	4 (11.1)
Excessive physical work	4 (11.1)
Poor personal hygiene	2 (5.6)
Vices (sex)	1 (2.8)
Female Adolescents (41 responses)	
Bad companions/bad lifestyle/careless	15 (36.6)
Age makes them more vulnerable/weaker	14 (34.1)
Poor diet/nutrition	6 (14.6)
Poor personal hygiene	3 (7.3)
Excessive physical work	2 (4.9)
Vices (sex)	1 (2.4)
Men (38 responses)	
More vulnerable/weaker	12 (31.6)
Excessive physical labor	9 (23.7)
Poor diet/nutrition	7 (18.4)
Behavior (run wild, roam around)	4 (10.5)
Vices (sex, alcohol)	4 (10.5)
More exposure to wet/cold/wind	2 (5.3)
Women (48 responses)	
More vulneravble/weaker/delicate	15 (31.3)
Behavior (run wild, roam around)	14 (29.2)
Excessive physical work	7 (14.6)
Bad diet/nutrition	6 (12.5)
More exposure to wet/cold/wind	3 (6.3)
Excessive sexual relations	2 (4.2)
Poor personal hygiene	1 (2.1)

Table 3. Reasons Reported by Subjects for Hypothetical Change in the Behavior of Their Social Network Members if Discovered that the Subject had TB

Subject Responses	No. (%)
Spouse/Partner (84 responses)	
Negative changes	
Social rejection and isolation due to fear of getting a dangerous disease	52 (61.9)
No longer healthy or don't cure fast enough	17 (20.2)
Lose love or trust, considered irresponsible (carelessness) to get TB	7 (8.3)
Resentment that patient has disease and/or because they have to take care of patient	5 (6.0)
Positive changes	
More love and support	3 (3.6)
Children (98 responses)	
Negative changes	
Social rejection and isolation due to fear of getting a dangerous disease	64 (65.3)
No longer healthy or don't cure fast enough	16 (16.3)
Lose love or trust, considered irresponsible (carelessness) to get TB	8 (8.2)
Fighting/tired/irritable/lack patience/angry because have disease or have to take care of patient	6 (6.1)
Positive changes	
Give increased care/love/support	4 (4.0)
Parents (76 responses)	
Negative changes	
Social rejection and isolation due to fear of getting a dangerous disease	53 (69.7)
No longer healthy or don't cure fast enough	12 (15.8)
Lose love or trust, considered irresponsible (carelessness) to get TB	7 (9.2)
Fighting/tired/irritable/lack patience/angry because have disease or have to take care of patient	2 (2.6)
Positive changes	
Give increased care/love/support	2 (2.6)

Table 3. Reasons Reported by Subjects for Hypothetical Change in the Behavior of Their Social Network Members if Discovered that the Subject had TB

Subject Responses	No. (%)
Friends (123 responses)	
Negative changes	
Social rejection and isolation due to fear of getting a dangerous disease	83 (67.5)
No longer healthy or don't cure fast enough	22 (17.9)
Lose love or trust, considered irresponsible (carelessness) to get TB	11 (8.9)
Fighting/tired/irritable/lack patience/angry because have disease or have to take care of patient	5 (4.1)
Positive changes	
Give increased care/love/support	2 (1.6)
Co-workers (86 responses)	
Negative changes	
Social rejection and isolation due to fear of getting a dangerous disease	58 (67.4)
No longer healthy or don't cure fast enough	15 (17.4)
Lose love or trust, considered irresponsible (carelessness) to get TB	8 (9.3)
Fighting/tired/irritable/lack patience/angry because have disease or have to take care of patient	3 (3.5)
Positive changes	
Give increased care/love/support	2 (2.4)

Figure 1. Map of South America Showing Location of Ecuador (CIA, 2008)

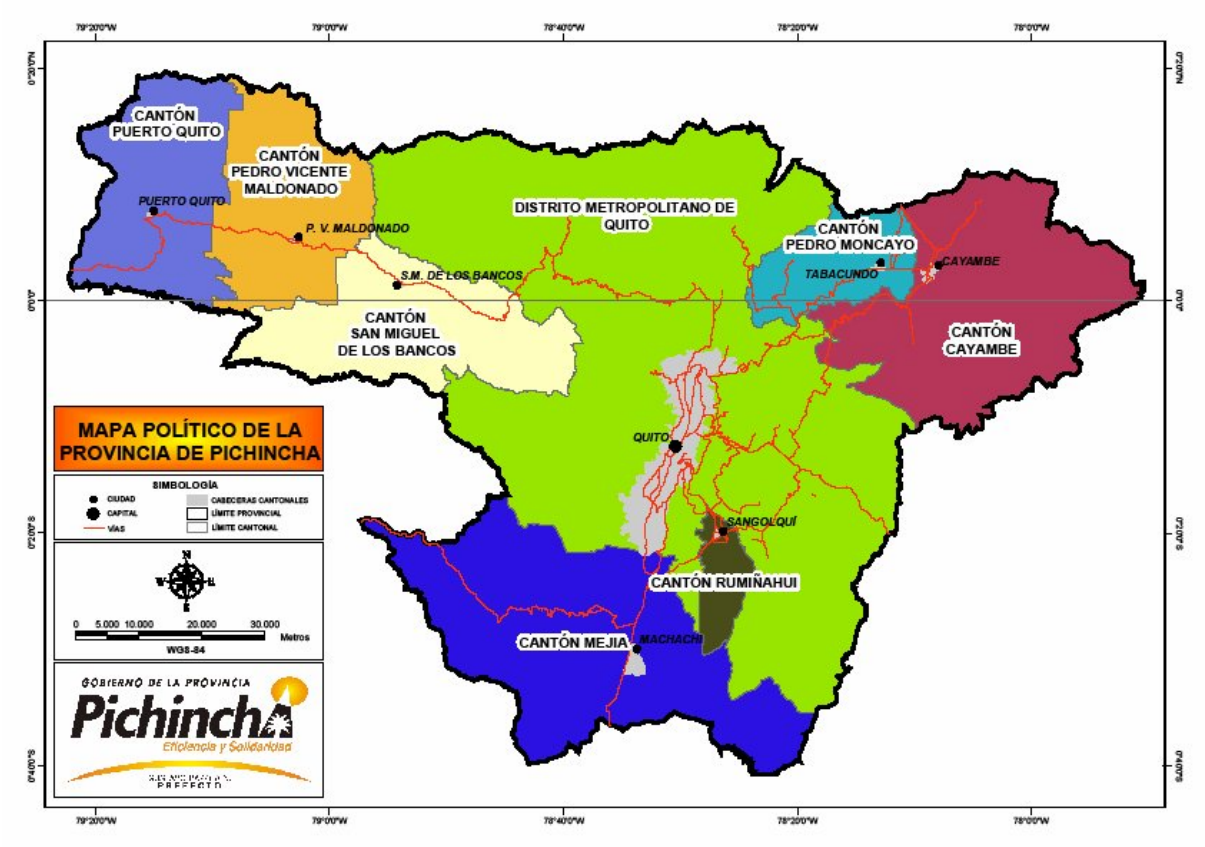

Figure 2. Political Map of Pinchincha Province, Ecuador, Showing the Location of the Two Locations in the Study (Gobierno de la Provincia de Pichincha, 2008).

CURRICULUM VITA

Yamira Araujo was born in Ciudad Juarez, Chihuahua. She is the second daughter of Angel Araujo and Alejandra Saenz Araujo, she is a nutritionist and graduated from Universidad Autonoma de Ciudad Juarez (UACJ) in the fall of 2004. She then entered the Graduate School at The University of Texas at El Paso (UTEP) in the summer of 2005 with TIES Program sponsored by USAID. While pursuing a master´s degree in health promotion, she worked with Dr. Mary Margaret Weigel and Dr. Rodrigo X. Armijos as a research assistant (RA) during the summer of 2005, and later worked with Dr. Brenda Smith, Dr. Maria Duarte, Dr. Joao Ferreira Pinto, and other professors as a teaching assistant (TA). She completed twoInternships during her master with Pan American Health Organization (PAHO), and Paso Del Norte Health Foundation. During her studies, she was a member of Eta Sigma Gamma, a National Professional Health Honorary Society.

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