“To my husband, and my sons, Sebastian, Sergio, Sebastian Jr. and Ricky”
ACKNOWLEDGMENTS

First, I would like to thank all members of my committee, Dr. Allan Burns for his support and guidance as the chairman, Dr. Willie Baber for working with me and for his valuable assistance with making it possible for me to finish this program successfully. I would also like to express my deep appreciation to Dr. Michael Lauzardo for his contribution as a member of my committee but especially for believing in me and supporting my dreams since the beginning of this journey; without his support none of this would have been possible.

I would also like to express my special gratitude to all my workmates and friends from the SNTC for continually reminding me that my work was appreciated.

I would also thank all my professors from the Latin American Center, the Anthropology Department and the College of Public Health at the University of Florida for contributing to my professional development.

Furthermore, I thank all people that granted me access to the community to conduct this study and I want to acknowledge the Interdisciplinary Field Research Grant for providing funding for it.

I also thank my friends that supported me and make this journey easier for me.

Most importantly, I would like to thank my family. Thanks go to my husband and sons for all their patience, support and encouragement throughout this process. I could not have asked for a better family. I thank them for sharing their wife and mother during this time and supporting my professional development. Like most things, this success is only meaningful because of them.
# TABLE OF CONTENTS

ACKNOWLEDGMENTS ...............................................................................................................4

LIST OF TABLES ...........................................................................................................................7

LIST OF FIGURES .........................................................................................................................8

LIST OF ABBREVIATIONS ..........................................................................................................9

CHAPTER

1 INTRODUCTION ..................................................................................................................12

   Problem Statement ..................................................................................................................12
   Research Question and Purpose of the Study ........................................................................14

2 LITERATURE REVIEW OF TUBERCULOSIS AND STIGMA ........................................16

   Introduction .............................................................................................................................16
   Tuberculosis Overview ...........................................................................................................16
   Scope of TB: Epidemiology ...................................................................................................18
   Contact Investigation ..............................................................................................................19
   Stigma Background ................................................................................................................21
   Summary .................................................................................................................................30

3 METHODOLOGY .................................................................................................................32

   Introduction .............................................................................................................................32
   Research Design .....................................................................................................................32
       Purpose ............................................................................................................................32
       Hypotheses ......................................................................................................................33
           Hypothesis #1 ...........................................................................................................33
           Hypothesis #2 ...........................................................................................................33
           Hypothesis #3 ...........................................................................................................34
   Community ......................................................................................................................36
   Sampling ..........................................................................................................................38
   Sample Size .....................................................................................................................39
   Instruments .......................................................................................................................39
   Data Collection ................................................................................................................42
   Data Analysis ...................................................................................................................43
   Variables ..........................................................................................................................43
       Demographic variables .............................................................................................44
       Reliability .....................................................................................................................45
       Contact investigation comfort (dependent variable) CIC index...............46
Perception of stigma related with tuberculosis (independent variable)
TB stigma index ................................................................. 46
Immigrant experience (independent variable) MG index ........................................ 46
General knowledge about tuberculosis (independent variable) TB
knowledge index ............................................................... 46

4 RESULTS ........................................................................................................................................ 48

Overview of the Chapter ................................................................................................................. 48
Community Demographics .............................................................................................................. 48
Descriptive Statistics .................................................................................................................... 50
Linear Regression .......................................................................................................................... 53
Qualitative Results ....................................................................................................................... 54

5 DISCUSSIONS AND CONCLUSIONS ......................................................................................... 65

Introduction ..................................................................................................................................... 65
Statement of the Problem ............................................................................................................... 65
Review of the Methodology ........................................................................................................... 67
Interpretation of Results ................................................................................................................ 68
Conclusions ....................................................................................................................................... 72
Implications ..................................................................................................................................... 74
Recommendations ........................................................................................................................ 76

LIST OF REFERENCES ..................................................................................................................... 79

BIOGRAPHICAL SKETCH ................................................................................................................. 84
# LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>3-1</td>
<td>Cronbach’s Alpha coefficients</td>
<td>47</td>
</tr>
<tr>
<td>4-1</td>
<td>Demographics</td>
<td>57</td>
</tr>
<tr>
<td>4-2</td>
<td>The importance of tuberculosis to participants</td>
<td>57</td>
</tr>
<tr>
<td>4-3</td>
<td>The relationship of tuberculosis to stereotypes</td>
<td>58</td>
</tr>
<tr>
<td>4-4</td>
<td>Tuberculosis knowledge in the community</td>
<td>58</td>
</tr>
<tr>
<td>4-5</td>
<td>Immigration experience</td>
<td>58</td>
</tr>
<tr>
<td>4-6</td>
<td>Level of comfort in the contact investigation interview</td>
<td>59</td>
</tr>
<tr>
<td>4-7</td>
<td>Stigma related with TB regressed on the likelihood of TB of been equal to any other problem.</td>
<td>59</td>
</tr>
<tr>
<td>4-8</td>
<td>Level of comfort during contact investigation regressed on the level of stigma related with TB, the level of stigma related with the migration experience and the level of knowledge about TB.</td>
<td>59</td>
</tr>
</tbody>
</table>
# LIST OF FIGURES

<table>
<thead>
<tr>
<th>Figure</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2-1</td>
<td>Contact investigation. concentric circle approach.</td>
<td>31</td>
</tr>
<tr>
<td>3-1</td>
<td>Map of Hillsborough County</td>
<td>47</td>
</tr>
<tr>
<td>4-1</td>
<td>Years of United States residency.</td>
<td>60</td>
</tr>
<tr>
<td>4-2</td>
<td>English proficiency</td>
<td>60</td>
</tr>
<tr>
<td>4-3</td>
<td>Time spend with other people from county of origin</td>
<td>61</td>
</tr>
<tr>
<td>4-4</td>
<td>Visa status</td>
<td>61</td>
</tr>
<tr>
<td>4-5</td>
<td>Tuberculosis and perceived stigma.</td>
<td>62</td>
</tr>
<tr>
<td>4-6</td>
<td>Likelihood of disclosing tuberculosis status</td>
<td>62</td>
</tr>
<tr>
<td>4-7</td>
<td>Distribution of frequencies across CI comfort index values</td>
<td>63</td>
</tr>
<tr>
<td>4-8</td>
<td>Perceived negative migration experience.</td>
<td>63</td>
</tr>
<tr>
<td>4-9</td>
<td>Perceived TB stigma</td>
<td>64</td>
</tr>
<tr>
<td>4-10</td>
<td>Distribution of frequencies across TB knowledge index values</td>
<td>64</td>
</tr>
<tr>
<td>5-1</td>
<td>Cultural model for tuberculosis stigma. Biocultural interaction</td>
<td>77</td>
</tr>
<tr>
<td>5-2</td>
<td>Cultural model for tuberculosis stigma. No biocultural interaction</td>
<td>78</td>
</tr>
<tr>
<td>ABBREVIATION</td>
<td>DESCRIPTION</td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
<td></td>
</tr>
<tr>
<td>CB</td>
<td>Cultural Brokers</td>
<td></td>
</tr>
<tr>
<td>CDC</td>
<td>Centers for Disease Control and Prevention</td>
<td></td>
</tr>
<tr>
<td>CI</td>
<td>Contact Investigation</td>
<td></td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
<td></td>
</tr>
<tr>
<td>LTBI</td>
<td>Latent Tuberculosis Infection</td>
<td></td>
</tr>
<tr>
<td>MDR-TB</td>
<td>Multi Drug Resistant Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>TB</td>
<td>Tuberculosis</td>
<td></td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
<td></td>
</tr>
<tr>
<td>XDR-TB</td>
<td>Extremely Drug Resistant Tuberculosis</td>
<td></td>
</tr>
</tbody>
</table>
Generally speaking, tuberculosis (TB) control programs in the United States have successfully achieved their goals; however, the poor decrease of TB incidence among foreign-born population has prevented tuberculosis control programs from achieving their ultimate goal of “TB elimination.” TB in the USA affects primarily foreign-born and within that group, Mexicans are the principal ethnicity represented. An integral component of TB control is timely identification of cases through contact investigation (CI) and subsequent treatment, if required. Unpublished data from the Bureau of Tuberculosis and Refugee Health of the Florida Department of Health suggest that in Florida, Mexicans tend to identify fewer contacts during TB contact investigation than the average patient. Specific factors influencing CI are not well characterized, although stigma has been mentioned. It is imperative to determine how stigma influences CI involving those cultures most affected by TB given that stigma is a cultural construct.

The purpose of this study was to determine if the stigma related to TB influences the effectiveness of tuberculosis contact investigation among Mexicans living in Central Florida. A nonexperimental cross-sectional survey research design using mixed methods, where quantitative data served as the primary source was utilized. Components of several
existing instruments to measure stigma were modify for use in this study. The community selected for the study was a small church-based community from Hillsborough County in Florida. Forty two surveys and four face-to-face interviews were conducted. Data were analyzed using descriptive statistics and linear regression in SPSS.

The majority of the participants were young adult females, with low levels of education and low socioeconomic status. Although most participants reported that they have lived in the United States more than 5 years, they show low English proficiency and limited interaction with people from other than their own country. The majority of participants do not have a legal immigration status.

The analysis of the results showed no statistically significant weak relationships between the dependent and the independent variables. These results contrast with what was hypothesized. The sampling design and some characteristics of the population, such as being a member of a church-based community, may have influenced these results.

Stigma seems to be a more intricate construct than what has been portrayed in the literature. Additional research is needed to untangle the complexity of TB related stigma in multicultural environments.
CHAPTER 1
INTRODUCTION

National security in the United States is currently considered a top priority on the country’s agenda. Immigration, both documented and undocumented, plays a key role in the security of the nation. One of the contexts within which immigrants are considered to be a challenge for the nation’s security is within the public health sector. Tuberculosis (TB) is a good example of a disease considered a public health threat and because it is intimately linked with the foreign-born it has also been associated with immigration issues and national security. Surveillance data has shown a significant disparity of TB incidence among US-born and foreign-born. While overall TB incidence rates are decreasing fast, those of foreign-born origins are going slower. There is a need to explore and understand what the obstacles are for the reduction of TB in the foreign-born to alleviate the effect that this group has on the overall effectiveness of TB control programs.

Problem Statement

Tuberculosis is a communicable disease caused by bacteria, and although it has had an effective treatment for more than 60 years, approximately 2 million people around the world still die because of it. In the United States TB is also a problem. Although TB incidence in the United States is under control, some minorities groups are still being affected. For example, in 2005, foreign-born individuals represented more than half of the total cases in the United States and Mexicans alone accounted for 23% of this group (Centers for Disease Control and Prevention [CDC], 2006).

The foreign-born population in the United States has maintained, as a group, almost the same incidence rate of TB during the past decades. Meanwhile, all other groups within the United States have successfully contributed to the overall decrease of TB incidence (CDC, 2007). The fact that the foreign-born are not responding in the same way that the other groups
are, suggests that this population may not be appropriately reached by current approaches of tuberculosis control programs.

Numerous studies have been completed over the last few decades regarding health and migration. Specific studies in TB have been conducted to better understand cultural differences and how to reach the foreign-born population. Special emphasis has been placed in understanding cultural differences to better deliver health care to this population. Stigma is one of the cultural constructs studied by researchers. However, stigma is a concept broadly used in research without a precise definition. A literature review conducted by Van Brakel (2006) reviewed the work done to measure health related stigma and found that TB studies investigating stigma used mainly qualitative methods and are minimal when compared to studies on other diseases. Although stigma in relationship to TB has not been completely understood and described, the difficulty in controlling TB among foreign-born persons has been linked to it. Most of these studies associate stigma and TB with effects related to the search for medical care and adherence to treatment. However, little has been done to study the effects of stigma on the outcomes of contact investigation. Contact investigation of patients with active tuberculosis is an important component in tuberculosis control programs in the United States. When a person is diagnosed with active TB disease, apart from receiving medical care, these patients are asked to participate in a contact investigation process. The contact investigation process aims to identify persons that could be at risk of being infected with the *Mycobacterium* and offer testing and appropriate treatment if they are infected.

Foreign-born populations represent a challenge to public health in the United States, and within them, Mexicans represent the largest single group. It is necessary to conduct research that helps to better understand these populations in order to control TB in the United States. The
studies must be specific to the Mexican population and target specific cultural characteristics within the group.

Florida is among the top ten states with high incidence rates of TB. Within Florida, Hillsborough County ranks in the top four counties according to TB rates. Inside this group of four counties, Hillsborough has the second highest percentage of foreign-born TB incidence. (Bureau of TB and Refugee Health [BTBRH], 2007).

Unpublished data from the Florida Department of Health, Bureau of Tuberculosis and Refugee Health suggest that in Florida, Mexicans tend to identify fewer contacts during TB contact investigation than the average patient. This characteristic deserves to be explored as it may be one factor contributing to the slow decline in TB incidence among this population. A low detection of possible contacts could be keeping TB incidence rates high due to the ineffective detection of TB infection among contacts. Failing to detect these cases may allow the infection to develop to active TB disease and further TB spread. However, little is known about the factors that might influence contact investigation and even less is known about TB contact investigation among Mexican-born populations in the United States.

Research Question and Purpose of the Study

The purpose of this study is to determine if stigma related with tuberculosis and immigrant experience influences the effectiveness of tuberculosis contact investigation among a small community of Mexicans living in Hillsborough County, Florida. This is nonexperimental research study using a cross sectional survey design. The study used mixed methods where quantitative data served as the primary source of data. Qualitative data were used as a secondary source to provide context and to better understand the community.

After this Introduction, the second chapter will review the conceptual framework related to the study. Rather than attempt to present a comprehensive discussion about tuberculosis and
stigma, I chose to review more indepth topics related to stigma and tuberculosis that were relevant for this research. Chapter 3 presents detail about the research design and the methodology used in the study. This chapter includes descriptions of the community, sampling, sample size as well as all methodology used to collect data and for the analysis of the data. Chapter 4 presents the results of the study including demographic description, descriptive statistics, statistical analysis and interpretation of the results. Also this chapter provides the finding from the interviews conducted in this study. Chapter 5 provides the discussion and conclusions.
CHAPTER 2
LITERATURE REVIEW OF TUBERCULOSIS AND STIGMA

Introduction

Tuberculosis (TB) is one of the oldest infectious diseases affecting and killing humans in the world and is taking new strength during “The Third Epidemiological Transition” (Barrett, Kuzawa, McDade, & Armelagos, 1998). “The Third Epidemiological Transition” corresponds to the current phenomenon of emerging infection diseases characterized by three major trends: unprecedented number of new diseases, increased incidence and prevalence of old infectious diseases, and a rapid rate increasing of a new generation of antimicrobial-resistant strains (Barrett et al., 1998). The fast growth of new strains of microorganisms resistant to drugs is faster than the development of new drugs to combat them. This situation is pushing the public health infrastructure to its limits leading them to not have the ability to control these infections. This is what is being called “The Post Anti-Microbial Era” (Cohen, 1992). Tuberculosis is now recognized as a reemerging infection disease threatening global public health in this period of history.

This chapter reviews the literature to provide background information related to tuberculosis, including active TB disease and latent TB infection (LTBI). An overview of the scope of TB is presented with the epidemiology of TB in the world, in United States and among the foreign-born within the United States. Contact investigation is described and stigma is reviewed.

Tuberculosis Overview

Tuberculosis, caused by the *Mycobacterium tuberculosis complex*, is usually spread from person to person when diseased people cough, talk, sing, or sneeze, and airborne infectious particles are dispersed and inhaled by other people. Most individuals who become infected do
not develop the disease because their body's immune system keeps the infection under control. However, if the person is infected, the infection can persist for years in the body, perhaps for life, waiting patiently for the best moment to attack. Latent TB infection (LTBI) is when a person has the *Mycobacterium tuberculosis* in the body but the body’s immune system is keeping the bacilli under control. Infected persons remain at risk for developing the disease at any time in their life, especially if for any reason their immune system becomes impaired. Although the disease usually affects the lung, it can occur at virtually any site in the body.

After the introduction of anti-TB medication in the late 1940s, there was hope that tuberculosis would soon be eradicated. There was a steady decrease in the incidence of TB in the United States from 1953 through 1984. However, from 1985 through 1992 the number of reported TB cases increased by 20% in spite of the public health system in the United States. The are several reasons for this tuberculosis explosion; the increase in HIV/AIDS infection, increased immigration, and the weaknesses of the tuberculosis programs due to a false feeling of safety TB control. New efforts were made to control TB infection and even though the disease is now considered once again under control, surveillance data have shown that tuberculosis in the United States disproportionately affects some racial/ethnic minorities, especially foreign-born populations (CDC, 2007a). Also new strains of *Mycobacterium tuberculosis* are now challenging the United States and the world; this new bacteria has shown greater resistance and persistence in doing damage to humans. Tuberculosis can now be found in forms that are resistant to TB medication, such as Multi Drug Resistant TB (MDR-TB) and Extremely Drug Resistant TB (XDR-TB). This new global emergency has reversed years of progress in public health because these new strains have higher mortality rates, higher infectious periods and a higher treatment cost. What is really unfortunate is that MDR-TB and XDR-TB did not occur in
a natural way, it was produced as the result of inadequate treatments, non-adherence and poor tuberculosis control management allowing the *Mycobacterium* to evolve.

**Scope of TB: Epidemiology**

Currently, one third of the world’s population carries the organism that leads to active TB disease (World Health Organization [WHO], 2007). Among these two billion people, approximately 9 million people will develop the disease worldwide every year and almost 2 million will die because of it (CDC, 2007b). Every second someone in the world is infected with TB (WHO, 2007). The most affected areas remain in the poorest areas of the developing world. Countries in Sub-Saharan Africa are the most affected, where TB still takes a great toll on its population. But other regions in the world are also affected; Asia, Europe and Latin American are suffering from this communicable disease. Also, drug resistant TB is widespread and affects individuals all over the world. The World Health Organization (WHO) estimates that there are nearly half a million new cases of MDR-TB, about 5% of the total nine million new TB cases worldwide each year (WHO, 2008). There are some “hot spots” of MDR-TB and XDR-TB and these are mostly in the poor and middle income countries of the world.

Despite all effort made around the World, TB remains a global public health problem. In the developed world, TB incidence is lower but it remains a concern. The United States incidence rate of TB in 2006 was 4.6 cases per 100,000 habitants (CDC, 2007a). Although the incidence has successfully decline after the alarming breakout in the 80’s, fifty states annually report new cases (CDC, 2007a) and MDR-TB and XDR-TB are reported as well. However, much like between countries, within the United States tuberculosis disproportionately affects the poor. Surveillance data has shown that the incidence of TB in the United States is greater among some minority groups, especially the foreign-born. The proportion of total cases occurring in foreign-born persons has been increasing since 1993. In 2006, 57% of TB cases occurred in
foreign-born persons (CDC, 2007a). During the last two decades, the incidence has been declining, but for the foreign-born population the decline in incidence has been at a slower rate.

The foreign-born population from the region of Latin America and the Caribbean represent a major proportion of foreign-born TB cases in the United States (CDC, 2006); of the 7,799 TB cases reported among foreign-born persons in 2006, 45% occurred among persons born in the Americas region, and for this group, Mexicans are the largest single group (CDC, 2007a).

The factors that may contribute to this disparity are complex. Some anthropologists argue that the failure to control infectious disease is related to the lack of knowledge about health education and related behaviors (Manderson, 1998). Others argue that the reason for TB disparity relate to poverty, unequal opportunity, structural violence and the lack of access to adequate biomedical services (Farmer, 1999, 2003). However, regardless of this tension, it is imperative to conduct research that untangle the complexity of this dilemma and enlighten the path that will lead to the successful intervention that will achieve the ultimate goal, reduction and eventual elimination of TB in this population.

**Contact Investigation**

An important part in the fight to stop the dissemination of TB, regardless of the rates of disparity, is the timely detection of cases and proper treatment. For this purpose it is necessary to identify those individuals that could be at risk of infection due to proximity to active TB cases. Contact investigation of patients with active tuberculosis is an important component in tuberculosis control programs in the United States (CDC, 2005a). When a person is diagnosed with active TB disease, apart from receiving medical care, these patients are asked to participate in a contact investigation process. The contact investigation process aims to identify those persons that could be at risk of being infected with the *Mycobacterium* and offer them testing and appropriate treatment if they are infected (CDC, 2005b).
The goal of a contact investigation is to identify approximately 10 contacts per active TB case. A study found that close contacts of an active TB case were 100 times more likely to be diagnosed with TB than the general populations (as cited in CDC, 2005b). This high prevalence among contacts is what urges the contact investigation of all new active TB cases. The ultimate goal of identifying contacts is to diagnose LTBI and active TB cases, to provide treatment for LTBI or active TB among contacts and ultimately to stop further TB spread by prevention and early detection of active TB cases.

Contact investigation helps to identify those persons that spent time with the patient in optimal conditions for tuberculosis transmission during the period that the patient was considered infectious. Factors that play a role in the decision of initiating a contact investigation are disease related: characteristics (a) clinical, (b) radiological, and (c) of laboratory; or related with the host: (a) presence of behaviors that increases aerosolization of respiratory secretions, (b) age, and (c) HIV status. Once the decision of initiating a contact investigation is made, it is necessary to collect as much information as possible regarding the patient, including disease characteristics, time of early symptoms, and all information about contacts as well as the physical characteristics of exposure locations. Identification of contacts follows a concentric circle analysis (CDC, 1999). In this approach (fig.2.1), the original TB patient (the index case) is at the center. The circle is divided into three concentric rings to represent the levels of risk: close contact (high risk) and other than close contact (middle risk and low risk). The circle is also divided in segments that represent the three types of environment where the contact may have taken place: home, work and leisure environment.

The first step of a contact investigation is to identify close contacts (first circle) of the Index case in their home, their work and in those places where they spent their leisure time.
Using the results obtained in this first step and the evidence of transmission in the first circle, the decision is made whether it is necessary to expand the investigation to the “other than close contacts.”

The best way to identify contacts is to understand the patient social networks through the contact investigation interview. With this interview, health care providers may identify persons with whom the patient has spent time as well as the details of this contact regarding frequency, duration, and proximity (Shrestha-Kuwahara, Wilce, DeLuca, & Taylor, 2003). This interview is expected to provide adequate information that leads to the identification of those that could be at risk, thereby allowing health professionals to diagnose, treat patients, and contain the spread of TB.

Low results in contact investigation could be related to multiple factors, some of them connected to the health system and other factors related to the community or to individuals. Barriers for the identification of contacts could be related to economic factors, social factors or cultural factors, among individuals as well as in the health institutions. Some of these factors may include interviewer skills, interviewer understanding of the patient’s social setting, and the patient’s ability and willingness to share information (Reichler et al., 2002). Factors that may influence the identification of contacts are not well characterized, however. Shrestha-Kuwahara et al. (2003) completed a study that described TB patients’ perceptions of the contact investigation interview, and the researchers identified potential factors associated with identifying contacts. Stigma, language barriers, cultural insensitivity, and mistrust may all contribute to the outcomes of contact investigation (Shrestha-Kuwahara et al., 2003).

**Stigma Background**

*Mycobacterium tuberculosis* was first described on March 24, 1882 by a German physician named Robert Koch (Hass & Hass, 1996). At that time the *Mycobacterium* was known as the
tubercle bacillus. Apart from the great medical achievement that this discovery represented, the description of the bacillus changed the way people saw tuberculosis. Although previous to the discovery of the bacillus, others had introduced the idea of the “germ theory” regarding the cause of TB it was until the discovery of the bacillus that the argument regarding the cause of tuberculosis finally ended (Hass & Hass, 1996). It was after knowing the real cause of TB that tuberculosis started to be strongly viewed as an undesirable disease (Dubos, 1996). There were now good reasons to fear the presence of people with tuberculosis and people with tuberculosis started not only to confront their own debility and possible death but also they have to deal with isolation and the anger of an intolerant phobic society (Ott, 1996). It was at the end of 1800s and the beginning of 1900s when in United States the popular image of tuberculosis started to be associated with poverty and people of non Anglo-Saxon ethnicity (Ott, 1996).There is a misconception by the general public regarding “undesirable” characteristics of high risk groups due to the manner in which this information is communicated to them by the medical field (Ott, 1996). Epidemiological and other health related fields’ use of risk factors based on social characteristics tends to support social differences as threat. These social differences associated with the risk groups can become identifiable by the public and they are then held as scientific truth leading individuals to reject those that have these characteristics.

Currently in United States, most of the risk factors associated with TB are socially based such as addictions, homelessness, history of incarceration and foreign-born status (CDC, 2000), conditions that are also strongly related to undesirable behaviors. In addition, the foreign-born may also experience the negative effects of anti-immigration attitudes. Although these risk factors have scientific bases associated to the characteristics that facilitate TB spread, the information is not accurately transferred to the general public
This unique social aspect of tuberculosis awakened the interest of researchers regarding the stigma associated with the disease. At the end of the 90’s research interest in the implication of stigma in tuberculosis control started to emerge. Although the number of studies conducted relating stigma and TB is not close to the number found in studies relating stigma to other diseases such as AIDS and mental health, currently it appears to have its niche in the world of TB academia and the studies about stigma associated with TB and its implication in TB control increase each year.

However, regardless of the number of studies conducted with an emphasis on stigma, stigma is a concept broadly used in research without a precise definition. The word stigma is repeatedly used in medical research but not well understood. Since Goffman’s book (1963), numerous scholars from different disciplines have conducted research on stigma but because it is a vague concept and it operates at different levels, the idea of “stigma” is used in different ways. As a sociologist, Goffman studied stigma as a property related to normative behaviors in society that generate stigmatized identities in individuals. In medicine, Goffman’s conceptualization of stigma is commonly applied to individuals in spite of Goffman’s group-level reference for stigma. This discrepancy in the level of application of Goffman’s theory may lead to erroneous conclusions.

A more comprehensive model of culture is required in order to resolve this individual versus group discrepancy noted in medical research linked to stigma. Prior to the influence of Ward Goodenough (1981 [1967]), and other social scientists interested in relating culture to both individuals and to groups, culture was limited to normative and behavioral terms. This is reflected in Goffman’s early work on stigma. The contribution of Goodenough, and others, was to define culture in ideational terms (values and beliefs), and to develop models of culture based
upon language. Like language, culture is learned by individuals. This approach shifted the study of culture from groups to an emphasis on individuals, and learned behavior. This shift was controversial because a behavioral definition of culture can lead to observable behaviors and patterns in groups, whereas culture defined in ideational terms cannot be directly measured. However, an ideational model of culture, such as the one proposed by Goodenough, contributes to a better understanding of how the perception of stigma in individuals would relate to their interactions with each others.

Goodenough’s model of culture includes culture as it relates to groups and culture as it relates to individuals. This allows for the articulation of culture at both levels, so that we may perceive stigma as a process. The culture of a group may be seen subjectively as the system of values and beliefs a person attributes to a set of other persons (Goodenough, 1981). However this subjectivity is any individual’s operating culture, the particular set of values and beliefs that she uses to interpret the behavior of others or to guide her own behavior on a given occasion (Goodenough, 1981). Thus, the differences between groups are relative in Goodenough’s model and dependent upon interaction. This view of culture contrasts with culture defined in normative terms, as implied in Goffman’s definition of stigma. Goodenough’s model allows us to understand stigma as a process involving individuals and groups.

Goffman’s (1963) work, Goodenough’s (1981) model, and Link & Phelan’s (2001) work together provide the bases to better understand stigma. According to Goffman (1963, chap. 1), stigma is an attribute possessed by a person (mark) that is deeply discrediting causing her to be viewed as less than fully human because of it. Goffman makes strong emphasis in stigma as a relationship between the mark and the group-related stereotype ascribed to that mark. But he does not explain the process of how stigma develops or how it is maintained. Relating
tuberculosis to stigma is challenging because the definition proposed by Goffman assumes a visible “mark,” or physical difference that TB as a disease does not have. TB could be linked to visible attributes like the cough and disease consumption, as well as other attributes rooted in socioeconomic differences perceived as a proxy for the disease. What makes stigma interesting and complicated, according to Link and Phelan, is that stigma is not only the attribute (label) but the consequent set of characteristics linked to that attribute (stereotype) and the following responses to the stereotype (status loss and discrimination). Link and Phelan assume a given stigma and then look at process; this can be associated with Ward Goodenough’s model of culture.

“Conceptualizing Stigma” (Link & Phelan, 2001) provides a good concept of stigma to work with in relationship to TB. The authors state that: “stigma exists when all its components converge” (Link & Phelan, 2001, p. 367). They recognize five components of stigma: (a) the first one is the action of people distinguishing and labeling differences; (b) the second corresponds to the action of linking labels to negative stereotype, (c) the third refers to the action of placing distinct categories to make a line between “us” and “them,” (d) the fourth is related to the resulting status loss and discrimination, and (e) the fifth refers to the indispensable presence of power for stigma to exist. Based upon Link and Phelan’s work, stigma may be present even if a visible label is not present. According to this definition of stigma, the label “Tuberculosis people” will be described using all five components.

The first component of stigma is the action of people learning and labeling differences; this will be what Goffman (1963) refers to as the attribute or mark. This action may also apply to differences learned and labeled, but not directly visible, and they will only be meaningful in the context of time and culture modeled by Ward Goodenough (1981). For this component to be
applicable to tuberculosis, first, one should expect that people will perceive tuberculosis as a
difference in a specific period of time and in a cultural context, and that this difference would
rise above all other attributes, including those that are visible or those that are not visible. As a
result, tuberculosis has had different meanings attached to it. We can find tuberculosis hidden all
over scientific and fiction literature with its various names now known as conditions probably
caused by tuberculin bacilli (Dubos, 1996). There are enough novels, dramas, plays and stories
in fiction literature that suggest that there was a time when TB was seen as a melancholic tragedy
that affects all. During the XIX Century, protagonists of famous theatrical plays suffered from
tuberculosis and famous people died because of it. Because many famous people suffered and
died from tuberculosis it was also thought to be a symbol of intelligence (Dubos, 1996). After
the introduction of better sanitation systems and public health infrastructure, tuberculosis
incidence started to decline. The differences between who was affected and who was not
became clear. Tuberculosis started to take different meanings, and probably because of the
decrease in incidence of the disease, the romanticism surrounding it disappeared. The “germ
theory” of disease produced further changes in attitude toward tuberculosis, both in popular view
and in the literature. Now, after having been both a symbol of the hero and of beauty, TB as an
infectious disease became contagious and unclean, making affected people seem undesirable and
untouchable (Dubos, 1996).

Thus, as Dubos notes, differences are meaningful only in the context of a specific time and
culture; difference will only be understood and classified in the context of what is important and
socially accepted. There is a social norm that will dictate what differences should be important
and what should be ignored. It is not well known how culturally created categories arise and how
they are maintained, but they will only matter in the cultures in which they are embedded. In this
sense, I suggest that tuberculosis in the United States is a difference considered important enough to be raised to a category of label, though the invisibility of the TB label is tied to other labels that are visible. This association follows from the literature; for example, surveillance data in the United States indicates that tuberculosis is more common among person born outside its borders, and these same people are affected by it the most. Places outside the borders of the United States are diverse and each one is unique. If stigma emerges, in part, as a difference that is defined in some way by the culture; then, stigma may emerge in the context of cultural differences in which the critical difference is a disease, unseen. But, is it possible to explain how the differences named “tuberculosis people” affect the host culture compared to persons representing another culture, and more affected by the disease?

The second component of stigma corresponds to the action of linking the differences, reflecting different cultures, to a category of labels that become negative attributes or stereotypes. These linkages between labels and stereotypes also will be defined by specific periods of time and in relationship to a given culture. The host society defines what labels correspond to which attributes. Attributes become so deeply imprinted in the minds of people that they became unaware of them (Link & Phelan, 2001); similar to how individuals acquire linguistic competence (Goodenough, 1981).

The literature on tuberculosis suggests different beliefs and attitudes in many different cultures, but this literature does not apply a model of culture that would describe stigma. Instead, there is an emphasis of stigma simply as involving some type of cultural difference. For example; in a cultural feasibility study with the objective of identifying factors that may shape the behaviors toward screening and treatment in Haitians community from South Florida (Coreil, Lauzardo, & Heurtelou, 2004), the researchers found that stigma and fear of isolation were
important factors. Another study, conducted in Cali, Colombia, explored the correlation of the beliefs about TB mechanism of transmission and the attitudinal aspect of TB stigma, finding that contagiousness and severity perception are the main predictors of prejudice (Jaramillo, 1999). A study conducted to describe the socio-cultural aspects of tuberculosis (TB) among Mexicans in the United States (Joseph, Waldman, Rawls, Wilce, & Shrestha-Kuwahara, 2007) found results suggesting that the Mexican-born persons are not homogenous in their perceptions toward TB, including stigma and that the level of stigma changes depending on the TB status and TB educational exposure. In this study they found that participants anticipate greater stigma than the stigma actually experienced by persons with active TB. Among those with TB disease, perceived stigma did not prevent disclosure of status. A different study was conducted to describe socio-economic consequences of tuberculosis in Vietnam with special reference to gender differentials concerning social stigma and isolation (Long, Johansson, Diwan, & Winkvist, 2001). It was found that male patients often worried about economic-related problems, while female patients worried about social consequences of the disease. According to their results they conclude that stigma might play a greater role among females than males because of their greater focus on social consequences.

Numerous studies conducted in different cultural contexts suggest that culture is an important component of stigma related to TB, and that it will define its characteristics and implications. These various studies indicate that the label “tuberculosis people” will have different meanings and linkages to different stereotypes according to the culture in question. The most common stereotype mentioned in the literature regarding tuberculosis is the belief that people with TB are poor and dirty people with bad habits (Johansson et al., 1996; Kelly, 1999;
Also, tuberculosis is strongly attached to foreign-born status (Porter & Kessler, 1995).

The third component in the work of Link and Phelan (2001) relates directly to the process of stigma in which a line is drawn between “them” and “us”, the “tuberculosis people” and “us.” This level of culture is better described by Goodenough (1981), who states that culture may be understood as a taxonomic hierarchy of what he calls public cultures or subcultures. These subcultures are based upon the classification of groups according to degrees of similarity and differences in their respective public cultures. A group’s public culture is defined as an individual’s perception of values and beliefs that a group’s members expect one another to use as their operating culture in dealing with others (Goodenough, 1981). This level of culture allows us to describe how stigma emerges in the interactions of public cultures.

The forth component of stigma, according to Link and Phelan (2001), is related to the resulting status loss and discrimination. However, the hierarchy implied in the discrimination and loss of status requires description. In Goodenough’s model (1981), the notion of hierarchy or a distinction between “them” and “us,” arises in the interactions of individuals and requires some understanding of previous experiences of individuals representing different groups. The label of “tuberculosis people” of the American host group is linked to the stereotype “immigrant status,” and this stereotype triggers the behavioral responses that are discriminatory, and that reinforce the label. This process would reflect inter-cultural interaction, but hierarchies of public cultures also operate intra-culturally. While this process is difficult to observe, the outcomes are linked to tuberculosis studies where researchers have found that patients are afraid of losing their job and various other forms of discrimination.
The fifth component of stigma, according to Link and Phelan, is related to the imperative necessity of a relation of power in hierarchies of public culture (Goodenough, 1981). In saying this, it is necessary that the people who are stigmatizing others have a higher social or cultural status of power over those who are being stigmatized, and are able to enforce the stigma over those suffering from it. Tuberculosis is a disease of minorities, poverty, and the foreign-born. This situation of unequal power places the host “public culture” in a powered position against those affected.

**Summary**

Stigma exists according to the beliefs and values learned in a given cultural context. It develops in the minds of people as a process triggered by the linkages to stereotypes and the consequent behavioral response to persons likely to carry TB. The relationships between those who stigmatize and those who are stigmatized are reinforced by unequal power relations embedded in a hierarchy of public cultures.

The label “tuberculosis people” links negative characteristics such as poverty, poor hygiene, and other bad habits to people from a different country, usually a poor country with a different culture. This perception triggers behavioral responses that reject others and place social distance between “them” and “us,” and those who suffer the disease risk being rejected by friends and family, isolated from society and to have unequal opportunities in a powerless situation.

Although stigma in relationship to tuberculosis is not well understood and is not well described, the difficulty in controlling TB among foreign-born persons has been linked to stigma. Stigma in patients with tuberculosis has been frequently mentioned emphasizing cultural differences, according to the society in question (Castillo, 2001; Coreil et al., 2004; Hudelson, 1996; Jaramillo, 1999; Joseph et al., 2001; Macq et al., 2005; Menegoni, 1996; Poss, 1998).
Most of these studies relate stigma and TB with its effects on medical care and adherence to treatment. However, little has been done to study the effects of stigma on the outcomes of contact investigation. A study conducted on foreign-born TB patients’ perceptions of the contact investigation interview (Shrestha-Kuwahara et al., 2003), identified stigma as a chief factor affecting the contact investigation outcome. This study also identified the impact of language barriers, cultural insensitivity, and mistrust on the effectiveness of contact investigation. The elements mentioned above could be associated with the status of foreign-born status that is somehow tied to the label of “tuberculosis people.” Therefore, it is important to explore this relationship.

Figure 2-1. Contact investigation. Concentric circle approach. (CDC, 1999)
CHAPTER 3
METHODOLOGY

Introduction

The previous chapter reviews the literature on stigma, tuberculosis, tuberculosis contact investigation, and stigma in tuberculosis. This chapter aims to describe the procedures used in this study. The objectives and the description of the research design will be discussed at the beginning of the chapter followed by the research questions which guided the study. The selection of the community of study, the criteria for selecting the participants within the community, sample size and all instruments needed in this research will be described followed by a brief description of the process of the data collection. The chapter ends with a description of all the variables included in the study and the description of data analyses used.

This study does not attempt to explore the relationship between patients and doctors or any other relationship between patients and the health care providers. This study aims to understand the presence of stigma embedded in the society.

Research Design

Purpose

The purpose of this study was to determine if stigma related with TB and the immigrant experience affects the likelihood of identifying contacts during the tuberculosis contact investigation. The study focused on Mexican migrants living in central Florida.

This study is a nonexperimental research using a cross-sectional survey design. The study used mixed methods where quantitative data served as primary source of data. Qualitative data was used as secondary source to provide context and to better understand the community.

The surveys and interview guides were designed and conducted by the researcher. All instruments were developed originally in English and translated into Spanish for its application.
A panel of experts composed of faculty members from the University of Florida in the areas of Anthropology, Medical Anthropology, and Biomedicine reviewed the instruments used in this study. The protocol of this study was submitted to the Institutional Review Board of the University of Florida and approved prior to data collection. The surveys and interviews were conducted in Spanish.

The hypotheses are on the classical format to facilitate the definition of all variables in the statistical analysis conducted in this research, acknowledging all the limitations of statistical analyses in the understanding the processes of social stigma (Goffman, 1963; Link & Phelan, 2001). The following hypotheses are a simplification of stigma as a process; simplification is required for the purpose of measurement. For example, the hypotheses below do not address directly the foreign-born versus host culture process of stigma formation. The following hypotheses assume the existence of the perception of stigma.

Hypotheses

Hypothesis #1

$H_0$: “There is no association between the perceived level of stigma related to tuberculosis and the likelihood of identifying contacts during a TB contact investigation”

$H_a$: “The higher the perceived level of stigma related with TB the lower the likelihood of identifying contacts during a TB contact investigation”

Hypothesis #2

$H_0$: “There is no association between the immigrant experience and the likelihood of identifying contacts during a TB contact investigation”

$H_a$: “The higher the level of negative immigrant experience the lower the likelihood of identifying contacts during a TB contact investigation”
**Hypothesis #3**

H₀: “There is no association between the level of knowledge about TB and the likelihood of identifying contacts during a TB contact investigation”

Hₐ: “The lower the level of knowledge about TB the lower the likelihood of identifying contacts during a TB contact investigation”

Having been born in Mexico gave me the advantage of being a native Spanish speaker. The Spanish speaking ability and knowledge of Mexican culture facilitated access to the community. However, these advantages did not prevent me from some unanticipated challenges while carrying out this study.

My experience working in the Southeastern National Tuberculosis Center (SNCTC) for more than two years also brought some advantages that facilitated the selection of a research site. While working at the SNCTC, I learned the importance of tuberculosis in Florida, especially among the foreign-born. By 2006, Florida ranked according to rate in seventh place nationwide and 45% of its cases were among foreign-born and within them, 18% were from Mexico (CDC, 2007). In Florida, the four first counties ranked according to TB rate are, Dade County, Orange County, Duval County, and Hillsborough County occupying the 1ˢᵗ, 2ⁿᵈ, 3ʳᵈ, and 4ᵗʰ place, respectively (Bureau of TB and Refugee Health, 2007a).

Within these four counties, Hillsborough is the second with more TB cases among foreign-born, surpassed only by Miami Dade. (Bureau of TB and Refugee Health, 2007b, 2007c, 2007d, 2007e). In Hillsborough County in 2006, 46% of TB cases were in the foreign-born population.

I selected Hillsborough County for my study because it is one of the counties with more problems of TB among the foreign-born. In addition, the study required access to a small community mostly of Mexican-born people with long-term residency in the United States. In Hillsborough these types of communities are more prevalent compared to other parts of Florida.
To test my hypotheses I needed to develop constructs that allow me to measure the effect of the variables. Because this research did not use TB patients to test these hypotheses, I chose to measure the low contact identification during the TB contact investigation with the level of comfort participants have in responding to the questions health care providers usually ask during the contact investigation interview. The rationale for this decision was that TB patients during the contact investigation are asked several questions regarding their private lives in order to identify the patients’ network and to identify the likelihood of TB spread. However, the patients may feel uncomfortable answering these questions assuming perceived stigma is present. The level of comfort participants have regarding this questionnaire may affect the likelihood of TB patients answering questions about their private life, affecting in turn the level of information health care providers receive and the likelihood that healthcare providers would be able to identify those contacts that may be at risk.

Due to the fact that this research did not use TB patients to measure TB stigma, a scale of hypothetical questions regarding how a person would feel if they had TB was constructed. Therefore, this scale is intended to understand TB stigma as a perception in the general community, regardless of the presence or absence of TB disease. Measuring the perceived stigma in the general population and not in TB patients could provide valuable information regarding the perception of stigma present in the general community. This information may be valuable to understand the perception of stigma present in patients before they are confronted with the diagnosis of TB.

Regarding immigrant experience a few questions regarding their own experience of perceived discrimination against them because of their condition as migrants as well as attitudes and beliefs toward their own condition as immigrants were included in the survey instrument.
When the first five participants were surveyed, it was clear that Spanish-speaking ability was not enough. The educational level and the particular characteristics of the community made communication difficult. The Likert scales were particularly difficult for them to understand; it seems that they had some confusion with intervals in their responses.

After the pre-test of the survey questions, some modifications were made to the survey questions. New strategies were also designed to better administer questions based on the Likert scales. At this moment I realize that there were validity issues with the instrument, particularly in relationship to the use of the Likert scales. I stopped the data collection at that point and went back to review the instruments. I developed further strategies that helped me to better explain what was expected from the participants in response to these scales. I modified the language, rephrased the scale labels to use simple words like “more or less”, “a big no” or “a big yes” to differentiate between the levels of agreement or disagreement with the statements presented in the survey, “the big no or yes strategy.” Another aspect considered after this first survey day was that the level of literacy in this community required reading the survey to them.

Community

*Note: the name of the small town “the three siblings” and the church “Perpetuo Socorro” where the study took place are not the real names. To protect identities and maintain confidentiality, all names are fictitious.*

For the purpose of this research it was necessary to identify a community and culture composed of Mexicans in Hillsborough County, a county known to have high incidence of TB among Mexicans. A key informant assisted me in selecting the community. The Community selected is part of a church located in Hillsborough County in the state of Florida. The sampled population was participants in “Perpetuo Socorro” church activities, persons originally from Mexico, and persons older than 18 years. The study took place in two areas of this County, one
was in Ruskin, Florida and the other one was a small community located nearby that for this study will be identify as “the three siblings.” In Ruskin, Florida, the data collection took place in the local Community Health Center and in “the three siblings” the study took place in the “Perpetuo Socorro” Church.

Information regarding specific demographics about Mexican-born population is difficult to find due to the mobility of the population and other sensitive immigration issues that prevent accurate collection of demographic data. However, some information may be found that help to picture the community where this study took place. The 2000 Census reported a population of 998,948 for Hillsborough County, with 17.99% reporting a Hispanic or Latino race. The Census of 2000 reported for Ruskin, Florida a population of 8,321 with a 36.73% of residents reporting Hispanic or Latino race. “The three siblings” has a population of 3,095 with a 73% self reported Hispanic or Latino ethnicity. From the 73% of the Hispanics living in the area, 66% are originally from Mexico.

A Dissertation presented to the graduate school of the University of Florida (Unterberger, 2005) portray the poor living conditions, the strong ties in the community and the vivid Mexican culture in the area. In her paper she describes how the community develops to be a town mostly composes by Mexican. At the middle of the 20th Century, “The three siblings” population was about 50% African American. After a series of freezes that destroyed the harvests, the main way of living for the area, African American locals started to move out of the area looking for better opportunities. Meanwhile Mexican immigrants began to arrive and started to overtake the town. The population grew from 1979 to 1990 from 1500 to almost 3000 mostly due to Mexican immigrants (Maio, Mohlman, & Capanna, 1998). Unterberg also describe the festivals and other activities that resemble a small town in Mexico.
Sampling

A snowball strategy (Bernard, 2006) was used to identify the community and the persons who served as cultural brokers. Contacts from within the SNCTC assisted me in identifying the correct venues that guided me to the best community. Numerous calls and informal interviews with stakeholders took place until the appropriate community was found. Two weeks were spent selecting the most suitable community in the county and the best way to access it. After several attempts, I was directed to the Coordinator of Migrant Outreach at the Local Community Health Center in Ruskin, Florida, during the summer of 2007. Together we identified a community with the characteristics I needed and that the Coordinator also knew well. The community selected was a church-based community named “Perpetuo Socorro.” After this initial planning, a meeting with the coordinator at the church, where the study was going to be conducted, took place and arrangements were made to collect data during regular social church activities.

The coordinator of migrant outreach also introduced me to woman in charge of events in the Church, and together we planed how best to reach the larger community. From key informants I obtained qualitative information about tuberculosis and contact investigation. Two key informants were cultural brokers, bicultural persons with extensive knowledge about health care delivery in the community selected for this study. One informant was familiar with health care issues of Mexican-born persons but did not identify as a community member, and the other key informant was knowledgeable about health care issues and also identified as a member of the community selected.

The “Perpetuo Socorro” church has weekly organized events. Hispanic people participate and receive different types of information, guidance and education, and faith meetings. They also receive help with different aspects of administrative paperwork, such as for Medicaid and Medicare. During these activities participants also receive donation of food and other donations.
and free services. After participating in different activities with them, people started to feel comfortable with my presence. At that point I interviewed two community members regarding their personal opinion, feelings and fears about TB, other health issues, and their migration status. Attending Church activities gave me the opportunity to meet the people, and over time this interaction helped me to define the community.

For the quantitative part of this study, the sampling technique used was convenience sampling. Only persons participating in the church activities older than 18 years old were subject to the study, and the selection of the sample was only limited by the proximity of the subject in the moment the survey was being applied and their willingness to participate.

Sample Size

The sample size was calculated according to the needed ratio of cases to independent variables in multiple regressions. According to Tabachnick & Fidell (1989), this ratio has to be substantial for the study to have meaning. The authors state that “a bare minimum requirement is to have at least 5 times more cases than independent variables.” Participants were verbally invited to participate; the informed consent was read and signed before the application of the instrument. A total of 42 surveys were collected in a period of two weeks at the end of the summer 2007.

Instruments

The focus of this study was to determine whether the perception of stigma related to tuberculosis and the immigrant experience were possible causes of low contact identification during the tuberculosis contact investigation. The study used mixed methods where quantitative data served as the primary source of data. Qualitative data was used as the secondary source to provide context and to better understand the community. Quantitative data were collected with surveys and qualitative data with face-to-face interviews and informal conversations during
church activities and other social functions. Ethnographic interviews of key informants were also conducted.

**The survey:** The survey consisted of 53 questions divided in five sections: (a) general knowledge on TB, (b) stigma related to TB, (c) immigrant experience, (d) comfort during contact investigation interview, and (e) demographics.

The first section was designed to collect important information reflecting participants’ understanding on tuberculosis. This section contained 15 questions, labeled “TB Knowledge.” In this section participants were asked to determine whether the statement presented is true or false. To develop this section, different surveys and structured interview guides previously used by other researchers were modified (CDC, 1994-1995; Shrestha-Kuwahara & Joseph, 2002). The first three questions explored what the participants understood regarding the importance of TB and who is affected by TB. The following questions, four to fifteen, provided information regarding the participants understanding about TB’s transmission and treatment.

The second section of the survey was designed to collect data about stigma in relationship to tuberculosis. This section captured the participant’s perceptions of stigma using hypothetical questions. This section was named “TB stigma.” These questions were designed to use Likert scales to measure the level of agreement participants have with the statements presented to them. This section contained nine questions. To develop this section different surveys and structured interview guides previously used by other researchers were modified into Likert scale type questions (CDC, 1994-1995; Shrestha-Kuwahara & Joseph, 2002-2004).

The third section of the survey was designed to collect data about immigrant experience. This section explores participants’ perceptions on their particular experiences regarding migratory status in the United States. These questions were designed to function as Likert scales.
measuring the level of agreement participants have with the statement presented in the survey. This section had six questions, and it was developed based on other general stigma measurement instruments (King et al., 2007).

The fourth section of the survey focused on the participant’s level of comfort disclosing personal information to health care providers. This section was designed to measure the participant’s level of comfort using a Likert scale where participants were asked to hypothetically express their level of comfort providing personal information to healthcare professionals. This section had 12 questions and it was designed using general information, guidelines, and instructions to conduct a tuberculosis contact investigation interview (CDC, 1999, 2005a; Wolman, Bhavaraju, Napolitano, & Kantor, n.d.).

The fifth section of the survey collected demographic data from participants. Ten questions were included here, regarding age, gender, socioeconomic status, education, acculturation, immigration status, and household characteristics.

**The interview:** Two different interview guides were used in this study. One was designed to collect data from cultural brokers and the second was designed to collect data from community members.

**Cultural brokers:** An ethnographic interview was used to establish the key informants’ beliefs and knowledge about TB, and insights on their perceptions regarding the community’s health care concerns and barriers to migrants. This interview also included an activity where the interviewer pretended to be an immigrant asking for help and guidance regarding health issues and the interviewee played the role of a guide for the community. Cultural brokers (CB): The term cultural broker is used to refer to those people that serve as links between the mainstream culture and the subcultures (Gentemann & Whitehead, 1983). These people are at some degree
acculturated in both cultures, facilitating human communication and interaction among persons from both cultures. CBs were included to facilitate the interaction between the researcher and the community and to corroborate the validity of the instruments.

**Community members:** using informal interviews, community members were asked questions regarding TB and the importance of TB contact investigation. They were allowed to talk freely about these, and other, topics they recognized as important in relation to health and health services, as well as their migrant status.

**Data Collection**

**The survey:** Data collection took place during the summer of 2007 in the “Perpetuo Socorro” church, during the church community organized activities. All data collection was conducted in Spanish. Community members were informed by their leader about my presence in the church, my intentions there, and verbally invited the community to participate in the research. After this announcement to all community members, I personally approached each potential participant to explain in detail the purpose of my visit. Then, I invited them again to participate in the survey. The informed consent was read to those who chose to participate, and they were asked to sign it before starting the survey. I read the questions to all participants, and used the strategies previously planned to better explain the Likert scales and to give participants a consistent idea of the meaning of their level of agreement and comfort to these scales, “the big yes or no strategy.”

**The interviews:** Participants were invited to participate in the research and they read and signed the informed consent. The interviews were audio recorded to facilitate the analysis of the information obtained.
The interviews collected with the cultural brokers took place one in the church and a second interview took place in the Local Community Health Center at Ruskin, Fl. Cultural brokers were recognized by community members as persons with the tools necessary to better navigate the health system. The interview guide was followed but informants were allowed to expand upon any of their comments.

The interviews collected with the community members took place in the church. Community members were individually interviewed in nonformal settings.

Data Analysis

The data obtained from the 42 surveys were analyzed using SPSS. Descriptive statistic analysis, cross tabulations, and simple linear regression analysis were the procedures used to analyze the survey data.

Some sections of survey are designed as Likert scales, Likert scales are often used to gather information in different disciplines related to attitudes, beliefs, emotions, and values to access constructs that are not directly measurable (Babbie, 2004; Selltiz, Wrightsman, & Cook, 1976). Although, Likert scales are ordinal scales, they can be used to construct indexes to be use in statistical analysis. Likert scales are normally used as interval scales in social sciences. To follow this practice, it is required the use of a scale with at least 5 points, because scales with fewer than 5 points violate assumptions of normality (Garson, 1998). Discussing the effects of departure form intervalness on parametric statistics, Jaccard and Wan (1996, p.4) state that “For many statistical tests, rather severe departures do not seem to affect Type I and Type II errors dramatically.”

Variables

The survey used in the study included five sections, each one related to the variables of interest. All questions were pre-coded and participants chose the best response to the questions.
The sections regarding TB stigma, immigrant experience and the level of comfort during the contact investigation interview were designed as likert scales. The section of TB knowledge involved yes or no questions, and demographics section provided options from which to choose the most appropriate response.

**Demographic variables**

**Socio-economic status (SES):** To assess the socio-economic status, the survey included a question with a pre-coded respond with three options to chose from, - Low, medium or high SES.

**Gender:** The survey included a question asking the gender of the participants-responses were pre-coded as Female or Male.

**Education:** A question was included in the survey for participants to self report their highest level of school completed. Pre-coded responses included: Elementary school, Middle school, High school, and University. There was included a “No Applicable” response for those who have not completed any education.

**Age:** The survey included a pre-coded question with four different options for age group. Participants were asked to choose between these age groups: 18-30, 31-40, 41-50, and more that 50 years old.

**Acculturation:** To assess acculturation three survey items were included. Length of residency in the United States with four pre-coded responses options: less than 1 year, between 1 and 5 years, between 5 to 10 years and more than 10 years. Self reported English proficiency and time spent with people from their own Country completed the acculturation section.

**Migration status:** One survey item was included with a specific question regarding their migration status. Because of the sensitivity of this question the answers were only reported as documented or undocumented migration status.
**Household:** The survey included two items regarding the household composition. One was about their marital status and the second was about the current household composition specifically currently, with whom they live.

**Reliability**

With the intent to quantify constructs that are not directly measurable I developed a multiple-item Likert scale. When using Likert-type scales it is imperative to calculate and report Cronbach’s alpha coefficient for internal consistency reliability (Gliem & Gliem, 2003). Cronbach’s alpha is a test of reliability technique that provides a unique estimate of the reliability for a given test, and provides a number between 0 and 1. The closer Cronbach’s alpha coefficient is to 1.0 the greater the internal consistency of the items in the scale. George & Mallery suggest a rule of thumb on how to interpret this number as follows “_ > .9 should be considered Excellent > .8 – Good, _ > .7 – Acceptable, _ > .6 – Questionable, _ > .5 – Poor and _ < .5 – Unacceptable” (as cited in Gliem & Gliem, 2003, p. 87). The reliability of each construct in the study is shown in table 3.1.

From the set of nine questions on the section of TB stigma, three questions were used for the TB stigma construct. The Cronbach’s Alpha coefficient obtained was .862. This construct has a good reliability according to the rule of thumb to interpret Cronbach’s Alpha coefficient. This construct was called TB Stigma Index.

From the set of six questions in the section about immigrant experience, four questions were used for the MG construct. The Cronbach’s Alpha coefficient obtained was .762. This construct has an acceptable reliability Cronbach’s Alpha coefficient according to the rule of thumb. This construct was called MG Index.
For the 12 questions of the section in contact investigation comfort, the Cronbach’s Alpha coefficient obtained was .935. This construct has an excellent reliability Cronbach’s Alpha coefficient according to the rule of thumb. This construct was called CIC Index.

**Contact investigation comfort (dependent variable) CIC index**

To construct this index, an average of all twelve values was obtained to make one total value for the CIC Index. The maximum value for this index is five and the minimum value is one; were five corresponds to very comfortable and one to very uncomfortable.

**Perception of stigma related with tuberculosis (independent variable) TB stigma index**

To construct the index only three items from the section were used; an average of all three values was obtained to make one total value for the TB stigma Index. The maximum value for this index is five and the minimum value is one; were five corresponds to high levels of perception of stigma and one to the lowest.

**Immigrant experience (independent variable) MG index**

Only four items were included in the construct. To construct the MG Index, an average of all four values was obtained to make one total value for the MG Index. The maximum value for this index is five and the minimum value is one; were five corresponds to high levels and one to the lowest.

**General knowledge about tuberculosis (independent variable) TB knowledge index**

The first section provided information regarding the overall TB knowledge the participants have. This section contains 15 questions long “yes or no “answers. Each correct answer received a value of one and zero for wrong answers. To construct the TB Knowledge Index, all the values obtained were totaled to make one single value. The maximum value with all correct answers is 15; the minimum value with all incorrect answers is zero.
Table 3-1. Cronbach’s Alpha Coefficients.

<table>
<thead>
<tr>
<th>Construct</th>
<th>Cronbach's Alpha</th>
<th>N of Items</th>
</tr>
</thead>
<tbody>
<tr>
<td>TB stigma</td>
<td>.862</td>
<td>3</td>
</tr>
<tr>
<td>MG</td>
<td>.762</td>
<td>4</td>
</tr>
<tr>
<td>CI</td>
<td>.935</td>
<td>12</td>
</tr>
</tbody>
</table>

Figure 3-1. Map of Hillsborough County (University of South Florida, 2001): The red box shows the area the study took place.
Overview of the Chapter

In the previous chapter the research design and methods of the study, including the variables, the instruments, data collection techniques, and analyses, were described. In this chapter the results of the study are reviewed. The first step in this chapter is to describe demographic findings of this research. Specifics regarding each of the items included regarding demographic data will be describe according to the results obtained using descriptive statistic analysis with SPSS. After reviewing the demographics of the community this chapter continue with the description of the dependent and independent variables used. The first part included a description of the items included in the survey, followed by a description of the constructs used in the analysis. The third part of the chapter refers to the statistical analysis used to test the hypothesis. A brief summary of the major findings from the interviews is described at the end of this chapter.

Community Demographics

The sample consisted of 42 members of the “Perpetuo Socorro” church that participated in the activities organized by the church during August 2007. From all church members invited to participate in my study, only 3 of them chose not to do it. Table 4.1 summarizes the demographics of the participants.

The church members that chose to participate in the study were predominantly female (62%). It is important to note that the members that chose not to participate were in the 2 females and 1 male. The sample only included community members older than 18 years old. In general the sample was composed mostly from young adults, 46% of all participants were “between the age of 18 and 30 years old,” and 76% of all participants reported belonging to an
age group younger than 40 years; 17% of the participants were older than 50 years old. Participants were asked to identify their socio-economic status (SES) (high, middle, or low); 69% of the participants responded to have a low SES and 31% to have a middle SES.

Regarding education, the survey asked participants to place themselves in the category to which they belong according to the level of school they have completed. People that did not complete any school level were placed in the N/A category (7.1%). 42.9% of all participant responded that they had completed elementary school, 28% completed middle school, 14% high school, and 3 participants (7.1%) responded that they had some university education (Table 4.1).

To profile the acculturation among community members, two questions were included in the survey regarding the number of years each respondent has been in the United States, and their English proficiency. Almost half of the participants (48%) reported having 10 years or more of residency in the United States residency, 19% a have lived here between 5 and 10 years, 24% between 1 and 5 years, and 10% less than a year (fig 4.1). Regarding English proficiency, 26% of the participants do not to speak English at all, 57% speak a little English, and 10% speak some English. Only 7% of all participants said they are proficient speaking English (Fig 4.2).

To better understand the community, a question regarding the amount of time they spend with other people from their country of origin, and a question regarding immigration status were included in the survey. Participants responded that they are more likely to spend time people from their home country; 23.8% of all participants responded they spend all the time, 47.6% responded to spend most of the time, 26.2% responded that some time, and only 2.4% responded that they never spend time with people from their own country (Fig 4.3). For the question about whether they have a VISA or not to be in the United States, 42% of the participants do have a VISA and 62% of all participants do not (Fig 4.4).
Participants were asked about the composition of their households. 83.3% of all participants live with their family, 4.8% live with friends, 7.1% live with coworkers, and 4.8% live alone. 47.6% were married, 28.6 % single, 4.8% divorced, and 9.5% widowed; the remaining participants placed themselves in the category of other.

**Descriptive Statistics**

Participants were asked to respond to questions regarding the importance of the tuberculosis. Table 4-2 shows the results of these questions

61.9% of participants responded that they totally agree that TB would be as important as any other of their problems and 21.4% responded that they agreed with this statement. 83.3% either agreed or totally agreed with this statement. However, when asked if this problem is important for people coming to the United States, 42.9% totally agreed and 2.4% agreed, and the sum of this percentage do not represent the majority (45.3%).

Participants were asked to respond to questions about tuberculosis as a disease, whether TB affects only poor people and do they think tuberculosis is a disease of the past. 78.6% answered that they do not think Tb only affects poor people, and 71.4% did not think TB affected people in the past (table 4.3).

Knowledge about TB: The survey asked participants about their knowledge of TB to understand how much they know about TB. Table 4-4 is the percentage of people that answer correctly regarding different topics about TB.

The majority of respondents knew the correct responses. With respect to TB transmission, if people were presented with a true statement, then they were more likely to respond correctly; if they were presented with incorrect statements, then their responses where less accurate. 73.2% of participants knew that TB is spread through the air and 90% knew that it is transmitted person to person. With respect to prevention and treatment, people knew that TB can be prevented.
(83.3%) that TB have an available treatment (78.6%) and that is necessary to take a treatment to get better (93% in average)

**Perceived TB stigma:** These questions may reflect stigma as perceived by members of this community. Hypothetical questions were asked regarding how participants would feel if they had TB. More than 60% of all participants were more inclined to totally agree with the statement that they would feel badly about themselves if they have TB (fig 4-5). However, in general, more than 80% of participants responded “totally agree” or “agree” that they would tell others their TB condition. No considerable difference is observable regarding to whom they would disclose their TB status (fig 4.6)

Table 4-5 shows the results of the survey section on immigrant experience. Number of responses, the possible values and the mean and standard deviations, are reported. In general, participants are not afraid to go to a clinic due to their migration status. Also, participants have not experience discrimination in healthcare settings or discriminated by employers. However, in questions regarding their feelings, the averages are slightly higher compared to the questions regarding their own experience with discrimination. The highest average corresponds to their perception that opportunities are lacking.

Regarding the level of comfort, participants were asked to respond to the level of comfort they would feel in the presence of a health care worker if they were asked personal questions about their private lives. Table 4-6 shows the means and the standard deviation of each of the 12 questions. The maximum value is 5, this corresponds to the highest level of comfort, and 1 refers to the lowest. The means of all questions are higher than 3, reflecting that most participants feel comfortable. However, some slight differences are observable. Participants are
less comfortable responding to questions about their sexual partners and about the places where they spend the night, followed by income and guests in the home.

**CIC index:** The histogram in Figure 4-7 shows the frequency distribution for each one of the possible values of Contact Investigation Comfort index). 42 cases were included. The mean of the sample was 3.60 with a standard deviation of .76. We can observe also that the distribution is close to normal. It is interesting to note that almost 60% of the respondents are located above 3.5 in this CIC and 100% is above 2. These results could reflect higher levels of comfort different from what it was expected to find in this population.

**Perceived TB stigma index:** A perceived stigma related to TB index was created with the mean of the values from 3 questions. This index was called TB stigma. The chart in Figure 4-9 shows two categories for stigma (Low and High). 42 cases were included. The mean of the sample was 1.62 with a standard deviation of 1.06. It is interesting to note that the majority of the respondents are located below 2.5 in this index suggesting that the perceived level of stigma related to TB in this specific community was lower than expected.

**Immigrant experience index:** An index was created with the average of 4 items from the questions regarding migration experience. This index was called MG. The chart in Figure 4-8 shows two categories for MG (Low and High) values of MG index. 42 cases were included. The mean of the sample was 2.01 with a standard deviation of 1.08. It is interesting to note that the majority of the respondents are located below 2.5 in this index suggesting that the negative immigrant experience in this specific community was lower than expected.
**TB knowledge index:** An index was created with the sum of the 15 questions regarding TB knowledge. This index was called TB Knowledge. The histogram in Figure 4-10 shows the frequency distribution for each one of the possible values of TB Knowledge index. 42 cases were included. The mean of the sample was 11.18 with a standard deviation of 2.043. We can observe also that the distribution is proximal to normal distributed.

### Linear Regression

Although this study is a nonexperimental research and its sample is not a simple random sample, the data obtained with the survey was analyzed with linear regression.

Perceived TB stigma index was regressed on the “the likelihood of TB of been equal to any other problem” and the results are shown on Table 4-7. The results indicate the more different in importance related with all their problems participant think TB is, the more perceived stigma related to TB they would have (B .440 and R-squared.241). The results are statistically significant (p-value 0.001).

To test the null hypothesis #1 “There is no association between the perceive level of stigma related to tuberculosis and the likelihood of identifying contacts during a TB contact investigation”, CI Comfort Index was regresses by the independent variables perceived TB stigma using SPSS. Table 4-8 shows the results. 42 cases were included. Results show a very weak negative relationship represented by a B coefficient of -.095 and a R squared of .018, with a p-value .399.

To test the null hypothesis #2 “There is no association between the immigrant experience and the likelihood of identifying contacts during a TB contact investigation”, CI Comfort Index was regresses by the independent variables related to immigrant experience using SPSS. The results are on Table 4-8. 42 cases were included. Results show a very weak negative relationship
(B coefficient -.048 and R squared of .005). The result of this analysis were not statistically significant (p-value .668)

To test the null hypothesis #3 “There is no association between the level of knowledge about TB and the likelihood of identifying contacts during a TB contact Investigation”, CI Comfort Index was regresses by the independent variables TB knowledge using SPSS. The results are on Table 4-8. 42 cases were included. Results show a weak positive relationship (B coefficient .078 and R squared of .209). Results were not statistically significant (p-value .184).

Although the results show the expected relationship to reject the null hypothesis, none of the results shows strong evidence to conclude that these relationships are not due to chance.

**Qualitative Results**

**Cultural brokers (CB):** The term cultural broker is used to refer to those people that serve as links between the mainstream culture and the subcultures (Gentemann & Whitehead, 1983). This people are at some degree acculturated in both cultures, facilitating human communication and interaction among persons from both cultures. In this study, CBs were included to facilitate the interaction between the researcher and the community as well as to serve as a proof to the instruments.

Two kind of CB were included: A CB that identify itself as a community member and a CB that does not identify itself as a community member. The cultural broker who identifies himself as a community member stated that he did not have knowledge about TB other than he has been tested and was negative. He also considered that in this community TB was not something people talk about or even think about: “In the community you never hear about TB.” The participant and cultural broker who did not identify himself as a community member had general knowledge about TB but he stated also that TB is not a problem in the community: “I do not think that TB is something that is in their minds, unless someone close to them has it.”
This cultural broker did not think TB was prevalent in the community: “TB is contagious; I imagine that if someone has TB we would all know it.” Both cultural brokers think that migrants in the community share information regarding health services as well as other services where they can receive health care. “La comunicacion entre ellos es tremenda” (Communication among them is huge). “If someone has a problem, their friends or neighbors will provide with guidance to where they can go.”

The CB who identifies himself as a community member states that he feels that people in the area are very sensitive to the migrants. “They feel OK when they approach to any agency to receive help. The people who provide services to them are very caring with the migrants. They feel welcome.” Also, the sharing of information among community members provides them with a sense of security regarding immigration issues. “They know how migration agencies work. The MIGRA is not looking for them in health care facilities”, however, the CB that do not identify himself as a community member said that “even if they kind of know, they will want to make sure that they are safe.”

I asked the CB about the barriers that this community experiences in health care facilities. But this concern, according to the CB, is the least of this community’s problems. Instead, their major concerns involve money, transportation, language barriers. They will place their health in a less important level compared to these other needs: “They need to survive, and do what they are here to do, work and get money. Their health is less important. Unless their health status unable them to work, they will not look for help, they need to work” “if they have TB I am positive that they will receive health services until it is very advance.”

“At the Church, they all fell safe. They know that we have contact with several agencies where that can receive help. If someone has a problem, they know we will help them and that we
will refer them to this other agencies to receive what they need.” “Among them, they spread the word; they are very communicative with the new ones. They share the information they have with others.”

According to these findings, it seems to me that the community is not concerned about TB, even if they do think sometimes about TB; they have more important things to be worry about placing any health related issues to less important levels. Also, the community is very supportive. They are taking care of themselves sharing all the information they have to facilitate anything among them.

**Community members:** Community members agree that they will not withhold valuable information from health care professionals because they fell responsible for the health of others. One of them had received LTBI treatment and stated: “I did not have any bad feeling against the person who made me infected, on the contrary, I kind of are grateful that this person protected my health” “I do not think people should reject the ones that have TB and say their names to health care professionals,. They are protecting their health.”

The other participants had never had contact with TB but his stamens were similar to the previous one” If I have TB I will make sure that health care professionals know who my contacts are, I don’t care if they fell upset, with time they will understand but I will not feel OK if I put someone at risk.”

According to these qualitative findings, it seems for me that the community is very loyal and that they will care more about the well being of their own community than anything else. The community recognized that they may be subjects to rejection but they are not afraid of it because they are positive that people with time will understand and the satisfaction of doing the right thing to protect them is more valuable.
Table 4-1. Demographics

<table>
<thead>
<tr>
<th>Demographics</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>38</td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
</tr>
<tr>
<td>18 to 30</td>
<td>45.2</td>
</tr>
<tr>
<td>30 to 40</td>
<td>31</td>
</tr>
<tr>
<td>40 to 50</td>
<td>7.1</td>
</tr>
<tr>
<td>More than 50</td>
<td>16.7</td>
</tr>
<tr>
<td><strong>SES</strong></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td>69</td>
</tr>
<tr>
<td>Middle</td>
<td>31</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>N/A</td>
<td>7.1</td>
</tr>
<tr>
<td>Elementary</td>
<td>42.9</td>
</tr>
<tr>
<td>Middle school</td>
<td>28.6</td>
</tr>
<tr>
<td>High school</td>
<td>14.3</td>
</tr>
<tr>
<td>University</td>
<td>7.1</td>
</tr>
</tbody>
</table>

Table 4-2. The importance of tuberculosis to participants

<table>
<thead>
<tr>
<th>TB would be a problem as important as any other of my problems</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally agree</td>
<td>61.9</td>
</tr>
<tr>
<td>Agree</td>
<td>21.4</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>2.4</td>
</tr>
<tr>
<td>Disagree</td>
<td>9.5</td>
</tr>
<tr>
<td>Totally disagree</td>
<td>4.8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>TB is a big problem for people coming to the USA</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Totally agree</td>
<td>42.9</td>
</tr>
<tr>
<td>Agree</td>
<td>2.4</td>
</tr>
<tr>
<td>Neither agree nor disagree</td>
<td>16.7</td>
</tr>
<tr>
<td>Disagree</td>
<td>14.3</td>
</tr>
<tr>
<td>Totally disagree</td>
<td>23.8</td>
</tr>
</tbody>
</table>
Table 4-3. The relationship of tuberculosis to stereotypes

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>YES</th>
<th>NO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Only affect poor people</td>
<td>42</td>
<td>21.4</td>
<td>78.6</td>
</tr>
<tr>
<td>Only affected people in the past</td>
<td>42</td>
<td>28.6</td>
<td>71.4</td>
</tr>
</tbody>
</table>

Table 4-4. Tuberculosis knowledge in the community

<table>
<thead>
<tr>
<th>TB transmission</th>
<th>n</th>
<th>Correct</th>
<th>Incorrect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Through the air</td>
<td>41</td>
<td>73.2</td>
<td>26.8</td>
</tr>
<tr>
<td>With food and water</td>
<td>42</td>
<td>40.5</td>
<td>59.5</td>
</tr>
<tr>
<td>Sexual relations</td>
<td>42</td>
<td>42.9</td>
<td>57.1</td>
</tr>
<tr>
<td>Congenital</td>
<td>41</td>
<td>46.3</td>
<td>53.7</td>
</tr>
<tr>
<td>Bug bites</td>
<td>41</td>
<td>53.7</td>
<td>46.3</td>
</tr>
<tr>
<td>Person to person</td>
<td>42</td>
<td>90.5</td>
<td>9.5</td>
</tr>
</tbody>
</table>

Cure and prevention

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Correct</th>
<th>Incorrect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Can be prevented</td>
<td>42</td>
<td>83.3</td>
<td>16.7</td>
</tr>
<tr>
<td>Have treatment available</td>
<td>42</td>
<td>78.6</td>
<td>21.4</td>
</tr>
<tr>
<td>Need treatment to get better</td>
<td>42</td>
<td>93</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 4-5. Immigration experience

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Totally disagree</th>
<th>Totally agree</th>
<th>Mean</th>
<th>Std. Dev</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feel afraid to go to the clinic</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>1.62</td>
<td>1.306</td>
</tr>
<tr>
<td>Had been discriminated by healthcare workers</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>1.76</td>
<td>1.246</td>
</tr>
<tr>
<td>Had been discriminated by employer</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>1.95</td>
<td>1.361</td>
</tr>
<tr>
<td>I feel alone</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>2.10</td>
<td>1.527</td>
</tr>
<tr>
<td>I would have better opportunities if I was a non migrant</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>3.74</td>
<td>1.531</td>
</tr>
<tr>
<td>People had made me feel ashamed of my self</td>
<td>42</td>
<td>1</td>
<td>5</td>
<td>2.24</td>
<td>1.511</td>
</tr>
</tbody>
</table>
Table 4-6. Level of comfort in the contact investigation interview.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>42</td>
<td>3.57</td>
<td>1.129</td>
</tr>
<tr>
<td>People I live with</td>
<td>42</td>
<td>3.79</td>
<td>.842</td>
</tr>
<tr>
<td>Income</td>
<td>42</td>
<td>3.50</td>
<td>1.065</td>
</tr>
<tr>
<td>Work place</td>
<td>40</td>
<td>3.73</td>
<td>1.012</td>
</tr>
<tr>
<td>Occupation</td>
<td>40</td>
<td>3.73</td>
<td>1.012</td>
</tr>
<tr>
<td>Transportation</td>
<td>42</td>
<td>3.88</td>
<td>.739</td>
</tr>
<tr>
<td>Where do you spend leisure time</td>
<td>42</td>
<td>3.62</td>
<td>1.168</td>
</tr>
<tr>
<td>With ho do you spend leisure time</td>
<td>42</td>
<td>3.57</td>
<td>1.016</td>
</tr>
<tr>
<td>friends</td>
<td>42</td>
<td>3.74</td>
<td>.939</td>
</tr>
<tr>
<td>Sexual partners</td>
<td>40</td>
<td>3.23</td>
<td>1.143</td>
</tr>
<tr>
<td>Guest at home</td>
<td>42</td>
<td>3.52</td>
<td>.890</td>
</tr>
<tr>
<td>Places where they spend the night</td>
<td>42</td>
<td>3.38</td>
<td>.987</td>
</tr>
</tbody>
</table>

Table 4-7. Stigma related with TB regressed on the likelihood of TB of been equal to any other problem.

<table>
<thead>
<tr>
<th>The level of stigma related with TB regressed on the importance attributed to tuberculosis.</th>
<th>N</th>
<th>B</th>
<th>R</th>
<th>R-square</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>TB would be a problem as important as any other of my problems</td>
<td>42</td>
<td>.440</td>
<td>.491</td>
<td>.241</td>
<td>.001</td>
</tr>
</tbody>
</table>

Table 4-8. Level of comfort during contact investigation regressed on the level of stigma related with TB, the level of stigma related with the migration experience and the level of knowledge about TB.

<table>
<thead>
<tr>
<th>Level of Comfort during contact Investigation regressed on the level of stigma related with TB, the level of stigma related with the migration experience and the level of knowledge about TB.</th>
<th>N</th>
<th>B</th>
<th>R</th>
<th>R-square</th>
<th>Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>TB stigma</td>
<td>42</td>
<td>-.095</td>
<td>.134</td>
<td>.018</td>
<td>.399</td>
</tr>
<tr>
<td>MG experience</td>
<td>42</td>
<td>-.048</td>
<td>.068</td>
<td>.005</td>
<td>.668</td>
</tr>
<tr>
<td>TB Knowledge</td>
<td>42</td>
<td>.078</td>
<td>.209</td>
<td>.044</td>
<td>.184</td>
</tr>
</tbody>
</table>
Figure 4-1. Years of United States residency

Figure 4-2. English proficiency
Figure 4-3. Time spent with other people from county of origin.

Figure 4-4. Visa status
Figure 4-5. Tuberculosis and perceived stigma. (If I have TB it will make me feel bad about myself)

Figure 4-6. Likelihood of disclosing tuberculosis status. (If I have TB I would tell to my friends, the people I live with, my coworkers?)
Figure 4-7. Distribution of frequencies across CI comfort index values.

Figure 4-8. Perceived negative migration experience.
Figure 4-9. Perceived TB stigma.

Figure 4-10. Distribution of frequencies across TB knowledge index values
CHAPTER 5
DISCUSSIONS AND CONCLUSIONS

The previous chapters reviewed the literature regarding tuberculosis, TB contact investigation and stigma. The methodology used in this study was described and the results were presented. Chapter five starts with a synopsis of each stage of the study, followed by the discussion of results and conclusions drawn from them. The chapter ends with the implications concerning this study and the recommendations for future research.

Introduction

Generally speaking, tuberculosis control programs in the United States have successfully achieved their goals; however, the slow decrease of TB incidence among foreign-born population has prevented tuberculosis control programs to achieve their ultimate goal of “TB elimination.” The success of these programs depends on the development of interventions to reach this population. The development of these interventions relies on the knowledge that researches could gain referent to specific cultural characteristics as well as specific implications of these characteristics for TB control for the specific culture.

Stigma related with tuberculosis is one of this culture characteristics mentioned in the literature but in need of more research.

Statement of the Problem

The foreign-born population in the United States has maintained, as a group, almost the same incidence rate of tuberculosis (TB) during the past decades. Meanwhile, all other groups within the United States have successfully contributed to an overall decrease in these rates (CDC, 2007). The fact that this group is not responding in the same way than others are, suggests that this population may not be appropriately reached by current approaches for tuberculosis control programs.
Florida is among the top ten states with highest incidence rates of TB. Within Florida, Hillsborough ranks among the top four counties in highest rates of TB. Inside these four counties, Hillsborough has the second highest percentage of foreign-born TB incidence (Bureau of TB and Refugee Health, 2007). Unpublished data from the Bureau of Tuberculosis and Refugee Health of the Florida Department of Health, suggest that in Florida Mexicans tend to identify fewer contacts during TB contact investigation than the average patient. Contact investigation is an inquiry in the patient’s network with the purpose to identify those that could be infected due to proximity with the active TB case. The poor identification of contacts is a characteristic that deserves to be explored as it may be one factor contributing to the slow decline in TB incidence among this population. A low detection of contacts is likely to reduce the effectiveness of programs aimed to reduce TB incidence rates. Failing to detect these cases in a timely manner may allow the infection to develop into active TB disease promoting further TB spread. However, little is known about the factors that might influence contact investigation and even less is known about TB contact investigation among Mexican-born populations in the United States.

It is needed to determine if stigma is a possible cause in low contact identification during contact investigation. The purpose of this study was to determine if stigma related with TB and immigrant experience affect the likelihood of identifying contacts during tuberculosis contact investigation in a small Mexican-born community in Hillsborough County in Florida. To investigate this, three hypotheses were included in this study

**Hypothesis #1:** \( H_0: \) “The higher the perceived level of stigma related with TB the lower the likelihood of identifying contacts during a TB contact investigation”
Hypothesis #2: H$_{a}$: “The higher the level of negative immigrant experience the lower the likelihood of identifying contacts during a TB contact investigation”

Hypothesis #3: H$_{a}$: “The lower the level of knowledge about TB the lower the likelihood of identifying contacts during a TB contact investigation”

**Review of the Methodology**

This is a cross-sectional nonexperimental research. Mixed methods were used throughout the study; quantitative and qualitative data were treated as primary and secondary sources of data, respectively. Qualitative data were used by the researcher to better understand the community during the stage of interpretation of results, and to provide context where it was required during the discussion of the results.

The community selected for the study was a small church-based community from Hillsborough County in Florida. The snowball sampling strategy (Bernard, 2006) was used to identify the community and the persons who served as cultural brokers. Quantitative data were collected through structured questionnaires. Qualitative data were collected through face to face interviews and informal conversations during church activities and other social functions; ethnographic interviews of key informants were also conducted. The surveys and interviews guides were designed and conducted by the researcher. All instruments were developed originally in English and translated into Spanish for its use. A panel of experts integrated by faculty members of the University of Florida in the areas of Anthropology, Medical Anthropology, and Biomedicine reviewed all data collection instruments. The protocol of this study was submitted to the Institutional Review Board of the University of Florida and approved prior to data collection. All activities related to collection of data took place in Spanish.

The questionnaire contained 53 items distributed in five sections: (a) general knowledge on TB, (b) stigma related to TB, (c) immigrant experience, (d) comfort during contact investigation
interview, and (e) demographics. Many of the questions in each section were adapted from similar studies, and are consistent with the instruments commonly used to investigate stigma associated with TB, (Robin Shrestha-Kuwahara & Joseph, 2002), and contact investigation interview (CDC, 1999, 2005a; Wolman et al., n.d.). Some other questions were developed by the researcher based on theory.

A total of 42 participants were surveyed. The data obtained from these 42 questionnaires were analyzed using SPSS. Descriptive statistics and simple linear regression were the procedures used to analyze the data. Four indexes were created, one for the dependent variable (CIC index), and three for independent variables (TB stigma index, TB Knowledge Index, and MG index). CIC measures comfort during contact investigation interview, TB stigma measures the perceived stigma related to TB, TB Knowledge measures the level of knowledge about TB, and MG measures the negative immigrant experience. The reliability and validity of each index was tested using Cronbach’s Alpha.

**Interpretation of Results**

In this study, conducted in Hillsborough County in the state of Florida, the participants were mostly young adult females, with low levels of education and low socioeconomic status as compared to the general US population, all members of the “Perpetuo Socorro” Church. Although most participants reported having long time (more than 5 years) of residence in the United States, they show low English proficiency and limited interaction with people other than from their own country. The majority of participants do not have a legal immigration status.

In the CIC Index, almost 60% of the respondents were located above 3.5, where 5 corresponded to the highest level of comfort when being asked by health care professional questions about their personal lives. In the TB stigma Index, the majority of the respondents (80%) were located below 2.5, where five was the maximum value corresponding to the higher
perception of stigma related to TB. In the TB Knowledge Index, the mean of the sample was 11.18 with a standard deviation of 2.04. The maximum value was 15 for the highest level of knowledge about TB, suggesting that the TB knowledge in this specific community was higher than expected. Finally, in the MG Index, the majority of the respondents are located below 3, where five correspond to the worst immigration experience suggesting that the negative immigrant experience in this specific community was lower than expected.

To test the three hypotheses, the indexes for TB stigma, migration experience, and TB knowledge were treated as independent variables for the Hypotheses 1, 2, and 3, respectively. These indexes were individually regressed against the dependent variable represented by the CIC index.

For Hypothesis 1, linear regression analysis showed a very weak negative relationship (R-square .018; B -.095); this result was also not significant (p-value=.399). Therefore, it is not possible to conclude that the higher the level of perceived stigma related with TB the lower the level of comfort as previously suspected. For Hypothesis 2, linear regression analysis showed also a very weak negative relationship (R-square .005; B -.048); this result was also not significant (p-value .668). Therefore, it is not possible to conclude that the higher the level perceived negative immigrant experience the lower the level of comfort as previously suspected. Finally, for Hypothesis 3, linear regression analysis showed a very weak positive relationship (R-square .044; B .078); this result was also not significant (p-value .184). Therefore, it is not possible to conclude that the lower the level of knowledge about TB the lower the likelihood of identifying contacts during a TB contact Investigation as previously suspected.

The results show that in all three cases, the relationship represented by the slope (B) corresponds to the expected findings based on literature. It is possible to observe that the
perceived TB stigma is negatively affecting comfort during the contact investigation interview, which is consistent with previous research that suggested that as TB stigma increases, the level of comfort during the contact investigation interview diminishes (Shrestha-Kuwahara et al., 2003); however this study used qualitative methods only.

The non significant p-values of these results could be result of the small sample size used in the study. The relationships observed in these results may be stronger if a larger sample was used. Stigma may not be common enough to be detected in a small sample.

The fact that this is a church-based community may have also affected the results. This community receives information related to health, and other issues, through the church. This may promote an increased level of comfort in the interaction with health care professionals. The factor “Church Community” may be associated with the attenuation of stressors due to religion’s promotion of social support, a sense of belonging, and convivial fellowship (Levin, 1994). This increased sense of belonging and fellowship could enhance the willingness to protect their community against any threat, including health threat. One natural way of protecting their community would be to provide accurate and complete information to health staff in order to prevent further dissemination of a disease. Community is important, and people would sacrifice their own interests to protect it.

The literature suggests that stigma may influence the likelihood of identifying contacts, however, it is also mentioned that language barriers and cultural insensitivity play a role in the process (Shrestha-Kuwahara et al., 2003). It is possible that health care providers serving this community are specialized in the care of immigrant clients; therefore they are culturally sensitive and Spanish speakers. These characteristics may bring in turn trust, a factor identified as positively affecting the identification of contacts (Shrestha-Kuwahara et al., 2003).
When asked to respond whether they agreed or not to the statement that “If I had TB it would be as important as any other of my problems,” the majority of the participants either agreed or totally agreed. The participants did not seem to consider TB as something different that any other problem common in their lives.

It is important to consider that according to the literature (Link & Phelan, 2001), the society needs to identify a difference as important and give it a special category that elevates this difference to a category of label. The results to this question may suggest that participants in the study do not place tuberculosis in a special place and probably the label “tuberculosis people” do not apply to them. Also, linkage from the label “tuberculosis people” to negative stereotypes may be absent. These results could reflect that in their understandings and in their culture, TB does not have a special place in their lives or the difference named “tuberculosis people” is not as special as we imagined. For these participants, tuberculosis may not be different enough from having the flu, or another common disease, that it deserves a label, and most likely will not detonate the chain reaction to negative stereotypes and subsequent behavioral respond.

Also, when asked if they agreed or not with the statement that “TB is a disease of poor people” the majority answered that they did not agree, suggesting that there is not a perceived association between poverty and the label of “tuberculosis people.” These results suggest that even if a label were formulated, poverty, the most common stereotype mentioned in the literature linked to tuberculosis (Kelly, 1999; Macq et al., 2005), is more likely not to be present in this community, at this particular time and cultural context.

The fact that members of this community spend most of the time with people of their own country of origin reflects isolation from American culture. This factor could protect the
community from perceiving stigma in the way Americans do due to the lack of bicultural interaction.

When the TB stigma index was regressed against the answers to the question concerning the relative importance of TB in the lives of the participants, the result was consistent with what was anticipated. Those participants that perceived TB to be very different in importance compared to any other problem common in their lives also ranked higher on stigma related to TB. This finding is consistent with what the literature on stigma suggests regarding that the difference needs to be important enough to be raise to the category of a label (Goffman, 1963, Link & Phelan, 2001).

The qualitative findings suggest that in the community participants were more concerned about protecting their community than of the possibility of being isolated for being sick. According to these qualitative findings, it seems that the community is very loyal and that they will care more about the well being of their own community than anything else. The participants recognized that they may be subjected to rejection but they are not afraid of it because they are confident that over time people will understand, and they consider the satisfaction of doing the right thing to protect them more valuable. Also, from the cultural brokers’ answers was possible to understand that the community is not concerned about TB, even if they do think sometimes about TB, they have more important things to be worry about; this situation makes them to place any health related issues to less important levels. Also, the community is very supportive. They are taking care of themselves sharing all the information they have to facilitate anything among them.

**Conclusions**

From the results of this study it can be concluded that the members of the community have high level of knowledge on TB, have low level of stigma related with TB, and in general, they
have a positive migrant experiences. These results also support the theory on stigma that describes the necessity of identifying a difference to be important for stigma to be present. The results also show that this community does not relate TB with poverty contrasting to what is speculated in the literature referent to stigma associated with TB.

It can also be concluded that the slopes of the lines with a larger sample may show a stronger association than the observed in this study. That is that as stigma increases the comfort during the interview may decrease originating fewer shares of contacts.

There are findings in this study that suggest that the community is very concerned about their own and that TB as well as other health related issues do not play an important role in their daily life and that their main concern is to use the time wisely to be able to fulfill their basic economical necessities.

Stigma in association to tuberculosis has been studied from different points of view. Although the presence of stigma on TB has not been studied as much as other diseases such as AIDS it did have its boom during the last decade. Although in academia stigma related to TB is not that common, in the day to day TB clinic activities the term is used with relative high frequency. However, the understanding of the word stigma may be different from the clinic to the academic theory. The loose use of the concept may be reflected in research. It is common to find the use of stigma in the literature with lack of definition.

There are several issues regarding this topic. One is the constant use of the word stigma to explain undesirable behaviors from the patients in day to day clinic activities. This use of the word stigma in TB clinic may confound the real presence of stigma and the real effect of stigma related to the disease in TB control.
Other aspects may be the discrepancies in the understanding and in the beliefs that each group may have regarding tuberculosis. These discrepancies may be present between countries, social class or any other aspect that could modify the group experience and/or the individual experience with the disease.

Regarding the identification of contacts it is also possible that many other aspects could be influencing the number of contact identified by a Mexican-born patient. Apart from other cultural, social or language barriers, other more simple causes may be present. Perhaps, they do have fewer contacts because they live socially isolated. It is also possible that they do not really know the people with whom they work because of the high mobility. Although cultural differences may play a huge role in the control of TB, many other reasons may explain this lower identification of contacts of the Mexican-born group compared with other groups in America and not all of those necessarily need to be link to complex cultural differences as it is speculated

**Implications**

When I decided to conduct this study, I decided to measure the behavioral response to establish the presence of perceived stigma; questions regarding status loss and discrimination were included in the instrument. Figure 5.1 represents a conceptual model of the process of stigma proposed by Link and Phelan (2001), with the incorporation of concepts from the model of culture proposed by Goodenough (1981) and assuming a biocultural interaction as part of the process. According with Link and Phelan, stigma exists when its five components converge: (a) the difference “label”; (b) the link of the labels to stereotypes; (c) the status loss and discrimination; (d) the line between “them” and “us”; and (e) the relationship of power. They propose that this process will be meaningful only in the context of a culture. Culture became important in the sense that the culture of a group will allow a person’s operating culture (learned beliefs and values) including the importance attributed to a difference (label) and the stereotypes
linked to that label. In a biocultural interaction among two different cultures of a group both cultures incorporate part of their values and beliefs into the process of learning, resulting in the formation of a single set of values and beliefs for this particular group. This single set of values and beliefs would allow the members of the group to share equally the labels and stereotypes associated with it, and therefore, the subsequent behavioral responses. We could define this common group as “the Mexican American culture.” If these conditions are met the process of stigma could go until the end (behavioral responses) in the shared path. For stigma to exist a relationship of power among both groups intervening in the process is also needed.

The problem with the conceptual model presented in Figure 5.1 is its reliance on the assumption of the existence of a meaningful interaction between both cultures in the group due to geographical reasons, the “Mexican-American culture.” It did not take into account the possibility of a lack of interaction among both groups in the processes of learning belief and values. In this study, it was observed that the migrant members of this community are isolated from the mainstream American culture. This has allowed them to maintain a set of values and beliefs very similar to what they originally had and, most likely, behavioral responses consistent with it. Figure 5.2 represents how the conceptual model should look when a poor interaction between groups is present. In this case, each group has a separate set of beliefs and values which allows for the existence of different labels and resulting stereotypes, as well as behavioral responses and other processes. It is important to note that there may be some kind of interaction, because the community is not closed to the larger society, which may result in some overlapping of their paths. This means that persons living in the same geographical area may socially interact but may not share culture.
If there were no interactions among both group cultures, each one will follow their own path and characteristics of the process would be independent one from the other. In that case we have to expect that each group will have the elements to initiate the process of stigma and to maintain it. We will also expect that the labels and their associated stereotypes would probably differ from one to the other. Also we would expect that the behavioral response would not necessarily be the same.

If we take in consideration all these possible scenarios, we can easily understand how difficult it could be to measure stigma especially when more than one culture of a group is involved.

**Recommendations**

Tuberculosis in the foreign-born population needs to be addressed. Studies that provide direction to the people in charge of the development of intervention programs in this population are needed. However, stigma related with tuberculosis needs to be clarified. It is necessary to develop models of TB related stigma that allows untangling this complex cultural construct. Assumptions regarding the topic need to be put away and a new generation of research explaining stigma, its specific characteristics as well as its implications in the control of TB, need to emerge.

Medical anthropologist have the responsibility to help the health sector in the understanding of cultural features that make difficult the delivery of health care as well as the control of infectious diseases. If an understanding of stigma is going to occur it needs to be in collaboration with this discipline. This study provides a model in its first stages that need to be worked out.

Socioeconomic and political issues need to be included in the study of stigma. Especially in immigrant populations that hold a story of socio politico and economic disadvantages.
Critical medical anthropologist with their unique theories to explain health related disparities supported by Latin-American scholars using socio politic and economic theories may reach to a better explanation in this topic.

The understanding of stigma in relation with tuberculosis and its effect in the control of tuberculosis in foreign-born population need to be addressed in a multidisciplinary approach.

**Cultural Model for Tuberculosis Stigma**

![Diagram](image)

Figure 5-1. Cultural model for tuberculosis stigma. Biocultural interaction.
Cultural Model for Tuberculosis Stigma

Figure 5-2. Cultural model for tuberculosis stigma. No biocultural interaction.
LIST OF REFERENCES


http://www.doh.state.fl.us/Disease_ctrl/tb/WorldTBDay/2006/Factsheets/Fact_Sheet-Duval06pdf45kb.pdf

http://www.doh.state.fl.us/Disease_ctrl/tb/WorldTBDay/2006/Factsheets/Fact_Sheet-Hillsborough06pdf45kb.pdf

http://www.doh.state.fl.us/Disease_ctrl/tb/WorldTBDay/2006/Factsheets/Fact_Sheet-Dade06pdf45kb.pdf

http://www.doh.state.fl.us/Disease_ctrl/tb/WorldTBDay/2006/Factsheets/Fact_Sheet-Orange06pdf45kb.pdf


Levin, J. S. (1994). Religion and health: is there an association, is it valid, and is it causal? *Social Science & Medicine, 38*(11), 1475-1482.


http://maps.communityatlas.usf.edu/hillsboroughcommunity/index.asp?id=12057&level=


http://www.wpro.who.int/media_centre/fact_sheets/fs_20060829.htm


BIOGRAPHICAL SKETCH

Paula C. Hamsho-Diaz was born in Veracruz, Mexico, on June 1st, 1972. She obtained a professional medical degree from the Universidad Veracruzana in 2001. Before moving to Gainesville, Florida, she worked at an NGO dedicated to assisting HIV/AIDS patients and at the Universidad Veracruzana. Paula has been a Graduate Research Assistance at the South Eastern National Tuberculosis Center (SNTC) providing critical support in activities involving Puerto Rico and other Spanish speaking initiatives and assisting the SNTC in the translation of various CDC and other materials. She also contributed to the development of the new international initiative at the SNTC. She started the Master of Arts degree in Latin American studies at the University of Florida in 2006. Her program was concentrated in anthropology with special emphasis on medical anthropology; she also completed a Public Health Certificate during this period. After graduation, she will continue working at the SNTC.