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Walden University

College of Health Sciences

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Walden University
2016

Abstract

Differences in Treatment-Seeking and Treatment-Adherence Factors for Tuberculosis in
Armenian Versus Non-Armenian Populations of Los Angeles County

by

Tanya M. Ferguson

MS, California State Polytechnic University, Pomona, 2006

BS, California State Polytechnic University, Pomona, 1996

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Health, Health Sciences - Epidemiology

Walden University

May 2016

Abstract

Tuberculosis (TB) is a deadly, yet curable, infectious disease that continues to be a global health threat. Armenia suffers from rising TB incidence and mortality rates. Armenians living in Los Angeles (LA) County, where TB incidence is higher than national averages, is the second largest Armenian community in the world; therefore implications are that many TB cases are attributed to this group. Using the social ecological model as a theoretical framework, this concurrent, mixed-methods study compared Armenians to non-Armenians in LA County about their knowledge of TB and perceived barriers to seeking and adhering to treatment. Bivariate chi-square analysis from online surveys of 55 Armenians and 72 non-Armenians revealed significant differences in their source of TB knowledge and compliance upon diagnosis. Multinomial logistic regression analysis was completed using the following significant predictor factors: classification, home remedy use, age, education, and primary household language. Parallel, in-depth interviews of 10 Armenians and 8 non-Armenians further corroborated that, although both populations were aware that TB exists, knowledge relating to TB mode of transmission, global incidence, and treatment options was generally lacking. However, the Armenian population was more eager to help others and urge seeking treatment when receiving a positive diagnosis, whereas non-Armenians expressed lack of willingness to physically assist patients. These findings have implications for positive social change, as they can inform the efforts of public health and health care entities in more effective disease management, resource allocation, and patient care. Such efforts should help decrease TB prevalence in the U. S. Armenian population and potentially Armenia.

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Dedication

This dissertation is dedicated to my mom, JoAnn. While she is no longer a physical presence in my life, her grace, virtue, and family values eternally resonate in all aspects of my life. All of my accomplishments are a reflection of her spirit and love. The importance of embracing our Armenian culture continues to be influential in my life, which served as an inspiration for this study. I love you (քեզ Սիրում եմ).

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Chapter 1: Introduction to the Study

Introduction

Tuberculosis (TB) is an ancient, communicable disease that has adversely affected humanity for centuries. Antiquated terms used to describe this disease characterized by wasting include *phthisis* by the ancient Greeks, *tabes* by the Romans, *rajayakshma* by the Hindus, and *consumption* in Victorian England (Nelson & Williams, 2007, p. 653). Despite medical advances and extensive research into biological characterizations of the disease and the causative agent, *Mycobacterium tuberculosis*, TB continues to be a detriment to the health of modern society.

TB is one of the world's deadliest, yet curable, diseases. In 2014, there were an estimated 6.0 million new cases of TB and 9.6 million total who fell sick with the disease (either from active or latent forms), 5.4 million of which were men, 3.2 million were women and 1.0 million were children (World Health Organization, 2015). In total, there were 1.5 million TB-associated deaths, ranking alongside HIV as the leading cause of death worldwide, primarily afflicting those living in low- and middle-income countries (Centers for Disease Control and Prevention, 2012b; WHO, 2015). In developed countries, disease management has improved and therefore new infections have declined; however, significant morbidity and mortality associated with disease persists, particularly in susceptible populations (WHO, 2012b). In both developed and developing countries, the populations most susceptible to TB infection and complications with treatment include HIV/AIDS patients, immigrants, the homeless, low socioeconomic populations,

and those in correctional facilities. In 2014, of the 1.2 million deaths associated with HIV, 400,000 (one-third) were co-infected with TB (WHO, 2015).

In particular, the Eastern European country of Armenia is adversely affected by tuberculosis and complications associated with the emergence of multi-drug resistant (MDR-TB), extensively drug resistant TB (XDR-TB), and total drug resistant TB (TDR-TB). The World Health Organization (WHO) has designated Armenia as one of the 18 high-priority countries for TB control among the WHO's European Region and the top 27 in MDR-TB burden countries in the world (Hayrapetyan, 2012). In 2010, Armenia's Ministry of Health (MOH) began working in conjunction with Stop TB in order to reduce TB incidence in the country by taking control of the National Tuberculosis Programme, NTP, (WHO, 2013). Furthermore in 2011, Armenia's MOH joined and participated with other health ministries from at-risk Eastern European countries in establishing annual TB-related symposia (Medecins Sans Frontieres, n.d.). Efforts in Armenia are ongoing to improve the national health care infrastructure in order to strengthen the program's impact on disease incidence and associated morbidity and mortality.

TB incidence in Los Angeles County (LA County) is higher than national averages. In 2013, there were 667 confirmed cases (7.0 per 100,000), which is higher than California's case rate of 5.7 per 100,000 and more than twice the national of 3.0 per 100,000 (California Department of Public Health, 2015; County of Los Angeles Public Health, 2015; Salinas et al., 2016). Furthermore, the Armenian population in this area, particularly in the City of Glendale, is the second largest Armenian community in the world, second only to Yerevan, Armenia (Hayk the Ubiquitous Armenian, 2012). Based

on the high Armenian population and high disease incidence in the community, the implications are that many of the TB cases are attributed to Armenians living in the area. Therefore, the study explored the perceived barriers to TB treatment-seeking and treatment-adherence among Armenians living in LA County, barriers that could impact TB incidence among the target population. Using a concurrent, mixed-methods study including in-depth surveys, ethnography (qualitative), and questionnaires (quantitative), Armenians and non-Armenians living in LA County were interviewed to gain a better understanding of their TB knowledge and perceived barriers to treatment. Differences between Armenians living in LA County and non-Armenian populations with respect to physical, psychosocial, cultural, or behavioral factors and beliefs may impact TB knowledge, treatment-seeking, and treatment-adherence. Thus, public health approaches to treating and decreasing TB incidence in this population would be influenced. The implications for social change involve decreasing TB incidence and prevalence in the Armenian population within the United States, and potentially within native Armenia, through more effective disease management, resource allocation, and patient care efforts. Such approaches and efforts may be extended to other diseases as well.

The following overview covers disease history, current trends in TB research, including diagnosis, genetic variants, treatment and therapy, susceptible populations, and major barriers to treatment seeking and treatment compliance, both in developing and developed countries, particularly Armenia and the United States, respectively. A more thorough review of many of these topics is presented in Chapter 2. Next, brief

descriptions of the study's purpose, theoretical framework, research questions and hypotheses, assumptions, limitations, scope, and significance will be discussed.

Chapter 3 is devoted to a more thorough discussion of research methodology for this study. Chapter 4 is centered on addressing the research questions and hypotheses, including data collection and detailed analysis using statistically-derived findings. Finally, Chapter 5 is a review of the study's purpose, methodology, and research questions with interpretations of the data and the study's implications for social change.

Background

Disease History and Etiology

TB has historical negative implications on the health of mankind. Dating back to the Middle Ages, TB incidence has experienced fluctuations due to associated time-specific events, for example the HIV/AIDs pandemic in the 1980s, or changes in public health practices (Beltz, 2011, pp. 208–209). If left untreated, active TB—and latent TB infection (LTBI) upon reactivation—can be deadly, with mortality rates of up to 50% (Beltz, 2011, p. 211).

In 1882, Robert Koch discovered the causative agent of tuberculosis, *Mycobacterium tuberculosis* (Mathema, Kurepina, Bifani, & Kreiswirth, 2006). *M. tuberculosis* is a slow-growing obligate aerobic bacillus with a thick waxy cell envelope that is readily transmitted through aerosols: coughing, sneezing, laughing, talking, or singing. It's primary targets are the lungs and respiratory tract, where only a few viable bacilli are required to initiate infection (CDC, 2012a). Inhalation of released mycobacteria may result in active (primary) or latent infection, with one-third of those exposed becoming

infected and 10% becoming symptomatic (Mathema et al., 2006). Primary active pulmonary TB may take several weeks from the time of exposure; it manifests as a persistent illness with bloody sputum and shortness of breath. With latent TB, mycobacteria are present but go dormant and infected individuals are asymptomatic (CDC, 2012a). A weakening of the immune system years later may cause bacterial replication to take over and persist, leading to reactivation and ultimately active pulmonary TB infection (Paulson, 2013).

Diagnosis, Therapy, and Prevention

TB diagnosis and detection may be achieved through several avenues, depending upon available resources, infrastructure, extent of infection, and bacterial load. Active pulmonary TB is traditionally diagnosed through smear microscopy or culture-based methods of sputum specimens (Ferguson et al., 2016). While microscopic analysis of sputum samples is rapid, cheap, and specific, it suffers from low sensitivity, particularly for specimens with low bacterial load (paucibacillary), cases of extra-pulmonary TB, and analysis in microscopy centers or voluntary counseling and testing centers (VCTs) with minimal infrastructure (Niemz, Ferguson, & Boyle, 2011). Culture-based methods have a greater degree of sensitivity but are limited by the time taken to culture the slow-growing TB bacterium, which may take 4–6 weeks (Nelson & Williams, 2007, p. 656). The longer turnaround time presents a major hurdle to effective disease treatment and patient case management (Niemz & Boyle, 2012).

Some nonculture-based methods for TB diagnosis include chest X-rays, Mantoux tuberculin skin tests, and nucleic acid testing (NAT). For chest X-rays, lesions in adults

are typically found on the apical or posterior portion of the upper lobes of the lungs (Beltz, 2011, p. 214). The Mantoux tuberculin skin test reveals a hypersensitive lesion from the injection of purified protein derivative (PPD) under the skin of the forearm. Previously exposed individuals or those who have been vaccinated will react to form a 10mm reddened lesion 3 days post-PPD injection (Beltz, 2011, p. 214). While effective, neither method can discern between active and latent TB infections.

NAT is rapidly emerging as the most sensitive, specific, and rapid method for TB diagnosis, including MDR-TB, particularly in developed countries, resulting in positive patient outcomes (Niemz & Boyle, 2012; Niemz et al., 2011; Schumacher et al., 2016). While gaining regard as the most reliable method for TB detection, NAT may be complicated by cell physiology (including sample preparation and nucleic acid isolation), specimen type and pathogen load, patient age, and HIV-1 co-morbidity (Ferguson et al., 2016; Niemz & Boyle, 2012). Current NAT may use the polymerase chain reaction (Ling, Flores, Riley, & Pai, 2008) or isothermal amplification schemes such as loop-mediated isothermal amplification (Boehme et al., 2007, 2010), cross-priming amplification (Fang et al., 2009), helicase-dependent amplification (Ao et al., 2012; Motré, Kong, & Li, 2011; Torres-Chavolla & Alocilja, 2011), or transcription-mediated amplification (Pfyffer, Kissling, Wirth, & Weber, 1994). Cepheid's GeneXpert MDR/RIF is a fully integrated NAT-based system that has received WHO's endorsement for TB diagnosis and rifampin-resistant testing in laboratories of developing countries, and has undergone large-scale rollout in high-TB-burden countries, notably South Africa (Kingsley, 2011). Since the massive rollouts of the GeneXpert, time to treatment

initiation, particularly for *Rif*-resistant MDR-TB, has been decreased significantly, improving treatment outcomes (Stagg et al., 2016).

Morbidity and mortality are highly associated with a rigorous treatment regimen, drug resistance, and nonadherence (Phillips, 2013). *M. tuberculosis* contains a thick waxy cell envelope that is highly impermeable to antibiotics and the bacilli may be present in various stages of growth: actively growing, semi-dormant, and dormant (Nelson & Williams, 2007, p. 666). Therefore, drugs with different modes of action are required for effective treatment and treatment must be adhered to for 6–12 months. This, in conjunction with hepatotoxicity from an extensive drug regimen, results in treatment nonadherence and the emergence of drug resistance (MDR-TB, XDR-TB, or TDR-TB).

First-line TB drugs include isoniazid, rifampicin, pyrazinamide, streptomycin, ethambutol, and thiacetazone. The first three are bactericidal and the last three are bacteriostatic (Nelson & Williams, 2007, p. 666). As resistance to the first line of drugs began to emerge, second-line treatment for TB was developed. Second-line treatment involves fluoroquinolones or injectable drugs such as amikacin, kanamycin, or capreomycin (Warren et al., 2009). Worldwide, the incidence of single-drug resistant TB ranges from 0–56% and MDR-TB from 0–23% of TB cases, with the highest incidence of MDR-TB cases in the Soviet Union, Eastern Europe, and China (WHO, 2008). XDR-TB, which is resistant to fluoroquinolone, rifampicin or isoniazid, and any of the three injectables and TDR-TB, began emerging in 2006 and 2009, respectively (Udwadia, Amale, Ajbani, & Rodrigues, 2012; Velayati et al., 2009).

In 1995, the WHO and StopTB initiated the Direct Observed Therapy Short Course (DOTS) in an effort to improve adherence through patient supervision by healthcare workers (Naidoo, Dick, & Cooper, 2009). With DOTS, health care workers are assigned to monitor patients closely and actively observe that patients are taking each prescribed dose of the antituberculin medication. While DOTS was initially viewed as an effective means to manage patient compliance, it is now viewed as flawed. Much of the inconsistency in DOTS' success is attributed to lagging government involvement, insufficient resources, and insufficient support systems (Naidoo & Mwaba, 2010).

Susceptible Populations and Reported Barriers

Populations highly susceptible to TB infection and complications with treatment in both developed and developing countries include HIV/AIDS patients, immigrants, the homeless, drug users, low socioeconomic populations, and those in correctional facilities. Reported psychiatric and psychosocial factors affecting treatment adherence include poverty, disease coinfection (e.g., cardiovascular, HIV, hepatitis), social stigma, unsupportive social and work environments, disbelief in the health facility and staff, helplessness, hopelessness, and depression (Fry et al., 2005; Kandula, Dworkin, Carroll, & Lauderdale, 2004; Naidoo et al., 2009). Molecular factors also play a role, where genetic variation in both host and pathogen are highly influential in the efficacy of disease transmission (Mathema et al., 2006). Many such studies have been conducted on a variety of susceptible populations, including various ethnicities; however, TB prevention studies specific to Armenians living within the United States and in their native country are lacking.

Current State of TB in Armenia

In Armenia, TB continues to be a major public health challenge, with escalating incidence and mortality rates. In 2011, there were an estimated 55 newly reported cases per 100,000 and a mortality rate of 8.8 per 100,000 (WHO, 2012a) with a growing burden of MDR-TB (WHO, 2014). Of the newly diagnosed TB cases in Armenia, roughly 9.4% were found to be MDR-TB and 43.0% of previously treated cases became MDR-TB (Truzyan, Crape, Grigoryan, Martirosyan, & Petrosyan, 2015; WHO, 2015). The country of Armenia faces several challenges in achieving adequate TB control: (a) high incidence of MDR-TB, (b) low socioeconomic status among its population, (c) emigration/immigration, (d) lack of public awareness, (e) HIV/AIDS co-infection, (f) poor hygiene, (g) unsanitary conditions, and (h) transmission in children (Ministry of Health of Republic of Armenia, 2007; WHO, 2015). While there is a fundamental understanding about some of these national hurdles, deficiencies remain. As a result, this controllable and curable disease is proving to be national health threat to Armenians. As Armenians immigrate to other countries, including the United States, infected individuals pose an international health risk to everyone they come in contact with.

Current State of TB in the United States

In the United States, TB is a highly managed disease where all 50 states and U.S. territories are mandated to report TB cases (Myers, Westenhouse, Flood, & Riley, 2006). All states have TB control programs that report to the national surveillance systems, the Online Tuberculosis Information System (OTIS) and the National Prevention Information Network (NPIN). As a result, TB incidence in the U.S. is at its lowest since the 1950s

when national surveillance was first implemented. From 1985–1992, the United States experienced a resurgence of TB, which was accompanied by MDR-TB and to a lesser extent, XDR. In 2015, 9,563 cases of TB were reported in the United States, an increase from the 9,406 cases reported in 2014 but a decline from the 10,528 cases reported in 2011 (CDC, 2012d; Salinas et al., 2016). This is promising but falls short of goals set by the CDC. In 1989, its Strategic Plan for the Elimination of Tuberculosis called for complete eradication by 2010. However, the goal has been hindered by the resurgence of TB due to the HIV/AIDS epidemic, increased immigration by individuals from countries in which the disease is endemic, MDR-TB, and transmission in congregate settings (CDC, 2011). In 2011, 62% of all TB cases in the United States were attributed to foreign-born persons, where the case rate for foreign-born persons was estimated to be 11.5 times higher than among U.S.-born individuals. MDR-TB cases has shown a decrease since surveillance began in 1993 with 1.3% of cases showing resistance to multiple drug treatments (CDC, 2012d). The cost of hospitalization for an XDR TB patient in the United States was estimated to average \$483,000, approximately twice the cost for MDR TB patients. Due to TB's limited response to antibiotics, mortality rates among XDR patients parallel those of TB patients in the pre-antibiotic era (CDC, 2009a).

California has one of the highest incidence rates of TB in the United States (CDC, 2013). In 2013, TB incidence in California was estimated to be 7 cases per 100,000, of which 30.5% were located in LA County (County of Los Angeles Public Health, 2015). LA County has a high population of immigrants, where native countries may have endemic TB. Many immigrants enter the United States without reporting latent or active

disease for fear of being deported. Therefore LA County has a high incidence of both latent and active TB, particularly in clustered communities. Furthermore, the homeless population is highly susceptible due to a nomadic lifestyle and insufficient tracking for continuous treatment. LA County is home to one of the largest homeless populations, particularly in Skid Row, where recent spikes in TB have been experienced (“Tuberculosis Outbreak Among Homeless In Los Angeles, Calif. [VIDEO],” 2013).

LA County’s Department of Public Health Tuberculosis Control Program (TBC) has a multifaceted control program that concentrates on disease surveillance and epidemiology. The program includes vital case reporting into the TB registry, MDR-TB treatment and monitoring, screening of refugees and immigrants entering the county, health education for medical staff and at risk communities regarding disease treatment and recognition (both latent and active forms), and legal enforcement of noncompliant carriers and offenders who may be putting communities at risk for disease transmission (including homeless populations). Such an approach is essential for achieving the program’s vision of eliminating TB from “indigenous and resident populations” (Los Angeles County Department of Public Health, n.d.). It is a nationally and internationally renowned program due to essential elements such as assigned Extended Role Nurses (ERN) who are made available to help ensure treatment compliance. Enlisted specific health care facilities throughout LA County are equipped with specialized staff and equipment to support program needs, and provide informational and educational programs for staff and the community (Nitta & Davidson, 2003).

Research Gap

A gap exists in understanding the factors that influence treatment-seeking and adherence among Armenians living in LA County. By better understanding the perceived barriers to seeking treatment and adhering to it, it is expected that TB health outcomes in this susceptible population will be greatly improved both domestically and in their native country, where TB-associated morbidity and mortality is high. There are also significant public health implications for implementing improved TB prevention efforts in the Armenian community, as well as other immigrant populations.

Problem Statement

Despite national and statewide efforts to reduce TB, its incidence in California remains the highest in the United States (CDC, 2013). Of the 2,169 reported cases in California in 2013, 662 cases (30.5%) were located in LA County (County of Los Angeles Public Health, 2015). The LA County Department of Public Health's (LACDPH's) Tuberculosis Control Program actively performs surveillance of TB cases, particularly in immigrant populations, and provides treatment throughout the course of the disease. The City of Glendale, located within LA County, has experienced the largest influx of Armenians nation- and world-wide. There are an estimated 80,000 Armenians and their descendants living in Glendale, making it the second largest Armenian community on the planet, behind only Yerevan, Armenia (Hayk the Ubiquitous Armenian, 2012). Despite the availability of publicly funded TB diagnosis and treatment, 18% of all new TB cases (118 cases) in LA County in 2013 were found in Glendale and surrounding cities within the Service Planning Area (SPA-2) (County of Los Angeles

Public Health, 2015). While the number of TB cases within SPA-2 hasn't been clearly defined as Armenian or non-Armenian, the implication that many of these cases are attributed to Armenians is based upon their prevalence in the community and the disease incidence in their native country. Therefore, the overall purpose of this study was to use mixed-methods research to explore differences in barriers to treatment-seeking and compliance in Armenians versus non-Armenians, with a potential impact on TB prevalence within the local Armenian community.

Purpose of the Study

The purpose of this concurrent mixed-methods study was twofold: (a) to explore the differences in factors (physical, psychosocial, cultural, or behavioral) relating to TB knowledge, treatment-seeking and adherence in Armenians versus non-Armenian residing in LA County and (b) how such differences may impact the reduction of TB incidence in this susceptible population. For this mixed-methods study, a survey was utilized to explore whether such barriers to treatment-seeking and adherence differed between Armenian and non-Armenian individuals residing in LA County, with potential implications for reduction in disease incidence. This was followed by the qualitative component involving in-depth interviews of both Armenians and non-Armenians living in LA County to understand general perceptions about TB, along with perceived barriers to TB treatment and treatment adherence in both groups.

The qualitative portion of this concurrent mixed-methods study was an ethnography where shared beliefs, behaviors, and knowledge relating to TB treatment-seeking and adherence among Armenians were explored. The study is also aligned with

phenomenology, where Armenians' individual experiences of TB were described by the interviewees and subsequently grouped thematically. In-depth interviews were conducted using the social ecological model, SEM (discussed below), and the belief or behavioral patterns of the culture-sharing Armenian group in Glendale and surrounding areas. For the quantitative portion of the study, the association between the dependent variable—knowledge about TB treatment seeking and treatment adherence— and the independent variables—barriers or factors relating to TB treatment seeking and adherence—were explored using a survey questionnaire. Such factors included demographic (Armenian versus non-Armenian), socioeconomic, cultural, behavioral, and/or individual beliefs. Furthermore, (a) differences in such perceived barriers and (b) characteristics of other non-Armenian populations were assessed.

Research Questions and Hypotheses

This mixed-methods study addressed the following research questions and tested the associated null and alternative hypotheses:

1. What are the perceived barriers to treatment seeking and adherence for tuberculosis in an Armenian population living within the United States?
2. Is there a difference in barriers to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations living in Los Angeles County and which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence?

H_A^2 : There are differences in factors relating to treatment-seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

H_0^2 : There are no differences in factors relating to treatment-seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

In the quantitative study (RQ2), the dependent variable, knowledge about TB treatment-seeking and treatment-adherence, was explored in relation to the independent variables, barriers, or factors about TB treatment-seeking and treatment-adherence. A more detailed discussion of the research questions and associated hypotheses is addressed in Chapter 3.

Theoretical and Conceptual Framework

Theoretical Framework

The theoretical framework used for this study was the SEM. SEM is widely used in public health and incorporates key principles from community- and individual-based approaches of prevention, with emphasis on the environment. Here, four interrelated factors are addressed: (a) the individual and risk behaviors, (b) relationships, (c) community and environment, and (d) societal /cultural norms. Several studies involving TB transmission amongst various populations across the United States have been reported (Hawker, Bakhshi, Ali, & Farrington, 1999; Myers et al., 2006).

Studies involving decreasing the transmission of TB or other infectious diseases have also used grounded theory (Daftary, 2012; Daftary & Padayatchi, 2012; de Souza &

Guerreiro Vieira da Silva, 2011; Dodor & Kelly, 2010; Johansson & Winkvist, 2002; Onifade et al., 2010); the Theory of Social Stigma (Castro & Farmer, 2005); or the theory of social determination (de Queiroz, De-La-Torre-Ugarte-Guanilo, Ferreira, & Bertolozzi, 2012). However, SEM is a more dynamic and applicable model. TB, in particular, is a dynamic disease that involves personal factors (e.g., biology, personal competence, resilience), social factors (e.g., family influences, social norms), and sociocultural-environmental factors (e.g., socioeconomic, cultural identity, knowledge, and motivation), all of which SEM accounts for.

Conceptual Framework

The qualitative portion of the mixed-methods study is grounded by ethnography, with aspects of phenomenology. Ethnography-based approaches are well-suited for this study due to the emphasis on social interactions, behaviors, and perceptions within a particular group (Reeves, Kuper, & Hodges, 2008). Phenomenology explores what and how something is experienced by a particular population, as individuals, and are then universally grouped based on reported experiences (Creswell, 2012, p. 76). For this study, in-depth interviews of Armenians and non-Armenians living in LA County were conducted to gain insight into perceived barriers to treatment-seeking and treatment-adherence for TB. Currently, there are no reports in the literature describing this, despite the high incidence of TB in Armenia. The current literature discusses psychosocial and psychiatric barriers in other ethnicities and groups living in their native country and upon immigration to the United States. Such barriers and groups will be discussed in detail in Chapter 2.

When conducting ethnography, it is important to engage in cultural immersion to gain a better understanding of the native language and social norms. Having been raised with significant Armenian influences throughout my life, these experiences can be leveraged not only for accessing the population but also relating to participants. Further immersion involves the ability to converse with participants in their native language, if need be, and therefore Armenian language classes were taken concurrent with this study in conjunction with assistance from Armenian speaking family and friends. Both were critical for preparing the questionnaire and survey, pretesting the questionnaire and survey, and conducting final interviews with participants.

The ethnography approach complements the aforementioned theoretical framework guiding the study, SEM. Here, the inter-relationship between intra-personal, interpersonal, sociocultural-environmental, and behavioral influences guided the framework. When addressing the independent variables of barriers to treatment-seeking and treatment-adherence for TB in the Armenian community, cultural influences and patterns may play an important role in behaviors and outcomes. Depending on the overall outcome of this study, findings may suggest that observed differences in barriers to treatment in the Armenian community versus non-Armenian community living in LA County are critical for effective disease management and subsequent reduction of TB incidence.

Nature of the Study

The intent of this concurrent, mixed-methods study was to identify differences in perceived barriers or factors (physical, psychosocial, cultural, or behavioral) in

Armenians versus non-Armenians (independent variable) for TB treatment-seeking and adherence (dependent variable), with potential implications for disease incidence and prevalence. In the study, perceived barriers and factors were explored using in-depth interviews with Armenians and non-Armenians in the community. The rationale for combining both quantitative and qualitative data was to better understand this research problem by converging broad numeric trends and detailed interview data in an effort to reduce morbidity and mortality associated with TB incidence and prevalence in Armenians.

For the qualitative aspect of this project, ethnography-focused pursuits were implemented. Here, interviews were conducted with 10 Armenians and 8 non-Armenians in LA County to understand perceived barriers and factors relating to TB treatment and adherence. For the quantitative aspect of this project, 200 LA County residents were intended to be surveyed for differences in perceived barriers or factors to TB treatment and adherence; however, due to challenges in recruiting, only 127 LA County residents were ultimately recruited (55 Armenian and 72 non-Armenian). Initially, convenience sampling was exercised where Armenian family members and friends acted as gatekeepers for gaining access to subjects. Subjects for both parts of the study were both women and men, ranging in age from 21 to > 70 years old. Subjects were not current TB positive patients; however, patients who underwent treatment and were TB negative were not discouraged from participating in the study.

Operational Definitions

Bactericidal: Describes the killing of bacteria; may be achieved by inactivating metabolic mechanisms or breakdown of cell wall (Nelson & Williams, 2007, p. 666).

Bacteriostatic: Describes the non-killing mechanism that controls or stops bacterial cell growth or reproduction (Nelson & Williams, 2007, p. 666).

Congregate Setting: Settings where people meet or gather, including the workplace, shelters, schools, social or recreational settings, or places of worship. They are treated as high TB-contact areas and special control measures are of interest (New Jersey Medical School National Tuberculosis Center, 2004).

Direct Observed Therapy Short Course (DOTS): Observed treatment by medical staff to ensure treatment compliance throughout the required treatment duration, which is generally four to twelve months (Naidoo et al., 2009).

Extensively Drug Resistant Tuberculosis (XDR-TB): TB resistant to fluoroquinolone, rifampicin or isoniazid, and any of the three injectables (capreomycin, kanamycin, and amikacin) (Velayati et al., 2009).

First line antituberculosis drugs: Most commonly used treatment for TB. Drugs include isoniazid, Rifampicin, Pyrazinamide, Streptomycin, Ethambutol, and Thiacetazone (Nelson & Williams, 2007, p. 666).

Health Insurance Portability and Accountability Act (HIPAA): Patient security and privacy act established in 1996 to protect the privacy of individually identifiable health information including date of birth, any portion of an address, date(s) of service, and diagnosis (Issel, 2009, p. 533).

Latent Tuberculosis Infection (LTBI): Asymptomatic form of TB that may become active at any time. Detectable using the PPD skin test (Nelson & Williams, 2007, p. 660).

Los Angeles County Department of Public Health (LACDPH): Public Health Department serving LA County in California whose mission is “to protect health, prevent disease, and promote health and well-being” (County of Los Angeles Public Health, n.d.-a).

Multi-Drug Resistant Tuberculosis (MDR-TB): TB strains resistant to multiple anti-tuberculin drugs, both first line and second line (Mathema et al., 2006).

Nontuberculous Mycobacteria (NTM): A group of microorganisms within the Mycobacterium genus that cause an array of diseases that include TB-like lung disease, lymphatic and systematic diseases, and disease of the bone, skin, or soft tissue. They are often misdiagnosed as *M. tuberculosis* (Raju, Raju, Zhao, & Rubin, 2016).

Nucleic Acid Testing (NAT): Detection of a pathogen’s nucleic acids (DNA or RNA) for the rapid diagnosis of an infectious disease which generally involves sample preparation, amplification, and detection methods (Niemz et al., 2011).

Paucibacillary: A low bacterial load of *Mycobacterium tuberculosis* bacilli in patients which compromises accurate disease diagnosis (Dam & Bose, 2002).

Purified Protein Derivative (PPD): A solution prepared from cultures of tubercle bacilli. It was originally developed by Robert Koch in 1890 as a cure for TB and is now used as an intracutaneous injectable diagnostic for the Mantoux tuberculin skin test (Nelson & Williams, 2007, p. 661).

Second line treatment: Fluoroquinolones or injectable drugs, amikacin, kanamycin, or capreomycin (Warren et al., 2009).

Service Planning Area (SPA): A geographic region within LA County of which there are eight. Due to the enormous size of the county, they are broken down to “develop and provide more relevant public health and clinical services targeted to the specific health needs of the residents in these different areas” (County of Los Angeles Public Health, n.d.-b).

Social Ecological Model (SEM): A prevention framework developed by the CDC that accounts for interactions between individual, relationship, community, and societal factors (CDC, 2009b).

Total Drug Resistant Tuberculosis (TDR-TB): *Mycobacteria tuberculosis* resistant to all available treatment (Velayati et al., 2009).

Tubercle: Segregated region of the lungs produced by the host’s immune system for the containment of *M. tuberculosis* (Beltz, 2011, p. 222).

Tuberculosis Control Program (TBC): LA County’s Department of Public Health TB prevention program launched in 1996 with a mission of preventing the “transmission of TB within LA County through early detection of active disease and treatment of latent infection” (Nitta & Davidson, 2003).

Voluntary counseling and testing centers (VCTs): Primary health care facilities in high burden low resource settings which administer testing and counseling for HIV/AIDs and more recently, TB (African Medical and Research Foundation, 2013; Los Angeles County Department of Public Health, n.d.).

Assumptions, Scope, Delimitations and Limitations

Assumptions

A key assumption of this study was that Armenians residing in LA County, particularly in Glendale or SPA-2, are primary contributors to TB incidence in the region due to their high population in the area. Further collaboration with LACDPH's TBC program are necessary to fully characterize case ethnicity specifics, without violating privacy laws covered by HIPAA, and are recommended for future studies.

A second key assumption was that barriers to treatment-seeking and treatment-adherence for Armenians will be different than what has been reported for other populations. Current barriers, as discussed previously, include HIV/AIDS status, immigration, socioeconomic status, disease co-infection, social networks, molecular co-factors, and various psychiatric conditions, such as helplessness and depression. Coming from a strong Armenian upbringing, it is known that Armenians are a very tight social group, bound by traditions and internal social norms, many of them brought over from Armenia. Therefore, it is of great interest to see how these factors may influence perceptions regarding TB and TB seeking behaviors.

Scope and Delimitations

The study examined TB and barriers to treatment-seeking and treatment-adherence in Armenians in LA County. While LA County houses the largest population of Armenians in the country and world—aside from Armenia itself (Hayk the Ubiquitous Armenian, 2012)—generalizability may be compromised. It is believed that this study involved a representative pool of Armenians living in the United States; however, social

and economic factors impacting the study may differ in Armenians living in other parts of the nation or world.

Additionally, assumptions regarding TB incidence in LA County, particularly in SPA-2 were made, where case reports are being correlated with Armenian dominance in the area and disease trends in native Armenia. Currently, Armenians are classified with the White/Caucasian race and thus TB cases in LA County are reported as such.

Therefore, determining patient ethnicity as Armenian on a case-by-case basis may be challenging and may be worth exploring in future studies.

Limitations

This study suffered from several limitations; they needed to be addressed and interpreted when deriving final conclusions. One key limitation of this study pertains to TB case reporting in LA County. While the actual numbers are up to date due to extensive reporting mandates by the county, determining patient ethnicity as Armenian on a case-by-case basis may be challenging. Currently, Armenians are classified with the White/Caucasian race. The current implications of the study rely on the fact that many of the cases within SPA-2 are attributed to Armenians based upon their prevalence in the community (Hayk the Ubiquitous Armenian, 2012) and disease incidence in Armenia (WHO, 2012a).

Another limitation is that this study focused only on Armenians residing in LA County. LA County houses the largest population of Armenians in the country and world, aside from Armenia itself (Hayk the Ubiquitous Armenian, 2012); therefore, it is believed that the study involved a representative pool. However, the social and economic factors

impacting the study may not be generalizable to Armenians living in other parts of the world.

Further limitations involve those factors that may threaten validity and reliability when conducting qualitative studies, including recall bias and sampling strategies (Creswell & Plano Clark, 2011, p. 211; Frankfort-Nachmias & Nachmias, 2008, p. 150). Recall bias may severely impact the study and overall outcomes should be addressed through appropriate instrumentation and surveys. Sampling strategies are another concern and may severely impact data analysis and results. Surveys and/or in-depth interviews with Armenians in the community were accessed through gatekeepers from family, church, and community groups to understand perceived barriers to treatment and follow-up, including current knowledge base about the disease and accessibility from TBC. Conducting in-depth interviews also offer challenges including logistics, time, and rationalization and coding of responses.

A final threat to validity and reliability involved instrumentation, which, in this case, was a questionnaire. An original questionnaire was generated to ensure cultural sensitivity and relevance to the Armenian community. This presented some challenges because there were no assurances about its validity and coherence. Therefore, pretesting was required to ensure the questionnaire's appeal and ease of comprehension. To remove some ambiguity, the questionnaire was provided in English and Armenian. The questionnaire for the non-Armenian group was also subjected to pretesting to address some of the same issues and to ensure clarity.

Significance of the Study

TB morbidity and mortality are highly associated with treatment regimen and nonadherence. Varying growth patterns and specialized biological characteristics of *M. tuberculosis* create complex antibiotic treatments and chemotherapy that require up to 12 months. DOTS was initiated in 1995 and continues to be promoted to improve patients' adherence through the use of supervision by healthcare workers; however, success has been inconsistent due to lagging government involvement, available resources, and insufficient support systems (Naidoo & Mwaba, 2010).

A thorough understanding of barriers and factors relating to treatment-seeking and adherence is vital for complete disease management and control. Barriers to TB treatment and treatment compliance for some immigrant populations have been discussed in the literature. Such barriers include gender (Onifade et al., 2010), social stigma (Daftary, 2012; Dodor & Kelly, 2010), poverty and sub-standard housing, disease coinfection (e.g., cardiovascular, HIV, hepatitis), unsupportive social and work environments, incarceration, disbelief in the health facility and staff, helplessness, hopelessness, and depression (Fry et al., 2005; Kandula et al., 2004; Naidoo et al., 2009; Tupasi et al., 2016). However, TB prevention studies are severely lacking for Armenians living in the United States and Armenia, particularly qualitative studies, which generate firsthand accounts of the social situation within the Armenian community.

Positive Social Change

This research fills the gap in understanding treatment-seeking barriers in this susceptible population, with potential public health implications for other diseases in

addition to TB. Implications for social change involve decreasing TB prevalence in the Armenian population in the United States—and potentially within native Armenia—through more effective disease management, resource allocation, and patient care.

Summary

This chapter highlighted TB background and current trends relating to disease diagnosis, genetic variants, treatment and therapy, susceptible populations, and major barriers to treatment-seeking and treatment-compliance, in both developing and developed countries. Furthermore, barriers and factors relating to treatment-adherence for non-Armenian populations living abroad were discussed. This served to present the problem statement, research questions and hypotheses, significance of inquiry within an Armenian population, definition of terms, and the assumptions and limitations within the literature.

Chapter 2 provides extensive background information on TB and discusses the literature in light of the current study's research question, hypotheses, problem statement, and objectives. Specifically, this chapter will compare the literature on barriers to TB treatment-seeking and adherence in immigrant populations, though those specific to Armenians are severely lacking. Literature exploring the health system in Armenia, in conjunction with studies addressing other infectious diseases in Armenians in their native country and the United States, will also be explored in an effort to uncover social and behavioral trends that may be useful for the qualitative surveys.

In Chapter 3, a more detailed discussion of study design, research methodology, participant sampling and instrumentation will be presented. In Chapter 4, the results and

statistically-derived findings from the two study components will be presented in detail and related back to the research questions and hypotheses. Finally in Chapter 5, a summary and interpretation of the study findings will be detailed, as well as recommendations for future research and implications for social change.

Chapter 2: Literature Review

Introduction and Background

TB is a deadly, yet curable, infectious disease. High morbidity and mortality rates are associated with a rigorous treatment regimen, nonadherence, and the emergence of resulting drug-resistant strains (Mathema et al., 2006; Sacchetti, Rubin, & Freundlich, 2008). Highly susceptible populations in both developed and developing countries include the homeless, immigrants, HIV/AIDS patients, low socioeconomic populations, and those in correctional facilities. Increased susceptibility reflects inadequate medical care, poor living conditions, high incidence of multidrug resistance, loss to follow-up, or low treatment adherence (Beltz, 2011, pp. 206–207; Mathema et al., 2006; Sacchetti et al., 2008). Loss to follow-up and low treatment adherence are of particular interest to public health where a variety of approaches and barriers have been investigated in an effort to improve TB outcomes and disease surveillance, most notably DOTS (Nelson & Williams, 2007, pp. 685–688; WHO, 2010, 2012b), and improved diagnostics (McNerny, 2011; Program for the Appropriate Technology in Health, 2011; Small & Pai, 2010).

Armenia suffers from a high incidence of multidrug resistance TB and has therefore been designated by the WHO as one of the 18 highest priority countries for TB control in the Europe Region (Hayrapetyan, 2012; WHO, 2012b). Furthermore, it is one of the top 27 countries in the world burdened by MDR-TB (Hayrapetyan, 2012). On the other hand, the County of Los Angeles in California suffers from relatively high TB-incidence trends and ranks one of the highest in the country with 30.5% of the cases reported in California located in LA County (County of Los Angeles Public Health,

2015). Additionally, LA County is home to the highest population of Armenians, aside from Yerevan, Armenia's capital and largest city. While TB data collected by the LACDPH's Tuberculosis Control Program don't differentiate Armenian as ethnicity, implications are such that this cultural group may contribute to the inflated incidence rates with LA County. Therefore, the goal of this study was to utilize a mixed-methods ethnography approach to explore differences in factors (e.g., physical, psychosocial, cultural, or behavioral) relating to TB knowledge, treatment-seeking and adherence in Armenians versus non-Armenian residing in LA County and how such differences may impact the reduction of TB incidence in this susceptible population.

TB is a dynamic and historical disease that continues to perplex scientists and researchers seeking to reduce morbidity and mortality relating to the causative agent. As a result, the body of knowledge is expansive and continues to grow. The literature relating to TB covers disease epidemiology, breakthrough in diagnostics, hurdles associated with drug resistance, and problems associated with treatment adherence. Much of latter is done in the context of general susceptible populations (e.g., HIV positive, homeless, poor, immigrants, incarcerated), with little emphasis on specific cultures where familial influences and traditions may have a profound impact on TB knowledge and treatment adherence behaviors. Armenians, in particular, are a susceptible population with strong family influences; however, very few studies have been dedicated to this group. Susceptibility within this population relates to high incidence in their native country, inadequate health care, poor disease tracking, poor education regarding the disease, poverty, migrant workers, and immigration to foreign lands where assimilation

by this “hidden minority” may prove to be a challenge (Bakalian, 2011; Truzyan et al., 2015; Vink et al., 2005). A few studies exist which explore TB-associated problems in their native country (Breitscheidel, 2006; Breitscheidel, Stamenitis, & Bosch, 2010; Ehlman et al., 2007; Grigoryan et al., 2008; Ministry of Health of Republic of Armenia, 2007; Truzyan et al., 2015; Vink et al., 2005); however, to the best of my knowledge, no studies of Armenians living the United States were uncovered relative to TB or any other infectious disease where an ethnography approach was utilized for understanding Armenian patient health care seeking behaviors within an unfamiliar health care system.

The following chapter presents a critical review of the literature in an effort to establish an understanding of the current state of TB in the developed and developing world, with particular interest in the Armenian community. The literature search strategy will be discussed which covers databases and key terms utilized for conducting the exhaustive search. Furthermore, support for the theoretical foundation and conceptual foundation will be discussed. Key variable and concepts relating to the study specifically will also be discussed, including concepts relating to both the qualitative and quantitative components of the study. A summarization of key findings in the literature will also be highlighted as a transition into the methodological approaches discussed in Chapter 3 is made.

Literature Search Strategy

Databases, Search Engines, and Keywords

In conducting this exhaustive literature search, the databases used were Web of Science, PubMed/MEDLINE, Google Scholar, and Science Direct. The keywords were

as follows: *tuberculosis, Armenia, education, epidemiology, theory, social ecological model, Eastern Europe, drug resistance, directly observed treatment, disease barrier Armenia, Armenia health barriers, Armenia United States disease, Armenia culture health, ethnographic study, Armenian culture, prison, tuberculosis HIV, tuberculosis immigrant, tuberculosis diagnostic, tuberculosis social determinants, tuberculosis stigma, tuberculosis treatment barrier, and tuberculosis behavior*. Some common abbreviations included TB, MDR-TB, XDR-TB, TDR-TB, DOTS, and TB-HIV. The selected literature addressed key research goals, disease epidemiology, and identifying gaps in the literature. Documents were obtained via electronic download or interlibrary loan. As relevant documents were being downloaded, cataloging and subsequent categorization was done using the bibliographic software, Zotero (Roy Rosenweig Center for History and New Media, Fairfax, VA), which interfaces directly with word processing software to facilitate proper APA citation formatting throughout the writing process.

Scope of the Literature

A literature review based on the terms described above was an extensive and iterative process. Peer reviewed articles were searched and read, if they explicitly related to topics relevant to the scope of the study. Most of the literature searched was very current, spanning over the past 10 years. However, primary peer-reviewed articles cited numerous times by the more recent publications were also read in order to get a complete understanding of the concept addressed. This was particularly true when investigating theoretical foundation and conceptual framework. Background relating to TB

epidemiology and initial research in theoretical framework was also obtained from books addressing infectious diseases and theories in public health, respectively.

Theoretical Foundation

The theoretical foundation for this study is based upon the SEM (CDC, 2009b). SEM is a dynamic behavioral intervention model which focuses on the individual, community, the environment, and interactions thereof. TB is a dynamic disease that is influenced by the interplay of many factors including: personal factors (e.g., biology, personal competence, resilience), social factors (e.g., family influences, social norms), and sociocultural-environmental factors (e.g., socioeconomic, cultural identity, knowledge, and motivation). SEM is adaptable to many public health applications and has therefore been applied to a variety of public health intervention strategies.

SEM has been used frequently in infectious disease and sociological epidemiology (Green, Lewis, & Bediako, 2005; Hosek, Harper, Lemos, & Martinez, 2008; Murray, Oxlade, & Lin, 2011; Reifsnider, Gallagher, & Forgione, 2005). SEM epitomizes social epidemiology with ecological factors at its core that present integral principles that serve as a foundation for explaining potential causal relationships between disease and social and biological conditions (Krieger, 2001) and address complex community-based problems relating to health disparities (Green et al., 2005; Reifsnider et al., 2005). Here, key principles are incorporated from community- and individual-based approaches of prevention with an emphasis on the environment. As seen in Figure 1, SEM addresses four inter-related factors: the individual and risk behaviors, relationships, community and environment, and societal /cultural norms (CDC, 2009b). The individual

is central to the model where internal determinants such as knowledge, attitudes, and beliefs come into play. The next layer considers external forces attributable to interpersonal processes and relationships such as social interactions with family, partners, and friends. The next level of community includes individuals, businesses, institutions, or organizations that collectively form a social construct or community. Finally, the outermost level, social structure / public policy, incorporates environmental and/or governmental changes, to effectively influence change (California Department of Public Health, n.d.; CDC, 2009b).

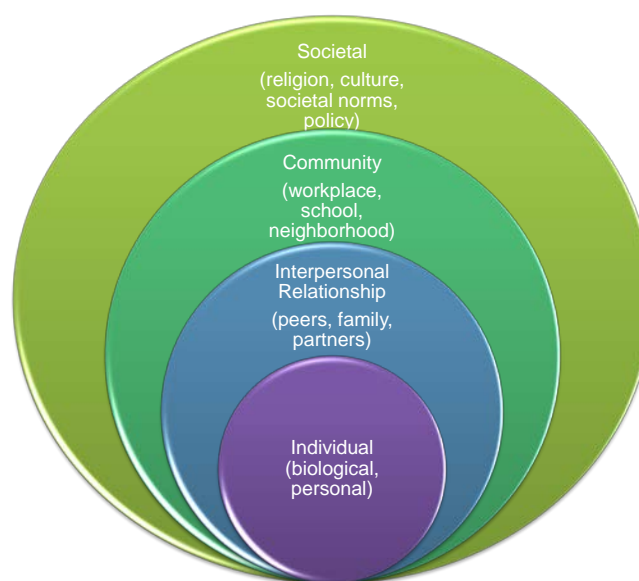


Figure 1. The four levels and main influences involved in the social ecological model (SEM). Adapted from *The Social-Ecological Model: A Framework for Prevention - Violence Prevention - Injury Modified*, by CDC, 2009b, Retrieved February 5, 2013, from <http://www.cdc.gov/violenceprevention/overview/social-ecologicalmodel.html>.

SEM has been more widely used for studies addressing many facets of TB transmission, treatment and prevention, including health disparities, ethnic differences,

socioeconomics, immigration, and psychosocial factors amongst various populations both nationally and internationally. More specifically, one relevant study by Myers et al. (2006) explores TB transmission in California using an ecological approach. Using the U.S. Census data for California, ecological variables such as racial/ethnic distribution, immigration, education level, employment status, poverty, and crowding were incorporated and related to new TB cases, using pediatric cases as a measurement of transmission. Overall, lower median incomes, racial/ethnic minorities, and immigrants were found to have higher rates of pediatric tuberculosis. While extremely relevant to this study, there was no differentiation of Armenians as an ethnicity so specific insight into this group is not provided.

Other groups such as Hawker et al. (1999), Harling et al. (2008), Marx et al. (2007), Barr et al. (2001), Tupasi et al. (2016), and Holtgrave et al. (2004) have utilized SEM to investigate the impact of various ecological factors (namely poverty, SES, and ethnic differences) on TB transmission treatment adherence in a variety of populations in the United States and abroad. Again, none of these studies explicitly discuss any such factors within the Armenian community, either in the United States or Armenia. Murray, Oxlade, and Lin (2011) have expanded upon SEM and used mathematical modeling to further explore the dynamics associated with social, environmental and biological determinants of TB in an effort to improve intervention strategies. While the study has some limitations due to the static nature of mathematical modeling, associations between TB infection and smoking, indoor air pollution, alcohol use, diabetes, nutrition, crowding, migration, aging, and economic trends were projected (Murray et al., 2011).

Conceptual Foundation: Armenian Ethnography Elements

One component of this mixed-methods study involved ethnography in relation to the Armenian culture. Distinctive with their shiny black hair, prominent nose, and the tell-tale “ian” (or variations thereof) at the termination of their familial name, Armenians are rich in close family bonds, cultural quips with ancestral origins, and the strength and desire to survive. Despite the Armenian genocide in 1915 by the Turks, the Spitak Earthquake of 1988, and the dissolution of the Soviet Union in 1991, Armenians have learned to come together in order to survive and move forward. Many of these historical events also resulted in the immigration of Armenians to other parts of the world, including the United States, Europe (e.g., United Kingdom), and Latin America. With immigration comes the desire to assimilate within the host society while also struggling to also maintain cultural identity. William Saroyan, a well-known American-Armenian author, epitomized Armenians best in a series of short stories in *Inhale and Exhale*” (1936, p. 438):

I should like to see any power of the world destroy this race, this small tribe of unimportant people, whose wars have all been fought and lost, whose structures are crumbles, literature is unread, music is unheard, and prayers are no more answered. Go ahead, destroy Armenia. See if you can do it. Send them into the desert without bread or water. Burn their homes and churches. Then see if they will not laugh, sing, and pray again. For when two of them meet anywhere in the world, see if they will not create a new Armenia.

The Armenian genocide of 1915 not only is a significant part of the Armenian history but also contributes to the strong cultural identity and presence of Armenians. First-generation Armenians and genocide survivors have openly exercised their ability to share their experiences with next generations of family members and friends in an effort to keep their stories alive. With these stories and experiences, descendants of the victims and survivors have yet another common thread with which to weave their Armenian culture together with others regardless of where they live. Also interwoven within these stories are traditional beliefs about life, health, happiness, politics, social conduct and business that seem to transcend time; some with a scientific basis and others more folkloric. Armenians are also a very spiritual, yet superstitious, group of people and actively ward off bad or evil throughout their daily events, primarily through the use of the *kapoot achk* (blue eye) which wards off ill fortune brought about from the evil eye (Best Country Reports, 2011, p. 17). Regardless of the validity, such beliefs impact decisions that are made within their daily lives and must therefore be realized and understood when attempting to address or improve health outcomes. If a disease like TB is not understood (including symptoms, modes of transmission, and treatment) and an explanation is not culturally relevant, Armenians may rely upon the *kapoot achk* as the primary means of fighting the disease and therefore result in poor health outcomes. By integrating *kapoot achk* as part of the education and intervention plan, disease treatment seeking and adherence behaviors may improve.

Several other events central to Armenian history which impact their health in particular are the Spitak Earthquake of 1988 and the crumbling of the Soviet Union in

1991. In fact, the fall of the Soviet Union is viewed as a major event that led to the rise of TB and MDR-TB in that region (Phillips, 2013). While part of the Soviet Union, Armenians had access to free health care, though access for women was sparse. Once the Soviet Union dissolved, resources for the delivery of adequate health care in Armenia also suffered where much of the burden fell on limited and underpaid physicians and nurses (Amoros, Callister, & Sarkisyan, 2010). Therefore, the overall health of Armenians suffered and health-seeking behaviors also changed. In 2002, the Center for Health Services Research and Development of the American University of Armenia conducted an assessment to identify vulnerable population groups and specific health education needs. Four main highly susceptible populations included children under the age of 5, the elderly, pregnant women, and adolescents. Afflictions ranged from acute respiratory disease (including TB), poor nutrition, poor reproductive health, poor dental health, dangers from alcohol and passive smoking, physical inactivity, poor hygiene, poor mental health, accidents, cardiovascular disease, and cancer (Center for Health Services Research and Development, American University of Armenia, 2002).

Economic uncertainty following the breakup of the Soviet Union also forced many Armenians to seek seasonal work in neighboring TB-burdened countries and then return to Armenia following work completion. As a result, migrant workers have been found to have higher incidence of TB (particularly MDR), HIV co-infection, delayed treatment initiation, and increased loss to treatment follow-up due to migration between affected countries, with inadequate reporting systems to track them (Truzyan et al., 2015). Poor economic status has also seen a rise in injection drug use in Armenia.

Injection drug users (IDUs) have a higher incidence of HIV, which is problematic for the activation of latent TB. According to Ghukasyan (1999), IDUs in Armenia are misinformed about their TB status, uninformed about TB-HIV synergy, and tend to avoid TB health clinics for fear of incarceration or involuntary detention.

The earthquake of 1988 also hampered the country's health status, despite still being part of the Soviet Union. Significant lives were lost, people were displaced, and infrastructure was severely destroyed (Doarn & Merrell, 2011). Furthermore, the aftermath of the earthquake resulted in an increase in post-traumatic stress disorder, anxiety, depression (Goenjian et al., 2000), along with a breakdown in overall healthcare services (Doarn & Merrell, 2011).

A major consequence of the aforementioned tragedies in recent Armenian history is the immigration of Armenians to distant lands. As Armenians flee from their native country in the hope of a better life, issues and sensitivities relating to assimilation and maintaining cultural identity surface (Bakalian, 2011). Many immigrant populations such as Armenians are misunderstood or viewed as clannish and are targeted as being problematic. The ability to assimilate and assume anonymity may appear to be advantageous in terms of escaping stereotypes and social stigma, as demonstrated by Armenians living in London (Talai, 1986). However, Armenian pride and the desire to preserve their culture seem to supersede taking the easy path where ancestral value systems, language, food, and religious ideologies are incorporated into their daily lives and communities. First-generation Armenian parents have to make the decision as to whether they should raise their children according to Armenian customs and teach them

their native language or to completely submerge them in English-American lifestyle in order to simplify their assimilation (Imbens-Bailey, 1996; Phinney, Ong, & Madden, 2000). However, the decision to adopt non-Armenian values and norms may prove to be challenging when making general life decisions involving community socialization, education, and workplace policies. Many explanations, or lack thereof, of social norms may be misconstrued or misinterpreted, thereby compromising the social balance between cultural beliefs and superstitions and local norms. Such conflict contributes to the appeal of conducting an ethnographic study in relation to disease and disease outcomes in the American-Armenian community where ambiguities in health seeking behaviors and knowledge may exist.

Armenians living in the United States are a rarely studied group and considered to be a hidden minority. More specifically, studies involving American-Armenians in the social sciences are quite limited (Bakalian, 2011). Therefore, the ethnographic component of this study could fill the gap in gaining insight into perceived barriers to treatment-seeking and treatment-adherence for tuberculosis, particularly those that are specific to cultural attitudes, influences, and behaviors. Furthermore, studies incorporating ethnography and TB are limited. Park and Littleton (2008) conducted an ethnography in New Zealand to explore the impact of immigration on TB incidence influxes within the country. Overall, it was found that immigrants were responsible for the increase in active and latent cases of TB within the country. Therefore, the investigators proposed the use of such information to incorporate social support programs specific for such groups into their healthcare system. They also found the results to be a

threat to their national health and have proposed modifications in their immigration policies. Investigations into barriers to treatment-seeking behaviors in such groups were not discussed. This study may also set precedence in this area of TB research as well.

Key Variables and Concepts

The causative agent of tuberculosis, *M. tuberculosis*, is a complicated micro-organism that contributes to the complexity of the disease and disease outcomes. Disease epidemiology, rigorous treatment regimen, insufficient health care and treatment support, and a variety of social determinants are all dynamic contributors to poor health outcomes related to the disease. Many of these contributors translate across country borders while others are unique to specific races or cultures. The studies described herein will highlight many of these areas in general terms and more specifically as they relate to the Armenian community, albeit limited.

Disease Epidemiology, Diagnosis, and Treatment

M. tuberculosis is a slow-growing obligate aerobic bacillus with a thick waxy cell envelope that primarily targets the lungs and respiratory tract (Beltz, 2011, p. 212; Mathema et al., 2006; Nelson & Williams, 2007, p. 654). The thick waxy cell envelope presents challenges for TB diagnosis and treatment (Velayati et al., 2009), which will be also be discussed in detail below. *M. tuberculosis* is readily transmissible through aerosolization of only a few viable tubercle bacilli resulting from coughing, sneezing, laughing, talking, or singing (CDC, 2012a). Upon inhalation of released mycobacteria, active (primary) or latent (LTBI) infection may result, with one-third of those exposed becoming infected and 10% eventually becoming active and symptomatic (Mathema et

al., 2006). Most active cases take several weeks from time of exposure; however immuno-compromised individuals may experience rapid progressive primary tuberculosis. If left untreated, active TB can be quite deadly with mortality rates of up to 50% (Beltz, 2011, p. 211). With latent TB, mycobacteria are dormant and individuals are asymptomatic (CDC, 2012a). LTBI can reactivate years following primary infection; which may be triggered by the weakening of the immune system as with HIV co-infection, age, malnutrition, poor living conditions, and poor hygiene.

Disease diagnosis varies, depending upon the country, available resources, infrastructure, and extent of infection. Such variability and potential inadequacies can prove to be problematic due to the nature and potential lethality of the disease. Traditional diagnosis of active pulmonary TB is performed using smear microscopy, culture-based methods of sputum specimens, or chest x-ray (Beltz, 2011, pp. 214–216; Nelson & Williams, 2007, p. 664; Niemz & Boyle, 2012). Though outdated, these technologies are amenable to high burden low resource settings due to simplicity and low cost; however, they suffer from insufficient sensitivity and specificity, inadequate speed, and inconsistent availability in health clinics or VCTs where many patients first seek care (Niemz & Boyle, 2012; Niemz et al., 2011; Small & Pai, 2010). Patients are also requested to produce multiple sputum specimens to confirm a positive result, which may result in loss to follow-up if the patient does not return due to logistical challenges (Lawn et al., 2013; Niemz & Boyle, 2012; Niemz et al., 2011). In Armenia, the standard mode of TB diagnosis is chest x-ray due to the inaccessibility of sputum microscopy. This trend is attributed to the lack of involvement by health practitioners and nurses, quality

microscopes, reagent and supply procurement, and adequately trained personnel (Vink et al., 2005). According to a recent WHO Global TB report, in Armenia there are only 26 laboratories performing smear microscopy with only 4% using LED microscopes, 1 laboratory performing culture and drug susceptibility testing, and 2 performing NAT via Cepheid's GeneXpert® MTB/RIF (WHO, 2015).

The implementation of NAT is moving to the forefront of TB diagnostics. NAT has been found to be more sensitive, specific, and rapid than current methods and also facilitates the diagnosis of multidrug resistant TB, thereby positively impacting patient outcomes (Niemz & Boyle, 2012; Niemz et al., 2011; Schumacher et al., 2016; Small & Pai, 2010). While highly advantageous, worldwide implementation of TB NAT is hampered by complicated cell physiology, specimen type, patient age, HIV-1 comorbidity, expense, and complexity of systems. The waxy bacterial wall makes the pathogen very difficult to lyse which limits the amount of DNA template liberated for amplification. Furthermore, HIV-1 co-infected individuals and young children may produce insufficient volumes of sputum and therefore paucibacillary, which may limit target yield (Niemz & Boyle, 2012). Current NAT may involve the polymerase chain reaction (reviewed by Ling et al., 2008) or isothermal amplification schemes such as loop-mediated isothermal amplification (Boehme et al., 2007, 2010), helicase-dependent amplification (Ao et al., 2012; Motré et al., 2011; Torres-Chavolla & Alocilja, 2011), transcription-mediated amplification (Pfyffer et al., 1994), or cross-priming amplification (Fang et al., 2009). The most prominent and highly endorsed system by the WHO, StopTB, FIND, and local health ministries is Cepheid's GeneXpert® MDR/RIF. The

GeneXpert® MDR/RIF is fully integrated assay system that incorporates TB diagnosis and rifampin resistance testing. The WHO has recommended its use in areas where rates of MDR-TB is high and serve as a replacement for smear microscopy, particularly in district and sub-district level laboratories of developing countries (Lawn et al., 2013). The adoption of the GeneXpert® MDR/RIF has revolutionized TB NAT testing, with next generation systems moving toward the patient bedside or point-of-care. This will further improve patient health outcomes, where diagnosis and treatment can be implemented in a single visit which is particularly important in areas where patients live remotely and have to travel great distances to obtain results and receive treatment (McNerny, 2011; Niemz & Boyle, 2012; Niemz et al., 2011).

Historically, effective TB treatment has proven to be a challenge even when antibiotics were first introduced in the 1940s. Even then, the emergence of initial antibiotic resistance was seen almost immediately. The use of a first-line drug regimen of isoniazid or rifampicin was developed over the subsequent 30 years; however resistance to both drugs was not labeled as MDR until the early 1990's (Sullivan & Amor, 2013). Contributing factors to the complexity of TB treatment include the emergence of multi-drug resistant strains (MDR, XDR, and TDR-TB) and biological factors, such as its thick waxy cell envelope, slow growth, and disease-causing nontuberculous mycobacteria (NTM). Such characteristics are key contributors to the high morbidity and mortality rates associated with the disease. The thick waxy coat makes the pathogen highly impermeable to antibiotics and in conjunction with its slow growth rate, several classes of antimicrobials are used to target various stages of growth (Nelson & Williams, 2007, p.

666). Furthermore, the treatment must be adhered to for 6 - 12 months, depending upon patient treatment compliance, drug resistance status, and HIV status. This may be further complicated by the improper diagnosis of diseases caused by NTMs as TB, which leads to the unnecessary and improper treatment administration of TB drugs further selecting for MDR-TB strains (Raju et al., 2016). The incidence of multidrug resistant TB (MDR, XDR, or TDR) varies depending upon the region. In 2011, 9.5% of all new TB cases in Armenia were estimated to be MDR (WHO, 2012b); whereas 1.3% of new cases in the United States were estimated to be MDR (CDC, 2012d).

Recent challenges in the administration of adequate treatment involve shortages of first- and second-line drugs and the lack of new anti-tubercule drugs in the pharmaceutical pipeline. In the United States, there have been recent reports of shortages of the commonly used first-line drugs, isoniazid and rifampin, and second-line drugs used to treat MDR. In late 2012, shortages of isoniazid were reported by the CDC and many state public health departments (CDC, 2012f, p. 13); whereas in early 2013, rifampin shortages were reported (“Rifampin for Tuberculosis in Short Supply,” 2013). Most of the shortages have been attributed to failed manufacturing lots and priority given to global markets. Shortages for second-line drugs in the United States have been reported since 2005, primarily due to high demand and priorities internationally and manufacturing problems by major pharmaceutical manufacturers (McNamara, 2013). Manufacturing problems, in conjunction with very few new developed and FDA approved drugs, are another hurdle for effective treatment. In the past decade, only 10 potential viable drugs have progressed into the clinical development pipeline, with only 6

specific to TB (Ma, Lienhardt, McIlleron, Nunn, & Wang, 2010). In late 2012, Johnson & Johnson received FDA approval for a new class of anti-tubercule, Sirturo or bedaquiline, which has been shown to be effective against drug-resistant TB strains; however, it has been shown to work better with combined with other TB therapeutics and mortality rates from drug toxicity appear to be roughly five times higher than standard regimens (Thomas, 2012). Furthermore, Sutezolid (Sequella) is also in late stage clinical trials and continue to show promise, though faces similar hurdles (Maxmen, 2013; “New TB drug offers glimmer of hope in S.Africa,” 2015). With the help of Doctors Without Borders, the introduction of bedaquiline to MDR patients in Armenia is bringing hope to patients who had previously been unsuccessful on other therapies (Al Jazeera, 2014). While TB diagnostics continue to advance and improve rapid disease diagnosis, treatment shortages may prove to be yet another hurdle in effective TB disease management.

Current global health systems are not able to effectively diagnose and treat TB, particularly MDR-TB, primarily due to the inability to prevent treatment interruption during immigration (Tschampl, Garnick, Zuroweste, Razavi, & Shepard, 2016). Therefore, national and international surveillance of TB cases has been made top priority by national health ministries and the WHO. Within the United States, all 50 states and territories have TB control programs that report to national surveillance systems, Online Tuberculosis Information System (OTIS) and National Prevention Information Network (NPIN). Individual counties within the states also have TB control programs that serve to complement statewide and national systems. In an effort to improve international surveillance and treatment programs, the WHO has created subgroups or regions to

facilitate global case reporting. The WHO subgroups include the African Region, Region of the Americas, Eastern Mediterranean Region, European Region, South-East Asia Region, and the Western Pacific Region (WHO, 2012b). The Country of Armenia falls within the European Region. In 2012, there were a total of 182 Member states and 204 countries and territories actively collecting more than 99% of the world's TB cases reported data (WHO, 2012b). In 2003 to 2004, the CDC conducted a study on TB surveillance efforts in the Republics of Armenia and Georgia to investigate the impact of the fall of the Soviet Union on disease surveillance efforts. Overall, major improvements in TB public health efforts for both countries were needed; however, it was noted that in 2007 Armenia's National Tuberculosis Programme (NTP) was receptive to critique and stopped charging for TB services (Ehlman et al., 2007). This supersedes when Armenia's Ministry of Health began working in conjunction with Stop TB to reduce TB incidence, which occurred in 2010 (WHO, 2013). Furthermore, Armenia's MOH has been taking a more proactive approach by joining other at-risk Eastern European nations and establishing symposia to discuss TB-related issues. In 2015, Armenia hosted a TB symposium entitled "New treatments and approaches to Tuberculosis" (Medecins Sans Frontieres, n.d.).

Also incorporated into the WHO global surveillance program and the Millennium Development Goal (MDG) are Direct Observed Therapy Short Course DOTS and DOTs Plus programs in order to ensure treatment adherence. DOTS was first initiated in 1995 by the WHO and StopTB to improve treatment adherence by incorporating a supervisory healthcare worker to monitor patients taking the prescribed dosage of the treatment

regimen (Naidoo et al., 2009). Key components of an effective DOTS program include: (a) governmental commitment to controlling TB, (b) microscopic detection of symptomatic patients, particularly those seeking care, (c) short-course therapy with supervised treatment for at least the first 2 months, (d) systematic tracking of cases and outcomes, and (e) a reliable supply of anti-TB drugs (Nelson & Williams, 2007, pp. 666–667). While DOTS was initially viewed as an effective means to manage patient compliance with 20 million lives saved (WHO, 2012b), it is now viewed as being flawed with improvements needed. Much of the inconsistencies in success may be attributed to lagging government involvement, insufficient resources, and insufficient support systems (Naidoo & Mwaba, 2010).

DOTs Plus was initiated in 1999 by the WHO and its partners to monitor, manage, and improve outcomes for MDR-TB (WHO & StopTB, 2006). One of the main hindrances with DOTs Plus is the overall expense of the treatment regimen. Unless medications are supplied for free or at a severely discounted rate, there is no guarantee that a patient will comply with treatment. In Armenia, those with confirmed MDR or chronic cases that failed according to DOTS, receive DOTS-Plus. However, due to a shortage of state funds and anti-TB medications to complete the treatment regimen, individuals are forced to pay out-of-pocket and may not be able to do so because they are too expensive (Breitscheidel, 2006). In a pilot study looking into the benefits of DOTS implementation in Armenia, Georgia, and Azerbaijan in 1999, results looked promising where TB incidence significantly decreased after 3 months of treatment implementation

(Zalesky et al., 1999). However, similar studies have not been conducted recently, particularly after StopTB stepped in to assist Armenia's NTP in 2010.

With the advent of new virtual technological advances that allow for real-time communication, such as live streaming and Facetime, and the global availability of mobile devices, improvements in DOTs is possible. Mobile Direct Observation of Treatment (MDOT) and Virtually (video) Observed Therapy (VOT) are showing marked improvements in TB treatment adherence by bridging the gap between patient and caregiver interactions. Costs associated with travel and work absenteeism, along with the ability of the healthcare worker to visibly watch the patient take their medication shows some real promise in combating attrition (Hoffman et al., 2010; Story et al., 2016). While studies are still in their early phases, the WHO is beginning to incorporate digital product specifications into their diagnostics profiling requirements.

TB Susceptible Populations

Key populations that are highly susceptible to TB transmission, infection, and complications with treatment in both developed and developing countries include: HIV/AIDS patients, immigrants, the homeless, drug users, those in correctional facilities, and those low socioeconomic populations, of which the latter will be discussed in more detail in the qualitative and quantitative components below.

Those individuals co-infected with HIV present one of the largest challenges when trying to reduce TB transmission, morbidity, and mortality. Of the 9.6 million new TB cases in 2014, 13% were co-infected with HIV. Of the 1.2 million HIV-attributed deaths, 400,000 were co-infected with TB (WHO, 2015). Furthermore, infected

individuals with latent TB and HIV are more likely to develop active TB than those who are HIV negative due to a compromised immune system (CDC, 2012d). Aside from increasing the possibility of TB transmission, treatment is compromised. For individuals with drug susceptible TB, a minimum treatment of 6 months of first-line anti-tubercule drugs is recommended; however rifampicin has been shown to adversely interact with many anti-retroviral drugs (CDC, 2012c; Maartens & Wilkinson, 2007). Furthermore, concurrent treatments require a large amount of pills to be taken on a daily basis. Pill count was found to be a deterrent when complying with treatment for both diseases (Gebremariam, Bjune, & Frich, 2011). Therefore, DOTS is highly recommended for disease management for such cases. In an effort to reduce HIV and other co-infections of opportunistic infectious diseases (e.g., TB, Hepatitis, syphilis), many countries attempted to restrict travel of HIV positive individuals, Armenia being one of them. Here there were no restrictions for travelling within the country; however those foreign HIV positive travelers requesting visas for long term stays were denied visas. Proof of HIV-negative status was also required for granting of a visa. While the WHO found that such a policy had no significant impact on disease spread, such policies have remained in place though Armenia is reportedly working on changing such regulations (Lazarus, Curth, Weait, & Matic, 2010).

Aside from HIV co-infected individuals, immigrant populations are responsible for many of the TB cases, particularly in the United States. In 2011, immigrants within the United States were responsible for 62% of all TB cases with a case rate 11.5 times higher than U.S. born individuals (CDC, 2012d). This is primarily attributed to

reactivation of latent TB (CDC, 2012e; Mathema, Kurepina, Bifani, & Kreiswirth, 2006). Upon reactivation, they have no or insufficient health care to take care of the extensive treatment regimen. An altered short course rifampin and pyrazinamide is available for this group but problems with hepatotoxicity and adherence results in no real improvement. Because of problems associated with hepatotoxicity, there is also a large distrust of the American medical system for TB care (Kandula et al., 2004). As a result, the CDC, state and local health departments have mandatory domestic TB screening of refugees which not only identifies positive LTBI cases but also facilitates effective treatment for those immigrants directly affected and their family members (CDC, 2012e; Los Angeles County Department of Public Health, n.d.).

The homeless population also present challenges for controlling TB transmission rates. The homeless tend to suffer from poor mental and physical health, substance abuse problems, and insufficient health care that exacerbate the problem of TB transmission. At the beginning of 2013, spikes in TB were experienced in LA County's homeless population, Skid Row ("Tuberculosis Outbreak Among Homeless In Los Angeles, Calif. [VIDEO]," 2013). Furthermore, as a means of controlling the homeless population, law enforcement often times incarcerate them with deleterious effects on disease transmission rates. In a 2004 study by the CDC, the source of a TB infection in Kansas was linked to a homeless man, whom had presented with bloody sputum to a shelter's physician. There was no follow-up by the patient and was subsequently jailed in multiple facilities in Kansas. While still presenting with bloody sputum in these facilities, a tuberculin test or chest x-ray was not administered and he was eventually released back into the public

while still infected with TB. Contact investigations were conducted and two of his cellmates had active infections and 19% were diagnosed with latent TB (CDC, 2004).

In the United States and abroad, inmates in correctional facilities rank high among sources of TB within the infected population. Correctional facilities can be viewed as “incubators” for disease, where environmental and behavioral conditions contribute to high TB incidence (Beckwith, Zaller, & Rich, 2006). People from diverse backgrounds (e.g., immigrants, homeless, drug users, and HIV infected) live in close proximity for extended periods of time, participate in high risk behaviors, and have poor medical care, all of which facilitate rapid TB transmission (Dara et al., 2013). As a consequence, inmates are estimated to have a 17 times higher rate of TB than the general U.S. population (Lobato, Roberts, Bazerman, & Hammett, 2004). Reported barriers to treatment adherence among the incarcerated include unemployment, co-morbidity, malnutrition, and substance abuse and desired incentives for treatment compliance include financial, food, and employment (Fry et al., 2005). Following an inmate’s release, there is also great potential for TB to be brought into the general population and community, particularly when left undiagnosed and untreated. Similarly, workers at correctional facilities are also at risk for infection and can become vectors for bringing the infection out into the general population.

Similar trends are seen among incarcerates as compared to the general population worldwide (Dara et al., 2013). In the former Soviet Union, MDR-TB rates have been reported to be significantly higher in correctional facilities than the general population (Stuckler, Basu, McKee, & King, 2008). In an effort to reduce this alarming statistic, the

investigators proposed that the implementation of PCR-based detection systems, albeit more expensive, was better in the long run for effectively diagnosing and treating the disease (Winetsky et al., 2012). In Armenia specifically, TB and MDR-TB rates are reportedly higher in the incarcerated and former incarcerated (Breitscheidel, 2006; Grigoryan et al., 2008). This is attributed to poor living conditions, malnutrition, poor general health and hygiene, and lack of coverage by DOTS. Furthermore, prisoners with TB enter into the general community and may later be re-incarcerated again, contributing to the transmission cycle (Figure 2). Family, visitors, and prison staff are also at risk for developing active pulmonary TB (Breitscheidel, 2006).

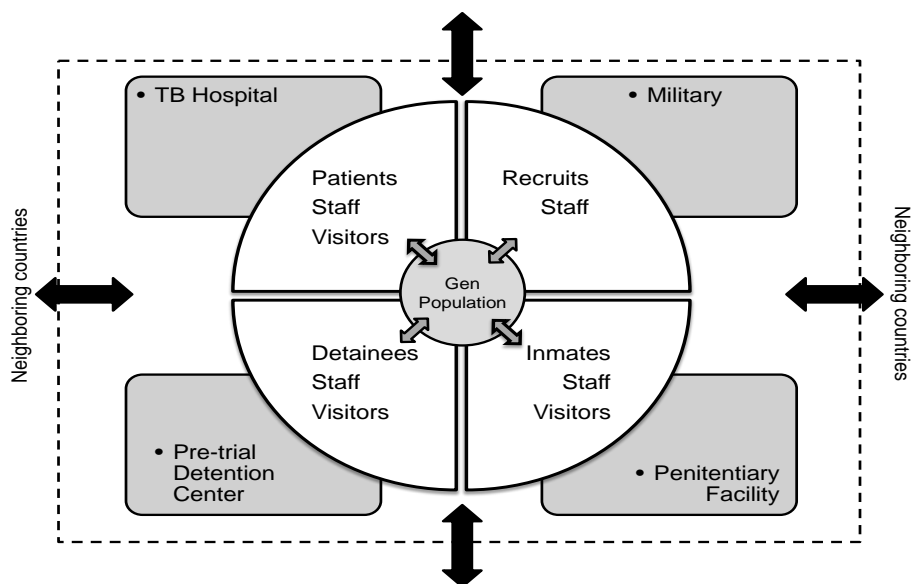


Figure 2. TB transmission cycle in Armenia, relative to the incarcerated and general population. Adapted from “Tuberculosis in Armenia: still an open question,” by L. Breitscheidel, 2006. *The Internet Journal of Infectious Diseases*, 5(2).

Qualitative Component

The qualitative aspect of this mixed-methods study explored perceived barriers to treatment-seeking and adherence for TB in an Armenian population living within the

United States. While several systematic reviews have been conducted on qualitative studies addressing barriers and facilitators to TB treatment adherence, literature specific to Armenians living in the United States and their native country is severely lacking. Barriers to treatment-seeking and adherence in other populations, particularly immigrants, will be discussed in the next section, quantitative components.

A systematic review of current qualitative research investigating patient adherence to TB treatment was conducted by Munro et al. (2007) in order to get a comprehensive understanding of the dynamics relating to barriers to and drivers of TB treatment adherence. Of the over 7800 citations screened for, 44 were analyzed based on a set of established criteria. Reported factors by patients, caregivers, and health care providers were considered. Key factors and their interactions were broken down as structural (e.g., poverty and gender discrimination), social, health service, and personal factors. The investigators were not able to substantially identify a single factor effecting treatment adherence, but rather interactions thereof where it was recommended that new improved approaches should be patient centered with all influential factors being taken into account (Munro et al., 2007). Such an approach falls in line with the theoretical framework of the study, SEM, which is a dynamic model.

A second systematic review of qualitative research investigating the effectiveness of DOTS and TB management was conducted by Noyes and Popay (2007). A total of 58 studies were reviewed to address two main questions: (1) What does qualitative research tell us about the facilitators and barriers to accessing and complying with TB treatment? and (2) What does qualitative research tell us about the diverse results and effect sizes of

the randomized control trials included in the Cochrane Review? Overall, five themes were established: (a) socio-economic and material resources; (b) explanatory and knowledge systems; (c) stigma and public discourse; (d) sanctions, incentives, and support; and (e) social organizations and relationships (Noyes & Popay, 2007).

Furthermore, DOTS was found to be no more effective for ensuring treatment adherence than self-supervised drug administration which also suggests that more personalized treatment delivery systems need to be implemented.

In a study conducted by Tupasi et al. (2016), factors associated with loss to follow-up during MDR-TB treatment in a population in the Philippines were explored. In the case-control study of 273 adult patients, a five-level SEM model was used. It was found that two individual factors (alcohol abuse and general TB knowledge), two factors related to the healthcare setting (trust and support from staff, lack of assistance), and 1 factor relating to adverse reactions from treatment, particularly vomiting, were the most significant (Tupasi et al., 2016).

TB is debilitating to Armenia as a whole. In 2006, Breitscheidel, Stamenitis, and Bosch (2010) conducted an economic impact analysis of adult TB on the Armenian government. Based on yearly treatment costs of \$359 for smear positive and \$239 for smear negative individuals, the overall cost estimate for TB control in adults was \$1.41 million (USD). For a developing country like Armenia, this is prohibitively high resulting in insufficient resources to adequately treat and manage the disease and possibly contributing to the worsening of the epidemic in this country.

In a study looking into reasons for delayed TB treatment in Armenia, Schneider et al. (2010) interviewed 240 TB patients in two Armenian TB reference hospitals where questions regarding symptom recognition, time to seek medical attention after symptom onset, outcomes following their first medical visit, and when treatment was initiated following diagnosis. Significant factors associated with delayed medical attention included weight loss and fatigue, inability to recognize the symptoms as being TB, and inadequate diagnosis and/or referral after the first visit to the doctor (Schneider et al., 2010). Such findings suggest that enhanced knowledge regarding recognizing signs and symptoms of TB, along with improved medical care and staff would dramatically improve disease outcomes in Armenia.

In a 2008 report by Grigoryan et al. (2008) on behalf of the Center for Health Services Research and Development, American University of Armenia, a full assessment of the TB in Armenia was conducted. The assessment involved the investigation of the extent of disease burden, highly susceptible populations within the country, disease perceptions, diagnostic and treatment challenges, and methods of disease management improvement. The report found that highly susceptible populations included the homeless and the poor, migrant populations (particularly refugees), HIV co-infected, the incarcerated (current and former), orphans, those living in hospices and psychiatry hospitals, those with medical co-morbidities (e.g., pulmonary disease, diabetes, immunocompromised), those in close contact with TB infected individuals (e.g., school workers, municipal workers, health care, and public transportation), and drug users. Knowledge and attitudes regarding TB was very telling. In one survey, 91% could identify TB but

only half of those interviewed knew its mode of transmission. In another survey, the vast majority did not realize that TB was a public health problem, could not identify symptoms, and believed that they and their loved ones were not at risk. Social stigma is also high, where roughly 20% keep their family's TB status a secret. Furthermore, TB patients were ill-informed about the duration of treatment and the consequences regarding non-compliance or interrupted treatment (Grigoryan et al., 2008). All of these themes, in conjunction with an inadequate and burdened national TB control program, severely impact national TB management.

More specifically, Truzyan et al. (2015) looked at factors associated with TB incidence in Armenian migrants, who have shown a significant rise since the fall of the Soviet Union. Of the 95 migratory adults surveyed, 28.3% of respondents had MDR TB and 5.3% were co-infected with TB. Because many of the respondents were abroad when first diagnosed, time to treatment initiation and loss to follow-up upon returning to Armenia was significantly higher (Truzyan et al., 2015). Due to the increased potential for this group to spread the disease, as well as receive incomplete or inadequate treatment, the need for a global reporting and tracking system is clearly apparent and urged for by the researchers.

As can be seen from the few studies done on TB in Armenia, many of the inadequacies and barriers to treatment are associated with the lack of resources and funding allocated to the disease and the national health care system. While the Armenian National Tuberculosis Control Program has made great strides, much more needs to be done. However, studies regarding Armenians residing in their United States and their

perceptions regarding TB and access to health care could not be found in the literature.

Therefore, this study can address this gap.

Quantitative Component

A thorough understanding of barriers to treatment adherence is vital for complete disease management and control, regardless of the country afflicted. Reported psychiatric and psychosocial factors effecting treatment adherence include poverty, disease co-infection (e.g., cardiovascular, HIV, hepatitis), social stigma, unsupportive social and work environments, disbelief in the health facility and staff, helplessness, hopelessness, and depression (Fry et al., 2005; Kandula et al., 2004; Naidoo et al., 2009). Molecular factors also play a role, where genetic variation in both the host and the pathogen are highly influential in the efficacy of disease transmission (Mathema et al., 2006). All factors must be taken into account in order to achieve success. Individual or population-wide dynamics should be incorporated into a standardized basic model to see an impact on disease incidence. Therefore, a multifaceted approach will need to be implemented in order to achieve successful disease management and patient care.

The quantitative aspect of this mixed-method study sought to explore whether there are differences in barriers to treatment-seeking and adherence for TB in Armenian versus non-Armenian populations living in LA County and which factors (physical, cultural, psychosocial, behavioral) have the greatest influence. Here, the dependent variable, knowledge regarding TB treatment-seeking and treatment-adherence will be explored in relation to the independent variables, barriers or factors relating to TB treatment seeking and treatment adherence. As previously discussed, perceived barriers to

treatment in Armenians have been minimally explored in their native country but not in the United States. However, barriers to treatment in other populations, both in the United States and their native country, have been reported and will be discussed in order to ground the quantitative portion of the study.

TB burden has been shown to have a strong correlation with socio-economics: as socio-economics decline, TB burden increases. This is true within developed and developing countries, with the poorest countries having an even greater risk. In a study by Holtgrave and Crosby (2004), poverty, income inequality, and social capital had significant correlations with TB case rates in the United States. The CDC revealed similar findings in relation to TB, HIV, and hepatitis, and sexually transmitted diseases in an effort to improve interventions and bring these diseases to the forefront of public policy. Furthermore, TB rates among Hispanics and black populations is eight to nine times that of white populations (Sharpe, Harrison, & Dean, 2010). Similarly, as previously mentioned, immigrant populations are major contributors to increased TB incidence in the United States (CDC, 2012b; CDC, 2012d) and tend to fall within lower socioeconomic populations in the United States (Ho, 2004). Aside from monetary resources, social deprivation amongst many of the at risk populations (homeless, incarcerated, some immigrant populations) has been shown. However, the causal links between poverty, low socio-economics, and TB risk have not been pinpointed with certainty (Lönnroth, Jaramillo, Williams, Dye, & Raviglione, 2009). As sequencing technologies continue to evolve, more molecular factors and genetic variations in the host and the pathogen may fill this sociobiological gap.

For studies investigating psychological factors for TB treatment non-adherence, self-reporting of helplessness, anxiety, depression, social support, and quality of life were of primary concern. According to Carney and Freedland (2000, p. 200), depression has been found to have a profound impact on treatment adherence for many illnesses and therefore, such explorations are quite worthwhile and necessary. Severity of depression has been found to be related to duration of illness, disease severity, and response to therapy. Furthermore, it was found that in the presence of a great social support system (mainly comprised of family and friends), depressive symptoms were found to be decreased and/or relatively mild (Guo, Marra, & Marra, 2009; Naidoo et al., 2009; Naidoo & Mwaba, 2010). Some of the main causes of depression in TB patients which result in treatment non-adherence include altered social relationships, social stigma, financial burden and loss of income, lack of social support, and persistent cough and severity of symptoms (Issa, Yussuf, & Kuranga, 2009; Naidoo et al., 2009; Naidoo & Mwaba, 2010; Sulehri et al., 2010). Depression has also been reported in family members of those afflicted with the disease, which impacts social support for the patient (Ige & Lasebikan, 2011).

Perceived social stigma in particular, has been shown to have a significant effect on treatment initiation and adherence. Many investigators have reported that perceived stigma results in early defaulting on treatment (Liefoghe & Muynck, 2001; Munro et al., 2007; Naidoo et al., 2009; Naidoo & Mwaba, 2010). This may be further exacerbated by HIV co-infection where further stigma may be associated with the disease. Such feelings may be felt not only in the community but in the workplace and therefore feelings of

depression and the lack of desire to continue working may take place. As a consequence, it becomes imperative to educate the general public and those within the inner circle of the patient to improve general understanding about the disease and promote treatment adherence.

Summary and Conclusions

The preceding literature review provides a detailed representation of TB epidemiology, current problems relating to TB diagnosis, treatment, and patient management, vulnerable populations, and specific problems pertaining to the disease in Armenian populations. The extensive discussion relating to these topics reveals the dynamics surrounding the disease and how such interactions are central themes relating to the problem being investigated: barriers to treatment seeking and treatment adherence in a specific population, Armenians living in LA County in the United States. Such an understanding has significant public health implications for effective treatment management in this vulnerable population.

The theoretical framework and foundation explored further support the need for a dynamic approach for effective disease management. The social ecological model uses a multi-tiered approach for intervention where personal, social, and environmental influences are utilized. These play in nicely with current reported barriers to TB treatment seeking and adherence behaviors, which include psychological, psychosocial, physical, biological, and cultural factors. The latter becomes a central element to this study, where ethnography will serve as the theoretical foundation. Armenians are a proud group of people, rich in family ties, influences, and ancestral adages. An understanding of TB

knowledge and the interplay of cultural influences in the Armenian community will complement current understandings of perceived TB treatment barriers reported for other susceptible populations and groups.

The body of knowledge regarding TB epidemiology is vast and continues to grow due to the enormity and severity of the disease at a global level. A smaller subset of TB studies explores perceived barriers to treatment-seeking and adherence relative to susceptible populations. However, a serious gap exists in the body of knowledge relating to the Armenian community, both living in the United States and in Armenia. To the best of my knowledge, there are no studies of Armenians living in the United States with respect to TB or any other infectious disease behaviors or interventions. TB studies of Armenians living in Armenia exist, but are limited. Those addressing perceived barriers to treatment and knowledge are even narrower in scope.

In Chapter 3, the study design will be discussed, along with methodologies that will be used to effectively address such gaps. Chapter 3 includes the methodology utilized in this study to investigate the barriers to treatment-seeking and adherence in Armenian versus non-Armenian populations. Included in this chapter will also be a description of research design and approach, an understanding of the sample population with justification of the sample size used, diagnostic measures and instruments used to confirm disease prevalence and coding for barriers to TB treatment.

Chapter 3: Research Methods

Introduction

As identified in the literature review, there is a gap in knowledge about the perceived barriers to TB treatment-seeking and adherence of Armenians living in the United States— a susceptible population. Therefore, a mixed-methods study was conducted and focused on Armenians living in LA County. This chapter details the qualitative and quantitative methodological approaches that were used to investigate the TB knowledge, TB treatment-seeking and TB-adherence behaviors of Armenians versus non-Armenians living in LA County. This chapter will include specifics on participant selection and recruitment, the research setting, instrumentation, the pilot study, and data analysis.

Setting

Several settings were employed for this study until the proper sample size was met for each study. This was highly contingent on the success of recruitment for any given setting. All recruiting was done in LA County, with emphasis on SPA-2. Candidates were invited via social media and flyers, initially targeting local churches, church groups, and community centers located within the county. Quantitative surveys were administered online. More details on sampling and recruitment procedures are provided in the next sections.

Research Design and Rationale

The goal of this mixed-methods study was to explore the differences in factors relating to TB knowledge, such as (a) physical, psychosocial, cultural, or behavioral; (b)

treatment-seeking and adherence among Armenians and non-Armenian living in LA County; and (c) how such differences may impact the reduction of TB incidence in this susceptible population. The purpose of this concurrent mixed-methods study was to address the following research questions and hypotheses:

1. What are the perceived barriers to treatment seeking and adherence for tuberculosis in an Armenian population living within the United States?
2. Is there a difference in barriers to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations living in Los Angeles County and which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence?

H_A^2 : There are differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

H_0^2 : There are no differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

Ethnography was one aspect of this study. Ethnography involves full immersion in the culture under study in order to get a clear picture of daily life events, family dynamics, and social interactions to enhance the observer's ability to describe such events and perceptions in detail (Robson, 2011, p. 142). Due to the extensiveness of ethnography studies, they typically take a long time to conduct (Robson, 2011, p. 143); however, having had significant Armenian influences throughout my life, these

experiences were leveraged not only for expediently accessing the population but also relating to participants. Further immersion on my part as the researcher involved the ability to converse with participants in their native language, if need be. Therefore, Armenian language courses were pursued in conjunction with assistance from Armenian speaking family and friends. This was critical when preparing the questionnaire, pretesting the questionnaire, and conducting final interviews of participants.

The mixed-methods study is a convergent parallel design. This design is an intuitive and efficient approach whereby two different methods are utilized to obtain triangulated results about a singular topic (Creswell & Plano Clark, 2011, pp. 77–78). In this study qualitative and quantitative data were collected concurrently, analyzed, and then merged during interpretation of the data (Figure 3). The rationale for combining both quantitative and qualitative data is to better understand this research problem by converging numeric trends and detailed data in an effort to reduce morbidity and mortality associated with TB incidence and prevalence in Armenians. Such an approach is common when the researcher is interested in triangulating methods by making direct comparisons and contrasts between quantitative statistical results with qualitative findings for validation purposes (Creswell & Plano Clark, 2011, p. 77). Furthermore, a more complete understanding of the ethnographic influences may be achieved with such an approach.

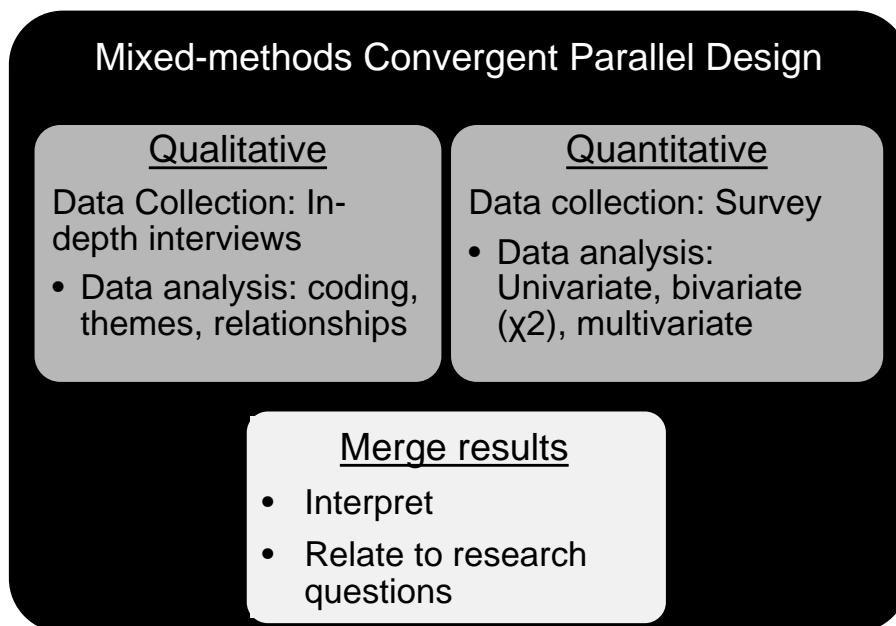


Figure 3. Basic schematic for this mixed-methods convergent parallel design study. Adapted from *Designing and Conducting Mixed Methods Research* (p. 118), by J. Creswell and V. Plano Clark, 2011, Los Angeles, CA: SAGE Publications, Inc.. Copyright 2011.

The qualitative aspect entailed conducting in-depth interviews of Armenians and non-Armenians living in LA County to understand general perceptions about TB, along with perceived barriers to TB treatment and treatment adherence. Ethnography was emphasized here where shared beliefs, behaviors, and knowledge relating to TB treatment-seeking and adherence among Armenians and non-Armenians were explored. Using SEM as the foundation for the theoretical framework and belief or behavioral patterns of the culture-sharing Armenian group in Glendale and surrounding areas, appropriate interviews and questionnaires were administered for data collection. The quantitative aspect of this study used a survey to explore whether such barriers to treatment-seeking and adherence differ in Armenian versus non-Armenian individuals residing in LA County, with potential implications for reducing disease incidence. Here,

an association between the dependent variable, knowledge regarding TB treatment-seeking and treatment adherence, and the independent variables, barriers or factors relating to TB treatment-seeking and adherence was explored. Such factors included demographics (Armenian versus non-Armenian), socioeconomic, cultural, behavioral, and/or individual beliefs. Furthermore, differences in such perceived barriers and characteristics from other non-Armenian populations have been assessed.

In concurrent mixed-methods studies data collected from the qualitative study and quantitative study are analyzed separately and then merged. The merged results from data analysis are then related back to the research questions (Creswell & Plano Clark, 2011, p. 221). Data analysis strategies will be described in detail later in this chapter.

Role of the Researcher

In ethnography, researcher involvement can vary depending upon the level of immersion desired. Generally, both observation and participation within the group's natural setting is required (Robson, 2011, p. 144); therefore, my role was an observer-participant with more emphasis on being a participant particularly during the qualitative portion of the study where in-depth interviews were conducted.

Personal and/or professional relationships were avoided. For those in the local Armenian community in particular, there was the possibility that the researcher might be familiar with the participant; however, those who have been in close contact with the researcher throughout the years were strictly avoided in order to prevent bias or ethical dilemmas.

Methodology

Participant Selection

The participants involved with this study were Armenians and non-Armenians living in LA County. The goal of the study is not to make generalizations but to get an in depth and comprehensive understanding of potential treatment-seeking and adherence behaviors and factors in Armenians versus non-Armenians living in LA County. For the qualitative portion of the study, sampling was purposeful and non-probabilistic where individuals were selected based upon proximity, availability, and ethnicity, following Walden's IRB approval (number 04-24-14-0230517). With respect to proximity, individuals had to reside in LA County. Furthermore, ethnicity designation is an important selection criterion where both Armenians and non-Armenians living in the area are necessary. Aside from ethnicity, efforts were made to match participants closely based upon other characteristics such as gender, age group, and zip code or city of residence.

The primary method of purposive sampling involved snowball sampling. This approach may be implemented when one or more individual from the population of interest is identified and once interviewed, they are asked to identify other potential members of the population (Robson, 2011, p. 275). Primary access was gained through local Armenian churches, church groups, community centers and businesses in LA County (primarily SPA-2). A similar approach was used for selecting non-Armenian participants.

For the quantitative element, both Armenian and non-Armenian participants were selected based upon convenience sampling. Here, the closest and most convenient persons were recruited in a continual manner until the appropriate sample size was reached (Robson, 2011, p. 275). Ethnicity was the principal factor for recruiting potential participants: Armenian or non-Armenian. LA County has a diverse racial make-up where 71.6% are White, 9.3% Black, 14.5% Asian, 1.5% American Indian, 0.4% Native Hawaiian/Pacific Islander, and 2.8% multiple races. Of the White population, 48.2% are classified as Hispanic or Latino and 27.3% as White alone, including Armenians (U.S. Department of Commerce, 2013). Therefore, racial breakdown was selected for with further stratification of “White” to differentiate Armenians from non-Armenians. For the data analysis, further stratification of race may be required to determine if there are significant differences among specific races, such as Armenians versus Hispanics.

For both studies, ethnicity was the primary selection criterion, although participants had to speak and read English or Armenian fluently. Participants were not excluded based on gender and were adults, and therefore ≥ 18 years of age. Current TB positive patients and those with latent TB were excluded; however, patients who had undergone treatment and were TB negative were not discouraged from participating. For data analysis, stratification based upon previous TB history may be required. Participants were required to live in LA County, which was verified with proper identification and compared to a list of zip codes or city names in LA County (County of Los Angeles, 2011). Zip codes within SPA-2 (County of Los Angeles Public Health, n.d.-b), which

includes the city of Glendale, were preferred. Participants were pre-screened to ensure that these criteria were met.

To facilitate recruitment for both studies, invitations were provided via social media, flyers, or in the case of snowball sampling, were given to participants following participation to explain the study to potential future participants. For social media, a Facebook page was set-up specifically for the studies. Linked-In and Reddit (Reddit.com) were also utilized, with a link to the Facebook site provided. For other recruitment approaches utilizing flyers, the invitation was posted in public areas in the region of interest, upon permission from the proprietor or from other participants in the case of snowball sampling. For continuity, the Facebook page and flyer were similar in appearance and content (see Appendices H, I, J, and K). The researcher could be contacted via personal e-mail or through a personalized Quick Response (QR) code that was scannable with a smart device, such as a cell phone or tablet.

For the qualitative part of the study, 10 Armenians and 8 non-Armenians participated in the in-depth interviews addressing TB knowledge and perceived barriers to treatment-seeking and treatment adherence. With qualitative studies, there appears to be more ambiguity when determining appropriate sample size. According to Rudestam and Newton (2007, p. 107), 20 to 30 participants may be regarded as a sufficient sample size, though others whom are representatives of grounded theory believe 5 to 6 participants are sufficient. An important factor for determining an appropriate sample size in qualitative studies is saturation in order to fully develop a model or concept (Creswell, 2012, pp. 88–89). Here saturation is desirable where all possible answers or trends have

been revealed and there is no added benefit in interviewing additional participants (Robson, 2011, p. 148). This was taken into account when conducting interviews for the qualitative study, though original proposed numbers were found to be suitable. Due to the implementation of a convergent parallel design for this study, those who participated in the qualitative study were not eligible to participate in the quantitative study. Following the completion of the qualitative interview process, participants were given a \$10 Target gift card to extend appreciation for their involvement in the study.

For the quantitative component, the recruitment of 200 participants was proposed: 100 Armenians and 100 non-Armenians living in LA County. Participants were recruited using social media and flyers, as described previously. Surveys were administered online using the online survey tool, SurveyGizmo (www.surveygizmo.com).

Calculation of sample size was done a priori using correlations reported in the literature regarding reported barriers to treatment in various populations and social determinants effecting TB incidence in the United States. In a study by Holtgrave and Crosby (2004), correlations between societal predictor variables and TB cases were calculated using Pearson's correlation coefficient (r). From this, coefficients of determination (r^2) were calculated, which were used to determine effect size for this study. Coefficients ranged from 0.132 to 0.485, depending upon the variable. No such information was available in the literature for Armenians living in Armenia or in the United States. Therefore, using G* Power 3 calculator software (<http://www.psych.uni-duesseldorf.de/abteilungen/aap/gpower3/>) and Exact test parameters of bivariate normal mode and an alpha level of 0.05, effect sizes range from 0.363 to 0.696, with resulting

sample sizes of 92 and 20, respectively. Since information on this population is less defined in the literature, an effect size of 0.363 was used and thus, roughly 100 Armenians and 100 non-Armenians were desired for surveying.

Instrumentation: Qualitative

The qualitative study involved in-depth interviews with Armenians and non-Armenians to get a thorough understanding of TB knowledge and perceptions relating to the disease and treatment. Since this study was relatively unique, the interview guide with open-ended questions was generated by the researcher; however, several pre-tested questionnaires were used to generate some of the reference questions (Bakalian, 2011, pp. 476–494; Jakubowiak et al., 2008; Xu et al., 2009). Interviews were tape recorded, with permission from the participants, and were referenced when any questions or ambiguities in response scripts arose.

Data triangulation was exercised to establish validity. Here, more than one method of data collection was utilized (Creswell & Plano Clark, 2011, pp. 209–210; Robson, 2011, p. 158) where transcripts were cross-checked with interview recordings. Furthermore, the dissertation supervisor (V.M.) examined accuracy of transcription, coding, and resulting common themes and conclusions. Proper coding and subsequent interpretation is important for integrating themes with quantitative study results. Questionnaires were administered in English and Armenian, with pretesting serving as a means to validate the translation of the questions. Furthermore, someone fluent in Armenian was available to administer or clarify questions to native Armenian speaking participants.

For the culturally relevant questions pertaining to Armenians, Bakalian (2011) provided many pertinent questions relating to the study topic. In this study, the author was interested in learning about challenges with assimilation faced by Native Armenians as they immigrated to the United States. The questionnaire was mailed to Armenians living in the New York and New Jersey area as part of the author's dissertation at Columbia University in the field of Sociology. Furthermore, in a study by Xu et al. (2009), a mixed-methods approach was used for studying TB treatment adherence and barriers to adherence in China. Insight from healthcare workers was also solicited, which was a consideration for this study. Some examples of the open-ended questions in the interview guide are the following (See Appendix B for Armenian translation):

Basic background information – Armenian participants

1. Did you emigrate from Armenia?
 - a. How long have you lived in the United States?
 - b. In what city are you currently residing?
2. Do you read/write Armenian? How well?
3. Is Armenian spoke in your household? If so, how often?
4. Do you read Armenian literature, watch Armenian TV programs (e.g., Armenian Teletime), or listen to Armenian radio?
 - a. If yes, which ones?
 - b. How often?
5. Do you patronize businesses or seek professional assistance (e.g., medical doctors) because they are Armenian?

6. Are you involved with community activities or organizations (e.g., Armenian Church, Massis Guild, Ararat Home)? Which ones?
7. Do you have *kapoot ach* (blue eye) in your residence?

Basic background information – non-Armenian participants

1. Did you emigrate from another country?
 - a. If yes, which country?
 - b. How long have you lived in the United States?
 - c. In what city are you currently residing?
2. Do you read/write in another language? Which one?
3. Is English the primary language spoken in your household? If no, what other language is spoken?
4. Are you involved with community activities or organizations? Which ones?

General Background questions - all

1. What year were you born?
2. What is your marital status?
3. Please describe your residence type. Do you own or rent?
4. How many people are living in your household?
 - a. Please describe relation to you.
 - b. Please describe gender and ages of each.
5. What is your highest level of education?
6. What is your occupation?

7. What is your total annual household income (pre-tax)?
8. Do you have health insurance?
9. How frequently do you visit a local physician annually? Do you trust your local physician?
10. When either you or family/friends are diagnosed with any disease, do you seek spiritual guidance?
11. When you are feeling sick, do you use home remedies such as massages, herbs, oils, drink herbal or spiced teas? Which ones specifically?
 - a. If yes, do you practice this prior to seeking help from a physician?
 - b. Upon visiting a physician, do you continue the use of home remedies while under a physician's care?

TB specific questions - all

1. Are you familiar with the disease, tuberculosis (TB)? If yes, please describe what you know about it, including modes of transmission.
2. Is TB infectious to others? Please describe.
3. Have you heard about recent reports of tuberculosis cases in the news?
 - a. In the United States?
 - b. In other countries? Which ones?
4. Is TB a treatable disease?
 - a. What do you know about the treatment?
 - b. Are any of these factors a deterrent for seeking or adhering to treatment? Which ones?

5. If TB is mentioned by family, friends, or news reports, what are your initial reactions and feelings?
6. If you re diagnosed with TB in the future (or have been diagnosed in the past), what will be/have been your feelings towards this event?
7. If someone in your family, close friends, or colleague mention that he/she has TB, what will be your feelings towards this event?
8. Has anyone in your family been diagnosed with TB?
 - a. If yes, did your behavior toward him/her change?
 - b. Describe how you felt when you learned of the diagnosis.
9. Are you aware of TB treatment facilities in Los Angeles County and the services provided?
 - a. If no, if information was made available, (perhaps in Armenian for Armenians only), would you be more inclined to read about the disease?
 - b. Would you inform others in your community?
10. Are you aware of any social or community support groups for dealing with the disease? If yes, please describe.

Instrumentation: Quantitative

Pilot Study

In order to determine comprehensibility and appropriateness of the quantitative survey, a pilot study was conducted. According to Creswell (2012, p. 165), pilot testing is advisable for refining questions and research instruments, assess bias, and adapt research

procedures. For this study, the preliminary quantitative research instrument was distributed to a panel of experts with qualifying credentials (e.g., PhD for at least five years in academia or research within the scientific community). The instrument was administered in paper form and through the online forum, SurveyGizmo, in order to also assess the test-taking environment. Revisions to the instrument were made according to recommendations and feedback by the panel. Subsequently, a small sample (15 to 20 people) was selected to pilot test the revised survey. Participants for the pilot study were both Armenian and non-Armenians living in LA County and were recruited in the same fashion as the main study (flyers, consent forms etc.). This was also conducted in the same online test-taking environment as the officially launched study.

Survey

For the quantitative portion of this mixed-methods study, a pre-tested survey questionnaire was administered to roughly 200 participants, approximately 100 Armenian and 100 non-Armenian, to further understand TB knowledge in the two populations and to determine if there are differences among the two groups. Questions were similarly phrased as in the qualitative study; however, questions were closed-ended and options were provided in more of a Likert scale format to facilitate quantitation and data analysis. Some questions allowed for the participant to fill-in a response as well as select multiple options.

A key threat to validity and reliability for quantitative studies involves instrumentation, which in this case was the survey questionnaire. An original questionnaire was generated in order to ensure cultural sensitivity and relevance to the

Armenian community. This presented some challenges because, as an original questionnaire, assurances regarding its validity and cohesiveness may be lacking. Therefore, pretesting was required to ensure questionnaire appeal and ease of comprehension. To remove some ambiguity, the questionnaire was provided in English and Armenian. Pretesting also ensured that all translations were comprehensible and accurate.

Questions included in the survey questionnaire were (See Appendix C for Armenian translation):

Basic background information

1. How old are you?
 - a. 18-20, b. 21-30 c. 31-40, d. 41-50, e. 51-60, f. 61-70, g. > 70 years old
2. What is your gender?
 - a. Male b. Female
3. What is your race?
 - a. White, non-Hispanic or Latino, b. White, Armenian, c. White, Hispanic or Latino, d. Black / African American, e. Asian, f. American Indian / Alaskan native, g. Native Hawaiian or Pacific Islander, h. two or more races, Armenian i. two or more races, non-Armenian
4. What is your ethnicity?
 - a. Non-Hispanic, Latino, or Spanish origin, b. Mexican, Mexican-American, Chicano, c. Puerto Rican, d. Cuban, e. other Hispanic, Latino, or Spanish origin (e.g., Argentinian, Columbian, Dominican, Salvadoran)

5. What is your country of origin (fill in)? _____
6. How many years have you been living in United States?
 - a. a. less than 1 year b. 1-5 years c. 6-10 years d. 11-20 years e. > 20 years
7. What city do you currently reside in?
 - a. Glendale, b. Pasadena/South Pasadena, c. Burbank, d. San Fernando, e. Santa Monica/West Los Angeles, f. Downey/Montebello/South Gate, g. other _____
8. What is your marital status?
 - a. Single, never married, b. married, c. divorced, d. widowed, e. separated
9. How many people are living in your household (excluding yourself)?
 - a. 0, b. 1 c. 2-4, c. 5-6, d. > 6
10. Describe their relationship to you? (select all that apply)
 - a. Spouse or partner, b. child, c. sibling, d. elderly parents or grandparents, e. other _____
11. Is English the primary language spoken in your household? a. yes b. no
12. What other languages are spoken in your household?
 - a. Armenian, b. Spanish, c. none, d. other _____
13. What is your highest level of education?
 - a. High school, b. some college, c. bachelor's degree, d. graduate / professional degree
14. What is your occupation?

- a. Unemployed, b. retired, c. homemaker, d. student, e. professional (doctor, lawyer, teacher), f. manual laborer (skilled or unskilled worker)

15. What is your total annual household income (pre-tax)?

- a. 0-\$25,000, b. \$25,001-\$40,000, c. \$40,001-\$60,000, d. \$60,001-\$80,000, e. \$80,001-\$100,000 f. > \$100,000

16. Do you have health insurance? a. yes, b. no

17. Do you trust your primary care physician? a. yes, b. no, c. I don't have one

18. Do you seek spiritual guidance upon diagnosis of any disease, either for you or family/friends? a. yes, b. no

19. When feeling sick, do you use home remedies (e.g., massages, herbs, oils, drink herbal or spiced teas)? A. yes, b. no

TB specific questions

1. Have you heard of the disease tuberculosis (TB)? a. yes, b. no

2. How have you heard about TB? (check all that apply)

- a. TV, b. Internet, c. family or friends, d. newspaper/magazine e. other_____

3. Do you believe that TB is a modern day health problem in the US? a. yes, b. no

4. Do you believe that TB is a modern day health problem internationally?

- a. yes, b. no

5. How is TB transmitted?

- a. Coughing, sneezing, b. touching, c. sexual contact, d. food/water ingestion, e. smoking, f. imbalance of hot and cold, g. do not know
6. What is the most common symptom of TB?
 - a. Coughing, b. sneezing, c. loss of appetite, d. tiredness/fatigue, e. bleeding, e. do not know
7. Are you aware of treatment available for treating TB? a. yes, b. no
8. How long is the treatment regimen?
 - a. 3 days, b. 1 week, c. 1 month, d. > 6 months, e. do not know
9. Is TB treatment 100% effective? a. yes, b. no, c. do not know
10. Is TB a curable disease? a. yes, b. no, c. do not know
11. If TB is mentioned by family, friends, or news reports, what are your initial reactions and feelings?
 - a. Frightened, b. informed, c. indifferent, d. helplessness
12. Have you or anyone in your family been diagnosed with TB? a. yes, b. no
13. If yes, how did you feel? (select any that apply)
 - a. Frightened, b. informed, c. indifferent, d. helpless, e. depressed
14. What factors do you associate with TB? (select any that apply)
 - a. Poverty, b. foreign-born, c. HIV status, d. drug history, e. low social class, f. sexual orientation, g. mental illness, h. religion, i. a common disease, k. a curable disease, l. smoking, m. imbalance of hot and cold, n. incarceration
15. If someone has TB, you think that (select any that apply):

a. he/she probably did something wrong, for example use of drugs, b. it's a punishment given by the God, c. he/she has the disease because of his/her racial background, d. it could happen to anyone

16. If you had TB, would you:	1 Strongly disagree	2 Disagree	3 No Opinion	4 Agree	5 Strongly Agree
a. Trust doctors to cure it?					
b. Be compliant with doctors' instructions regarding treatment?					
c. Seek treatment outside the hospital/ private practice setting					

17. If you would seek treatment outside of a hospital/ private practice setting, where would you go? (select any that apply)

- a. Chiropractor, b. Acupuncturist, c. Homeopathic doctor/nutritionist, d. Religious/ church leader, e. massage therapist, f. home remedies (herbs, oils, teas), g. I wouldn't.

18. Are you aware of TB treatment facilities in Los Angeles County and the services provided? a. yes, b. no

19. If no, if information was made readily available, would you be more inclined to read about the disease and inform others in your community? a. yes, b. no

20. Are you aware of social support groups in your community for dealing with the disease? a. yes b. no

Recruitment, Participation, and Data Collection

All participants were recruited using social media and flyers in public places such as local churches, church groups, community centers and businesses located within LA County. Participant recruitment for the qualitative study also involved snowball sampling, as described earlier, in order to gain access to Armenians and non-Armenian living in LA County, primarily SPA-2. The project goals were outlined and informed consent was obtained in order to move forward with the in-depth interviews as well as with the completion of the surveys. Furthermore, participants were alerted to the fact that a follow-up may be required if there are ambiguities in responses or if something required clarification. An Armenian speaker was present for Armenian participants to ensure that all intentions and goals were understood, and also provided a signed confidentiality agreement in order to be included in the study.

For those who responded positively to the invitation, an email and phone number of the researcher was made available to all interested parties. A separate email and phone number was set-up by the researcher to maintain professionalism and exclusivity to the study. For those completing the quantitative survey online, the letter of consent (Appendices D, E, F, and G) was checked to reflect participant willingness to agree to study terms and participate. They were available in English or Armenian, depending upon participant preference. Upon completion, a thank you was generated. A \$10 Target gift card was also provided as compensation for those who participated in the qualitative component of the study.

All data have been stored electronically, with backups on a separate password protected computer. Furthermore, recordings for the qualitative interviews were copied and serve as a backup in case the original becomes compromised from overuse or researcher error during transcription.

Data Analysis

In the study, perceived barriers and factors were explored using in-depth interviews and surveys with Armenians and non-Armenians in the community. For the qualitative component, data and coding were divided based upon key words or phrases for each question, with the use of Microsoft Excel and Word software. Also, these data were analyzed thematically. Microsoft Word can be used for “coding and retrieving, semi-automated coding and inspection, creating hierarchies of code categories via indexing, global editing of theme codes, coding of ‘face sheet’ data, exploring relationships between face-sheet codes and conceptual codes, quantifying the frequency of code instances, and annotating text” (LaPelle, 2004). Further, thematic analysis was selected since it is a widely used approach for detecting, analyzing and reporting themes within qualitative data (Braun & Clarke, 2006). The six phases of analysis were the following: familiarizing with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes and finally producing a scholarly report of the analysis (Braun & Clarke, 2006).

For the quantitative component, the goal is to explore whether there are differences in barriers to treatment-seeking and adherence for TB in Armenian versus non-Armenian populations living in LA County and which factors (e.g., physical,

cultural, psychosocial, behavioral) have the greatest influence (Table 1). First, all data was entered into Statistical Program for Social Sciences (SPSS; IBM Corporation, version 21). Then, since all variables of the study were categorical, frequencies were calculated and reported. Second, bivariate analysis (chi-square test) was used to test the strength of associations between independent (barriers or factors relating to TB treatment seeking and adherence, such as ethnicity, demographics, cultural beliefs etc.) and dependent variables (knowledge regarding TB treatment seeking and treatment adherence). Finally, the estimates of the relative risks of the dependent variable were reported by calculating the odds ratios (ORs) and the corresponding 95% confidence intervals (CIs), using multinomial logistic regression analysis (for more details on the statistical procedures, see Table 2). The dependent variable was knowledge regarding TB treatment seeking and treatment adherence and predictors were all the aforementioned independent variables. Significant confounders, as well as interactions were retained in the models. Deviance residuals were calculated to evaluate the model's goodness-of-fit. All reported probability values (p-values) were compared to a significance level of 5%.

In order to integrate the data from the qualitative and quantitative studies, the data were analyzed separately and then merged. The merged results from data analysis were then related back to the research questions.

Table 1
Variables, Research Questions, and Items on Surveys

Research Question	Variable	Item number(s) in Survey
1. What are the perceived barriers to treatment seeking and adherence for Tuberculosis in an Armenian population living within the United States?	1. Ethnicity/race (IV)	“TB Specific” #14, 15
	2. Cultural beliefs (IV)	“TB Specific” #14, 15
	3. Demographics (IV)	“TB Specific” #14, 15
	4. Religion (IV)	“TB Specific” #15, 17
	5. Knowledge (DV)	“TB Specific” # 1-13, 16, 18,19
2. Is there a difference in barriers to treatment seeking and adherence for Tuberculosis in Armenian versus non-Armenian populations living in LA County and which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence?	1. Ethnicity/race (IV)	“Basic background information” # 3, 4; “TB Specific” #14, 15
	2. Cultural beliefs (IV)	“Basic background information” #17, 19; “TB Specific” #5, 14, 15
	3. Demographic (IV)	“Basic background information” # 1, 2, 5-15, “TB Specific” #14, 15
	4. Religion (IV)	“Basic background information” # 16, 18; “TB Specific” #15, 17
	5. Knowledge (DV)	“TB Specific” # 1-13, 16, 18, 19

Note. IV = independent variable; DV = dependent variable

Table 2
Statistical Procedures Per Research Question and Hypothesis

Research Question	Hypothesis (Ha)	Variables	Statistical Procedure/ Analysis
RQ2: Is there a difference in barriers to treatment seeking and adherence for TB in Armenian versus non-Armenian populations living in LA County and which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence?	There are differences in factors relating to treatment seeking and adherence for TB in Armenian versus non-Armenian populations in LA County	IV: barriers / factors DV: TB knowledge	1. Univariate: Frequency 2. Bivariate: Chi-square test (χ^2) 3. Multivariate: Multinomial Logistic Regression (Odds Ratios (ORs) and Confidence Intervals (CIs))

Threats to Validity

When a study is tailored to a specific population, threats to external validity occur through generalizability (McKenzie, Neiger, & Thackeray, 2009, p. 369). With this

particular study, the focus was on Armenians residing in LA County. LA County is home to the second largest population of Armenians in the country and world (Hayk the Ubiquitous Armenian, 2012), and therefore it is believed that it the study involves a representative pool. However, the social and economic factors impacting the study may not be generalizable to Armenians living in other parts of the world. Furthermore, cultural elements will be specific only to Armenians, and possibly those living the former Soviet Union, and may therefore lack generalizability to other populations. However, the goal of this study was to address the gap in developing suitable public health intervention TB programs specific for this at-risk population.

Sampling validity is also a potential concern. Here, the concern is whether the target population is adequately sampled by the instrument being used to measure or address the question. This is a problem when investigators construct and employ instruments for the first time (Frankfort-Nachmias & Nachmias, 2008, p. 150). Due to the specificity of this study design as it relates to a specific population, sampling validity may have become a threat. However, pilot testing was conducted ahead of time to ensure that the questionnaires were adequately measuring what they were intended to measure.

Trustworthiness

This mixed-methods study addresses the issue of credibility through the use of triangulation and peer review. Triangulation, the use of multiple methods of data collection to test hypotheses and measure variables (in this case qualitative and quantitative data, using convergent parallel design), is a useful strategy for limiting the validity of scope and minimizing specificity relating to a particular method of data

collection (Frankfort-Nachmias & Nachmias, 2008, p. 189). In this study, both in-depth interviews and questionnaire surveys were utilized. The in-depth interviews allowed for observation of participant as well as verbal content to each question. At the end of both studies, analyzed data were merged. If the findings obtained from the two collection methods concur, then the validity of findings are increased (Frankfort-Nachmias & Nachmias, 2008, pp. 189–190). Triangulation further established dependability of the study. Furthermore, the dissertation supervisor (V.M.) was incorporated to serve as a peer-reviewer to ensure proper interpretation of responses and results. This also serves as a means to improve dependability of the findings.

Transferability is similar to generalizability in that it can threaten the validity of a study if the population is too limited. Again, one component of this study was an ethnography focusing on Armenians living in LA County. Should other researchers attempt to replicate these finding, alterations may need to be made to accommodate specific attributes of the population being studied.

Ethical Considerations

This study was conducted in accordance with guidelines established by Walden University's IRB, approval number 04-24-14-0230517. All necessary IRB documentation is shown in Appendix A, which addresses access to participants, appropriate treatment of participants, and institutional permissions.

With research involving human subjects, ethics must always be considered and addressed in order to protect participant's basic human rights. Robson (2011, p. 200) has

highlighted ten questionable practices in social research that will be avoided and addressed in this study (Table 3).

Table 3

Ten Questionable Practices in Social Research

- 1** Involving people without their knowledge or consent
 - 2** Coercing them to participate
 - 3** Withholding information about the true nature of the research
 - 4** Otherwise deceiving the participant
 - 5** Inducing them to commit acts that may diminish self-esteem
 - 6** Violating rights of self-determination
 - 7** Exposing participants to physical or mental stress
 - 8** Invading their privacy
 - 9** Withholding benefits from some participants
 - 10** Not treating participants fairly, or with consideration, or with respect
-

When recruiting and enrolling participants, the project was explained clearly both verbally and in writing. For Armenian participants, an Armenian translator was made available during the qualitative component. All questionnaires were made available in Armenian. Upon acceptance, participants were required to read and sign the letter of consent form (Appendices D and E), reflecting their understanding of the project and their involvement. Confidentiality was ensured for the qualitative component; whereas anonymity and confidentiality was ensured for the quantitative component. Each participant was given a randomized code, which were used throughout the entire process, including data analysis. The peer-reviewer was not privy to any participant's name or information.

Data, including coding logs, were stored in a locked file cabinet, off-premises from the researcher for 5 years. Subsequent to this, all data, including transcripts and coding logs, will be destroyed.

Summary

This concurrent mixed-methods study is designed to address the gap that exists in the body of knowledge regarding perceived barriers to TB treatment-seeking and adherence relative to a susceptible population, Armenians living in the United States, namely LA County, and in Armenia. This was achieved through in-depth interviews and surveys designed to assess TB knowledge and treatment-seeking and adherence behaviors in Armenian versus non-Armenians living in LA County, using the convergent parallel design. Measures to ensure internal and external validity in the study, along with ethical concerns, were also addressed. Data analysis and interpretation of the two studies were conducted and then merged.

Chapter 4 will detail the results and findings from the two components of the study.

Chapter 4: Results

Introduction

The purpose of this mixed-methods study was to explore factors (physical, psychosocial, cultural, or behavioral) relating to TB knowledge, treatment-seeking and adherence among Armenians living in LA County and compare them to non-Armenian living in LA County. Such differences may impact the reduction of TB incidence in the highly susceptible Armenian population. To understand the general perceptions about TB, along with perceived barriers to TB treatment and treatment adherence in both groups, the qualitative component of this study used in-depth interviews of both Armenians and non-Armenians living in LA County. A survey was used with the quantitative component to explore whether such barriers to treatment-seeking and adherence differ between Armenians and non-Armenians living in LA County, which have implications for reduction in the incidence of disease. Both survey instruments were original and required pretesting or pilot testing prior to administration.

Research question 1 (RQ1) was a descriptive inquiry whereas Research question 2 (RQ2) was inferential in nature:

RQ1. What are the perceived barriers to treatment seeking and adherence for tuberculosis in an Armenian population living within the United States?

RQ2. Is there a difference in barriers to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations living in Los Angeles County and which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence?

H_A^2 : There are differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

H_0^2 : There are no differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

This chapter details the data collection methods and data analyses from both the qualitative and quantitative components. For the qualitative element, responses were tabulated using Excel and common themes extracted and organized Word. For the quantitative element, SPSS, version 21, software was used to conduct univariate, bivariate, and multivariate analyses of the data. The findings from both study components were further triangulated and themes merged and related back to the research questions.

Pilot Study

A pilot study was conducted for the quantitative survey to ensure comprehensiveness, appropriateness, and lack of bias of the questions, invitation, and testing forum. The preliminary quantitative research instrument was distributed in paper form and through the online forum to a panel of experts with qualifying credentials (e.g., PhD for at least five years in academia or research within the scientific community). Once feedback was provided by the expert panel, minor revisions were made to the survey instrument which included minor wording of question to remove ambiguities. Subsequently, a small sampling of 35 people comprised of 17 Armenians and 18 non-Armenians living in LA County were recruited in the same fashion as the main study

(flyers, consent forms etc.). Of the 35 recruited participants, 23 completed either the paper version, online version, or both. All participants were asked to keep track of time to completion and the invitation was adjusted to reflect the average time. Criticisms relating to the questions as originally proposed or the test taking environment were minimal. Some changes that were made included allowing participants to specify/ fill-in responses for the “other” option for background question SQ7 and tuberculosis-specific questions SQ2 and SQ13. This helped in further clarifying and stratifying answers for data analysis. Upon incorporating the suggested changes, the official study was launched in the online forum, SurveyGizmo.

Setting

For both the qualitative and quantitative component, Armenian translated questionnaires and surveys were made available to Armenian participants. Furthermore, an Armenian translator was available for all Armenian participant interviews. Initial questionnaire and survey questions were translated by a fluent Armenian speaker, whom is also employed as an English-Armenian translator. The questionnaires and surveys were translated into Western Armenian, as opposed to Eastern Armenian, because the primary dialect spoken in LA County is Western Armenian. While the two dialects have many similarities, any participants whom were more familiar with Eastern may have encountered minimal confusion. All of the translations were then back-translated to verify validity and accuracy of the questions by an unrelated Armenian speaker, whom is fluent in both Eastern and Western dialects. This individual also served as the translator for the face-to-face interviews. As recommended by Walden’s IRB committee, a

confidentiality agreement and NIH Human Subjects training were completed by the translator.

Demographics

For both the qualitative and quantitative study, participants living in LA County were recruited and classified as either Armenian or non-Armenian. A participant was classified as Armenian if they were born in Armenia, emigrated from Armenia, were two or more races (one of which being Armenian), and/or were born in the United States and speak Armenian in their household. All such information was extracted from various questions on both surveys and questionnaires. Furthermore, participants were required to live in LA County and be at least 18 years of age. Several participants from the quantitative study were removed post-participation due to the lack of fulfillment of these requirements.

Data Collection

Qualitative Component

For the qualitative study, the goal was to recruit 15-25 participants over 18 years of age living in LA County, with relative equal distribution between classifications of Armenian and non-Armenian. Ultimately, 10 Armenians and 8 non-Armenians met the specified criteria and were interviewed face-to-face. Table 4 summarizes the overall demographics of the Armenian and non-Armenian participants. The Armenian contingent has spent fewer years living in the United States than the non-Armenian group, though the age distribution is relatively the same among groups. This suggests that the

Armenians are likely more first and second generation where cultural traditions may be more influential.

Table 4
Characteristics of Individuals Interviewed about Tuberculosis Knowledge and Perceptions (n = 18)

Characteristics	No. of Individuals, Armenians (%)	No. of Individuals, Non-Armenian (%)
Classification	10	8
Gender		
Male	2 (20)	3 (37.5)
Female	8 (80)	5 (62.5)
Age		
18-30	3 (30)	1 (12.5)
31-40	0	2 (25)
41-50	1 (10)	2 (25)
51-60	3 (30)	0
>60	3 (30)	3 (37.5)
Country of Origin		
Iran	5 (50)	1 (12.5)
Iraq	3 (30)	0
Lebanon	1 (10)	0
Mexico	0	1 (12.5)
Romania	0	1 (12.5)
United States	1 (10)	5 (62.5)
Years in United States		
≤ 20 years	6 (60)	1 (12.5)
> 20 years	4 (40)	7 (87.5)
City Residing In LA County		
Altadena / Pasadena	2 (20)	5 (62.5)
Glendale	8 (80)	1 (12.5)
Granada Hills	0	1 (12.5)
Rancho Cucamonga	0	1 (12.5)
Marital Status		
Single, never married	3 (30)	1 (12.5)
Married	3 (30)	5 (62.5)
Divorced	1 (10)	2 (25)

(table continues)

Widowed	3 (30)	0
Separated	0	0
Residence Type		
Apartment, rent	0	1 (12.5)
Condominium, own	1 (10)	0
House, own	6 (60)	5 (62.5)
House, rent	3 (30)	2 (25)
Number of People in Household (excluding self)		
0	2 (20)	1 (12.5)
1	0	1 (12.5)
2-4	6 (60)	5 (62.5)
5-6	2 (20)	1 (12.5)
Primary Language Spoken in Household		
Armenian	10 (100)	0
English	0	5 (62.5)
Spanish	0	2 (25)
Other	0	1 (12.5)
Educational Level		
High School	2 (20)	3 (37.5)
Some College	0	0
Bachelor's Degree	6 (60)	4 (50)
Graduate/Professional Degree	2 (20)	1 (12.5)
Occupation		
Unemployed	0	0
Retired	1 (10)	3 (37.5)
Homemaker	3 (30)	0
Student	1 (10)	0
Professional	5 (50)	4 (50)
Manual Laborer	0	1 (12.5)
Annual Household Income		
\$0-\$40,000	6 (60)	1 (12.5)
\$40,001-\$100,000	3 (30)	4 (50)
>\$100,000	1 (10)	3 (37.5)
Health Insurance		
Yes	7 (70)	7 (87.5)
No	3 (30)	1 (12.5)
Trust Primary Care Physician		
Yes	7 (70)	7 (87.5)
No	2 (20)	1 (12.5)
Don't have one	1 (10)	0
Annual visits to Physician		
0-1	7 (70)	2 (25)
2-4	1 (10)	5 (62.5)

(table continues)

5-6	1 (10)	1 (12.5)
>6	1 (10)	0
Use Home Remedies		
Yes	10 (100)	8 (100)
No	0	0
Seek Spiritual Guidance		
Yes	6 (60)	4 (50)
No	4 (40)	4 (50)

Recruitment for the qualitative component was purposive and relied primarily on snowball sampling, as proposed. Overall, recruitment spanned over a period of two months, from February through the end of March of 2015. Many of the face-to-face interviews were conducted at the participant's residence or a friend's residence. This may have contributed to the participant's willingness to consent and conduct the interviews and therefore be open with their responses due to their increased comfort level. All interviews were recorded, with prior knowledge and consent by the interviewee. On average, each interview took ten minutes. Following the recorded interview, time was taken to explain tuberculosis, its history, and relevance to today in more detail. All participants appeared quite interested and appreciated this extra effort in order to understand that TB remains a public health threat, particularly among the Armenian community living locally and in their native country.

Quantitative Component

For the quantitative study, it was proposed to recruit 200 participants over 18 years of age living in LA County, half of which were Armenian and half non-Armenian. Overall, a total of 130 participants completed the survey; however, three were removed

from the study due to residing outside of LA County. This resulted in a final tally of 72 non-Armenians (56.7%) and 55 Armenians (43.3%) qualified participants. The resulting post-hoc power analysis was satisfactory > 0.90 . This was determined using G* Power 3 calculator software (version 3.1.4) and logistic regression test, an alpha level of 0.05, and an odds ratio of 0.347 (for “TB route of Transmission” as the dependent variable, with the weakest obtained significant p value, 0.05) as determined below in data analysis (Table 12).

Table 5 provides a summary of the demographics pertaining to both participant populations. More females participated in the survey than males (62.2% vs 37.8%), with the majority of participants living in the United States more than 20 years (89%). The latter observation is a more skewed than in the qualitative study where the populations were more even evenly distributed, with the Armenians having spent less time in the United States (< 20 years). Furthermore, 67.7% of participants were classified as professional (e.g., doctor, lawyer, teacher) and 50.4% have an annual household income $> \$100,000$, potentially impacting socioeconomic implications. While the majority of respondents trust their primary care physician (86.6%), 66.1% also rely on home remedies for personal medicinal therapy and 70.9% do not seek spiritual guidance upon receiving diagnosis of a disease for themselves or close family/friends.

Table 5
Descriptive Statistics – Demographic Variables (n = 127)

Demographic	Frequency (f)	Percent (%)
Classification	127	
Armenian	55	43.3
Non-Armenian	72	56.7

(table continues)

Gender		
Male	48	37.8
Female	79	62.2
Age		
18-30	32	25.2
31-40	49	38.6
41-50	28	22.0
>50	18	14.2
Race		
White, Non-Hispanic/Latino	55	43.3
White, Armenian	37	29.1
White, Hispanic/Latino	10	7.9
Black, African American	1	0.8
Asian	8	6.3
2 or more, Armenian	12	9.4
2 or more, non-Armenian	4	3.1
Ethnicity		
Non-Hispanic, Latino, or Spanish Origin	109	85.8
Mexican, Mexican American, Chicano	9	7.1
Cuban	1	0.8
Other Hispanic, Latino, or Spanish Origin (e.g., Argentinian, Columbian, Salvadoran, Dominican)	8	6.3
Country of Origin		
Armenia	4	3.1
Canada	1	0.8
Egypt	1	0.8
El Salvador	1	0.8
European Countries	2	1.6
Hong Kong	1	0.8
Iran	3	2.4
Japan	1	0.8
Lebanon	9	7.1
Mexico	1	0.8
Philippines	2	1.6
Turkey	1	0.8
United States	100	78.7
Years in United States		
≤ 20 years	140	11.0
> 20 years	113	89.0
City Residing In (LA County)		
Glendale	9	7.1
Pasadena/South Pasadena	31	24.4

(table continues)

Burbank	5	3.9
San Fernando	2	1.6
Santa Monica/ West Los Angeles	8	6.3
Downey / Montebello / South Gate	4	3.1
Other	68	53.5
Alhambra	4	3.1
Altadena	3	2.4
Azusa	1	0.8
Canoga Park	1	0.8
Cerritos	2	1.6
Claremont	5	3.9
Glendora	3	2.4
Hollywood	2	1.6
La Crescenta	1	0.8
La Habra	1	0.8
La Verne	1	0.8
Long Beach	5	3.9
Los Angeles	10	7.8
Monrovia	1	0.8
North East LA	1	0.8
Northridge	4	3.1
Norwalk	1	0.8
Pomona	4	3.1
Porter Ranch	3	2.4
Reseda	1	0.8
San Dimas	2	1.6
San Gabriel	1	0.8
Santa Clarita	1	0.8
Shadow Hills	1	0.8
South Bay	1	0.8
Sun Valley	1	0.8
Sunland	2	1.6
Tujunga	2	1.6
Upland	1	0.8
Venice	1	0.8
Winnetka	1	0.8
Marital Status		
Single, never married	53	41.7
Married	67	52.8
Divorced	4	3.1
Widowed	1	0.8
Separated	2	1.6
Number of People in Household (excluding self)		

(table continues)

0	15	11.8
1	25	19.7
2-4	81	63.8
5-6	5	3.9
>6	1	0.8
<hr/>		
Household Relation		
Spouse/ Partner	37	29.1
Spouse/Partner, Child	39	30.7
Spouse/Partner, Child, Elderly parent/ grandparent	1	0.8
Spouse/Partner, Child, Other	1	0.8
Spouse/Partner, Elderly parent/ grandparent, other	2	1.6
Spouse/Partner, other	1	0.8
Child	6	4.7
Child, Elderly parent/grandparent	1	0.8
Sibling	3	2.4
Sibling, Elderly Parent / grandparent	11	8.7
Elderly Parent / grandparent	5	3.9
Other	5	3.9
Friend	3	2.4
Housemate / Roommate	4	3.1
Niece	1	0.8
Whole family	1	0.8
<hr/>		
English Primary Spoken Household Language		
Yes	106	83.5
No	21	16.5
<hr/>		
Primary Household Language (non-English)		
Armenian	40	31.5
Spanish	8	6.3
None	72	56.7
Other	7	5.5
Arabic	1	0.8
Armenian, Russian	1	0.8
German	1	0.8
Korean	1	0.8
Mandarin	1	0.8
Russian, Turkish	1	0.8
Turkish, Arabic	1	0.8
<hr/>		
Educational Level		
High School	7	5.5
Some College	26	20.5
Bachelor's Degree	46	36.2

(table continues)

Graduate/Professional Degree	48	37.8
Occupation		
Unemployed	4	3.1
Retired	4	3.1
Homemaker	9	7.1
Student	18	14.2
Professional (e.g., lawyer, doctor, teacher)	86	67.7
Manual Laborer	6	4.7
Annual Household Income		
\$0-\$40,000	21	16.5
\$40,001-\$100,000	42	33.1
>\$100,000	64	50.4
Health Insurance		
Yes	120	94.5
No	7	5.5
Trust Primary Care Physician		
Yes	110	86.6
No	3	2.4
Don't have one	14	11.0
Seek Spiritual Guidance		
Yes	37	29.1
No	90	70.9
Use Home Remedies (herbs, teas, etc.)		
Yes	84	66.1
No	43	33.9

The survey was administered online through SurveyGizmo over the span of 8 months, from July 2014 to February 2015. Recruitment was again purposive where snowball sampling was the primary mode, relying on social media and paper flyers distributed in local businesses in the community to initiate awareness regarding the study. Recruitment proved to be challenging overall, which is likely due to the vastness of LA County despite extensive efforts by the investigator using the aforementioned avenues. Recruitment of the Armenian population proved to be particularly challenging as compared to non-Armenians despite the flyers and survey being made available in

Armenian. An additional fourteen participants, the majority being Armenian, failed to complete the survey and were thus eliminated from the participant response pool and subsequent data analysis. Here, all of the questions relating to demographics were completed with attrition occurring once tuberculosis-related questions were encountered.

Data Analysis

Qualitative Component

During each of the face-to-face interviews, a paper interview guide (Chapter 3 and Appendix B) was used for each individual to direct the flow of the interview questions and allow for note-taking, while everything was being voice recorded. This was also the case for those requiring the Armenian translator. Once all of the face-to-face interviews were completed, the recorded interviews were played repeatedly until every word was transcribed verbatim. The researcher also met with the Armenian translator on a separate occasion to transcribe all of the Armenian respondents verbatim. Copies of the written transcripts were de-identified and provided to the peer reviewer.

To facilitate finding themes, the responses to each question by each respondent were tabulated in an Excel spreadsheet. From there common themes and subthemes were identified and coded in Microsoft Word. Key themes and sub-themes relating to disease transmission and infectivity, incidence (national and international), treatment, and feeling and reactions to the disease were identified and tabulated for each population, see Tables 6 and 7 (Armenian and non-Armenian, respectively).

Quantitative Component

The quantitative survey was administered using SurveyGizmo which facilitated data analysis as all question results can be exported directly to Excel or SPSS. Also, outside of SurveyGizmo, a codebook was generated based on responses for each question (Appendix L). Some glitches relating to coding when exporting directly from SurveyGizmo to SPSS were discovered, so Excel was used as an intermediary. Once all of the responses from completed surveys were exported into Excel, they were first checked for qualifications (resident of LA County and 18 years or older). Three participants were disqualified based on these criteria. The responses were then coded using the codebook for each question and respondent using extensive “if-then” statements in Excel. All of the coded data were then input into SPSS to check for errors. Any missing values were designated as “999”. These coded data were cross checked by the peer-reviewer to ensure that no errors were present and that data analysis could proceed.

Results

Qualitative Component

Following the face-to-face interviews, the oral responses from the 10 Armenian (A) and 8 non-Armenian (NA) participants were transcribed verbatim. Two of the Armenian participants required the translator to be present during the interview and the translator subsequently assisted in translating the responses for the researcher. Furthermore, one of the Armenian participants (A10) had limited English skills, unbeknownst to the researcher. The translator was not present at the time of the interview; however, a family member was able to provide some assistance. Therefore,

information gathered from this respondent was limited. Following this, all responses were tabulated using Microsoft Excel. Themes and subthemes for each population were then analyzed in more detail using Microsoft Word (LaPelle, 2004).

RQ2 addresses factors relating to TB knowledge and perceptions (e.g., physical, cultural, psychosocial, behavioral) in Armenians and non-Armenians living in LA County, and to determine differences among the populations. TB-related responses were broken down and grouped based on disease knowledge and awareness, and disease perceptions. Knowledge- and awareness-based questions explored mode of transmission, incidence, ability to treat, and familiarity with treatment facilities and support programs. Perception-based questions explored personal reactions to hearing about the disease, either on the news, by a close family member or friend, or if they were to hypothetically personally contract the disease.

As can be seen in Tables 6 and 7, there are some similarities and differences in responses between the two populations. Both populations had general vague knowledge as to how TB is transmitted, its molecular properties, degree of infectivity, and national and international incidence. Both also felt like there “should be” a treatment available but didn’t have any details on regimen; however, only the Armenian population acknowledged the availability of a vaccine. When it came to perceptions and feelings about the disease, the Armenian population expressed more empathy, an overt willingness to help someone with the disease, desire to seek treatment or urge others to seek treatment, and seek spiritual guidance and outside education for themselves or others. When asked, all of the Armenian respondents had *kapoot ach* (blue eye) in their

homes, with A9 responding “Yes, it’s all around. It’s something an Armenian family has to have!” The non-Armenian population appeared more trepid, less willing to help others and urge them to seek treatment, and less open to seek spiritual guidance; however, they were very willing to educate themselves about the disease.

Table 6
Thematic Analysis of Tuberculosis Knowledge and Perceptions by 10 Armenian Adults

Theme / category	Subcategory	Selected Extract(s)
<i>TB Mode of transmission</i>	<i>Variable routes of transmission</i>	“Not so familiar with TB, think it’s airborne.” (A2) “Transmits, I think it’s a virus. Transmitted through bodily fluids.” (A6) “Transferred through mouth, cough, and close relations or contact.” (A7)
	<i>Awareness of infectivity</i>	“Contagious, in my time growing up TB patients weren’t allowed to stay inside at home. They were taken outside because very contagious or go to private hospital and stay there for years.” (A4)
<i>TB incidence</i>	<i>Unfamiliar with reports</i>	“Couple of incidence in the U.S. I didn’t follow-up but heard of that there were such things in different states.” (A1) “No, just Ebola!” (A9)
<i>TB treatable</i>	<i>Ignorance if curable</i>	“Should be treatable because it is bacterial. Like every other disease, depends upon level of how far you are and how damaged.” (A3) “For preliminary stages, yes, otherwise no.” (A5)
	<i>Ignorance of treatment</i>	“I think there is a medicine or pill for it. When I got my skin test, I was told not to go into the sun but I did anyway and it changed color. Therefore, I was given a prescription for medicine but never took it.” (A8)
	<i>Vaccine availability</i>	“There was an outbreak a long time ago and they couldn’t control it. They found vaccine for it, I think there is a vaccine for it.” (A6)
<i>Reaction if TB mentioned or contracted by others</i>	<i>Empathetic initial reaction</i>	“Going to be sad because person will endure a lot.” (A4) “Sad because it is a dangerous disease and try to prevent getting contaminated by using masks.” (A5) “Initially feel that they could be going through a lot of stress and pain, but would want to comfort them even though that is not really my personality.” (A6)

(table continues)

	<i>Overt willingness to help</i>	“Go visit and help. I’m not afraid of getting sick.” (A3) “I would try to help the person and support them and be there for them and comfort them.” (A8)
	<i>Spiritually influenced</i>	“Going to be careful around person and pray for them.” (A4)
	<i>Pro-active in providing advice for seeking treatment</i>	“I would feel sorry for them and make them seek treatment.” (A1)
	<i>Desire to improve disease knowledge</i>	“I would be curious as to how I could get it (e.g., from a person coughing). How is it transmitted? I would read about it more and inform myself.” (A8)
<i>Reaction if diagnosed with TB</i>	<i>Varied Initial reactions</i>	“I would be immediately angered but family would help me relax but I would still think about it.” (A6) “If I knew it was deadly, I would try hard to not let it kill me.” (A9)
	<i>Eager to seek treatment</i>	“I would stay away from everybody as soon as possible and start treatment as soon as possible.” (A1) “I would stay away from everybody and get complete treatment before going back into society.” (A5)
	<i>Seek outside knowledge or spiritual guidance</i>	“I would try to gain as much knowledge about the disease, read day and night in order to break it down and analyze it more as a physician. Secondly, try to use personal logic gained to see if maybe herbal medicine will help or maybe change environmental for a limited time.” (A3)
<i>Awareness of TB treatment facilities or support groups in LA County</i>	<i>Completely unaware</i>	“Aware of groups for drugs and all that, but not for TB unfortunately.” (A1) “Not specifically for TB but aware of clinics that offer but can’t tell for certain if only TB but assuming that there a lot clinics available for diagnosing or testing.” (A3)
<i>TB information seeking</i>	<i>Majority interested in information and informing others</i>	“No, not interested unless it becomes personal and am able to help them but would not seek in general.” (A3) “Yes, would love to hear more to know what’s going on and happening with the disease.” (A4)

Table 7
Thematic Analysis of Tuberculosis Knowledge and Perceptions by 8 Non-Armenian adults

Theme / category	Subcategory	Selected Extract(s)
<i>TB Mode of transmission</i>	<i>Variable routes of transmission</i>	<p>“TB is a blood disease or immune disease. Maybe sexually transmitted”. (NA1)</p> <p>“Disease that starts in the lungs, transmitted by viral, air, coughing. Transmitted using things that were in contacted with person that carries the disease, like drinking from same cup.” (NA5)</p> <p>“I don’t really know much about it. I’m assuming it is transmitted through moisture, saliva, sneezing, and maybe blood transfusions.” (NA7)</p>
	<i>Awareness of infectivity</i>	<p>“My understanding that it was a communicable disease and they had sanitariums for it.” (NA4)</p> <p>“Highly infectious. I have to be tested regularly as a public servant who works with children.” (NA6)</p>
<i>TB incidence</i>	<i>Unfamiliar with reports</i>	<p>“Don’t recall in the past few years, but measles has. There’s more incidence of cancer than TB.” (NA6)</p> <p>“It’s prevalent in poor countries that don’t have resources.” (NA7)</p>
<i>TB treatable</i>	<i>Ignorance if curable</i>	<p>“My assumption is that it’s treatable (and treatment is available) based on the fact that most diseases are, but don’t know if is life-saving or just prolong death.” (NA1)</p> <p>“Once you get it and don’t get medical attention, it’s very seldom that you thrive from it.” (NA3)</p>
	<i>Ignorance of treatment</i>	<p>“Don’t know specifics about treatment.” (NA7)</p> <p>“Treatable now but years ago it wasn’t.” (NA8)</p>
	<i>Vaccine availability</i>	<i>Vaccine not mentioned by any NA participant.</i>
<i>Reaction if TB mentioned or contracted by others</i>	<i>Trepid initial reaction</i>	<p>“Afraid to come in contact with person.” (NA3)</p> <p>“Concerned, if a family member. If in the news, then it could start an epidemic, so I would be concerned.” (NA5)</p>
	<i>Covert willingness to help</i>	<p>“It depends upon how close to me is in the neighborhood, then would be leery about going around and visiting or making contact.” (A3)</p> <p>“I would probably stay clear and would suggest that</p>

(table continues)

		they make everything possible so they don't contaminate other people." (NA5)
	<i>Non-spiritually influenced</i>	<i>There was no mention of praying for others or seeking outside spiritual guidance by any NA participants.</i>
	<i>Non-proactive in emphasizing treatment seeking activities</i>	<i>There was no mention of advising others to seek treatment upon mention of a diagnosis amongst NA participants.</i>
	<i>Desire to improve disease knowledge</i>	"I would start researching from many different sources (e.g., colleges and doctors) and compile my own thoughts." (NA1) "I would educate myself on what I can or cannot do around them to know how the possibility of transmission." (NA7)
Reaction if diagnosed with TB	<i>Trepid Initial reaction</i>	"I would be scared. Am I going to live? Could I give it to my kids?" (NA1) "I've never been diagnosed, but if I were I would be shocked." (NA5)
	<i>Willing to seek treatment</i>	"I would definitely seek medical treatment." (NA5) "I wouldn't be scared. It's just like any other disease and would go to doctor." (NA8)
	<i>Seek outside knowledge or guidance</i>	"I would immediately research to see exactly how scared I would be and how transmissible it is." (NA1)
Awareness of TB treatment facilities or support groups in LA County	<i>Completely unaware</i>	"Not aware but feel like there is because there are support groups for everything (e.g., drug abusers, sexual abusers, cancer, death). Don't know specifics on location. Don't know anyone who would seek it out unless had the disease." (N1) "Used to have a sanitarium in the Foothills many years ago (~50 years ago)." (N4)
TB information seeking	<i>Concordant interest in information and informing others</i>	"Yes, love educating self. Knowledge is power." (NA1). "If it were brief and not a book, yes would want to know if it was existing." (NA4)

Some of the questions not relating to TB yielded similar responses in regards to doctor trust, the use of home remedies, and spiritual guidance, with positive outlooks on

most accounts (Tables 4 and 8). For both groups, the majority (> 80%) expressed great trust in the ability of their doctor to effectively diagnose and treat any given disease; however, a minority ($\leq 20\%$) expressed a harsh distrust. Both groups had a similar distribution of individuals who seek spiritual guidance upon receiving news of a disease diagnosis for either themselves or close family/friends and those who don't. Overall, all participants opted for the use of home remedies, either prior to seeking a doctor's consultation and/or most continued taking the home remedy following prescription of treatment by a doctor.

Table 8
Thematic Analysis of Non-tuberculosis Perceptions by 10 Armenian and 8 Non-Armenian Adults

Theme / category	Subcategory	Selected Extract(s)
<i>Doctor Trust</i>	<i>Positive Outlook</i>	A1: "I don't have a particular one, but I should trust who I get." NA1: "Yes, but all are prone to error and some tests don't find things, for example cancer, heart condition, etc. Once see a physician, I trust them enough to ask for advice."
	<i>Negative Outlook</i>	A3: "Absolutely not!" NA5: "No!"
<i>Spirituality</i>	<i>Highly Spiritual</i>	A6: "Yes, the first thing I and my family does is seek spiritual guidance." NA1: "I'm a spiritual person but not religious, I do self-prayer but wouldn't physically seek it at a church or mosque. I would seek the best doctors in the world first."
	<i>Non-Spiritual</i>	A7: "No, goes to the doctor." NA7: "No, but some family might pray but not me personally."
<i>Use home remedies</i>	<i>Teas most preferred</i>	A4: "Yes, mint tea and Turkish tea." NA3: "Yes, it depends upon what it is at the time. There are certain herbs and teas that grow in yard (mint and mint bark)."
	<i>Alternative remedies</i>	A6: "My family and I give each other massages and I stay in bed." A4: "Massages on occasion."

Quantitative Component

RQ1 identifies the perceived barriers to TB treatment-seeking and adherence within the Armenian population surveyed in LA County. The independent variables (IV) include ethnicity/race, cultural beliefs, demographics, and religion, with knowledge being the dependent variable (DV). To address this, a univariate analysis was performed by comparing frequencies of responses for each question for those participants classified as Armenian. The responses were subsequently tabulated, including associating each question to specific independent variables to facilitate data interpretation (Table 9).

Questions relating to TB knowledge reveal that 98.2% of Armenians have heard of TB, with a singular source of knowledge coming from family and friends (27.8%) or school (12.7%) or a combination of sources such as TV, Internet, family/friends, and newspaper/magazines (11.1%). Armenian respondents believe it is a modern day health problem in the U.S. (63.6%) and internationally (89.1%), with coughing and sneezing as the primary mode of transmission (63.6%). While 54.5% believe there is a treatment available for TB, the majority of respondents are unaware of the duration of treatment regimen (61.8%), whether it is 100% effective (54.5%), or if the disease is curable (30.9%). 94.5% of the Armenian participants have never been diagnosed or know someone who has been diagnosed with TB and 41.8% feel informed at the mention of the disease. Factors associated with TB were found to be vast, with 20.9% believing it is a curable disease and 90.9% believing that contracting the disease could happen to anyone. If contracted, 92.7% trust their physician to cure it (58.2% strongly agree and 34.5% agree), 80% would comply with treatment recommendations (67.3% strongly agree and

12.7% agree), and 50.9% would not seek treatment outside of a hospital setting (23.6% strongly agree, 27.3% agree), though 76.4% also utilize home remedies.

Table 9
RQ1. What are the Perceived Barriers to Treatment-seeking and Adherence for Tuberculosis in an Armenian Population Living within the United States? (n = 55)

	Survey Question	Frequency (f)	Percent (%)	Associated Variable(s)
1	Heard of Tuberculosis			
	Yes	54	98.2	Knowledge
	No	1	1.8	
2	How have you heard about TB?			
	TV	5	9.3	Knowledge
	Internet	2	3.7	
	Family or friends	15	27.8	
	Newspaper/magazine	0	0	
	TV and Internet	1	1.9	
	TV and newspaper/magazine	1	1.9	
	Internet and family/friends	1	1.9	
	Internet and newspaper/magazine	1	1.9	
	Family/friends and other	4	7.4	
	Newspaper/magazine and other	1	1.9	
	TV, Internet, family/friends	5	9.3	
	Internet, family/friends, newspaper/mag	1	1.9	
	Internet, family/friends, other	1	1.9	
	TV, Internet, family/friends, newspaper/magazine	6	11.1	
	Other	10	18.5	
	Common Knowledge	1	1.8	
	Doctor	2	3.6	
	Health Center	1	1.8	
	Health Industry	1	1.8	
	Research	1	1.8	
	School	7	12.7	
	Required TB test	1	1.8	
	Work	1	1.8	
3	Modern day health problem in the US?			
	Yes	35	63.6	Knowledge

(table continues)

	No	20	36.4	
4	Modern day problem internationally?			
	Yes	49	89.1	Knowledge
	No	6	10.9	
5	Mode of transmission			
	Coughing, sneezing	35	63.6	Knowledge
	Touching	0	0	
	Sexual contact	0	0	
	Food/water ingestion	2	3.6	
	Smoking	0	0	
	Imbalance of hot and cold	0	0	
	Do not know	18	32.7	
6	Most common symptom			
	Coughing	34	61.8	Knowledge
	Sneezing	1	1.8	
	Loss of appetite	1	1.8	
	Tiredness/fatigue	8	14.5	
	Bleeding	1	1.8	
	Do not know	10	18.2	
7	Treatment available?			
	Yes	30	54.5	Knowledge
	No	25	45.5	
8	Length of treatment			
	3 days	1	1.8	Knowledge
	1 week	4	7.3	
	1 month	5	9.1	
	> 6 months	11	20.0	
	Do not know	34	61.8	
9	Treatment 100% effective?			
	Yes	12	21.8	Knowledge
	No	13	23.6	
	Do not know	30	54.5	
10	A curable disease?			
	Yes	33	60	Knowledge
	No	5	9.1	
	Do not know	17	30.9	
11	Initial reactions and feelings when mentioned by family, friends, or news?			
	Frightened	15	27.3	Knowledge
	Informed	23	41.8	
	Indifferent	16	29.1	
	Helplessness	1	1.8	
12	You or anyone in family diagnosed?			Knowledge

(table continues)

	Yes	3	5.5	
	No	52	94.5	
13	If yes, how did you feel?			
	Frightened	1	33.3	
	Informed	1	33.3	
	Indifferent	0	0	Knowledge
	Helpless	0	0	
	Depressed	0	0	
	Informed & Indifferent	1	33.3	
14	Factors associated with TB:			
	Poverty	2	3.6	
	Foreign-born	1	1.8	
	HIV status	0	0	
	Drug history	0	0	
	Low social class	0	0	
	Sexual orientation	0	0	
	Mental illness	0	0	
	Religion	0	0	
	A common disease	6	10.9	
	A curable disease	11	20.0	
	Smoking	2	3.6	
	Imbalance of hot and cold	4	7.3	
	Incarceration	1	1.8	Ethnicity/
	Poverty and low social class	1	1.8	Race
	Poverty and a common disease	1	1.8	Cultural
	Poverty and a curable disease	2	3.6	Belief
	Poverty, foreign-born, and low social class	3	5.5	Demographics
	Foreign-born and a curable disease	2	3.6	Religion
	A common disease and a curable disease	2	3.6	Knowledge
	A common disease and smoking	1	1.8	
	Poverty, foreign-born, a curable disease	3	5.5	
	Poverty, HIV status, and a curable disease	1	1.8	
	Poverty, drug history, and incarceration	1	1.8	
	Poverty, sexual orientation, religion, incarceration	1	1.8	
	Foreign-born, low social class, common disease, incarceration	1	1.8	
	A common disease, curable disease,	1	1.8	

(table continues)

	and smoking			
	A curable disease, smoking, imbalance of hot and cold	1	1.8	
	Poverty, foreign-born, curable disease, incarceration	1	1.8	
	Poverty, foreign-born, low social class, common disease, curable disease	1	1.8	
	Poverty, HIV status, drug history, common disease, smoking	1	1.8	
	Poverty, drug history, smoking, and imbalance of hot and cold	1	1.8	
	Poverty, foreign-born, low social class, curable disease, and incarceration	1	1.8	
	Poverty, foreign-born, low social class, curable and common disease, incarceration	1	1.8	
15	If someone has TB, you think that:			
	Did something wrong (e.g., drug use)	0	0	
	A punishment given by the God	1	1.8	Ethnicity/ Race
	Due to racial background	2	3.6	Cultural
	It could happen to anyone	50	90.9	Belief
	Did something wrong and it could happen to anyone	1	1.8	Demographics
	Due to racial background and it could happen to anyone	1	1.8	Religion
16a	If you had TB, would you trust doctors to cure it?			
	1. Strongly agree	32	58.2	Cultural
	2. Agree	19	34.5	Belief
	3. No Opinion	4	7.3	Demographics
	4. Disagree	0	0	Religion
	5. Strongly disagree	0	0	
16b	If you had TB, would you be compliant with doctors' instructions regarding treatment?			
	1. Strongly agree	37	67.3	Cultural
	2. Agree	7	12.7	Belief
	3. No Opinion	6	10.9	Demographics
	4. Disagree	2	3.6	Religion
	5. Strongly disagree	3	5.5	
16c	If you had TB, would you seek treatment outside a hospital/ private			Cultural
				Belief

(table continues)

	practice setting?			Demographics
	1. Strongly agree	5	9.1	Religion
	2. Agree	8	14.5	
	3. No Opinion	14	25.5	
	4. Disagree	15	27.3	
	5. Strongly disagree	13	23.6	
17	If seeking outside treatment, where would you go?			
	Chiropractor	0	0	
	Acupuncturist	0	0	
	Homeopathic doctor/nutritionist	4	4.3	
	Religious/ church leader	2	3.6	
	Massage therapist	0	0	
	Home remedies (herbs, oils, teas)	3	5.5	
	I wouldn't	35	63.6	
	Acupuncturist and homeopathic doctor	2	3.6	
	Homeopathic doctor and home remedies	1	1.8	
	Chiropractor, religious leader, home remedies	1	1.8	
	Acupuncturist, homeopathic doctor, home remedies	1	1.8	Cultural Belief Religion
	Homeopathic doctor, religious leader, home remedies	1	1.8	
	Chiropractor, Acupuncturist, Homeopathic doctor, and massage therapist	1	1.8	
	Chiropractor, Acupuncturist, Homeopathic doctor, and home remedies	1	1.8	
	Chiropractor, Acupuncturist, Homeopathic doctor, massage therapist, home remedies	1	1.8	
	Chiropractor, Acupuncturist, Homeopathic doctor, religious leader, massage therapist, home remedies	2	3.6	
18a	Aware of TB treatment facilities in LA County and the services provided?			Demographics
	Yes	8	14.5	Knowledge
	No	47	85.5	
18b	If no, if information was made readily available, would you be more inclined to read about the disease and inform			Cultural Belief Knowledge

(table continues)

	others in your community?			
	Yes	32	68.1	
	No	15	31.9	
19	Aware of community social support groups for dealing with the disease?			Knowledge
	Yes	5	9.1	
	No	50	90.9	
Basic Background Information				
18	Seek Spiritual Guidance			Religion
	Yes	24	43.6	
	No	31	56.4	
19	Use Home Remedies (herbs, teas, etc.)			Cultural Belief
	Yes	42	76.4	
	No	13	23.6	

RQ2 identifies which factors (e.g. physical, cultural, psychosocial, behavioral), if any, contribute to differences in knowledge (DV) relating to TB between Armenians and non-Armenians living in LA County. To explore this, bivariate chi-square (χ^2) analyses were performed with classification of populations (Armenian or non-Armenian) servings as the independent variable (IV). Table 10 summarizes all of the χ^2 results, highlighting significant factors ($p < 0.05$) and the effect size associated with these variables.

Table 10
RQ2. Bivariate Analysis ($n = 127$)

Dependent Variable	Independent Variable	χ^2	p	Interpretation	Effect Size (Cramer's V)
Heard of TB	Armenian-non Armenian	1.319	ns	Arm/Non-Arm status does not affect heard of TB	NA
Source of TB Knowledge	Armenian-non Armenian	40.213	0.037	There is a significant difference in TB knowledge source in Arm (9.3% TV, 3.7% Internet, 27.8% family/friends, 0%	0.565

(table continues)

				printed media, 10% other) as compared to non-Arm (1.4%, 0%, 11.1%, 2.8% 13.9%, resp)	
TB US Problem	Armenian-non Armenian	0.085	ns	Arm/Non-Arm status does not affect TB national awareness	NA
TB International Problem	Armenian-non Armenian	0.048	ns	Arm/Non-Arm status does not affect TB international awareness	NA
TB route of Transmission	Armenian-non Armenian	8.203	ns	Arm/Non-Arm status does not affect route of TB transmission knowledge	NA
TB Symptoms	Armenian-non Armenian	5.631	ns	Arm/Non-Arm status does not affect route of TB symptom knowledge	NA
TB Treatment Available	Armenian-non Armenian	0.073	ns	Arm/Non-Arm status does not affect TB treatment availability knowledge	NA
TB Treatment Length	Armenian-non Armenian	6.913	ns	Arm/Non-Arm status does not affect TB treatment duration knowledge	NA
TB Treatment Effectiveness	Armenian-non Armenian	1.279	ns	Arm/Non-Arm status does not affect TB treatment effectiveness knowledge	NA
TB Curable Disease	Armenian-non Armenian	0.883	ns	Arm/Non-Arm status does not affect TB disease status knowledge	NA
TB reactions	Armenian-non Armenian	2.212	ns	Arm/Non-Arm status does not affect reactions to TB diagnosis	NA
TB Diagnose family/friend	Armenian-non Armenian	0.392	ns	Arm/Non-Arm status does not affect personal TB diagnosis	NA
TB Diagnosis	Armenian-	5.625	ns	Arm/Non-Arm status	NA

(table continues)

Feelings	non Armenian			does not affect feelings toward TB positive individual	
Factors Associated with TB	Armenian- non Armenian	52.321	ns	Arm/Non-Arm status does not affect TB factors knowledge	NA
Trust Doctor to treat TB	Armenian- non Armenian	5.631	ns	Arm/Non-Arm status does not affect trust in physician's ability to treat TB	NA
Compliant with doctors' instructions regarding treatment	Armenian- non Armenian	11.630	0.020	Non-Arm significantly more compliant (strongly agree/agree) as compared to Arm (97.2% vs. 80%)	0.303
Seek treatment outside of doctor's care	Armenian- non Armenian	1.549	ns	Arm/Non-Arm status does not affect desire to seek outside treatment for TB	NA
Alternative Treatment types	Armenian- non Armenian	18.286	ns	Arm/Non-Arm status does not affect alternative treatment sought	NA
Aware of LA County TB treatment facility	Armenian- non Armenian	0.278	ns	Arm/Non-Arm status does not affect LA County TB treatment facility awareness	NA
Read about TB, if provided	Armenian- non Armenian	0.864	ns	Arm/Non-Arm status does not affect desire to read about TB if provided	NA
Aware of community TB support groups	Armenian- non Armenian	0.369	ns	Arm/Non-Arm status does not affect TB community support group awareness	NA
Seek spiritual guidance	Armenian- non Armenian	9.8883	0.002	Significantly more Arm seek spiritual guidance (43.6%) as compared to non-Arm (18.1%)	0.279
Use Home Remedies	Armenian- non Armenian	4.526	0.033	Significantly more Arm use home remedies (76.4%) as compared to non-Arm (58.3%)	0.189

(table continues)

Trust Primary Physician	Armenian- non Armenian	2.889	ns	Arm/Non-Arm status does not affect trust of primary care physician	NA
Have Health Insurance	Armenian- non Armenian	0.578	ns	Arm/Non-Arm status does not affect health care insurance procurement	NA
Gender	Armenian- non Armenian	0.201	ns	Arm/Non-Arm status is not affected by gender	NA
Years in US	Armenian- non Armenian	7.970	0.005	Arms have significantly fewer years in US (80% \geq 20 years) as compared to non-Arm (95.8%)	0.251
Marital Status	Armenian- non Armenian	1.405	ns	Arm/Non-Arm status is not affected by marital status	NA
Number of People in household (excluding self)	Armenian- non Armenian	13.138	0.011	Arm have significantly more people per household (83.6% \geq 2) as compared to non- Arm (56.9%)	0.322
English primary language spoken	Armenian- non Armenian	27.636	0.000	Arm have a significantly lower level of English as their primary language (63.6%) as compared to non-Arm (98.6%)	0.466
Level of Education	Armenian- non Armenian	12.755	0.005	Arm have a significantly lower level of education (12.7% High school, 25.5% some college, 27.3% Bachelor's, 34.5% Graduate/Professional) as compared to non- Arm (0%, 16.7%, 43.1%, 40.3% resp)	0.317
Occupation	Armenian- non Armenian	8.742	ns	Arm/Non-Arm status is not affected by occupation	NA

(table continues)

Annual Household Income	Armenian-non Armenian	3.565	ns	Arm/Non-Arm status is not affected by annual household income	NA
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The effect size was calculated using the 2-sided Pearson's chi-square value where p -values ≤ 0.05 were considered to be significant. Of those factors with significance, a Cramer's V scale was used to evaluate the strength of the effect size (d.f. ≥ 3): $< \pm 0.06$, small; ± 0.17 medium, and $\geq \pm 0.29$, large (Zaiontz, 2016). For this study, the effect size was calculated using only those factors relating to TB-specific questions. Other factors relating to background of the two populations also showed some significant differences with strength (Table 10) and will be discussed later in Chapter 5.

As seen in Table 11, those factors with the greatest significance and strength relate to how the two populations learned about the disease ("TBHearSource") and how compliant with a doctor's instructions would they would be if diagnosed ("TBWhatifB"). From these, the average Cramer's value was calculated, resulting in an effect size of 0.434.

Table 11
Effect Size Determination: TB-Specific Questions (n = 127)

Variable	Pearson's	Cramer's V
TBHearSource	0.037	0.565 large
TBWhatifB	0.020	0.303 large
Average		0.434

For RQ2, multinomial logistic regression was used to explore interactions between the nominal, multi-categorical dependent variables for any of the independent

variables. The dependent variables explored were those with large effect sizes and significant chi-square values ($0.1 > p < 0.05$) from the bivariate analysis, which included “TBHearSource, TBWhatifB (compliance), and TBTransmit” ($p = 0.084$, Cramer’s V 0.254). These variables were tested against predictor factors relating to demographics, religion, and cultural beliefs, focusing on those that were found to be significant in the bivariate analysis (Table 10).

Table 12 summarizes the significant findings and predictors, where the full model predicts significantly better than the null model. Overall, it was found that for the dependent variable, Source of TB knowledge (TBHearSource), classification (Armenian versus non-Armenian) and the use of home remedies were significant factors with the latter having a number of combinations of factors that are good predictors. For the dependent variable TB Route of Transmission (TBTransmit), classification and age were found to be significant, with “coughing and sneezing” representing a good predictor (OR 0.347; CI 0.134-0.838). For the question addressing compliance (TBWhatifB), classification, English spoken in household, and education were significant. However, in some cases there were limitations in the models where there were singularities with some of the predictor variables, suggesting they should be removed or merged (see notation ^a). Proposed mitigations will be discussed further in Chapter 5.

Table 12
RQ2. Multivariate Analysis (n=127)

Dependent Variable	Factor	<i>p</i>	Parameter Estimates		95% Confidence Interval (CI)	
			Predictor	<i>p</i>	Odds Ratio	Lower Upper
Source of TB	Classification	< 0.05		^a		

(table continues)

Knowledge (TB Hear Source)	(Armenian/ non- Armenian)						
Use of Home Remedies		< 0.05	Family/friends Internet + Newspaper/ Magazine	< 0.05 0.00	14.25 3.50e ⁸	1.16 3.50e ⁸	174.80 3.50e ⁸
			Internet + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			Family/friends + other	< 0.05	33.00	1.56	697.96
			Newspaper/ Magazine + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			TV + Internet + Newspaper/ Magazine	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			TV + Family/ friends + Newspaper/ Magazine	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			Internet + Family/friends + Newspaper/ Magazine	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			Internet + Family/friends + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			Family/friends + Newspaper/ Magazine + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			TV + Internet + Family/ friends + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
			Internet + Family/friends + Newspaper/ Magazine + other	0.00	3.50e ⁸	3.50e ⁸	3.50e ⁸
TB route of Transmission	Classification (Armenian/ non- Armenian)	0.05	Coughing/ sneezing	< 0.05	0.35	0.13	0.84
	Age	< 0.05	^a				
Compliance if Diagnosed	Classification (Armenian/ non- Armenian)	< 0.05	Strongly Agree	0.00	5.70e ⁻⁹	1.09e ⁻⁹	2.98e ⁻⁸

(table continues)

with TB (TBWhatifB)	non- Armenian)		Strongly Disagree	0.00	3.64e ⁻⁹	5.39e ⁻¹⁰	2.27e ⁻⁹
			No Opinion	0.00	2.50e ⁻⁸	2.50e ⁻⁸	2.50e ⁻⁸
	Years in US	< 0.05	Strongly Agree	0.00	3.28e ⁷	1.82e ⁶	5.91e ⁸
			Strongly Disagree	0.00	6.97e ⁷	3.38e ⁶	1.44e ⁹
			No Opinion	0.00	4.64e ⁸	2.09e ⁷	1.03e ¹⁰
	English spoken in household	< 0.05					
	Education	< 0.05					

^a Unexpected singularities in the Hessian matrix encountered, indicating that either some predictor variables should be excluded or some categories should be merged

^b low logistic coefficients

Summary of RQ1 Results

RQ1 is a descriptive inquiry that investigates the perceived barriers to treatment seeking and adherence for TB in an Armenian population living within the United States. The quantitative study utilized a series of online survey questions addressing knowledge-, cultural-, religious-, demographic-, and ethnicity-based inquiries (Table 9). Univariate analyses of the 55 Armenian respondents revealed themes relating to all independent variables. Some of the knowledge-based inquiries revealed that 98.2% of Armenians have heard of TB, with a singular source of knowledge coming from family and friends or school, or a combination of sources such as TV, Internet, family/friends, and newspaper/magazines. Furthermore, Armenian respondents believe TB is a modern day health problem both in the U.S. and internationally, with coughing and sneezing as the primary mode of transmission. While just over 50% believe there is a treatment available, the majority of respondents are unaware of the duration of treatment regimen, whether it is 100% effective, or if the disease is curable. Almost all of the Armenian participants

have never been diagnosed or know someone who has been diagnosed with TB, with less than 50% feeling informed at the mention of the disease. Factors associated with TB were found to be vast, with 20.9% believing it is a curable disease and 90.9% believing that contracting the disease could happen to anyone. If contracted, 92.7% trust their physician to cure it, 80% would comply with treatment recommendations, and just over half of respondents would not seek treatment outside of a hospital setting, though 76.4% also use home remedies.

Further support was achieved through the face-to-face interviews of 10 Armenian participants in the qualitative study, with some ambiguities. Here knowledge of TB existed but mode of transmission, incidence, and treatment characteristics (e.g., duration, type, and effectiveness) was more uncertain. The majority of Armenians expressed great trust in the ability of their doctor to effectively diagnose and treat any given disease; however, a minority expressed a harsh distrust. All of the respondents also opted for the use of home remedies, either prior to seeking a doctor's consultation and/or most continued taking the home remedy following prescription of treatment by a doctor. The culturally-based inquiry regarding the presence of *kapoot ach* in their house revealed that all of them had at least one, with one (A9) responding "Yes, it's all around. It's something an Armenian family has to have!"

Summary of RQ2 Results

RQ2 is inferential and explores differences in barriers to treatment seeking and adherence for Tuberculosis in Armenian versus non-Armenian populations living in LA

County and determines which factors (e.g., physical, cultural, psychosocial, behavioral) have the greatest influence? The alternative and null hypotheses are:

H_A^2 : There are differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

H_0^2 : There are no differences in factors relating to treatment seeking and adherence for tuberculosis in Armenian versus non-Armenian populations in Los Angeles County.

The quantitative element of the study involved surveying 55 Armenians and 72 non-Armenians residing in LA County. To determine significant differences, if any, between the two populations in regards to barriers to treatment-seeking and adherence for TB, bivariate chi-square (χ^2) analyses were performed with classification of populations (Armenian or non-Armenian) servings as the independent variable (IV) As can be seen in Tables 10 and 11, significant factors ($p < 0.05$) with medium to large effect sizes relate to how the two populations learned about the disease (“TBHearSource”) and how compliant with a doctor’s instructions would they would be if diagnosed (“TBWhatifB”). From these, the average Cramer’s V value was calculated, resulting in an effect size of 0.434.

Multinomial logistic regression was then used to explore interactions between these nominal, multi-categorical dependent variables for any of the independent variables. “TBHearSource”, “TBWhatifB” (compliance), and “TBTransmit” ($p = 0.084$, Cramer’s V 0.254) were tested against predictor factors relating to demographics,

religion, and cultural beliefs, focusing on those that were found to be significant in the bivariate analysis (Table 10). For the dependent variable, Source of TB knowledge (TBHearSource), classification (Armenian versus non-Armenian) and the use of home remedies were significant factors with the latter having a number of combinations of factors that are good predictors. For the dependent variable TB Route of Transmission (TBTransmit), classification and age were found to be significant, with “coughing and sneezing” representing a good predictor (OR 0.347; CI 0.134 - 0.838). For the question addressing compliance (TBWhatifB), classification, English spoken in household, and education were significant. However, in some cases there were limitations in the models where there were singularities with some of the predictor variables, suggesting they should be removed or merged.

The qualitative component of the study where 10 Armenians and 8 non-Armenians were interviewed face-to-face, found some similarities and differences in responses between the two populations. Both populations had general vague knowledge relating to route of transmission, degree of infectivity, molecular properties, and incidence. Both also felt like there “should be” a treatment available but didn’t have any details on regimen; however, only the Armenian population acknowledged vaccine availability. When it came to perceptions and feelings, the Armenian population expressed more empathy, an overt willingness to help someone with the disease, desire to seek treatment or urge others to seek treatment, and seek spiritual guidance and outside education for themselves or others. The non-Armenian population appeared more trepid, less willing to help others and urge them to seek treatment, and less open to seek spiritual

guidance; however, they were very willing to educate themselves about the disease. Both groups had a similar distribution of individuals who seek spiritual guidance upon receiving news of a disease diagnosis for either themselves or close family/friends and those who don't. Overall, all participants opted for the use of home remedies, either prior to seeking a doctor's consultation and/or most continued taking the home remedy following a physician's prescription of treatment.

Trustworthiness

When conducting a mixed-methods study, there are many important aspects that need to be considered to guarantee credibility and dependability. For this concurrent mixed-methods study, data triangulation was utilized to address these concerns. By utilizing multiple modes of data collection, e.g., observational from the face-to-face interviews of the qualitative study and online survey research from the quantitative study, specificity and validity concerns relating to a particular approach is minimized. For this study, data from the qualitative study and quantitative study were collected in parallel, analyzed separately, and then converged following data analysis. From this convergence, it was found that the findings from both studies are primarily in agreement, with some minor diverging trends. These are likely due to differences in survey environment (face-to-face versus remote and online), where the online participants appeared to be more informed about the disease overall irrespective of classification.

To further address potential issues relating to credibility and dependability, peer review was utilized as a mechanism for external checking the research process, remove threats of bias, provide analytical direction, and confirm results. For these studies, the

dissertation supervisor, V.M., served as the peer reviewer throughout the process by looking over all of the results (pilot study and final studies) and confirming appropriate implementation and analysis of all statistical tests used.

For an ethnography in particular, transferability or generalizability is a concern. Not only did this study focus on a particular population, Armenians, but was even more selective for those living in LA County. If other researchers attempt to replicate this study, it is likely that alterations may need to be made to account for attributes specific to the population being studied (e.g., demographics).

Data validity and reliability are serious concerns for any researcher. They can be threatened by the instrumentation used to conduct the study, particularly when developed by the researcher, as well as from data coding methods following data collection but prior to analysis. For the quantitative portion of the study, pilot testing was conducted to validate the instrumentation. The recommendations were incorporated into the final survey prior to recruitment and implementation online. Furthermore, a codebook was generated for each research question (Appendix L). This was approved by the peer reviewer V.M. prior to data analysis. All of the responses from completed online surveys were exported from SurveyGizmo into Excel, where the researcher manually coded all of the responses based on the approved codebook. This was transferred into SPSS and checked externally for errors by V.M.

Coding for qualitative studies may be more subjective which can offer challenges relating to reliability. For the qualitative component of this study, written transcripts were generated from the voice recordings. The data were then analyzed for key words and

phrases that relate back to the research questions. For these key themes, sub-themes were also formulated and indexed. These were cross-checked by the peer reviewer for errors.

Summary

The purpose of this mixed-methods study was to explore factors (physical, psychosocial, cultural, or behavioral) relating to TB knowledge, treatment-seeking and adherence in Armenians versus non-Armenian residing in LA County and whether differences exist between the populations. Univariate (frequencies), bivariate (chi-square), and multivariate (multinomial logistic regression) statistical analyses were implemented to determine factors and relationships. The qualitative component utilized face-to-face interviews with coded and grouped responses to address concerns relating to specificity and validity. Data from both study components were collected in parallel, analyzed separately, and then converged post-analysis.

The null hypothesis (H_0) for RQ2 is rejected in favor of the alternative hypothesis (H_A), “there are differences in factors relating to treatment-seeking and adherence for TB in Armenian versus non-Armenian populations in Los Angeles County”. The resulting post-hoc power analysis was satisfactory > 0.90 . Bivariate analysis determined that there are two factors that are significantly different between Armenian and non-Armenian populations: (a) the source of TB knowledge and (b) compliance with a doctor’s instructions if a TB diagnosis is received. The multivariate analysis found factors that were good predictors for each of these variables, though some limitations were found with the model (further discussed in Chapter 5). Some factors with significance include the use of home remedies (with many combinations of predictors), age, years residing in

the United States, education, and English as the primary language in the household. Analysis of the responses from the qualitative component revealed that both populations were in general uninformed about TB (e.g., transmission, treatment, curability, and incidence). The Armenian population appeared to be more willing to help others, while using caution, if diagnosed and trust their physician for diagnosing and treating; whereas, non-Armenians were less willing to help others and jeopardize their health and expressed less trust in their physician's ability to effectively treat the disease.

The results of the study will be summarized and interpreted further in Chapter 5. Furthermore study limitations, as well as recommendations for future research, social implications, the theoretical foundation (SEM), and conclusions of the study will be discussed.

Chapter 5: Discussion, Conclusions, and Recommendations

Introduction

TB continues to be a global public health problem and has been made a top priority disease for control and eradication by the WHO and national health ministries (WHO, 2015). Armenians, in particular, are a susceptible population due to high national incidence of MDR-TB, inadequate health care, poor disease surveillance, poor disease education, poverty, and emigration/immigration (Bakalian, 2011; Hayrapetyan, 2012; Truzyan et al., 2015; Vink et al., 2005); however, very few epidemiological or prevention studies have been dedicated to this group.

The purpose of this study was to explore differences in factors (physical, psychosocial, cultural, or behavioral) relating to TB knowledge, treatment-seeking and adherence in Armenians as compared to non-Armenians in LA County to determine which factors have the greatest potential impact on reducing TB incidence in this susceptible population. To do this, a mixed-methods study design was implemented using concurrent quantitative components, an online survey, followed by qualitative face-to-face interviews. Resulting data were analyzed separately and merged during the interpretation phase of the study.

For the quantitative component, 55 Armenians residing in LA County were surveyed through the online platform SurveyGizmo. Here, knowledge-, cultural-, religious-, demographic-, and ethnicity-based inquiries were investigated. Among the surveyed Armenian population, perceived barriers to treatment-seeking and adherence for TB were explored and analyzed for (Table 9). Knowledge-based inquiries revealed that

98.2% of Armenians have heard of TB, with knowledge coming from family and friends or school, or a combination of sources such as TV, Internet, family/friends, and newspaper/magazines. Furthermore, Armenian respondents believe TB is a global health problem, with the primary mode of transmission being coughing and sneezing. Factors associated with TB were found to be vast, with 20.9% believing it is a curable disease and 90.9% believing that contracting the disease could happen to anyone. While just over 50% believe that treatment is available, the majority were unsure of treatment details such as duration and effectiveness. Almost all of the Armenian participants have never been diagnosed or know someone who has been diagnosed with TB, with less than 50% feeling informed at the mention of the disease.

The qualitative component further supported the quantitative findings among the Armenian population. Here, 10 Armenian participants were interviewed face-to-face. Analysis of responses revealed awareness of TB; however, knowledge of the mode of transmission, incidence, and treatment characteristics (e.g., duration, type, and effectiveness) was absent. The culturally based inquiry on the presence of *kapoot ach* in their residence revealed all of them had at least one.

Differences in barriers to treatment-seeking and adherence for TB in Armenian and non-Armenian populations in LA County were identified using bivariate chi-square (χ^2) and multivariate multinomial logistic regression analyses of the online survey data. When comparing data from the 55 Armenians and 72 non-Armenians surveyed, significant factors with medium to large effect sizes were: (a) how the two populations learned about the disease (“TBHearSource”) and (b) how compliant with a doctor’s

instructions would they would be if diagnosed (“TBWhatifB”). Using Cramer’s V calculations, the resulting effect size was 0.434 (see Tables 10 and 11). Multivariate analyses of these factors, along with an additional factor of how TB is transmitted (TBTtransmit, $p = 0.084$), revealed predictor factors such as classification, the use of home remedies, age, education, and English as the primary household language to be significant. The null hypothesis (H_0) for RQ2 is rejected in favor of the alternative hypothesis (H_A), “there are differences in factors relating to treatment seeking and adherence for TB in Armenian versus non-Armenian populations in LA County”.

When exploring differences in the two populations, the qualitative component revealed some similarities and differences in responses. Amongst the 10 Armenians and 8 non-Armenians interviewed, both populations had vague knowledge relating to route of transmission, degree of infectivity, molecular properties, and incidence. Both also believed that there “should be” a treatment available but didn’t have any details on regimen; however, only the Armenian population acknowledged vaccine availability. When exploring perceptions and feelings, the Armenian population expressed more empathy, an overt willingness to help someone with the disease, desire to seek treatment or urge others to seek treatment, and seek spiritual guidance and outside education for themselves or others. The non-Armenian population appeared more trepid, less willing to help others and urge them to seek treatment, and less open to seek spiritual guidance; however, they were very willing to educate themselves about the disease. Both groups had a similar distribution of individuals who seek spiritual guidance upon receiving news of a disease diagnosis for either themselves or close family/friends and those who don’t.

Interpretation of the Findings

Results from this study confirm, and extend, the very limited knowledge relating to TB awareness and barriers to treatment seeking and adherence in an Armenian population. In an extensive report by Grigoryan et al. (2008), TB knowledge and attitudes of Armenians living in Armenia were assessed. Of those interviewed, 91% could identify TB but only half knew how it was transmitted. Additionally, the vast majority did not realize that TB was a public health problem, could not identify symptoms, and believed that they and their loved ones were not at risk. Social stigma was also high, where roughly 20% keep their family's TB status a secret. Furthermore, TB patients were ill-informed about the duration of treatment and the consequences regarding non-compliance or interrupted treatment (Grigoryan et al., 2008).

In both the quantitative and qualitative components of this study, > 90% of respondents were aware of TB; with the qualitative component revealing that majority of the participants were uninformed regarding transmission, and 63.6% of the quantitative participants aware that coughing and sneezing are the primary mode of transmission. In regards to treatment, 61.8% of respondents from the quantitative component had no idea about duration of treatment and 54.5% didn't know if the treatment was effective. The lack of familiarity regarding treatment was also supported by the qualitative study, though similar trends were also seen in the non-Armenian counterparts.

Fears relating to social stigma didn't seem as apparent in either the quantitative or qualitative components of this study; however, very few respondents either had the disease or knew of someone who had it. In the quantitative component, 90.9% felt if

someone had TB, it could happen to anyone and was not attributable to race or was a punishment by God. In the qualitative study, most Armenians would be empathetic to those with TB, would be eager to help, and would urge the patient to seek treatment immediately; however, the non-Armenian contingent were more trepid, less eager to help, and would stay isolated from the patient. The proactive response in Armenians is contrary to what was reported by Ige and Lasebikan (2011) where family members of patients reported increased depression and helplessness.

Schneider et al. (2010) explored reasons for delaying TB treatment in patients in Armenia where significant factors included weight loss and fatigue, the inability to recognize TB symptoms, and referral after the first doctor's visit. In the qualitative component of this study, the majority of Armenian respondents reported that they would immediately seek treatment upon receiving a positive diagnosis and would urge close family and friends to do the same; however, their inability to recognize symptoms as TB or utilize home remedies first may in actuality result in delays in seeking treatment. In the quantitative aspect of this study, 61.8% of Armenians identified coughing as the most common symptom of TB; however, other characteristics such as bleeding, loss of appetite, and fatigue were far less recognizable. Because coughing is a common symptom of many diseases and 76.4% also utilize home remedies, individuals may delay consulting with a physician for proper diagnosis and treatment. Therefore, the findings by Schneider et al. (2010) and this study suggest that enhanced knowledge regarding recognizing signs and symptoms of TB, along with improved medical care and staff would dramatically improve disease outcomes in the Armenians living in the United

States and Armenia. Furthermore, it is evident that the lack of studies relating to TB in Armenian populations perpetuates the problem of poor disease outcomes.

The social ecological model serves as a strong theoretical foundation in social epidemiology, particularly for improving infectious disease outcomes, by explaining potential causal relationships between disease and social and biological conditions (Krieger, 2001) and addressing complex community-based problems relating to health disparities (Green et al., 2005; Reifsnider et al., 2005). As depicted in Figure 1, SEM addresses four inter-related factors: (a) the individual and risk behaviors (e.g., knowledge, attitudes, beliefs); and (b-d) interpersonal relationships, community and environment, and societal /cultural norms, such as social interactions, social constructs, social structure, and public policy (California Department of Public Health, n.d.; CDC, 2009b). All levels constructively work together to positively influence change.

SEM has been widely used in TB studies addressing transmission, treatment and prevention, including health disparities, ethnic differences, socioeconomic, immigration, and psychosocial factors amongst various populations both nationally and internationally. Myers et al. (2006) utilized an ecological approach for exploring TB transmission in California by focusing on racial/ethnic distribution, immigration, education level, employment status, poverty, and crowding obtained from U.S. Census data and related them to new TB cases. Using pediatric cases as a measurement of transmission, it was found that pediatric TB cases were elevated in lower median incomes, racial/ethnic minorities, and immigrants. While this study explored such factors in an Armenian population, the ability to find causation and link them to new TB cases in LA County is

difficult and beyond the scope of this study due to the classification of Armenians as White/Caucasian for census data. Due to Armenians' declared willingness to help others in the qualitative component as compared to non-Armenians, this would be interesting to explore how it may impact population-specific treatment adherence efforts.

Other groups have utilized SEM to investigate the impact of various ecological factors (particularly poverty, SES, knowledge, and ethnic differences) on TB treatment adherence in a variety of populations in the United States and abroad (Barr et al., 2001; Harling et al., 2008; Hawker et al., 1999; Holtgrave & Crosby, 2004; Marx et al., 2007; Tupasi et al., 2016). Murray et al. (2011) incorporated mathematical modeling with SEM to further explore the dynamics associated with social, environmental and biological determinants of TB in an effort to improve intervention strategies. Here, associations between TB infection and smoking, indoor air pollution, alcohol use, diabetes, nutrition, crowding, migration, aging, and economic trends were projected. Tupasi et al.'s study conducted in the Philippines (2016) further supports some of these findings where alcohol abuse was a significant limiting factor in MDR-TB treatment adherence. However, none of these studies explicitly discuss any such factors in relation to an Armenian population living either in the U.S. or in their native country. Findings from this study reveal there are some significant differences in knowledge and compliance in Armenian versus non-Armenian participants and therefore population-specific education and treatment efforts may improve disease outcomes.

Limitations of the Study

One limitation of the study was the population size surveyed for the quantitative component. Prior to launching the online survey, an a priori power analysis was conducted based on an effect size of 0.363, derived from relevant literature. From this, it was estimated that 100 Armenians and 100 non-Armenians be surveyed to achieve significant power. After eight months of purposive recruiting, 55 Armenians and 72 non-Armenians were enrolled and completed the survey. An additional three were eliminated for living outside LA County and 14 more were lost to attrition and incomplete surveys, most of which were Armenians who failed to respond to any questions relating to TB. Challenges with recruiting were likely due to the vastness of LA County and difficulties penetrating the Armenian community, despite providing all recruitment and survey materials in Armenian. To address this limitation, a post-hoc power analysis using G* Power 3 calculator software (version 3.1.4) and logistic regression test ($\alpha = 0.05$, OR = 0.347 for “TB route of Transmission” as dependent variable with the weakest significant p value, 0.05), was conducted and a satisfactory power analysis > 0.90 was attained.

Another limitation relates to instrumentation. An original survey and questionnaire was generated to ensure cultural sensitivity and relevance to the Armenian community. This presents some challenges because, as an original questionnaire, assurances regarding its validity and cohesiveness may be lacking. Both were made available in English and Armenian, with accuracy of translations for the Armenian versions verified by an outside native Armenian speaker. A pilot study of the online survey was performed to ensure questionnaire appeal, ease of comprehension, and

comfort level within the online environment. The online environment for the quantitative survey may limit those who participated as a result of electronic access; however, the face-to-face nature of qualitative survey helps overcome this limitation. The online environment also allowed for participants to conduct searches to answers prior to responding, thereby biasing results; whereas the face-to-face interviews eliminate this possibility but instead introduces the possibility of recall bias. This was particularly evident with discrepant responses relating to TB transmission, where 63.6% of respondents from the online survey believed it was through coughing or sneezing, whereas the majority in the qualitative study had no idea.

Another specific limitation linked to instrumentation is data coding that occurred post-data collection and pre-data analysis. Despite conducting pilot testing of the online questionnaire prior to conducting the survey and checking the coded responses for errors externally in SPSS following data collection, unanticipated problems during analysis became evident. This is a consequence of the respondent's potential to make multiple selections or fill in responses for certain TB-specific questions, SQs 22, 34, 35, and 37. As can be seen in Tables 9, 10, and 12, these key questions had an abundant number of response combinations which complicated and convoluted the analysis. It is likely that more factors may have been found to be significant when conducting bivariate and multivariate analyses if only single answers were allowed and/or these questions were broken up into multiple questions.

A final limitation of this study effects generalizability or transferability which is attributed to ethnography. This study not only focuses on a particular population,

Armenians, but is even more selective for those living in LA County. LA County houses the second largest population of Armenians in the world, aside from Armenia itself (Hayk the Ubiquitous Armenian, 2012), it is therefore believed that the study involved a representative pool. However, the social and economic factors impacting the study may not be generalizable to Armenians living in other parts of the country or world. This is evident when comparing demographic characteristics of the Armenian to the non-Armenian population surveyed (Table 13, Appendix M). If this study is replicated or expanded upon, it is recommended that alterations be made to account for population-specific attributes, such as culture and demographics.

Recommendations for Future Research and Practice

This study fills the gap in understanding TB knowledge and barriers to treatment-seeking and adherence behaviors in an Armenian population living in LA County. Although the data are limited, some significant discoveries were found and may therefore be useful for implementing public health strategies specific for an Armenian community. From both the quantitative and qualitative component of this study, it is evident that the majority of Armenians trust their physician's ability to effectively diagnose and treat tuberculosis. Furthermore, upon diagnosis they would seek treatment immediately and adhere to the treatment under a physician's care. Therefore, it is very important to enroll physicians and healthcare workers as stakeholders for information dissemination, program planning, evaluation, and execution, particularly those practicing in communities heavily populated by Armenians. Within this, the physicians and healthcare workers will also stress the important of adherence and work with local spiritual leaders

to reinforce this message since Armenians are reportedly spiritual individuals and seek spiritual guidance along with physician care.

While physicians will be an important entity of an Armenian TB-specific public health program, information dissemination prior to contraction of the disease is also paramount so that disease symptoms can be identified earlier and transmission prevented within the community. Data from this study suggests that Armenians have varying avenues of knowledge relating to the disease from non-Armenians which can be leveraged. Armenians stated that television and family and friends were their main source of TB knowledge. Furthermore, the qualitative interviews revealed that the majority of Armenians listens to, watches, and reads media that are on Armenian stations and in their native language. Therefore, public service announcements should be developed in Armenian, utilizing culture-specific elements, and disseminated using the aforementioned media avenues detailing disease characteristics, transmission risks, and the benefits of treatment adherence. Because Armenians also reportedly gain their knowledge from family and friends, the dissemination of information gained from Armenian-specific media may begin to snowball as more Armenians become informed and spread the information to others. Armenians have tight familial bonds and are eager to help each other; therefore the potential to spread the disease through inadequate care or incomplete treatment can be leveraged through media, and further enforced through physicians and local spiritual leaders.

While this study provides evidence for Armenian-specific public health efforts, further research needs to be conducted in Armenian populations living in LA County,

other parts of the United States, and worldwide in order to improve generalizability. Due to increased access to the population of interest, studies conducted by medical facilities in LA County, more specifically in SPA-2, would further enhance the scope and outreach touched upon by this study, and would be beneficial in order to expand the knowledge-base. The expansion of such studies relating to this topic has potential public health implications for TB, as well as other infectious diseases.

The ability to use data from this study and relate them back to TB case reporting and incidence in LA County is a hurdle. Current TB case reporting in California is up to date due to extensive reporting mandates. LA County is responsible for 30.5% of the reported cases in California with 18% of these cases found in Glendale and surrounding cities within SPA-2 (County of Los Angeles Public Health, 2015). The City of Glendale, has experienced the largest influx of Armenians nation- and world-wide, making it the second largest Armenian community on the planet, behind only Yerevan, Armenia. While the number of TB cases within SPA-2 has not been classified as Armenian or non-Armenian, the implication that many of these cases are attributed to Armenians is based upon their prevalence in the community and disease incidence in their native country. Therefore, in order to get a true assessment of TB cases attributed to Armenians, it is recommended that a separate racial category for Armenians be included on medical forms in the area as was done for the quantitative survey. This may facilitate improving disease outcomes in Armenians by incorporating trends revealed by this study. Support for this is demonstrated by a study conducted by Myers et al. (2006) which utilized SEM to explore TB transmission in California. Using the U.S. Census data for California, ecological

variables such as racial/ethnic distribution, immigration, education level, employment status, poverty, and crowding were incorporated and related to new TB cases, using pediatric cases as a measurement of transmission. Overall, lower median incomes, racial/ethnic minorities, and immigrants were found to have higher rates of pediatric tuberculosis.

Finally, for those conducting additional studies it is recommended that the TB-specific survey questions be simplified so that the respondents cannot select or write in multiple responses. This became a limitation when analyzing the data. As evident in Tables 9, 10, and 12, the ability to select multiple responses introduced many combinations of possible answers, thereby convoluting results and revealing more factors of significance, particularly when conducting bivariate and multivariate analyses.

Implications

Literature exploring TB is expansive and covers topics relating to disease epidemiology, improved diagnostics, hurdles associated with drug resistance, problems associated with adherence, and at-risk populations. The latter is more focused on general susceptible populations (e.g., HIV positive, the incarcerated, homeless, immigrants, and the poor) with little emphasis on specific cultures where family and traditions may have profound influences on TB knowledge and treatment seeking and adherence behaviors. Armenians are a susceptible population with strong family influences; however very few studies have focused on this group living in their native country or those who have immigrated to other countries. Therefore, this research fills the gap in understanding treatment-seeking barriers in this susceptible population, with potential public health

implications for other diseases in addition to TB. Implications for social change involve decreasing TB prevalence in the Armenian population within the United States and potentially within native Armenia through more effective disease management, resource allocation, and patient care efforts.

The SEM incorporates key principles from community- and individual-based approaches of prevention with an emphasis on the environment. Due to the uniqueness of this study, it serves to impact TB disease management in the Armenian community primarily at the first two or three levels: individual, interpersonal, and community. It can serve as a foundation for future studies to eventually lead to customized social public policy to effectively influence change in this at risk population.

Conclusion

TB is one of the world's deadliest, yet curable, diseases, with an estimated 6.0 million new cases and 9.6 million total individuals who fell sick with the disease in 2014, 5.4 million of which were men, 3.2 million were women and 1.0 million were children. In total, there were 1.5 million TB-associated deaths, ranking alongside HIV as the leading cause of death worldwide, primarily afflicting those living in low and middle-income countries (WHO, 2015). Armenia, in particular, is adversely affected by TB and complications associated with the emergence of MDR-, XDR- and TDR-TB strains. The WHO has designated Armenia as one of the 18 high priority countries for TB control amongst the WHO's European Region and the top 27 in MDR-TB burden countries in the world (Hayrapetyan, 2012). The Armenian population in LA County, where TB incidence is higher than national averages (CDC, 2013; County of Los Angeles Public

Health, 2015), is the second largest Armenian community in the world, second only to Yerevan (Hayk the Ubiquitous Armenian, 2012). Therefore, implications are that many of the TB cases are attributed to Armenians living in the region of California.

Review of the literature and TB incidence and mortality reports suggests that Armenians are a highly susceptible population due to high national incidence of MDR-TB, inadequate health care, poor disease surveillance, poor disease education, poverty, and emigration/immigration (Bakalian, 2011; Hayrapetyan, 2012; Truzyan et al., 2015; Vink et al., 2005); however, very few epidemiological or prevention studies have been dedicated to this group living either in Armenia or the United States. To the best of my knowledge, none of the studies conducted focus on Armenians residing in the United States where knowledge regarding access to health care, particularly relative to TB, may be lacking. Therefore, this study filled the gap in the literature for this underserved, at-risk population.

Using a concurrent mixed-methods study including surveys (quantitative) and in-depth interviews (qualitative), Armenians and non-Armenians living in LA County were interviewed to gain a better understanding regarding TB knowledge and barriers to treatment. An understanding of differences in physical, psychosocial, cultural, or behavioral factors and beliefs may impact TB knowledge, treatment seeking and treatment adherence in Armenians living in LA County from non-Armenian populations, potentially influencing public health approaches to effectively treating and decreasing TB incidence in this population. For the quantitative component of the study, bivariate chi-square analysis revealed that factors with the greatest significance and strength relate to

how the two populations learned about the disease and how compliant with a doctor's instructions participants would be if diagnosed, resulting in an effect size of 0.434.

Multivariate multinomial logistic regression analysis revealed predictor factors such as classification, the use of home remedies, age, education, and English as the primary household language to be significant.

The qualitative component of the study further corroborated many of the findings from the quantitative component where, although the populations were aware that TB exists, knowledge relating to TB mode of transmission, global incidence, and treatment properties (e.g., duration, effectiveness, and specific types) was generally lacking. One major reported difference between populations was that the Armenian population was far more eager to help others and urge them to seek treatment upon receiving a positive diagnosis, whereas non-Armenians express the lack of willingness to physically assist patients. This is also counter to a study conducted by Ige and Lasebikan (2011) in a non-Armenian population where family members of patients reported increased depression and helplessness. In this study, the culturally-based inquiry regarding the presence of *kapoot ach* in their residence revealed all of the Armenian participants had at least one. Such a trend may be useful when developing TB awareness and treatment programs for this at-risk group.

This study serves as the first step in understanding perceived barriers to TB treatment-seeking and treatment adherence in Armenians living in LA County, with the goal of positively impacting TB patient outcomes through improved, population-specific public health efforts. Implications for positive social change include evidence to inform

more effective disease management, resource allocation, and patient care efforts to help decrease TB prevalence in the Armenian population within the United States and potentially native Armenia. Regardless of location, this will rely on the involvement of Armenian stakeholders including physicians and healthcare workers, spiritual leaders, and Armenian media sources to disseminate ethnically-sensitive information within the community.

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Appendix A: IRB Documentation

Dear Ms. Ferguson,

This email is to notify you that the Institutional Review Board (IRB) has approved your application for the study entitled, "Differences in treatment seeking and treatment adherence factors for tuberculosis in Armenian versus non-Armenian populations of Los Angeles County."

Your approval # is 04-24-14-0230517. You will need to reference this number in your dissertation and in any future funding or publication submissions. Also attached to this e-mail are the IRB approved consent forms. Please note, if these are already in an on-line format, you will need to update that consent document to include the IRB approval number and expiration date. Please also ensure the Armenian versions are appropriately updated to contain this information as well.

Your IRB approval expires on April 23, 2015. One month before this expiration date, you will be sent a Continuing Review Form, which must be submitted if you wish to collect data beyond the approval expiration date.

Your IRB approval is contingent upon your adherence to the exact procedures described in the final version of the IRB application document that has been submitted as of this date. This includes maintaining your current status with the university. Your IRB approval is only valid while you are an actively enrolled student at Walden University. If you need to take a leave of absence or are otherwise unable to remain actively enrolled, your IRB approval is suspended. Absolutely NO participant recruitment or data collection may occur while a student is not actively enrolled.

If you need to make any changes to your research staff or procedures, you must obtain IRB approval by submitting the IRB Request for Change in Procedures Form. You will receive confirmation with a status update of the request within 1 week of submitting the change request form and are not permitted to implement changes prior to receiving approval. Please note that Walden University does not accept responsibility or liability for research activities conducted without the IRB's approval, and the University will not

accept or grant credit for student work that fails to comply with the policies and procedures related to ethical standards in research.

When you submitted your IRB application, you made a commitment to communicate both discrete adverse events and general problems to the IRB within 1 week of their occurrence/realization. Failure to do so may result in invalidation of data, loss of academic credit, and/or loss of legal protections otherwise available to the researcher.

Both the Adverse Event Reporting form and Request for Change in Procedures form can be obtained at the IRB section of the Walden web site or by emailing irb@waldenu.edu:

<http://researchcenter.waldenu.edu/Application-and-General-Materials.htm>

Researchers are expected to keep detailed records of their research activities (i.e., participant log sheets, completed consent forms, etc.) for the same period of time they retain the original data. If, in the future, you require copies of the originally submitted IRB materials, you may request them from Institutional Review Board.

Sincerely,

Jenny Sherer, M.Ed., CIP

Associate Director
Office of Research Ethics and Compliance
Email: xxxxxxxx
Fax: xxx-xxx-xxxx
Phone: xxx-xxx-xxxx
Office address for Walden University:
100 Washington Avenue South
Suite 900
Minneapolis, MN 55401

Appendix B: Qualitative Interview Guide, Armenian translation

Հիմնական պատմական տեղեկություններ — Հայ Մասնակցություններ

1. Դուք Հայաստանե՞ն գաղթած էք:
 - ա. Որք՞ան ժամանակ է կ'ապրիք Ամերիկայի Միացեալ Նահանգներ:
 - բ. Ներկայիս ո՞րն է կ'ապրիք:
2. Հայերեն գրել ու կարդալ գիտե՞ք: Որք՞ան լաւ:
3. Ձեր տան մէջ հայերէն կը խօսի՞ք:
 - ա. Որք՞ան հաճախ:
4. Դուք Հայերէն գրականութիւններ կը կարդա՞ք: Հայկական հեռուստատեսադրոյումներ կը դիտե՞ք « օրինակ Հայկական Դէլեթայն» կամ հայկական ռատիոյ ծրագրի կ'ընէ՞ք:
 - ա. Եթէ այո, որ՞մէ կը եւ որք՞ան յաճախ:
5. Դուք կը նախընտրե՞ք հովանավորել գործի հաստատութիւններ, կամ բնորոշ մասնագիտական օգնութիւններ «օրինակ, բժշկական սպասարկութիւններ» մասնաւոր հայերու համար?
6. Կը մասնակցի՞ք համայնային գործունէութեան կամ կազմակերպութեան «օրինակ: Հայկական Եկեղեցի, Արարատ Տուն, Մասիս Կիլտ» Որք՞մէ կը
7. Ձեր ընտանիքին մէջ կապույտ աչքեր ունեցող կ'այ

Ընդհանուր պատմական հարցարան

1. Ո՞ր Տարին ծնած ես:
2. Ի՞նչ է քու ամուսնական վիճակդ:
3. Հաճիս նկարագրէ բնակավայրդ:
 - ա. Անձնակ՞ան է Թէ վարցու:
4. Քա՞նի անձ կը բնակի ձեր տան մէջ
 - ա. Հաճիս նկարագրէ՛ հարաբերութիւնը, սեռը, իւրաքանչիւրին տարիքը:
5. Ին՞չ են ձեր ամենաբարձր ուսման մակարդակը:
6. Ին՞չ գործով կ'ապրիք:
7. Ին՞չքան է ձեր տարեկան եկամուտը «առանձ տուրքի»:
8. Բժշկական ապահովագրութիւն ունի՞ք:

9. Տարին քանի անգամ կ'այցելեք ձեր տեղական բժիշկին:
- ա. Դուք կը վստահի՞ք ձեր բժիշկին :
10. Եթե դուք կամ ընտանիքի անդամներէն կամ ընկերներէն մէկը օրնորոշուի է ունի մէկ տեսակի հիւանդութեան, կը դիմե՞ք հոգեւոր առաջնորդութեան?
11. Եթե հիւանդ գրակ, կը նախնորոշե՞ք տնային միջոցներ օգտագործել, «օրինակ մերսումներ, խոտաբույսեր, բուսական կամ համեմուած թեյեր» Ո՞րմէկը:
- ա. Եթե այո՛, կը նախնորոշե՞ք տնային բուսական միջոցները փորձել նախքան բժիշկի դիմելը:
- բ. Եթե նույնիսկ բժիշկի երթաք կը շարունակե՞ք տնային միջոցները օգտագործել միեւնոյն ժամանակ:

Թոքախտի «TB» հեզորիտ հարցեր

1. Դուք ծանօթ եք Թոքախտի հիւանդութեան:
- ա. Եթե այո, ին՞չ գիտէք թոքախտի մասին, եւ ին՞չ միջոցով կը փոխանանուի:
- բ. Թոքախտը փոխանանա՞լիք է: Նկարագրէ՛:
2. Տեղեկացած է՞ք վերջին լուրերը թոքախտի վերաբերեալ:
- ա. Ամէրիկայի միեացեալ նահանգներու մէջ:
- բ. Տարբեր երկիրներու մէջ: Ո՞րմէկը:
3. Բուժելի է Թոքախտի հիւանդութիւնը:
- ա. Ին՞չ գիտէք բուժումի մասին:
- բ. Կը կարծե՞ք մարդիկ հաւատարմութեամբ կը բուժուին թէ ոչ սպասուելիքով:
4. Եթե Թոքախտի մասին ճշտի ձեր ընտանիքէն, ընկերներէն, կամ ալ տեղեկութիւններէն մէկուն, ին՞չ կ'ըլլայ ձեր նախնական արձագանքը եւ զգացմունքները հիւանդութեան նկատմամբ:
5. Եթե Թոքախտ էք կամ այդ հիւանդութիւնը ունեցած էք անցեալին: Ի՞նչ կ'զգայք:
6. Եթե ունի մէկը ձեր ընտանիքի անդամներէն, ընկերներէն կամ գործակիցներէն մէկը թոքախտ ըլլայ, Ի՞նչ պիտի ըլլայ ձեր զգածմունքները այդ իրադարձութեան նկատմամբ:
7. Ձեր ընտանիքէն ունի մէկը Թոքախտի հիւանդութիւն ունի: Եթե այո, ձեր վերաբերմունքը կը փոխուի անձին հանդէպ:
- ա. Նկարագրէ՛ ունեցած սգացումներդ անձին հանդէպ իր օրնորոշման շնորհիւ ետք:

8. Արդե՞՞օք տեղեակ էք Լոս Անճեւելոսի մէջ գտնուող Թոմախտանոցներու եւ կամ բուժող ծառայութիւններու մասին:

ա. Եթէ ոչ, ուրեմըն եթէ տեղեկութիւններ կարելի ըլլան, «թերեւս հայերենով, միայն հայերու համար» կ'ուզէ՞ք հետազոտել կարողալով հիւանդութեան մասին եւ բաժնեկցիլ ուրիշներու հետ ձեր գաղութէն ներս:

9. Դուք տեղեակ է՞ք ոեւէ համայնֆային աջակցութեան խումբերէն որոնք կ'զբաղուին Թոմախտի հիւանդութեան առնջութեամբ?

ա. Եթէ այո, նկարագրէ՛:

Appendix C: Quantitative Survey, Armenian translation

Հիմնական տեղեկություններ

1. Քանի տարեկան էք:
- | | | | | | | | |
|----|-------|----|-------|----|-------------|----|-------|
| ա. | 18-20 | բ. | 21-30 | գ. | 31-40 | դ. | 41-50 |
| ե. | 51-60 | զ. | 61-70 | է. | 70 եւ ավելի | | |
2. Սեռ
- | | | | |
|----|--------|----|--------|
| ա. | Իգական | բ. | Առական |
|----|--------|----|--------|
3. Ո՞ր ցեղի կը պատկանիս:
- | | | | |
|----|------------------------------------|----|---------------------------------|
| ա. | հերմակ, Ոչ-Սպանախոս կամ Լադին | բ. | հերմակ, Հայեր |
| գ. | հերմակ, Սպանացի կամ Լադին | դ. | Սեռ, Աֆրիկեան Ամերիկացի |
| ե. | Ասիացի | զ. | Ամերիկացի Հնդիկ/Բնիկ Ալաուացի |
| է. | Բնիկ Հավայացի կամ Խաղաղ Ովկիանոսցի | | |
| ը. | Երկու կամ ավելի ցեղեր, Հայեր | թ. | Երկու կամ ավելի ցեղեր, Ոչ-Հայեր |
4. Ինչ էք ծագումով
- | | | | |
|----|---|----|------------|
| ա. | Ոչ- Սպանացի, Լադին, կամ Սպանացի ծագումով | | |
| բ. | Մեքսիկացի, Մեքսիկացի-Ամերիկացի, չիլանո | գ. | Բորդոբիացի |
| դ. | Գուայացի | | |
| ե. | Տարբեր Սպանացի, Լադին, կամ Սպանացի ծագումով օրինակ (Արժանքինցի, Գուլամպիացի, Տոմինիացի, Սալվատորցի)։ | | |
5. Որ երկիրէն էք ծագումով (լեցուցէ՛ք խնդրեմ) _____
6. Քանի տարի է կ'ապրիք Ամերիկայի Միացեալ Նահանգները:
- | | | | |
|----|---------------------|----|---------------|
| ա. | 1 տարիէն պակաս | բ. | 1-5 տարիներ |
| գ. | 6-10 տարիներ | դ. | 11-20 տարիներ |
| ե. | 20 եւ ավելի տարիներ | | |
7. ներկայիս սրմէ՞կ ֆազաբը կ'ապրիք:
- | | | | | | |
|----|---------|----|-----------------------------|----|---------------|
| ա. | Կլէնտել | բ. | Բասատենա/Հարաւային Բասատենա | | |
| գ. | Պըրպէնֆ | դ. | Սան Ֆէրնանտո | ե. | Սանդա Մոնիֆա/ |

- Արեւմտեան Լոս Անճեւս Գ. Տաունի / Մոնթեպէլլօ / Սաուր կէյր է.
Ուրիշ _____
8. Ին՞չ է ձեր ամուսնական կարգավիճակը:
ա. Միայնակ, չ'ամուսնացած Բ. Ամուսնացած Գ. Բաժնուած
դ. Այրիացած Ե. Ջատուած, Մեկուսացած
9. Ձեզմէ գատ քանի հոգի կ'ապրի ձեր տան մէջ:
ա. 0 Բ. 1 Գ. 2-4
դ. 5-6 Ե. 6 եւ աւելի
10. Նկարագրէ՛ իրենց հարաբերութիւնները ձեր նկատմամբ: «ընտրել»
ա. Ամուսինը Բ. Երեխաները Գ. Եղբայր/Քոյր
դ. Տարեց ծնողներ կամ մեծ հայր եւ մեծ մայր Ե. Ուրիշ _____
11. Ձեր ընտանիքին հիմնական լեզուն Անգլեր՞ն է:
ա. Այո Բ. Ոչ
12. Ուրիշ լեզուներ կը խօսի՞՞ք ձեր տան մէջ:
ա. Հայերէն Բ. Սպաներէն Գ. Ոչ Դ. Ուրիշ _____
13. Ին՞չ են ձեր ուսման ամենաբարձր կրթութիւնը:
ա. Երկրորդական Բ. Քոլէճ Գ. Բակալաւրի աստիճան
դ. Միջին Մասնագիտութիւն / Մասնագիտական կրթութիւն
14. Ին՞չ գործով կ'գրադուիք:
ա. Անգործ Բ. Թրուակառու Գ. Պահող
դ. Ուսանող Ե. Մասնագիտական «բժիշկ, իրաւաբան, ուսուցիչ»
գ. Բանուր «հմուտ կամ ոչ հմուտ աշխատող»
15. Որ՞ն է ձեր ընդհանուր տարեկան եկամուտը: «նախատուրք»
ա. 0-\$25,000 Բ. \$25,000-40,000
գ. \$40,000-60,000 Դ. \$60,001-80,000
Ե. \$80,001-100,000 Գ. \$100,000 եւ աւելի
16. Բժշկական ապահուագրութիւն ունի՞ք:
ա. Այո Բ. Ոչ
17. Կը վստահի՞ք ձեր առաջնային խնամքի բժիշկին:

ա. Այո բ. Ոչ գ. Գաղաբար չունիմ

18. Եթէ դուք կամ ձեր ընտանիքի անդամներէն եւ ընկերներէն մէկը հիւանդանա, կը դիմէ՞ք հոգեւոր առաջնորդութեան:

ա. Այո բ. Ոչ

19. Եթէ հիւանդանա, կը նախնոր՞էք տնային միջոցներ օգտագործել: Օրինակ «մրսումներ, խոտաբույսեր, բուսական կամ համեմուած թէկէր»

ա. Այո բ. Ոչ

Թոքախտի (TUBERCULOSIS) նշաններ հարցեր

1. Լսած էք Թոքախտի հիւանդութեան մասին:

ա. Այո բ. Ոչ

2. Ին՞չպէս լսած էք Թոքախտի մասին: «ընտրէ»

ա. Հեռուստատեսիլ բ. Համաձայն գ. Օրաթերթ
դ. Ընտանիքի անդամներէն կամ բարեկամներէն ե. Ուրիշ _____

3. Կը հաւատա՞ք որ Թոքախտը ժամանակակից օրուա առողջապահական խնդիր է Ամերիկայի Միացեալ Նահանգներու մէջ:

ա. Այո բ. Ոչ

4. Կը հաւատա՞ք որ Թոքախտը ժամանակակից օրուա առողջապահական խնդիր է միջազգայինօրէն:

ա. Այո բ. Ոչ

5. Ին՞չպէս Թոքախտի հիւանդութիւնը կը փոխանցուի:

ա. Հագալով բ. Փոխադրով գ. Շոշափելով
դ. Սերական կապով ե. Կրկնութիւն / ջուր կուլ տալով
գ. Անհաւասարակշիւթիւն տափի եւ պաղի է. Չենք գիտեր

6. Ին՞չ եւն Թոքախտի ընդհանուր ախտանիշը:

ա. հագալը բ. փոխադրը գ. Ախորժակի կորուստ
դ. Յոգնածութիւն ե. Արիւնահոսութիւն գ. Չենք գիտեր

7. Դուք գիտա՞ք թէ մատչելի բուժումներ կան Թոքախտի հիւանդութիւնը բուժելու:

ա. Այո բ. Ոչ

8. Որ՞քան է բուժման տեսողութիւնը:

- ա. 3 օր
 դ. 6 ամիսէն աւելի ե. 7 օր
 գ. Մէկ ամիս
 Չենք գիտեր

9. Թոճախտի բուժման հարիւր տոկոս արդիւնաւօէր է:

- ա. Այո
 բ. Ոչ
 գ. Չենք գիտեր

10. Թոճախտը բուժելի հիւանդութիւն է:

- ա. Այո
 բ. Ոչ
 գ. Չենք գիտեր

11. Եթէ Թոճախտի մասին խօսուի ընտանիքիդ կամ ընկերներուդ միջեւ եւ կամ ալ լուրերու ընթացքին, ի՞նչ կ'ըլլայ ձեր նախնական ցուցմունքները եւ զգացումները:

- ա. Վախցած
 բ. Տեղեկացած
 գ. Անտարբեր
 դ. Անզգնական

12. Դուք կամ յետէ մէկը ձեր ընտանիքէն ունեցած է Թոճախտի ախտահանաչում:

- ա. Այո
 բ. Ոչ

13. Եթէ այո, ին՞չ զգացիք: «ընտրել»

- ա. Վախցած
 բ. Տեղեկացած
 գ. Անտարբեր
 դ. Անզգնական
 ե. Ճնշուած

14. Ին՞չ պատճառներ կրնան գործակից ըլլալ Թոճախտի հիւանդութեան հետ: «ընտրել»

- ա. Աղիաստութիւն
 բ. Արտաքին ծնունդ
 գ. Միավ կարգավիճակը
 դ. Թմրադեղերի պատ պատմութիւն
 ե. Ցած հասարակական կարգ
 գ. Սէռական կողմնորոշում
 է. Հոգեկան հիւանդութիւն
 ը. Կրօնք
 թ. Ծխել
 ժ. Տարածուած հիւանդութիւն
 ի. Բուժելի հիւանդութիւն
 լ. Անհաւասարակչութիւն տաքի եւ պաղի
 մ. ազատագրկման

15. Եթէ յետէ մէկը Թոճախտի հիւանդութիւն ունի կը կարծէ՞ք «ընտրել»

- ա. Ան հաւանաբար սխալ բան մը ըրած է, օրինակ դեղերու օգտագործում
 բ. Աստուծոյ կողմէն պատիժ
 գ. Ան հիւանդութիւնը ունի ցեղային հետին պատճառով
 դ. Կրնայ յետէ մէկուն պատահիլ

16.

Եթէ դուք Թոքախտի հիւանդութիւն ունիք,	Բնաւ համաձայն 1	Համաձայն չեմ 2	Գաղաբար չունիմ 3	Համաձայն եմ 4	Անբողջութեամբ համաձայն եմ 5
Կը վստահի՞ք ձեր բժիշկին՞					
Բուժման վերաբերեալ կը համապատասխանէք բժիշկներուն հրահանքներուն					
Կը նախնարէ՞ք բուժուիլ հիւանդանոցէն դուրս, անձնական բուժարաններու մէջ. Ընտրել վարի ցուցակէն:					

17. Եթէ կը նախնարէք բուժուիլ անձնական բուժարաններու մէջ, ու՞ր կը դիմէք: Ընտրել ցանկացածը «ընտրէ»

- ա. Բայրաբէրէրքը
- բ. Աֆուփանֆ չըր
- գ. Հոմոբաղիֆ
- դ. Բժիշկ/սննդաբան
- ե. Կրօնական/էկէղեցական առաջնորդ
- զ. Կենցաղային միջոցներ, օրինակ «դեղաբոյսեր, թէէր, եխդեր»
- զ. Ոչ մէկը

18. Դուք տե՞ղեակ էք Թոքախտի բուժարաններու եւ մատուցուած ծարայութիւններու մասին Լյոս Աննէլսի շքանշան մէջ:

- ա. Այո
- բ. Ոչ

19. Եթէ ոչ, եւ եթէ տեղեկութիւնները մատչելի են, կը նախնարէ՞ք աւելի հետազոտել եւ կարգաւ այդ հիւանդութեան մասին եւ տեղեկացնել ուրիշներուն ձեր համայնքէն ներս:

- ա. Այո
- բ. Ոչ

20. Դուք տե՞ղեակ էք հասարակական աջակցութեան խումբերու մասին որ կը զբաղուի այս հիւանդութեամբ ձեր համայնքէն ներս:

- ա. Այո
- բ. ոչ

Appendix D: Informed Consent Form (Qualitative)

Informed Consent Form

Title of Project: Differences in treatment seeking and treatment adherence factors for tuberculosis in Armenian versus non-Armenian populations of Los Angeles County

Name of Researcher: Tanya M Ferguson

You are invited to take part in a research study regarding tuberculosis knowledge and perceptions. The researcher is inviting Armenians and non-Armenians who reside in Los Angeles County to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named Tanya M. Ferguson, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to explore current knowledge and perceptions relating to tuberculosis, including the required course of treatment for disease cure.

Procedures:

If you agree to be in this study, you will be asked to:

- Participate in an-depth face-to-face interview, roughly 60 minutes in length. Interviews will be recorded for accuracy purposes.
- Your involvement will only require one interview; however, if there any answers that require clarification by the researcher, the researcher reserves the right to contact you by phone.

Here are some sample questions:

1. Are you familiar with the disease, tuberculosis (TB)?
 - a. If yes, please describe what you know about it, including modes of transmission.
2. Is TB infectious to others? Please describe.
3. Is TB a treatable disease?
 - a. What do you know about the treatment?
 - b. Are any of these factors a deterrent for seeking or adhering to treatment? Which ones?
4. If TB is mentioned by family, friends, or news reports, what are your initial reactions and feelings?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as stress. Being in this study would not pose risk to your

safety or wellbeing. However, if you are dealing any kind of problem regarding this research please call the toll free, 24-hour hotline of the Centers for Diseases Control and Prevention Lifeline at 1-800-273-TALK (1-800-273-8255); TTY: 1-800-799-4TTY (4889) to talk to a trained counselor.

The goal of this study is learn more knowledge and perceptions relating to tuberculosis and tuberculosis treatment in Armenian and non-Armenian populations living in LA County. Tuberculosis has great public health implications. A better understanding of key factors that may serve as barriers will improve patient management and disease outcomes.

Payment:

As gratitude for your participation, participants will receive a one-time \$10 prepaid gift card which will be presented at the termination of the interview.

Privacy:

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports.

Contacts and Questions:

You may ask any questions you have now. If you have questions later, you may contact the researcher via cell phone at xxx-xxx-xxxx or email to xxxxxxxxxxxx. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott who is the Walden University representative and is available to discuss this with you. Her phone number is xxx-xxx-xxxx. Walden University’s approval number for this study is 04-24-14-0230517 and it expires on 04-2015.

The researcher will provide you with a copy of this signed consent form to keep as a record of your participation in the interview.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant _____

Date of consent _____

Participant’s Signature _____

Researcher’s Signature _____

Appendix E: Informed Consent Form (Qualitative, Armenian translation)

Տեղեկացուած համաձայնութեան ձեւ

Վերնագիր Ծրագրի: Տարբերութիւնները բուժման նպատակին եւ բուժման պահպանման գործոնները Թոքախտի հիւանդութեան ընդէմ ոչ հայ բնակչութեան Լոս Անճելեսի շրջանին.

Հետազոտողի Անունը: Դանիա Մ. Ֆըրկըսըն

Դուք հրաւիրուած էք մասնակցելու հետազոտական ուսումնասիրութեան վերաբերեալ Թոքախտի (tuberculosis) գիտելիքներու եւ պատկերացումներու:

Հետազոտ **Tanya M. Ferguson** կը հրաւիրէ բոլոր հայերը եւ ոչ հայերը որոնք կը բնակին Լոս Անճելես քաղաքի մէջ որպէսզի մասնակցին Թոքախտի ուսումնասիրութեան. Այս ձեւը գործընթացի մէկ մասն է որ կը կ'ոչուի «Տեղեկացուած Համաձայնութիւն» որ թոյլ կ'ուտայ հասկնալու այս ուսումնասիրութեան նախնական որոշումն առնելը մասնակցելու կամ ոչ:

Այս ուսումնասիրութիւնը իրականացուած է հետազոտող **Դանիա Մ. Ֆըրկըսընի** կողմէն

Տոքոսթրական գիտական ուսանող **Ուալտըն (Walden)** համալսարանի մէջ:

Ընդհանուր Տեղեկութիւններ

Նպատակը այս ուսումնասիրութեան հետազոտել ներկայիս գիտելիքներն ու ընկալումը վերաբերուած Թոքախտի հիւանդութեան ինչպէս նաեւ անհրաժեշտութեան պարաֆային պէտք եղած լուծումը:

Ընթացքներ

Եթէ դուք համաձայն էք մասնակցելու այս ուսումնասիրութեան, ձեզմէ պիտի պահանջուի

- Մասնակցիլ դէմ առ դէմ հարցազրոյցի **60** րոպէական տեւողութեամբ: Հարցազրոյցները կ'արձանագրուի հետազոտողի նպատակով:
- Ձեր մասնակցութիւնը կը պահանջէ միայն մէկ անգամ հարցազրուցել բայց եթէ յետոյ հարցում պէտք է որ պարզաբանել, հետազոտողը իրավունք ունի ձեզ հետ հետախօսուի կապ պահել յստակացնելու համար:

Այստեղ կը գտնէք նման հարցումներ:

1. Դուք ծանօթ է՞ք Թոքախտի հիւանդութեան:

- ա. Եթէ այո, հաճիս նկարագրէ՛ ինչ որ գիտես անոր մասին ինչպէս նաեւ եղանակի փոխանձման:

2. Թոքախոտը փոխանց՞իլ հիւանդութիւն է: Բացատրէ:
3. Թոքախոտը բուժե՞լի հիւանդութիւն է:
 - ա. Ի՞նչ գիտէք բուժման մասին:
 - բ. Ուե՛լ մէկը կա՞յ այդ գործոններէն որ սպարնալիքով զսպման կը փնտոնէ կամ հաւատարմօրէն բուժման? Որ գործոնները:
4. Եթէ Թոքախտի մասին նշուի ձեր ընտանիքէն, ընկերներէն, կամ այլ տեղեկութիւններէն, ին՞չ կ'ըլլայ ձեր նախնական արձագանքը եւ զգացումները:

Կամաւոր Բնոյթը Ուսումնասիրութեան

Այս ուսումնասիրութիւնը կամաւոր է: Իւրաքանչիւրին անձ պիտի յարգէ ձեր որոշումը, եթէ մասնակցիք կամ ոչ, տարբեր վարուելակերպ պիտի չ'ունենաք, իսկ եթէ որոշէք մասնակցիլ նայնպէս կրնաք միշտ փոխել ձեր միտքը եւ չի շարունակել այս ուսումնասիրութեան:

Վտանգները եւ Օգուտները Ուսումնասիրութեան Մասնակցելու

Այս տեսակի ուսումնասիրութեան մասնակցիլը կը վտանգէ յառաջացնելով մանր անհանգստութիւններ առօրեայ կեանքէն ներս. Օրինակ ջղային դրութիւններ բայց չի վտանգեր ձեր ապահովութիւնը եւ կամ բարեկեցութիւնը:

Այսուամէնայնիս եթէ ուե՛լ մէկ հարց կամ խնդիր ունենաք այս հետազոտութեան առնչութեամբ, կը խնդրենք հեռաձայնել 24 ժամ ձրի թիւով հիւանդութիւնները վերահսկողութեան եւ կենսապահովման կանխարգիլման կեդրոնը, թիւն է 1-800-273-8255, իսկ լսել անկարողներու համար թիւն է 1-800-799-4889: Միշտ պիտի կրնաք խօսիլ մարգուած խորհրդատուի հետ:

Այս ուսումնասիրութեան նպատակն է գտնել եւ սորվիլ աւելի շատ գիտելիքներ եւ պատկերացումներ Թոքախտի առնչութեամբ եւ անոր բուժմանը հայերու կամ ոչ հայերու գտնուող Լոս Անճելոսի շրջանին մէջ:

Թոքախտի հիւանդութիւնը (Tuberculosis) ունի մեծ նշանակութիւն եւ առողջապահական հետեւանքներ: Աւելի լաւ հասկնալու եւնք հիմնական գործոններուն որոնք կը ծարայէն հիւանդին խոչնդոտները բարելաւելով ինչպէս նաեւ կարավարման եւ ելք գտնելու հիւանդութեան:

Վճարում

Որպէս երախտագիտութիւն, մասնակցողները մասնակցելու համար կ'ստանան մէկ անգամ \$10

Ամէրիկեան տուար իբրեւ նուէր գարդով որ կը տրուի հարցազրոյցը աւարտելէն ետք:

Մեկնութիւն / Գաղտնութեան պահպանման

Ուել մէկ տեղեկութիւն գաղտնի կը պահուին, հետագոտիչը չ'օգտագործեր ձեր անձնական տեղեկութիւնը նպատակէն դուրս. Նաեւ հետագոտողը չի պարունակեր ձեր անունը կամ ինքնութիւնը ուսումնասիրութեան հաղորդումներէն:

Կապեր եւ հարցումներ

Եթէ ուել մէկ հարցում ունիք, կրնաք հիմա հարցնել: Հետաքննող եթէ հարցեր ունենաք, կրնաք հետագոտին հասնիլ հեռաձայնելով xxxxxxxxxxxxxxxx կամ գրել հետեւեալ հասցէով xxxxxxxxxxxxxxxx եթէ ուզէք անձամբ խօսիլ ձեր մասնակցողական իրաւունքի մասին դուք կրնաք հեռաձայնել Dr. Leilan Edincott որ ինք Walden համալսարանի ներկայացուցիչն է, եւ միշտ պատրաստ է լսել ձեզ: Իր հերթին թիւն է xxxxxxxxxxxxxxxxxxxx: Walden համալսարանի ուսումնասիրութեան հաստատումի թիւն է, 04-24-14-0230517 կ'աւարտի 04-2015 թուին. Հետագոտողը ձեզի պիտի տրամադրէ կրկնօրինակ մը ստորագրուած համաձայնութեան ձեւէն ձեր մօտ ունենալու եւ պահպանելու ձեր հարցազրույցի մասնակցութեան բանաձեւը:

Համաձայնութեան Հաշտութեան Թուեր

Ես կարդացի վերի գրուած տեղեկութիւնները, գիտակցելով պարունակութեան կրնամ որոշում անել իմ ներգրաւածութեան մասին. Ստորագրելով ստորեւ, ես կը համաձայնիմ պայմաններուն ինչպէս որ նկարագրուած է վերի գրութեան մէջ:

Տպագիր: Անունը Մասնակիցի:
Թուականը Համաձայնութեան:
Մասնակիցի Ստորագրութիւնը:
Հետագոտի Ստորագրութիւնը:

Appendix F: Informed Consent Form (Quantitative)

Informed Consent Form

Title of Project: Differences in treatment seeking and treatment adherence factors for tuberculosis in Armenian versus non-Armenian populations of Los Angeles County

Name of Researcher: Tanya M Ferguson

You are invited to take part in a research study regarding tuberculosis knowledge and perceptions. The researcher is inviting Armenians and non-Armenians who reside in Los Angeles County to be in the study. This form is part of a process called “informed consent” to allow you to understand this study before deciding whether to take part. This study is being conducted by a researcher named Tanya M. Ferguson, who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to explore current knowledge and perceptions relating to tuberculosis, including the required course of treatment for disease cure.

Procedures:

If you agree to be in this study, you will be asked to:

- Participate in an online survey, roughly 15 to 20 minutes in length.

Here are some sample questions:

1. Have you heard of the disease tuberculosis (TB)? A. yes, b. no
2. How have you heard about TB:
 - a. TV, b. Internet, c. family or friends, d. newspaper/magazine e. other
3. Do you believe that TB is a modern day health problem in the US? a. yes, b. no
4. Do you believe that TB is a modern day health problem internationally? a. yes, b. no
5. How is TB transmitted?
 - a. Coughing, sneezing, b. touching, c. sexual contact, d. food/water ingestion, e. don't know

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. No one will treat you differently if you decide not to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study:

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as stress. Being in this study would not pose risk to your safety or wellbeing. However, if you are dealing any kind of problem regarding this research please call the toll free, 24-hour hotline of the Centers for Diseases Control and Prevention Lifeline at 1-800-273-TALK (1-800-273-8255); TTY: 1-800-799-4TTY (4889) to talk to a trained counselor.

The goal of this study is learn more knowledge and perceptions relating to tuberculosis and tuberculosis treatment in Armenian and non-Armenian populations living in LA County. Tuberculosis has great public health implications. A better understanding of key factors that may serve as barriers will improve patient management and disease outcomes.

Payment: None.

Privacy:

Any information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports.

Contacts and Questions:

You may ask any questions you have now. If you have questions later, you may contact the researcher via cell phone xxx-xxx-xxxx or email to xxxxxxxxxxxx. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott who is the Walden University representative and is available to discuss this with you. Her phone number is xxx-xxx-xxxx. Walden University's approval number for this study is 04-24-14-0230517and it expires on 04-2015.

Please print or save this consent form as a record of your participation in the survey.

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By completing the survey, I understand that I am agreeing to the terms described above.

Appendix G: Informed Consent Form (Quantitative, Armenian Translation)

Տեղեկացուած Համաձայնութեան ձեւ

Վերնագիր Ծրագրի: Տարբերութիւնները բուժման նպատակին եւ բուժման պահպանման Թոքախտի հիւանդութեան հայերու մէջ ընդեմ ոչ հայ բնակչութեան Լոս Անճելեսի քաղաքին մէջ:

Հետազոտի անունը **Tanya M. Ferguson**

Դուք հրաւիրուած էք մասնակցելու Թոքախտի (tuberculosis) հետազոտական ուսումնասիրութեան վերաբերեալ գիտելիքներու եւ պատկերացումներու: Հետազոտողը կը հրաւիրէ հայերը որոնք կը բնակին Լոս Անճելեսի քաղաքին մէջ որպէսզի մասնակցին ուսումնասիրութեան հետազոտութեան: Այս ձեւը մէկ մասն է գործընթացի որ կը կ'ընչուի «Տեղեկացուած Համաձայնութիւն» որ թոյլ կ'ուտայ հասկնալու սոյն ուսումնասիրութիւնը նախքան մասնակցի մասնակցելու որոշում առնելը:

Այս ուսումնասիրութիւնը իրականացուած է հետազոտ Դանիա Մ. Ֆըրկըսընի (**Tanya M. Ferguson**) կողմէն Բժշկական Գիտական Ուսանող **Walden** Համալսարանի մէջ:

Ընդհանուր Տեղեկութիւններ

Նպատակը այս ուսումնասիրութեան հետազոտել ներկայիս գիտելիքներն ու ընկալումը վերաբերուած Թոքախտի հիւանդութեան ինչպէս նաեւ անհրաժեշտութեան պարաֆային պէտք եղած բուժումը:

Ընթացքներ

Եթէ դուք համաձայն էք մասնակցելու այս ուսումնասիրութեան, ձեզմէ պիտի պահանջուի

- Մասնակցիլ համաձայն՝ միջոցով: Հետազոտութիւնը կը տեւէ մօտաւորապէս 15-20 վայրկեան:

Այստեղ կը գտնէք նման հարցումներ

1. Դուք ծանօթ է՞ք Թոքախտի հիւանդութեան (TB):

ա. Այո Բ. Ոչ

2. Ինչ՞ ձեւով լսած էք Թոքախտի մասին:

ա. Հետաւեալի Բ. Համաձայն Գ. Ընտանիք/բարեկամ
 դ. Օրաբերք/ամսաբերք Ե. Ուրիշ

3. Կը հաւատա՞ւք թէ Թոքախտը ժամանակակից օրուայ առողջապահական խնդիր է Ամէրիկայի Միացեալ Նահանգներու մէջ:

ա. Այո ք. Ոչ

4. Կը հաւատա՞ւք թէ Թոքախտը (TB) ժամանակակից օրուայ առողջապահական խնդիր է միջազգայինօրէն:

ա. Այո ք. Ոչ

5. Ինչպէս Թոքախտը կը փոխանանուի:

ա. Հագալով/փոխփոխով ք. Շոգաբերով գ. Սեռական կապով
 դ. Կրթութիւն/ջուր կուլ տալով ե. Չ'ենք գիտեր

Կամաւոր Բնոյթը Ուսումնասիրութեան

Այս ուսումնասիրութիւնը կամաւոր է, իւրաքանչիւր անձ պարտաւոր է յարգել մասնակիցին որոշումը, եթէ անձ մը չի մասնակցի այս ուսումնասիրութեան, տարբեր վարմունք պիտի չունենայ չի մասնակցելու համար. Իսկ եթէ որոշէք մասնակցիլ, յետաքային եթէ ձեր միտքը փոխէք, կրնաք ձեր աշխատանքին վերջ տալ ուսէ մէկ ժամանակ:

Վտանգները եւ օգուտները ուսումնասիրութեան մասնակցելու

Այս տեսակի ուսումնասիրութեան մասնակցիլը կը վտանգէ յառաջացնելով մանր անհանգստութիւններ առօրեայ կեանքէն ներս. Օրինակ ջղային դրութիւններ բայց չի վտանգեր ձեր ապահովութիւնը եւ կամ բարեկեցութիւնը:

Այսուամէնայնիս եթէ ուսէ մէկ հարց կամ խնդիր ունենաք այս հետազոտութեան առնչութեամբ, կը խնդրենք հեռաձայնել 24 ժամ ձրի թիւով հիւանդութիւնները վերահսկողութեան եւ կենսապահովման կանխարգիլման կեդրոնը, թիւն է 1-800-273-8255, իսկ լսել անկարողներու համար թիւն է 1-800-799-4889: Միշտ պիտի կրնաք խօսիլ մարգուած խորհրդատուի հետ:

Այս ուսումնասիրութեան նպատակն է գտնել եւ սորվիլ աւելի շատ գիտելիքներ եւ պատկերացումներ Թոքախտի առնջութեամբ եւ անոր բուժմանը հայերու կամ ոչ հայերու գտնուող Լոս Անճելեսի տրջանին մէջ:

Թոքախտի հիւանդութիւնը (Tuberculosis) ունի մեծ նշանակութիւն եւ առողջապահական հետեւանքներ: Աւելի լաւ հասկնալու եւնք հիմնական գործոններուն որոնք կը ծարայէն հիւանդին խոչնդոտները բարելաւելով ինչպէս նաեւ կարավարման եւ ելք գտնելու հիւանդութեան:

Վճատում: Անվճատ

Մեկնություն/Գաղտնություն պահպանման:

Ուելս մեկ տեղեկություն գաղտնի կը պահուին, հետագոտիչը չ'օգտագործեր ձեր անձնական տեղեկությունը նպատակէն դուրս. Նաեւ հետագոտողը չի պարունակեր ձեր անունը կամ ինքնությունը ուսումնասիրութեան հաղորդումներէն:

Կապեր եւ հարցումներ

Եթէ ուելս մեկ հարցում ունիք, կրնաք հիմա հարցնել : Հետաքննող եթէ հարցեր ունենաք, կրնաք հետագոտին հասնիլ հեռաձայնելով XXX-XXX-XXXX կամ գրել հետեւեալ հասցէով
 XXXXXXXXXXXXXXXXXXXX եթէ ուզէք անձամբ խօսիլ ձեր մասնակցողական իրաւունքի մասին դուք կրնաք հեռաձայնել Dr. Leilan Edincott ար ինք Walden համալսարանի ներկայացուցիչն է, եւ միտ պատրաստ է լսել ձեզ: Իր հերթին թիւն է XXX-XXX-XXXX Walden համալսարանի ուսումնասիրութեան հաստատումի թիւն է, 04-24-14-0230517 կ'աւարտի 04-2015 թուին.
 Կը խնդրեն տպել կամ պահպանել այս համաձայնութեան ձեւը որպէս արձանագրութիւն ձեր քննաչափութեան մասնակցութեանը:

Համաձայնութեան Հաւանատուութիւն

Ես կարդացի վերի գրուած տեղեկութիւնները, գիտակցելով պարունակութեան կրնամ որոշում առնել իմ ներգրաւածութեան մասին. Ամբողջացնելով համաձայնձային յետագոտութիւնը, կը հասկնամ որ ես համաձայն եմ վերի նկարագրուած պայմաններուն:

Appendix H: Recruitment Invitation, Quantitative



Participants needed for online research study



Wanted: Volunteers to help investigate differences in tuberculosis knowledge and perceptions for Armenians and non-Armenians residing in Los Angeles County

Who is Eligible?

- Armenians and non-Armenians residing in Los Angeles County
- At least 18 years of age
- Read and write English and/or Armenian fluently (an Armenian version will be available online)

You will be asked to:

- Provide informed consent
- To participate in an online multiple-choice survey (approx. 15-20 minutes)

This study is being conducted by Tanya M. Ferguson, a doctoral student in Public Health at Walden University. The title of the project is “Differences in treatment seeking and treatment adherence factors for tuberculosis in Armenian versus non-Armenian populations of Los Angeles County”. All information provided will remain confidential.

If you have any questions, please contact Tanya M. Ferguson at xxxxxxxxxxxxxxxxxxxx. If you are interested in participating, please go to xxxxxxxxxxxx or scan here:

TB Study2



Appendix I: Recruitment Invitation, Qualitative



Participants needed for research study



Wanted: Volunteers to help investigate differences in tuberculosis knowledge and perceptions for Armenians and non-Armenians residing in Los Angeles County

Who is Eligible?

- Armenians and non-Armenians residing in Los Angeles County
- At least 18 years of age
- Read and write English and/or Armenian fluently (a translator will be available)

You will be asked to:

- Sign an informed consent form
- Participate in a face-to-face interview (approx. 1 hour), with a potential for follow-up questioning if necessary*

*Participants will receive a pre-paid \$10.00 cash card as compensation immediately following the completion of the study.

This study is being conducted by Tanya M. Ferguson, a doctoral student in Public Health at Walden University. The title of the project is “Differences in treatment seeking and treatment adherence factors for tuberculosis in Armenian versus non-Armenian populations of Los Angeles County”. All information provided will remain confidential. If you have any questions or are interested in participating, please contact Tanya M. Ferguson at xxxxxxxxxxxxxxxxxxxx or scan here:

TB Study1



Appendix J: Quantitative Recruitment Invitation, Armenian Translation



Մասնակիցներ պետք են համաձայնության հետազոտական ուսումնասիրության համար



Կ'ուզուի՞ն. Կամաւորներ օգնելու հետախնդրանքան Թոքախտի (Tuberculosis) առնչութեամբ գիտելիքներու եւ պատկերացումներու տարբերութիւնները Լոս Անճելոսի մէջ բնակող հայերու եւ Լոս Անճելոսի մէջ չի չբնակող հայերու միջեւ:

Ո՞վ Իրավունք ունի:

- Հայերը եւ ոչ հայերը որոնք կը բնակին Լոս Անճելոս քաղաքի մէջ
- Անոնք որոնք առնուազն 18 տարեկան են:
- Անգլերէն գրել կարող գիտնալ եւ կամ շատ Լա հայերէն (Հայերէն տարբերակ պիտի գտնէք համաձայնութեան միտցով)

Պիտի խնդրուի ձեզմէ

- ներկայացնել տեղեկացուած համաձայնութիւնը
- Մասնակցի բազմակի ընտրութիւն հետազոտութեան հարցերուն համաձայնութեան միտցով (մտաւորապէս 15 – 20 վայրկեա տեսողութեամբ):

Այս ուսումնասիրութիւնը իրականացուած ա Դանիա Մ. Ֆըրքիլըսընի (Tanya M. Ferguson)-ի Հանրային Առողջապահութեան Գիտութիւններու Թեկնածու Ուսանող Walden համալսարանիմէջ: Ծրագրի Վերնագիրն է « Տարբերութիւնը բուժման նպատակին եւ բուժման հաւատարմութեան Թոքախտի (Tuberculosis) հիւանդութեան» Լոս Անճելոսի շրջանի մէջ ապրող Հայ եւ ոչ Հայ բնակչութեան միջեւ: Տրուած բոլոր տեղեկութիւնները կը մնան գաղտնի

Եթէ ոեւէ մէկ հարցումներ ունիք, դիմեցէ՛ք Դանիա Ֆըրքիլըսընի Tanya M.

Ferguson-ին, համաձայնութեան հասցենէ xxxxxxxxxxxxxxxx Եթէ հետաքրքրուած էք, մասնակցելու համար դիմեցէ՛ք հետեւեալ հասցէին՝

xxxxxxxxxxxxxxxxxxxxxx Կամ տուեալներու յաջորդաբար ընթերցումով (or scan).

Թոքախտի

Ուսումնասիրութիւն2



Appendix K: Qualitative Recruitment Invitation, Armenian Translation



Մասնակիցներ պիտի
են հետազոտական
ուսումնասիրության համար



Կ'ուզուիմ. Կամաւորներ օգնելու հետախնդրեան Թոքախտի (Tuberculosis) առնջութեամբ
գիտելիքներու եւ պատկերացումներու տարբերութիւնները Լոս Անճելէսի մէջ բնակող հայերու եւ
Լոս Անճելէսի մէջ չի չբնակող հայերու միջեւ:

Ո՞վ Իրավունք ունի:

- Հայերը եւ ոչ հայերը որոնք կը բնակին Լոս Անճելէս քաղաքի մէջ
- Անոնք որոնք առնուազն 18 տարեկան են:
- Անգլերէն գրել կարող գիտնալ եւ կամ շատ լաւ հայերէն գիտնալ (եթէ պէտք է թարգմանողը միշտ ուժի մէջ է):

Պիտի խնդրուի ձեզմէ

- Ստորագրել տեղեկացուած համաձայնութեան ձեւը
- Մասնակցիլ դէմ առ դէմ խորին հարցազրոյցի (մօտաւորապէս 1 ժամ) հետ հնարավորութիւն հետագայի հարցախնդրեան եթէ անհրաժեշտ է
- * Մասնակցողները մասնակցելու համար կ'ստանան մէկ անգամ \$10 Ամէրիկեան տոլար իբրեւ նուէր գարդավ որպէս երախտագիտութիւն որ կը տրուի հարցազրոյցը աւարտելէն ետք:

Այս ուսումնասիրութիւնը իրականացուած ա Դանիա Մ. Ֆըրկըսընի (Tanya M. Ferguson)-ի Հանրային Առողջապահութեան Գիտութիւններու Թեկնածու Ուսանող Walden համալսարանիմէջ: Ծրագրի Վերնագիրն է « Տարբերութիւնը բուժման նպատակին եւ բուժման հաւատարմութեան Թոքախտի (Tuberculosis) հիւանդութեան» Լոս Անճելէսի քրջանի մէջ ապրող Հայ եւ ոչ Հայ բնակչութեան միջեւ:

Թոքախտի
Ուսումնասիրութիւն1

Եթէ ռեւէ մէկ հարցում ունիք կաք հետաքրքրուած էք մասնակցութեան հարցով, դիմեցէք Դանիա Ֆըրկըսընի Tanya M. Ferguson-ին հետեւեալ էլէկտրոնային գրութիւնով XXXXXXXXXXXXXXXXXXXXXXXX (or scan) կամ տուեալներու յաջորդաբար ընթերցումը



Appendix L: Quantitative Survey Code Book

Survey Q#	SPSS Variable Name	Variable	Values or Explanation
1	Consent	Consent	1 = Yes 2 = No
2	Age	Age	1 = 18-20 2 = 21-30 3 = 31-40 4 = 41-50 5 = 51-60 6 = 61-70 7 = 71+
3	Gender	Gender	1 = Male 2 = Female
4	Race	Race	1 = White, Non-Hispanic/Latino; Caucasian, Non-Latino 2 = White, Armenian 3 = White, Hispanic/Latino; Caucasian, Latino 4 = Black, African American 5 = Asian 6 = American Indian/Alaska Native 7 = Native American/Pacific Islander 8 = 2 or more races, Armenian 9 = 2 or more races, non-Armenian
5	Ethnicity	Ethnicity	1 = Non-Hispanic, Latino, or Spanish Origin 2 = Mexican, Mex American, Chicano 3 = Puerto Rican 4 = Cuban 5 = Other Hispanic, Latino, or Spanish Origin (e.g., Argentinian, Columbian, Salvadoran, Dominican)
6	Origin	Country of Origin	Birth Country (fill-in)
7	YrsUS	Years living in US	1 = < 1 year 2 = 1 to 5 years 3 = 6-10 years 4 = 11-20 years 5 = > 20 years
8	CityReside	Current city	1 = Glendale 2 = Pasadena/South Pasadena 3 = Burbank

(table continues)

			4=San Fernando 5=Santa Monica/West LA 6=Downey/Montebello/S. Gate 7=Other (fill in)
9	MaritalStat	Marital Status	1=Single, never married 2=Married 3=Divorced 4=Widowed 5=Separated
10	PeopleHH	# in Household	1=0 2=1 3=2-4 4=5-6 5=>6
11	HHRelation	Household relationship	1=Spouse/Partner 2=Child 3=Sibling 4=Elderly parents or grandparents 5=Other (fill-in)
12	EnglishHHLang	English Primary Language	1=Yes 2=No
13	OtherHHLang	Other spoken language in household	1=Armenian 2=Spanish 3=None 4=Other (fill-in)
14	Education	Education Level	1=High School 2=Some college 3=Bachelor's degree 4=Graduate/Professional Degree
15	Occupation	Occupation	1=Unemployed 2=Retired 3=Homemaker 4=Student 5=Professional 6=Manual Laborer
16	HHincome	Annual Household income	1=\$0-\$25K 2=\$25001-\$40k 3=\$40,001-60k 4=\$60,001-\$80k 5=\$80,001-\$100k 6=>\$100k
17	HealthIns	Have Health insurance	1=Yes 2=No

(table continues)

18	PCPTrust	Trust Primary Care Physician	1=Yes 2=No 3= Don't have one
19	SpiritGuid	Seek Spiritual Guidance	1=Yes 2=No
20	HomeRem	Use Home Remedies	1=Yes 2=No
21	TBHear	Heard of TB	1=Yes 2=No
22	TBHearSource	Source of TB knowledge	1=TV 2=Internet 3=Family/Friends 4=Newspaper/Magazine 5=Other (fill-in) <More than 1 can be selected>
23	TBHealthProbUS	Modern day health problem-US?	1=Yes 2=No
24	TBHealthProbInt	Modern day health problem-worldwide?	1=Yes 2=No
25	TBTransmit	Mode of Transmission	1=Coughing/Sneezing 2=Touching 3=Sexual Contact 4=Food/Water Ingestion 5=Smoking 6=Imbalance of hot/cold 7=Don't know
26	TBSymptom	Most common symptom	1=Coughing 2=Sneezing 3=Loss of Appetite 4=Tiredness/fatigue 5=Bleeding 6=Do not know
27	TBtreatavail	Aware of available treatment	1=Yes 2=No
28	TBtreatlength	Treatment length	1=3 days 2=1 week 3=1 month 4=> 6 months 5=Do not know
29	TBtreateffective	Treatment 100% effective	1=Yes 2=No 3= Don't Know

(table continues)

30	TBcurable	Curable disease?	1=Yes 2=No 3= Don't Know
31	TBReactions	Initial reactions/feelings	1=Frightened 2=Informed 3=Indifferent 4=Helplessness
32	TBDx	Tb diagnosis person/friend/family	1=Yes 2=No
33	TBDxFeel	Feelings regarding diagnosis	1=Frightened 2=Informed 3=Indifferent 4=Helpless 5=Depressed <More than 1 can be selected>
34	TBAssocFactor	Factors associated with TB	1=Poverty 2=Foreign-Born 3=HIV status 4=Drug History 5=Low Social Class 6=Sexual Orientation 7=Mental Illness 8=Religion 9=Common Disease 10=Curable Disease 11=Smoking 12=Imbalance of Hot/Cold 13=Incarceration <More than 1 can be selected>
35	TBcausepercept	Perceptions regarding TB status	1=Did something wrong 2=Punishment by God 3=Disease due to race 4=It could happen to anyone <More than 1 can be selected>
36A	TBWhatifA	3 scenarios (strongly agree-strongly disagree)	1=Strongly agree 2=Agree 3=No opinion 4=Disagree 5=Strongly Disagree
36B	TBWhatifB	A)Trust Doctor 3 scenarios (strongly agree-strongly disagree)	1=Strongly agree 2=Agree 3=No opinion 4=Disagree

(table continues)

36C	TBWhatifC	B)Compliance 3 scenarios (strongly agree- strongly disagree) C)Seek outside treatment	5=Strongly Disagree 1=Strongly agree 2=Agree 3=No opinion 4=Disagree 5=Strongly Disagree
37	TBalttherapyseek	Alternate treatment sources	1=Chiropractor 2=Acupuncturist 3=Homeopathic Dr/Nutritionist 4=Religious / church leader 5=Massage therapist 6=Home remedy 7=I wouldn't <More than 1 can be selected>
38	TBtreatfacilityLA	Aware of TB facilities LA county	1=Yes 2=No
39	TBfacilityInform	Read about TB if info provided?	1=Yes 2=No
40	TBSocsupportgrp	Aware of community social support groups?	1=Yes 2=No

Missing values = 999

Appendix M: Demographics Comparison for Quantitative Survey

Table 13
*Descriptive Statistics – Demographic Variables for an Armenian and Non-Armenian
 Population Living in Los Angeles County (n = 127)*

Classification	No. of Individuals Armenian (%)	No. of Individuals non-Armenian (%)
Gender	55 (43.3)	72 (56.7)
Male	22 (40)	26 (36.1)
Female	33 (60)	46 (63.9)
Age		
18-30	17 (30.9)	15 (20.8)
31-40	22 (40)	27 (37.5)
41-50	7 (12.7)	21 (29.2)
>50	9 (16.4)	9 (12.5)
Race		
White, Non-Hispanic/Latino	6 (10.9)	49 (68.1)
White, Armenian	37 (67.3)	0
White, Hispanic/Latino	0	10 (13.9)
Black, African American	0	1 (1.4)
Asian	0	8 (11.1)
2 or more, Armenian	12 (21.8)	0
2 or more, non-Armenian	0	4 (5.6)
Ethnicity		
Non-Hispanic, Latino, or Spanish Origin	48 (87.3)	61 (84.7)
Mexican, Mexican American, Chicano	1 (1.8)	8 (11.1)
Cuban	0	1 (1.4)
Other Hispanic, Latino, or Spanish Origin (e.g., Argentinian, Columbian, Salvadoran, Dominican)	6 (10.9)	2 (2.8)
Country of Origin		
Armenia	4 (7.3)	0
Canada	0	1 (1.4)
Egypt	1 (1.8)	0
El Salvador	0	1 (1.4)
European Countries	0	2 (2.8)
Hong Kong	0	1 (1.4)
Iran	3 (5.5)	0
Japan	0	1 (1.4)
Lebanon	9 (16.4)	0

(table continues)

Mexico	0	1 (1.4)
Philippines	0	2 (2.8)
Turkey	1 (1.8)	0
United States	37 (67.3)	63 (87.5)
<hr/>		
Years in United States		
≤ 20 years	11 (20)	3 (4.2)
> 20 years	44 (80)	69 (95.8)
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City Residing In (LA County)		
Glendale	6 (10.9)	3 (4.2)
Pasadena/South Pasadena	16 (29.1)	15 (20.8)
Burbank	2 (3.6)	3 (4.2)
San Fernando	2 (3.6)	0
Santa Monica/ West Los Angeles	3 (5.5)	5 (6.9)
Downey / Montebello / South Gate	2 (3.6)	2 (2.8)
Other	24 (43.6)	44 (61.1)
Alhambra	0	4
Altadena	1	2
Azusa	0	1
Canoga Park	1	0
Cerritos	0	2
Claremont	0	5
Glendora	0	3
Hollywood	0	2
La Crescenta	1	0
La Habra	1	0
La Verne	0	1
Long Beach	0	5
Los Angeles	0	8
Monrovia	0	1
North East LA	0	1
Northridge	4	0
Norwalk	1	0
Pomona	1	3
Porter Ranch	3	0
Reseda	1	0
San Dimas	0	2
San Gabriel	0	1
Santa Clarita	1	0
Shadow Hills	1	0
South Bay	1	0
Sun Valley	1	0
Sunland	1	1
Tujunga	2	0

(table continues)

Upland	0	1
Venice	1	0
Winnetka	1	0
Marital Status		
Single, never married	23 (41.8)	30 (41.7)
Married	30 (54.5)	37 (51.4)
Divorced	1 (1.8)	3 (4.2)
Widowed	0	1 (1.4)
Separated	1 (1.8)	1 (1.4)
Number of People in Household (excluding self)		
0	4 (7.3)	11 (15.3)
1	5 (9.1)	20 (27.8)
2-4	42 (76.4)	39 (54.2)
5-6	4 (7.3)	1 (1.4)
>6	0	1 (1.4)
Household Relation		
Spouse/ Partner	9 (17.6)	28 (45.9)
Spouse/Partner, Child	20 (39.2)	19 (31.1)
Spouse/Partner, Child, Elderly parent/ grandparent	1 (2)	0
Spouse/Partner, Child, Other	0	1 (1.6)
Spouse/Partner, Elderly parent/ grandparent, other	0	2 (3.3)
Spouse/Partner, other	1 (2)	0
Child	3 (5.9)	3 (4.9)
Child, Elderly parent/grandparent	1 (2)	0
Sibling	1 (2)	2 (3.3)
Sibling, Elderly Parent / grandparent	9 (17.7))	2 (3.3)
Elderly Parent / grandparent	2 (3.9)	3 (4.9)
Other	4 (7.9)	1 (1.6)
Friend	1	2
Housemate / Roommate	3	1
Niece	0	1
Whole family	1	0
English Primary Spoken Household Language		
Yes	35 (63.6)	71 (98.6)
No	20 (36.4)	1 (1.4)
Primary Household Language (non-English)		
Armenian	40 (72.7)	0
Spanish	0	8 (11.1)
None	11 (20)	61 (84.7)

(table continues)

Other	4 (7.3)	3 (4.2)
Arabic	1	0
Armenian, Russian	1	0
German	0	1
Korean	0	1
Mandarin	0	1
Russian, Turkish	1	0
Turkish, Arabic	1	0
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Educational Level		
High School	7 (12.7)	0
Some College	14 (25.5)	12 (16.7)
Bachelor's Degree	15 (27.3)	31 (43.1)
Graduate/Professional Degree	19 (34.5)	29 (40.3)
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Occupation		
Unemployed	2 (3.6)	2 (2.8)
Retired	2 (3.6)	2 (2.8)
Homemaker	6 (10.9)	3 (4.2)
Student	12 (21.8)	6 (8.4)
Professional (e.g., lawyer, doctor, teacher)	30 (54.5)	56 (77.8)
Manual Laborer	3 (5.5)	3 (4.2)
<hr/>		
Annual Household Income		
\$0-\$40,000	13 (23.6)	8 (11.1)
\$40,001-\$100,000	17 (30.9)	25 (34.7)
>\$100,000	25 (45.5)	39 (54.2)
<hr/>		
Health Insurance		
Yes	51 (92.7)	69 (95.8)
No	4 (7.3)	3 (4.2)
<hr/>		
Trust Primary Care Physician		
Yes	45 (81.8)	65 (90.3)
No	1 (1.8)	2 (2.8)
Don't have one	9 (16.4)	5 (6.9)
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Seek Spiritual Guidance		
Yes	24 (43.6)	13 (18.1)
No	31 (56.4)	59 (81.9)
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Use Home Remedies (herbs, teas, etc)		
Yes	42 (76.4)	42 (58.3)
No	13 (23.6)	30 (41.7)