Distribution Agreement

Signature:

Rebecca Minneman 4/17/2012

Barriers to testing and treatment for Chagas disease among Latino immigrants in Georgia

By

Rebecca Minneman
Master of Public Health

Hubert Department of Global Health

Dr. Monique Hennink
Committee Chair

Dr. Juan Leon
Committee Member

Rebecca Minneman

Bachelors of Arts
Emory University
2007

Thesis Committee Chair: Monique Hennink, PhD

An abstract of
A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Hubert Department of Global Health
2012

Abstract

Barriers to testing and treatment for Chagas disease among Latino immigrants in Georgia

By Rebecca Minneman

Background: Chagas is a parasitic disease primarily affecting Latin Americans, which is increasing in the US due to the recent growth of the Latino immigrant population. The lack of testing and treatment of Chagas disease in the US increases the risk of serious health complications among infected immigrants and poses a risk of transmission from mother to child or via blood transfusions.

Goal: The goal of this study is to identify the barriers to testing and treatment of Chagas disease amongst Latino Immigrants in Georgia and to understand the process of seeking healthcare by Latino immigrants from which to develop effective treatment interventions.

Methods: In this qualitative study, nine focus group discussions were conducted with male and female Latino immigrants to understand their perceptions of Chagas disease and their process of seeking healthcare if they had Chagas symptoms. Grounded theory was used to collect and analyze the textual data to develop an inductive conceptual framework to explain the context and process of seeking healthcare for Chagas amongst this at risk population.

Results: Participants were not aware of Chagas disease. When asked how they would seek care for symptoms of Chagas disease, three distinct behaviors were identified: delaying treatment, using traditional remedies, and using either mainstream or alternative health providers. Health seeking behaviors and motivations differed for women and men, but the use of licensed medical providers was seen as a last resort due to the cost of healthcare, loss of earnings while seeking care and fear of diagnosis with fatal illness.

Discussion: The lack of awareness of Chagas disease amongst Latino immigrants in the US suggests a strong need for targeted education about the disease. Providing free or low cost services, mobile treatment clinics and education regarding Chagas disease is critical to increase testing and treatment for Chagas disease.

Barriers to testing and treatment for Chagas disease among Latino immigrants in Georgia

By

Rebecca Minneman

Bachelors of Arts
Emory University
2007

Thesis Committee Chair: Monique Hennink, PhD

A thesis submitted to the Faculty of the
Rollins School of Public Health of Emory University
in partial fulfillment of the requirements for the degree of
Master of Public Health
in Hubert Department of Global Health
2012

Acknowledgements

I would like to extend my thanks to Dr. Juan Leon. You have inspired me, motivated me and encouraged me to challenge myself. I have never had anyone make such an effort to help me to succeed in both my studies and my career. I continue to admire your balance, work ethic, patience and leadership and am grateful for all the opportunities you have provided for me. I truly would not be where I am today without your help. Additionally, I would like to thank Dr. Monique Hennink for her guidance in this project. I have learned so much and am grateful for your enthusiastic support and never-ending patience. Finally, I would like to thank all of my family and friends who have supported me in all of my undertakings.

Table of Contents

Contents

List of Figures

Role in Thesis/Manuscript

- Community outreach
- Formation of Community Advisory Board
- Participant recruitment
- Creation of focus group discussion guide
- Moderation of 5 focus group discussions
- Transcription of 4 focus group discussions
- Data Cleaning of 9 transcripts
- Data Coding of 9 transcripts
- Data Analysis of 9 transcripts
- Review of the literature
- Primary author of Manuscript

Review of the Literature

Attitudes and knowledge of Chagas disease among Latino immigrants in Georgia

Pathogenesis and Epidemiology of Chagas Disease:

Carlos Chagas, a Brazilian scientist, was the first to document Chagas disease (ChD) in 1909, and since that time, six groups of strains of *T. cruzi* classified by their geographical distributions and biological properties have been discovered [1, 2]. The protozoan hemoflagellate, *T. cruzi*, has three main mechanisms of transmission: vectorial, transfusion, and congenital. Alternative mechanisms of transmission include accidental (within laboratories working with *T. cruzi*), oral (from food or drink contaminated with infected Triatomine urine or fecal matter), and via organ transplantation [reviewed in [3]]. There have been several confirmed cases of oral transmission in Brazil, through contaminated food [reviewed in [4]]. Although there are no confirmed cases, other hypothetical mechanisms of transmission of ChD include breastfeeding in humans or animals [5], vectors other than triatomines, sex, and marsupial anal secretions [3].

Vectorial transmission is responsible for the great majority of infections in endemic areas (Latin America and parts of the southern United States). ChD is usually transmitted by large reduviid bugs of the triatominae subfamily living in endemic areas (Fig. 1). The triatomine bugs feed on blood, and infection usually occurs through contact of the feces of an infected triatomine with broken skin or mucosa. There are over 120 species of triatominae in Latin America and three transmission cycles: domestic, sylvatic and peri-domestic. The domestic cycle is usually sustained in rural or peri-urban areas where residences are constructed of adobe or thatch. The triatomines live in the walls or roofs of the housing and generally bite people at night. This cycle was responsible for the majority of human infections before vector control campaigns. The sylvatic cycle is usually sustained in non-domesticated areas. Infected triatomine bugs infect rodents, marsupials and other wild animals who act as hosts for *T. cruzi*. Finally, the peri-domestic cycle usually links the domestic and sylvatic cycles. The sylvatic bugs are attracted to domestic areas and residences due to light and food, and infect mammals that pass in and out of residences [reviewed in [6]].

Figure 1. Triatomine Bugs

In the developed world, due to better housing conditions and a lack of infected vectors, ChD is usually transmitted via blood transfusions and vertically. Due to the rise in immigration from endemic areas of Latin America to the United States and Europe, ChD is spreading via blood transfusion throughout the world. Additionally, ChD has been spread congenitally; approximately 5% of newborns, born to mothers who have Chagas disease will be infected [reviewed in [6]]. In a study in Choapa, Chile, 3.7% of women who gave birth in the region had ChD, and 2.7% of their newborns were infected [7].

Infection with ChD has two recognized phases: acute and chronic. When vectorial transmission takes place, there is an incubation period of approximately 7-15 days (up to 30 days for transmission via transfusion) and then the acute phase, characterized by patent parasitemia, begins. Acute infection, lasting 4-6 weeks, has very few signs and symptoms.

Romaña's sign, uniocular bipalpebral edema with regional lymphadenopathy is the most well-known symptom and its appearance is used to diagnose acute ChD, but occurs in less than 5% of infections [reviewed in [6]]. Other symptoms may include a non-specific febrile illness, or mild flu-like symptoms. Unfortunately, most acute infections go unrecognized [reviewed in [8]]. Most commonly, infections occur in early childhood and are not diagnosed immediately.

If the infected individual is not treated in the acute phase, they then enter the chronic phase, which can be either indeterminate or clinically evident. 70-80% of persons infected with ChD are indeterminate for the rest of their lives; 20-30% of infected individuals eventually enter a clinically evident stage, which typically affects the heart [9]. The indeterminate stage consists of a positive anti-*T. cruzi* serology results, normal ECG and radiological findings with respect to the chest, esophagus, and colon, and no symptoms or physical abnormalities. The clinically evident stage can develop up to twenty years after infection and can include Chagas cardiomyopathy, which consists of atrioventricular blocks dysrhythmias, thromboembolism, chest pain, chronic heart failure and death. Chagas heart disease is classified based on ECG status, presence of congestive heart failure, and left ventricular enlargement or ejection fraction [reviewed in [8]]. The course of ChD varies greatly, and in some regions like Brazil, ChD appears more often as an achalasia of the esophagus; in Chile it is more common to see megacolon [10]. The variation in clinical presentation is may be partly due to the great genetic variability of *T. cruzi* found in nature.

There is an ongoing debate as to whether or not all chronic cases of ChD should be treated. This debate centers around the lack of effective treatments for those patients with chronic ChD and the side effects associated with existing drugs used to treat ChD. Currently, available treatment for ChD consists of two drugs: Nifurtimox (NF) and Benznidazole (BNZ). Both of these drugs are more effective in the acute stage curing between 70-75% if all acute cases [reviewed in [10]]. 100% of congenital cases and 60% of children and adults with recent infection can be cured, but the efficacy of the drug therapy declines with the duration of the infection [11]. Both NF and BNZ target the amastigote forms of *T. cruzi*, which are responsible for the reproduction of the parasite in humans. Most patients with ChD require 30-60 days of treatment with either BNZ or NF. BNZ is more effective, but is associated with high rates of adverse effects, particularly in the first two weeks of treatment. Side effects can include hypersensitivity, myalgias, arthralgias, lymphadenopathy, polyneuropathy, paresthesias, polyneuritis, and bone marrow disorders. These can be controlled with symptomatic treatment, but motivate patients to stop treatment. Patients are more likely to stop treatment in the indeterminate phase when they experience these effects. Yet, despite these secondary effects, when used in the early indeterminate phase, BNZ has been shown to restrict progression of ChD and increase long term negative seroconversion [11]. There is no criterion for curing chronic cases since in many patients' serology remain positive for *T. cruzi* for years after therapy, although the levels may decrease. Thus, long term follow-up is needed to determine if a person has effectively been cured [10].

Aside from the lack of effective drugs and the side effects associated with treatment, another reason for the existing debate on the treatment of chronic ChD is the fact that there has been a lack of interest and experience in treating ChD in the developed world. This is partly due to the fact that ChD is a tropical disease, whose burden, until recently, has been concentrated in Latin America. Additionally, the great variability of the course of ChD, the lack of sensitive tests, the need for long term follow-up to evaluate the effectiveness of treatment, and the lack of provider experience in managing side effects of drug therapy present unique problems for diagnosis and treatment. Despite the pressing need for new, more effective drug therapies, few pharmacological companies have shown interest in developing drug therapies or vaccines against ChD. There are two other drugs, itraconazole and posaconazole being evaluated for use in treating ChD, but have yet to be shown to be effective and approved [10].

Burden of Chagas Disease:

The burden of ChD, caused by the parasite *Trypanosoma cruzi* (*T. cruzi*), is growing throughout the world. Previously, ChD was considered a neglected tropical disease, an infectious disease primarily found in tropical countries, which garnered little world attention. This is primarily because Chagas has been most prevalent in the 17 Latin American countries where it is endemic (Fig. 2) [reviewed in [6]]. Due to a rise in immigration from endemic countries, the prevalence of ChD has risen in other parts of the world like the United States and Spain. Between 8 and 15 million people are

Figure 2. Endemic Areas of Chagas

estimated to have ChD and 28-75 million people are at risk worldwide. Additionally, there are approximately 40,000-50,000 new cases of ChD per year across the globe [reviewed in [12]]. According to the WHO, ChD is responsible for 12,500 deaths per year and causes premature disabilities that are estimated to cost 818,000 Disability Adjusted Life Years (DALYS). These DALYs are lost due to cardiomyopathy without congestive heart failure, cardiomyopathy with congestive heart failure and megaviscera, all caused by infection with *T. cruzi*. Part of the burden caused by ChD is its effect on the Quality of Life (QoL) of those infected. When comparing ChD to non-ChD patients, ChD is associated with poor QoL scores in physical functioning and role-emotional domains. ChD patients expressed concealed fear of being unable to stop the disease and its potential for malign development [13].

Traditionally, Latin America has borne the majority of the burden of the morbidity and mortality associated with ChD. The prevalence of ChD has lessened from 6.5% in 1960s-70s to an average of 1.3% in 2000 in Latin America [14]. Yet the prevalence of ChD still varies greatly, ranging from 0.1% in Uruguay and Brazil to 30% in Colombia from 1990-2000 [15]. Despite successful campaigns against ChD in many of countries, the number of DALYS lost has increased from 641,000 in 1990 to 818,000 in 2000. This increase is largely due to the survival of individuals who had previously been infected with ChD and have now developed chronic cardiac and digestive lesions causing loss of productivity and quality of life [15].

In addition to the mortality and morbidity associated with it, ChD represents a significant economic burden for many countries. The majority of the economic burden associated with ChD has been in the developing world, specifically in Latin America.

Most Latin American countries have borne a high burden of disease and significant direct and indirect costs. For example, Brazil reported that aggregate costs due to ChD in the late 1980's exceeded US$250 million per year. Bolivia estimated costs at US$21 million in 1992. Uruguay reported costs to be $15 million in 1996. Chile estimated costs due to ChD to be between US$14-19 million in 1997 [reviewed in [6]].

Despite being considered a neglected tropical disease, the impact of ChD on Latin America has been decreasing due to success of control programs, but ChD is now emerging as a threat to the developed world. Through immigration from endemic areas, ChD has reached Europe, North America, Japan and Australia [16]. The United States is the country with the highest number of immigrants from Latin America, and it is estimated that approximately 300,167 people are infected with ChD in the US [17]. Not all of these cases are thought to be due to immigration, because US-infected vectors have transmitted ChD to humans in the United States. Seven autochthonous cases of ChD have been confirmed in Texas, California, Tennessee and Louisiana [18]. Additionally, infected vectors or mammals have been found in 82 of the 254 counties of Texas, and southeastern Texas (below 30^0N) has enhanced relative risk for ChD because it is a suitable habitat for vectors [19].

Few studies have examined the seroprevalence of ChD in US populations, despite the need to understand the potential public health burden of ChD. In 1987, 4.9% of Central American immigrants in Washington D.C. were positive for ChD [20]. In 2008 0.4% (1 of 274) of Hispanic surnamed immigrants in Dallas, Texas were positive for ChD [21]. In 1993, 2% of North Carolina migrant farmworkers were positive for ChD [22]. The prevalence of ChD in Latino immigrants in the United States demonstrates the potential for transmission to go undetected due to the migratory, isolated nature of immigrants and their low access to health care [22].

Spain, second only to the US, has a large immigrant population from Latin America, and thus has seen an increase in the burden of ChD. There are an estimated 1,607,699 immigrants from ChD endemic areas in Spain [23]. Several studies have examined ChD prevalence in Latin American immigrants in Spain. In a study completed in Madrid from 1989 to 2007, at the Tropical Medicine Referral Unit, 95 immigrants of 2,634 tested were positive for ChD (prevalence 3.6%). Of the 2,634 immigrants tested, only 684 of them were from potentially endemic areas. The majority of those with ChD were from rural areas, had seen the vector in their homes, and 90 of the 95 immigrants positive for ChD were from Bolivia [16]. In Barcelona, among a Latin American immigrant population with similar risk factors, a prevalence of 2.8% was found [24]. Similarly, the estimated number of infected Latin American immigrants has risen in Australia from 1,067 of the 65,255 (1.6%) in 2005-2006 to 1,218 of the 131,135 (0.9%) Latin American immigrants in 2011 [reviewed in [25]].

Since ChD can be transmitted not only by infected vectors, but also via blood transfusions, organ donations and vertically, it now constitutes a significant public health threat for non-immigrants in populations with large numbers of immigrants from ChD endemic areas [21]. With the spread of ChD to non-endemic areas, such as Europe and North America, it is important to consider the potential for transmission and the resulting impact [16]. To date, blood donor screening in the United States has resulted in recognition of over 1,300 cases of ChD [26]. Additionally, it is estimated that there are 63-315 congenital *T. cruzi* infections per year in the United States [17] and more should be anticipated because of increase in Latin American populations [21]. Thus, the burden of morbidity and mortality associated with ChD is now shifting from the developing world to the developed world, particularly to the US and Europe, with the increase in migration.

Campaigns against Chagas Disease:

Traditionally, campaigns to stop the spread of ChD have been concentrated on controlling transmission by triatomine vectors. When Carlos Chagas realized the potential impact of ChD, he created a two-pronged strategy to limit vectorial transmission of ChD by reducing contact with triatomines. The first part of the strategy consisted of improving housing, and the first official effort to reduce transmission of ChD was in 1918 in Araujo. The second part of the strategy focused on eliminating domesticated triatomines, and chemical compounds were employed against triatomines beginning in 1931 [27]. The first nationwide vector control programs were implemented in Argentina and Brazil in the 1960’s, closely followed by Chile and Uruguay. These had relatively high rates of success, but most achievements in vector control came from the coordination of groups of countries in endemic regions. A multinational program to eradicate triatomines called the Southern Cone Initiative was created in 1991, followed six years later by similarly coordinated efforts in Central America and Andean nations [reviewed in [6]]. The success of the Southern Cone Initiative has been well documented. In 2001, the World Health Organization (WHO) certified 4 of 18 endemic provinces in Argentina as free from vectorial transmission; similarly, 9 of 11 endemic states in Brazil as well as the countries of Chile and Uruguay have been certified as free from vectorial transmission of ChD. The rates of domestic infestation in these countries have been either eliminated or greatly reduced. The seroprevalence of ChD has decreased correspondingly. In Argentina the seroprevalence of ChD of men in the military between the ages of 18-20 fell from 5.8% in 1981 to 1.2% in 1993 [reviewed in [6]].

In addition to being very successful in reducing vectorial transmission of ChD, vector control campaigns have been cost-effective. Since 1991, the Southern Cone countries invested US$320 million in their campaign with a predicted internal rate of return of 14%. In actuality, the internal rate of return ranged from 30-60% in some regions. Given the economic burden that ChD poses on the health care system, without controlling vectorial transmission, each of the Southern Cone countries would have spent between US$14 million to US$205 million per year on medical care related to ChD in the 1990's. In Brazil, the cost of preventing one DALY was estimated to be US$260 in 1998. In Bolivia, the cost of preventing the loss of one year of life was estimated to be US$362 in 1997. Vector control programs are significantly less costly than treatment, with the same countries spending between US$4,000 to US$28 million on vector control in 1996 [reviewed in [6]].

While many vector control programs have had high rates of success, there are several challenges to maintaining these campaigns. In order to be effective, chemical applications have to be repeated seasonally, which requires money, equipment, maintenance and personnel that have to be mobilized and cover large areas in short amounts of time. In order to reduce cost, research has been done to create more cost effective and sustainable vector control strategies for endemic areas. The most efficient strategy in the Yucatan peninsula was found to be a combination of insect screens in outer zones to lessen exposure to sylvatic and peridomiciliated vectors, and cleaning peridomicile areas in the centers of towns [12]. Yet, there is evidence that triatomines are becoming resistant to chemical spraying in some countries, particularly Argentina and Bolivia. Additionally, despite great improvements in the chemicals used, insecticide sprays can cause untoward health effects on people who are exposed to them repetitively [28]. Finally, vector control needs to be coordinated and sustained in order to be effective, but in many places including Peru, it was irregular and unpredictable. In Peru, in 1995, there was an effort to eliminate triatomines which reduced average annual incidence of infection from 0.9% to 0.1%, but the rapid reemergence of triatomines demonstrates the necessity of continued control and surveillance [29]. Since the elimination of domestic vectors in many areas, the current challenge for many endemic areas is to control vectors which are not common in residences, but still transmit ChD through short visits to residences.

More recently, in addition to their efforts in vector control, many countries have instigated campaigns to eliminate transmission of ChD via blood. The ability of ChD to be transmitted via blood transfusions was documented in the 1950's, but only after the HIV/AIDS pandemic in the 1980's did endemic countries begin to establish protective measures [27]. Due to the success of vector control programs, in the 1980's blood transmission became one of the main mechanisms of transmission of ChD. Approximately 6.5% of blood donors in Latin America and 6.9% of donors in Brazil were positive for ChD in the 1960's and 1970's. Four decades later, the prevalence of blood donors positive for ChD have been reduced to 1.3% and 0.2% respectively [reviewed in [14]]. In 2001, 11 endemic countries screened >99% of blood donors for *T. cruzi*, 2 screened approximately

90% of donors, but 4 endemic countries screened less than 25% of donors [reviewed in [6]].

Unfortunately, controlling transmission via blood transfusions has several challenges. There are three techniques to test blood for ChD, enzyme linked immunosorbent assay, indirect immunofluorescence, and indirect haemagglutination. Yet, each of these techniques has high numbers of inconclusive results. Between 50% and 70% of blood considered ineligible due to ChD is from donors whose serological tests were inconclusive [30]. In addition to inconclusive reactions, places where prevalence is higher, including Argentina and Brazil, require two tests for donated blood because of the possibility of false negatives, but these tests cost significantly more [6]. The need to continue to invest in screening and developing new tests for ChD is paramount to stopping transmission by blood transfusion. The continued success of eliminating transmission of ChD through both vector control campaigns and screening blood donors for ChD depends on both political support and education [27].

As the number of Latin American immigrants in the developed world has risen, new efforts to control transmission of ChD have been instigated in non-endemic areas. Some countries with large Latin American immigrant populations like Spain, have made screening for Chagas mandatory, but in others, such as the United States, it is still voluntary. As of April 30, 2010, the United States Food and Drug Administration has approved two blood tests to screen for Chagas, but only 65% of the blood donated in the United States is screened [31]. Due to the tropical nature of ChD, other than some serological screening of blood donors, there has been very little done in the developed world to combat the rising prevalence of ChD. There are several strategies to reduce transmission and prevalence of ChD targeted at developed countries. These strategies include increasing serological screening for ChD and reducing inconclusive results by using epidemiologic profiles of blood donors at increased risk for ChD. This clinical-epidemiological screening is an auxiliary method to exclude risk donors and can help to reduce the unnecessary disposal of donated blood which has been misclassified as infected [30]. Additionally, some states in the United States have made ChD a reportable disease, where physicians have to inform the government when they diagnose a patient with ChD, allowing for better surveillance of ChD [19]. Other strategies for developed countries include developing better drugs and diagnostics, screening pregnant women from endemic areas to reduce vertical transmission, and educational campaigns for both medical providers and Latin American immigrants to inform them about the disease. Unfortunately, there is still a great need to implement these strategies in the developed world.

Health care seeking behavior of Latino immigrants:

Latinos in the United States have consistently been shown to be less likely to access health care. They are also more likely to rate their quality of treatment lower than other racial groups. As a group, they are less likely than other races to receive appropriate and timely treatment [reviewed in [32]]. This disparity in access to health care can be classified into two main reasons: structural barriers, which are objective barriers incorporated into the health care system, and cultural and belief barriers.

Structural barriers that affect access to health care among Latino immigrants include the cost of treatment, legal status, lack of insurance, and lack of interpreters [33].

Lack of insurance has been found to be the most important factor affecting access to health care for Latinos. Due to the fact that Latinos have lower incomes, work lower paying jobs without benefits like insurance, and often do not qualify for governmental aid because of their legal status, Latinos have the highest percentage of people in any racial group that are uninsured (32.1% of Hispanics vs. 12% non-Hispanic whites) [32].

In addition to structural barriers, many beliefs that are prevalent in the Latino community affect their access to health care. Often, Latinos fear the cost, potential for deportation, long waits, and discrimination that they associate with accessing healthcare. Even those Latinos who lack of experience in accessing health care have expressed their concerns for long waiting times, rudeness because of their race or ethnicity, and poor quality of service [33]. Most Latinos state that they think that they would receive better care if they were not Hispanic. 20% feel that their difficulty in accessing care was due to their race, and 30% had problems communicating with providers [32]. Latinos, particularly Spanish dominant Latinos, consistently rate their experiences with medical staff more poorly than non-Hispanic whites. Spanish speaking Latinos are more likely to rate the attention with which the medical staff listened, answered their questions, gave explanations, and supported them as *very poor, poor,* or *fair* when compared English speaking Latinos, and non-Hispanic whites [34].

Some of these beliefs and disparities in satisfaction with health care can be explained by a difference in cultural values. Key values for Latinos that help to define their access to health care and their perception of quality include: personalism (preference for their own ethnic or self-identified group), “respeto” (importance of personal integrity), “simpatía” (importance of smooth interpersonal relationships), and power distance (certain people deserve deference and respect) [35, 36]. Due to their value of “simpatia” and “respeto,” Latinos are very sensitive, and often perceive direct eye contact and informality as aggressive and a lack of respect. They are less likely to be comfortable with providers who they don’t perceive to be “simpatico” (nice), which can lead to dislike, lack of understanding, and a perception of poor service. Additionally, because of the value that Latinos place on respecting authority, many times patients will be unwilling to directly disagree with providers. Since Latino patients may be uncomfortable expressing their opinions, they will not share all of their information, comply with the provider’s recommendations or return [32]. Latinos are more likely to say that providers in the United States are hurried, come to quick conclusions with including the patient in the decision making process, and do not spend as much time with the patient as the patient would like. Since Latinos tend to take a more holistic view of health, where healing is a process which has many different parts including both physical and emotional symptoms. The doctor is expected to be a part of this process and take all the parts into account when treating a patient. The perceived lack of time and attention is another reason Latinos are often dissatisfied with their health care providers [33].

Because of a combination of structural barriers and cultural beliefs, Latinos in the United States have a variety of alternatives to mainstream health care. Depending on the gravity of the problem, some Latinos travel back to their home countries to seek care because they feel that medical care is more affordable and of higher quality due to the time spent with patients and holistic approach of the physicians [33]. Hispanics often self-medicate in order to avoid having to see a doctor. Many have friends or families who send them medicine from their home countries. These medicines are often perceived as more effective and affordable [32]. Another alternative to mainstream health care used by Latinos are herbal or botanical remedies. Latinos have a long history of using traditional herbs and remedies to cure their maladies; this tradition comes from their indigenous roots and the lack of medical care offered in their home countries. In addition to these remedies, Latinos have a strong belief in the supernatural and often go to folk healers to cure illnesses. Many Latinos go to folk healers before seeking other types of care due to the affordability and their strong beliefs in the efficacy of these therapies. Others use them in conjunction with mainstream medical care, or as an alternative when they cannot access care. Finally, in Ransford's study in 2010, 75% of participants stated that prayer was extremely important and 90% had prayed for either their own health or that of a family member. This use of herbs, folk healers, and prayer gives Latinos a greater sense of agency, which allows them to feel more in control of their health [33].

Communication of health information among Latino immigrants:

The communication of health information among Latino immigrant populations in the United States has proven to be a complicated process. In order to effectively communicate, both the source and the recipient must assign the same meaning to the message [35]. Little research on effective health communication with Latino immigrants has been completed, but the few studies on this topic recommend that when designing communication pathways, the receiver, the actual message, and the source must all be tailored to the Latino community [37].

Two important qualities affect the reception of health information within the Latino immigrant community: the diversity within the community and the cultural values of the population [38]. The Latino immigrant population in the United States is changing and growing very rapidly. It is very diverse in origin, socio-economic status (SES), level of acculturation, language abilities, education, literacy, age, and cultural values. All of these differences make it difficult to communicate with “Latino Immigrants” because messages that would be well received by highly educated, acculturated immigrants could be very different from those that would be successful with immigrants with lower SES who still strongly identify as Hispanic. Studies have attempted to divide this population by language abilities [38-40], income [41], and levels of acculturation measured by language abilities and preferences, self-identification as Hispanic and length of time in the US [42]. Yet, the diversity of the population remains to be a challenge for health communication necessitating well-defined groups as the intended audience for health messages.

Despite this diversity, some of the same cultural values held by Latino immigrants that affect access to health care can help to define what kind of health messages should be sent. Latinos generally tend to hold more collectivist attitudes and prioritize community more than non-Hispanic whites who are more individualistic. Additionally, Latinos place great value on familism (the importance of both nuclear and extended family) [35, 36]. Both collectivism and familism can be used to make health messages more effective. Most non-Hispanic whites in the United States are autonomous; they respond better to behavior change theories which emphasize the individual. Latinos often react differently because they place an emphasis on community and family, often prioritizing their family’s needs over their own. Latinos depend on family and friends to help solve problems and have a strong sense of obligation to their families. Thus, when communicating information to Latinos, it is more effective to tailor messages to families and communities as recipients.

In addition, messages should emphasize the potential effects of (un)healthy behaviors on families rather than individuals. Incorporating the importance of healthy families and communities, as well as an obligation to families and communities can help to ensure that the message is culturally appropriate and will be well received. Additionally, depending on which group of Latino immigrants are the target, often simple, low literacy materials with a limited number of key messages are most successful [43].

Similarly to the cultural beliefs regarding health care, the source and context of the message are very important to Latino immigrants. Ensuring that the message comes from a trusted source, preferably from an individual with whom Latinos can identify with, can help to improve reception. Additionally, context is very important for Latinos; the body language, order of the argument, source of the message, and tone of voice all contribute to the meaning that Latinos assign to the message. If all of these characteristics are not clear and culturally appropriate many times messages are misunderstood or disregarded [35].

Partly due to cultural beliefs and preferences, Latinos differ greatly in their search for health information in the media from non-Hispanic whites. Latinos tend to seek health information less than non-Hispanic whites, and they use and trust different sources of information than non-Hispanic whites. In 2011, Viswanath found that Hispanics were 0.42 times as likely to seek cancer information as non-Hispanic whites. Both English and Spanish speaking Hispanics were more likely to trust cancer information on television than non-Hispanic whites, and Spanish speaking Hispanics were also more likely to trust cancer information on the radio than non-Hispanic whites [38]. Similarly, in 2010, Clayman found that English speaking Hispanics are more exposed to the media (internet, radio, television and newspapers) and that they trust the internet, newspapers and magazines more than Hispanics who are not comfortable speaking English. Those Hispanics less comfortable with English are particularly vulnerable because of their lower SES, lower levels of education and lack of exposure to the media [39]. In 2008, Pena-Purcell found that Hispanics are less likely to seek health information on the internet than non-Hispanic whites (28.9% vs. 35.6%), particularly for those Hispanics with lower household income. They are also less likely to agree that health information on the internet: improves their understanding of medical conditions and treatments, improves patients' confidence discussing health concerns with their doctors, and helps patients get treatment that would not have received without it. There are several potential explanations for the lack of use and trust in the internet including the fact that ability to use internet depends on income, education, use and access. Additionally, internet health websites in Spanish are generally on a 10th grade reading level, which often exceeds that of the user. The impersonal nature of the internet could be unsuited to Latino cultural values of power distance and personalism because they are unsure of the source and find it to be alienating. Hispanics have also expressed a fear of information on the internet being unreliable [40]. In 2010, Delorme found that Hispanics rely on doctors, internet advertising, and direct to consumer advertising (DTCA) for prescription drug information instead of health related websites and health professionals, which are most used by non-Hispanic whites. Those Hispanics who strongly identify as Hispanics show particular reliance on television and DTCA for their prescription drug information, possibly because they cannot distinguish between advertising and non-promotional material due to lack of competency using the internet. While Hispanics use general media more than ethnic media, they are more critical of general media, and the more strongly they identify as Hispanic the stronger their preference for ethnic media is [42]. Telephones, tailored print media and campaigns that include a variety of different mediums have all been shown to be at least partially effective in communicating health information to Latino immigrants [41]

Other than the media, there are several different mediums through which health information can be effectively communicated to the Latino community. Community health advisors (CHAs), also known as promoters, have found to be effective in communicating basic health messages and linking the health providers to the community. Because CHAs are generally trusted community members, they are valued because of personalism and power distance. This makes them ideal messengers for the Latino community because they have the added benefits of being familiar with the culture and needs of the population [37]. In 2007, Carter found that Latino immigrants preferred for their sources of information on emergency preparedness to be (in ranked order): firemen and police, the Red Cross, someone trained with charisma, doctors, community leaders, television and radio, and newspapers in Spanish. Since the third most preferred source of information on emergency preparedness is a trained person with charisma, the CHA model has great potential with Latino communities. Latinos also state that they would like their source to be well informed, Latino, Spanish speaking, credible, and consistent, all of which are ideal for a CHA [43]. Inclusion of health information in literacy or English as a Second Language classes has also been shown to be an effective method of communication. Other health campaigns targeting the Latino community have had success using telephone and tailored print materials [41].

Latino immigrants in Georgia:

According to the U.S. Census Bureau, in 2010 the state of Georgia had the tenth largest Hispanic population in the United States with 853,689 people out of 9,687,653 identifying themselves as Hispanic (8.8%). The Hispanic population of Georgia accounts for 1.69% of Hispanics in the United States (total of 50,477,594). 53.94% of Hispanics in Georgia are male, and in general it is a very young population with a median age of 25.3 years compared to 40.3 years for non-Hispanic whites. The majority of Hispanics are Mexican in origin (60.85% of the Hispanic population and 5.4% of the Georgia population). Puerto Rico and Cuba are next most common origins, accounting for 8.43% and 2.93% of the US Hispanic population respectively (0.7% and 0.3% of the Georgia population). The majority of Hispanics rent (51.42%) but 35.95% own their homes with a mortgage or loan [44]. The Hispanic population in Georgia is the third fastest growing population in any state, and approximately half are U.S. citizens. Slightly more than half were born abroad, but Hispanic births have been rising rapidly. There are great disparities between Hispanics and other races in Georgia. Only 49.6% of Latino seniors graduate from high school, which is the lowest percentage for all races (other races range from 56.8% of Blacks to 76.6% of Asians). Additionally, 52.9% of Hispanics self-identify as not speaking English well or not at all. Despite their high labor force participation, Hispanics are more likely than other races to be poor with 98,930 (18.8%) below the poverty line in 2003 compared to 13.45% of the total population of Georgia. Additionally, in 2002 to 2003, 43% of nonelderly Latinos in Georgia did not have health insurance [45].

In general, the Hispanic population of Georgia is becoming more segregated. Five counties account for over half of Hispanics in Georgia; Gwinnet County, of which 20% of the population is Hispanic, has the largest population of Hispanics (162,035) followed by

Cobb, DeKalb, Fulton and Hall Counties. The recent rise in segregation has not made Hispanics less visible because they work in very visible occupations (construction, janitors, nannies, etc.). A backlash against Latinos has begun equating Latinos with illegal immigrants, which can be partially attributed to the current political climate in Georgia. State and local policies have encouraged segregation, by terrorizing populations and limiting access to employment, social services and higher education. Examples of these policies include: anti-congregating ordinances which are directed at Latino day laborers due to complaints that they threaten the peace and security of neighborhoods, the denial of drivers licenses to unauthorized immigrants despite the lack of public transportation and dispersal of jobs and health facilities, new housing ordinances against large households (Roswell passed a law in 2006 prohibiting more than three unrelated people to reside in one single family home), anti-overcrowding ordinances (Cobb regulates housing by requiring 50ft of sleeping space per person), and English only laws stating that all existing documents including the driver's written exam are only available in English [46].

Recently anti-immigrant sentiment has come to a head, with the passage of the House Bill 87 (HB87) on May 14, 2011. This law mandated that employers must verify legal status of all new employees, empowered local and state police to arrest illegal immigrants and transport them to jails, and castigated persons using false identification to be employed (up to 15 years in prison and $250,000 in fines). In addition, it punished people that knowingly transported or harbored illegal immigrants and gave law enforcement officers the ability to investigate immigration status if they had probable cause, but both of these have been revoked [47]. These laws exemplify the tension in the political climate regarding Latinos and have the potential to further marginalize and limit the health care access of this population.

Research Needs:

Due to the current political climate seen in recent anti-immigrant laws, and various other factors, currently there are no published studies regarding ChD in Georgia. As the Latino population in Georgia grows, the prevalence, morbidity, mortality and economic burden of ChD increases. Since Latinos are a marginalized, undeserved population, they are less likely to seek health care and health information, thus, they are unlikely to be aware of or be tested for ChD. Low levels of awareness, testing and treatment mean that transmission from mother to child and via blood donation increases risk of ChD for all of Georgia. In order to effectively determine the burden of ChD and the needs of the immigrants in Georgia and form the corresponding policies and programs to treat these immigrants, we need more precise information on gaps in the knowledge of Latino immigrants, how to communicate health information effectively to them, and a better understanding of how they access health care. In response to this gap in knowledge, the Center for Disease Control (CDC) has identified has identified three research needs with regard to ChD: 1) what is the burden of ChD in the Hispanic population in the U.S.; 2) what are the barriers preventing *T. cruzi* positive donors from receiving evaluation and treatment; and 3) what gaps exist in physician knowledge of ChD and how can those gaps be addressed.

Goal and Aims of the Project:

The goal of this project is to understand the levels of knowledge of Chagas disease, methods of communication, health-care seeking behavior, and the barriers to prevention and treatment of Chagas Disease among Latino immigrants in Georgia in 2011 in order to address needs 1-2. The aims of this project are to: 1) identify levels of knowledge of Chagas Disease among Latino immigrants in Georgia, 2) identify preferred sources of health information for Latino immigrants in Georgia, 3) identify common health care seeking behaviors of Latino immigrants in Georgia and the reasons behind them, and 4) identify the barriers to prevention and treatment of Chagas Disease among Latino immigrants in Georgia.

Significance:

The results from this study will be used to develop health education, outreach and interventions for Latino immigrants to prevent and treat ChD. A better understanding of effective methods of communication and the gaps in knowledge among Latino Immigrants will allow the CDC, state, and local governments to design and implement effective outreach programs and policies in order to diagnose, treat and prevent the spread of ChD. Additionally, these effective methods of communication will be used in the report on “The Status of Latino Health in Georgia” by the Hispanic Health Coalition of Georgia. The Leon Research Group will use these data to design an information guide on Chagas disease for Latino immigrants in Georgia. In addition, data from this project will serve to inform a new initiative by the Global Health Institute at Emory University to assess underserved Latino community needs and develop partnerships between Emory University and Atlanta community groups so as to improve the health of the Atlanta underserved Latino community.

Manuscript

Barriers to testing and treatment for Chagas disease among Latino immigrants in Georgia

Background: Chagas is a parasitic disease primarily affecting Latin Americans, which is increasing in the US due to the recent growth of the Latino immigrant population. The lack of testing and treatment of Chagas disease in the US increases the risk of serious health complications among infected immigrants and poses a risk of transmission from mother to child or via blood transfusions.

Goal: The goal of this study is to identify the barriers to testing and treatment of Chagas disease amongst Latino Immigrants in Georgia and to understand the process of seeking healthcare by Latino immigrants from which to develop effective treatment interventions.

Methods: In this qualitative study, nine focus group discussions were conducted with male and female Latino immigrants to understand their perceptions of Chagas disease and their process of seeking healthcare if they had Chagas symptoms. Grounded theory was used to collect and analyze the textual data to develop an inductive conceptual framework to explain the context and process of seeking healthcare for Chagas amongst this at risk population.

Results: Participants were not aware of Chagas disease. When asked how they would seek care for symptoms of Chagas disease, three distinct behaviors were identified: delaying treatment, using traditional remedies, and using either mainstream or alternative health providers. Health seeking behaviors and motivations differed for women and men, but the use of licensed medical providers was seen as a last resort due to the cost of healthcare, loss of earnings while seeking care and fear of diagnosis with fatal illness.

Discussion: The lack of awareness of Chagas disease amongst Latino immigrants in the US suggests a strong need for targeted education about the disease. Providing free or low cost services, mobile treatment clinics and education regarding Chagas disease is critical to increase testing and treatment for Chagas disease.

Introduction

With the rapid growth of the Latino population in the United States [44], the prevalence and burden of Chagas disease, caused by the parasite *Trypanosoma cruzi*, is increasing [48]. Worldwide, the United States is the country with the highest number of immigrants from Latin America, and it is estimated that approximately 300,167 people in the United States are infected with Chagas disease [17]. Additionally, it is estimated that there are 63-315 congenital *T. cruzi* infections per year in the United States [17] and more should be anticipated because of the increase in Latin American populations [49]. Only 65% of the blood donated in the United States is screened for anti-*T. cruzi* antibodies, and blood donor screening in the United States has resulted in recognition of 1,113 cases of Chagas disease nationwide from 2007 to 2010. Despite recommendation to seek medical treatment, only about 11% of new *T. cruzi* seropositive blood donors or their physicians have contacted Center for Disease Control (CDC) for treatment consultation [48]. The limited number of treatment consultations indicates a need to understand why so few seropositive donors have sought treatment. Latinos, as a marginalized, underserved population, are less likely to seek healthcare [33] which may affect their ability to be tested or treated for Chagas disease. This in turn may increase the number of people in the United States who suffer and seek care for adverse health effects of Chagas disease. Additionally, it increases the risk of transmission of Chagas disease from mother to child [50-52] and via blood donation for the United States population [53]. We need more precise information on the knowledge and perceptions of Chagas disease among Latino immigrants and a better understanding of how and when they access healthcare in order to understand create effective interventions to prevent transmission and treat infected immigrants for Chagas disease.

Chagas disease, caused by the protozoan hemoflagellate *T. cruzi*, is a generally treatable parasitic infection. Vectorial transmission is responsible for the great majority of infections in endemic areas (Latin America) due to housing conditions and the large number of infected vectors [reviewed in [6]]. In the developed world, due to better housing conditions and less infected vectors, Chagas disease is usually transmitted via blood transfusions and from mother to child [reviewed in [6]]. Chagas disease has two phases: acute and chronic. Acute infection, lasting 4-6 weeks, has very few signs and symptoms. The lack of definitive symptoms allows most infections to go unrecognized [reviewed in [6, 8]]. If the infected individual is not treated in the acute phase, they then enter the chronic phase, which can be either indeterminate or clinically evident. Only 20-30% of infected individuals enter a clinically evident stage, which typically affects the heart and, to a lesser degree, the gastrointestinal system [9]. The clinically evident stage can develop up to twenty years after infection and can include cardiomyopathy and megacolon, which if untreated can be fatal [10]. Both stages of Chagas disease can be treated with the two drugs currently available for Chagas disease: Nirfurtimox (NF) and Benznidazole (BNZ). In the U.S., both of these drugs are currently exclusively controlled and distributed by the Centers for Disease Control and Prevention (CDC) and are more effective in the acute stage. The efficacy of the drug therapy declines with the duration of the infection and are associated with high rates of adverse effects [10, 11]

With the rise in immigration from endemic areas of Latin America to the United States and Europe, the burden of morbidity and mortality associated with Chagas disease is now shifting from Latin America to parts of the developed world, particularly the United States [15, 49]. In the United States, seroprevalence rates ranging from 0.4% to 4.9%) have been documented in various immigrant populations [20-22]. Throughout Latin America, several multinational campaigns have been successful in controlling transmission by triatomine vectors and greatly reduced the rates of domestic infestation [reviewed in [6]]. In contrast, the burden and risk of Chagas disease for countries outside of Latin America is growing due to previously infected Latinos immigrating and to a lesser degree transmitting Chagas disease vertically and via blood transfusions to uninfected recipients [25].

As mentioned, of concern, only 11% of seropositive donors sought care treatment for Chagas disease in the United States [48] which may be a result of the existing disparities in income and access to healthcare between Hispanics and other races. Hispanics are more likely to be poor and uninsured, despite their high labor force participation than other race [45]. As a group, they are less likely than other races to receive appropriate and timely treatment. They have consistently been shown to be less likely to access healthcare and more likely to rate their quality of treatment lower than other racial groups. [33]. The reasons for this disparity in healthcare can be classified into two main reasons: structural barriers and belief barriers. Structural barriers that affect access to healthcare among Latino immigrants include the cost of treatment, legal status, lack of insurance, and lack of interpreters [reviewed in [32]]. Lack of insurance has been found to be the most important factor affecting access to healthcare for Latinos. Due to the fact that Latinos have lower incomes, work lower paying jobs without benefits like insurance, and often do not qualify for governmental aid because of their legal status, Latinos have the highest percentage of people in any racial group that are uninsured (32.1% of Hispanics vs. 12% non-Hispanic whites) [54]. In addition to structural barriers, many beliefs that are prevalent in the Latino community affect their access to healthcare. Often, Latinos fear the cost, potential for deportation, long waits, and discrimination that they associate with accessing healthcare [33]. Latinos, particularly Spanish dominant Latinos, consistently rate their experiences with medical staff more poorly than non-Hispanic whites [55].

Because of a combination of structural barriers and beliefs, Latinos in the United States use a variety of alternatives to mainstream healthcare. Hispanics often self-medicate or have friends or families send the medicine from their home in order to avoid having to see a doctor [33]. Due to their indigenous roots and lack of medical care offered in their home countries, Latinos have a long history of using traditional herbs and remedies to cure their maladies. These remedies are also used as alternative to mainstream care by immigrants in the United States [56].

Due to the rapid growth of the Latino population and their low levels of use of mainstream healthcare, the risk and burden of Chagas disease in the U.S. is increasing. To address these needs, the goal of this study is to understand the levels of knowledge of Chagas disease, identify common healthcare seeking behaviors, and the barriers to prevention and treatment of Chagas disease among Latino immigrants in Georgia in 2011. The state of Georgia was chosen as the study area because according to the 2010 United States Census

Bureau, Georgia had the tenth largest Hispanic population in the United States (8.8%) [44]. The Hispanic population in Georgia is the third fastest growing population in any state, and slightly more than half were born abroad [45]. The large immigrant population in Georgia increases the burden and risks associated with Chagas disease for all Georgians through vertical transmission and via blood donation (e.g. 17 out of 1,113 US infected blood donors were from Georgia between 2007 and 2010) [48]. Focus group discussions with Latino immigrants in Georgia were used to explore when Latinos decided to use mainstream healthcare, how they accessed healthcare and their knowledge and perceptions of Chagas disease. Participants were unaware of Chagas disease and described three distinct phases of seeking healthcare and the pathways in which they sought care and their reasons behind their decisions differed for women, day laborers and farmworkers. The results from this study will be used to develop health education, outreach and interventions for Latino immigrants to increase access to healthcare in order to prevent and treat Chagas disease and other diseases that disproportionately affect Latino immigrants.

Methodology

Study Sites:

This research was conducted in both urban and rural areas of Georgia to capture a broad range of experiences of Latino immigrants in the state. The urban study sites were located within the City of Atlanta, defined for the purpose of this study as Cobb, DeKalb, Fulton, and Gwinnett counties. Atlanta is one of the largest urban centers of the Southeastern United States with a population of 2,914,587 comprised of 7.87% of Hispanics, approximately half of which are foreign-borne [45]. Latino immigrants in Atlanta vary widely while many are legal residents, others who have no legal status in the United States. Atlanta was selected in order to include the experiences of urban Latino immigrants.

The rural study sites were located in Moultrie, Georgia and comprised of two farms employing immigrant workers. Moultrie (defined for the purpose of this study as Colquitt county) is a rural area which relies heavily on agricultural labor; it has a population of 42,053, of which 12.83% are Hispanic [44]. Moultrie was selected to capture the health seeking experiences of rural Latino immigrants, most of whom are men working on farms and whose perspectives on Chagas disease and accessing healthcare may be different from urban Atlanta–based Latino immigrants.

Study Population:

The target population for this study were immigrants, 18 years or older, who were born and lived in Latin America for at least ten years prior to the study, spoke Spanish, and were currently residing in the United States. No restrictions were applied for participant's length of residency in the United States.

Both female and male Latino immigrants were included in this study. Latina women mainly reside in urban areas of Georgia and were therefore only recruited from Atlanta, while Latino men reside in both urban and rural areas and were recruited from both study areas. In urban areas, men often work in the as day laborers in the informal job market, such as in construction, landscaping or painting; while in rural areas they are largely employed in the agricultural production sector as farmworkers. To capture the perspectives of different types of Latino immigrants we therefore report on three sub-groups of immigrants: women residing in Atlanta, and men residing in both Atlanta and rural areas of Moultrie, Georgia.

The perspective of women regarding Chagas disease and accessing healthcare was important because of their traditional role of caregivers in Latino cultures which may shape their motivations and the way that they care for their and their families' health. Additionally, due to the potential of mother to child transmission of Chagas disease, the levels of knowledge and attitudes towards Chagas disease among Latina women were important to document. In order to capture the perspectives of males living in urban areas, day laborers were recruited. The majority of male undocumented Latino immigrants in urban areas work as day laborers, and often have minimal access to healthcare due to their participation in the informal job market which does not provide health insurance and often has lower wages and the highly mobile nature of the population. Farm work (e.g. fruit picking, vegetable picking, planting and packaging) is the most common type of employment for male Latino immigrants in rural areas of Georgia. The temporary work visas extended to farmworkers and their tendency to live on the farms where they work affect their ability to access healthcare due to a lack of transportation, limited financial resources and limited time off from work.

Participant Recruitment:

Women were recruited only in the urban study sites of Atlanta, where most Latina immigrants reside. These female participants were purposively recruited using formal and informal networks because female Latino immigrants often do not work outside the home. Recruitment through formal networks was through existing community organizations, such as churches and classes (e.g. health classes for seniors and prenatal care classes) designed specifically to reach Latina women. Various types of organizations that served Latino immigrants were identified by the study's Community Advisory Board including Catholic and Methodist churches, the Latin American Association, and Prenatal Care classes. An informal network of an exercise group was also used. Recruitment through various networks involved contacting the organization's leader to explain the purpose of the study and to seek their assistance. Leaders interested in the study invited the study staff to attend a regular meeting of their group to describe the study and invite participation of members. A wide range of networks and organizations was used to recruit Latina immigrants to provide a diverse range of study participants. A total of 37 female participants were recruited for five focus group discussions.

Men were recruited in both urban and rural study sites. In the urban study sites many Latino immigrant men work as unskilled day laborers touting for work in public locations, therefore they were recruited using venue-based recruitment at these locations. Study staff visited locations where male Latino immigrants congregated looking for work (e.g. close to hardware stores, specific gas stations), approached immigrants explaining the purpose and process of the study, and asked eligible immigrants if they would be willing to participate. Due to difficulties finding suitable places to hold discussion groups and the reluctance of participants to leave the venues where they were still looking for work, only one discussion group of six day laborers was held. In the rural study sites in Moultrie, men were recruited through a mobile health clinic that served (mostly male) immigrants working on two farms. Study staff approached male immigrants after their clinic visit, explained the purpose and process of the study, and asked eligible immigrants if they would be willing to participate. Twenty three male farmworkers were recruited for three focus group discussions, creating a total of four male focus group discussions (one urban, three rural).

Data Collection:

Data were collected using focus group discussions, which were suitable to explore diverse perspectives on health knowledge and health seeking strategies explored in this study. Focus groups were stratified by gender (four male groups, five female groups) for group homogeneity so that participants feel comfortable sharing their perspectives and to allow for analytic comparisons between the views of men and women. Data were collected from May to August of 2011 until saturation when no more new information was identified

[57]. All focus group discussions were conducted in Spanish, moderated by Spanish speaking moderators who were of the same gender as the participants. A note taker was present at each group discussion, which lasted 60-75 minutes including the completion of a demographic survey. All group discussions were digitally recorded and the note-taker recorded key points in the discussion and which participant made them. Focus group discussions held in urban study sites were conducted in private homes, churches, restaurants, and non-governmental organizations offices. In the rural study sites data were collected at two farms, where discussion groups were held under a tent and in conjunction with a regular mobile health clinic. In order to maintain the privacy and confidentiality of participants, all discussion groups were held in the most private areas available, whether in separate rooms or in the case of outdoor settings in a tent. Participants were compensated with a meal or snacks for their time.

A semi structured question guide was used for the focus group discussions. The guide was translated into Spanish by study staff, pilot tested and refined before data collection. Four major topics were explored during the discussion including: access to health care, knowledge of Chagas disease and other vector-borne diseases, sources and methods of finding health information, attitudes and experiences of blood donation.

Additional data was collected from each participant via a brief demographic survey. The survey form was also translated into Spanish, pilot tested and refined. The survey collected individual data from each participant on their country of origin, time spent in Latin America, education and income. Study staff administered the surveys at the end of each group discussion either orally for those participants who were illiterate or in print for those who were literate.

This study was approved by the Emory University Institutional Review Board (IRB 00018964). Each participant was orally consented in Spanish before each focus group discussion and their consent for recording the discussion was sought. At the beginning of each group discussion, participants were asked to keep the issues discussed confidential by not sharing anything that was discusses outside of the group. At the end of the consent process, to ensure clarity, the participants as a group had to summarize their understanding of what their participation in the study would entail. At the end of the discussion, each participant was given a written copy of the oral consent in Spanish with contact numbers for the principal investigator and the Emory University Internal Review Board.

Data Analysis:

Each focus group discussion was transcribed verbatim, in Spanish, by members of the research team using the recorded discussion and notes taken during the discussion to clarify speakers. The data were then checked for accuracy by another team member and de-identified. Data were analyzed in Spanish. Using a grounded theory approach, data were analyzed in MAXQDA 2007 (Marburg, Germany) [58]. First, data were read and annotated to identify core themes raised, which were then developed into inductive and deductive codes and listed in a codebook. Inter-coder reliability was tested with an independent researcher who recoded a selection of text with the research team’s codebook. Code consistency was compared and all discrepancies were addressed. Thick descriptions of each core theme was developed by searching transcripts using codes to retrieve topical segments which were then read and summarized. Comparisons of each theme were made by gender to identify differences in context and explanations regarding how men and women seek health care and the process of care seeking. Comparisons were also made by men's employment type (e.g. day laborers vs. farmworkers). The various health-seeking behaviors described were grouped into four categories: seeking traditional remedies, waiting stoically, seeking mainstream healthcare providers and using alternative healthcare providers (e.g. physicians in their home countries and herbalists). The pathway between each category of health-seeking behavior was conceptualized and validated with data to create a model of healthcare seeking behaviors specific to the study population. The relevance of the model was verified for each group by returning to the coded transcripts and checking for agreement and discrepancies in the data.

Data Quality and Limitations:

The inductive approach of grounded theory used in this study allowed for issues to be understood in context and to closely reflect the opinions and voices of study participants. The quality of some data was reduced by the noise level of certain settings where group discussions were conducted which hampered clear recording of parts of the discussions, leading to some data loss. Once identified, this issue was mitigated by finding quiet settings and having the note-taker capture as much data as possible in addition to the digital recordings. Additionally, data quality may have been reduced because group discussions were not stratified by age, which may have created a hierarchy within some groups whereby some participants were less willing to contribute. This was mitigated by the use of pre-existing networks for recruitment when possible, which created groups of participants with high levels of familiarity and rapport. Additionally, those groups who were not recruited using pre-existing networks were homogenous on most other relevant characteristics including gender and occupation, which helped to mitigate the differences in ages. Finally, male immigrants who work in non-manual occupations in Atlanta were not recruited for this study due to their increased access to resources and healthcare because this research sought to understand the process of seeking healthcare among those immigrants who often have minimal access to mainstream healthcare, and thus have less opportunities to be tested or treated for Chagas disease.

Results

The goal of this study was to understand the barriers to testing and treatment for Chagas disease by describing the process of seeking healthcare by Latino immigrants, including the types of behaviors used in seeking care, the motivation for choosing those behaviors, and the pathway between behaviors. Because participants were unaware of Chagas disease, they could not describe how they sought care for Chagas disease. Instead, participants were asked to describe how they would seek care if they had symptoms of an illness that affected their stomach or their heart, because these are the areas primarily affected by Chagas disease. In brief, participants' descriptions of seeking healthcare for these illnesses featured three separate phases. The pathway through these phases differed for women, urban men and rural men. The primary barriers to using licensed medical providers to seek testing and treatment for illnesses included economic limitations, reservations about the quality of care they would receive and fear of being diagnosed with a grave illness.

Demographic data was collected for 58 of the 66 focus group participants (8 out of 9 discussion groups). One group of rural males did not complete the demographic survey due to weather constraints (n=8). Of those that completed the survey, the majority of participants were from Mexico (64%, n=37); approximately 16% (n=9) were from Guatemala, 7% were from other countries in Central America (n=4) and 13% were from various countries in South America, (n=8). Approximately half were married or had a domestic partner (n=33). Participants had a median age of 33 years old (range 19 to 89).

Of those who reported their household income (n=45), 44% reported less than $12,000 per annum (n=20) and 31% reported $12,001-$24,000 per annum (n=18).

Knowledge of Chagas Disease:

Before describing the process of seeking healthcare by Georgia Latino immigrants, it is important to describe the participants' levels of knowledge of Chagas disease because their perceptions and understanding of personal risk affects motivation to be tested or treated for Chagas disease. The majority of participants were unaware of Chagas disease. Only one participant in the entire study had heard of Chagas, through her daughter who has a PhD in microbiology. All other participants were unaware of Chagas disease, but the majority were able to report basic knowledge of other vector-borne diseases (e.g. Dengue fever and Malaria), including methods of transmission, risk, symptoms and prevention of these diseases.

Most male and some female participants recognized the vector of Chagas disease, the triatomine, when shown a picture or an example of it, by one of its' commonly known names across Latin America, "*chinche.*" It is important to note that the term "*chinche*" is used to refer to many different insects across Latin America that resemble the triatomine. Therefore, the term "*chinche*" does not refer specifically to the Chagas vector. Participants debated the name, origin, environment, and health effects of the bug that they referred to as *"chinche".* These results suggested that few participants had knowledge of the vector. Both men and women commonly confused the triatomine with bed bugs, and attributed a range of health problems including diarrhea and rashes to them. Some male participants described the vector to have acidic urine or foul smelling gas which irritated the skin. Although vectors do not expel gas, the saliva produced by triatomines may cause skin irritation [59].

Once the symptoms and transmission of Chagas Disease were explained by the study team, all participants expressed concern over how to recognize the symptoms associated with Chagas Disease to decide whether they needed to be tested for the disease. They were apprehensive about being unknowingly infected due to the lack of definitive symptoms and the long asymptomatic period. Of the information provided to focus group participants, they identified the lack of definitive symptoms, the length of the asymptomatic period and the potential gravity of the disease to be the most important points to communicate regarding Chagas Disease because of their fear of being unable to ascertain whether or not they were infected.

In general, women participants expressed much more interest in all aspects of Chagas Disease, particularly mother to child transmission and the cost of testing and treatment. Only female participants expressed concern about the possibility and mechanisms of mother to child transmission. For example when asked about what they would do if they found they were infected with Chagas Disease, one woman responded:

> *"I am more worried about my daughter because you say that it can be transmitted to children* [during pregnancy] *as well."* (Female, Group 4, P1)

In addition to women's apprehension regarding vertical transmission, they were also more concerned about the cost of testing and treatment, compared with men, and indicated that their ability to be tested or treated was dependent on the cost. The following quotation highlights the cost barrier to being tested for Chagas:

> *"The price. Right? It's not that one does not want to go to the doctor. It's not that you don't like that they check you and all. It's not that. It's because Hispanics generally don't have very much income, and even less than what we have* [is available] *because generally only the husbands work and everything has to come out of* [their salary]*."* (Female, Group 2, P2)

Process of Seeking Healthcare

Though participants had low levels of awareness surrounding Chagas disease, to understand the barriers to testing and treatment for Chagas disease, we sought to understand the process of seeking healthcare by Latino immigrants. In order to understand this process, the moderator asked participants to describe what they would do if they were ill, particularly if they had gastrointestinal or coronary symptoms, similar to those that may be caused by Chagas disease.

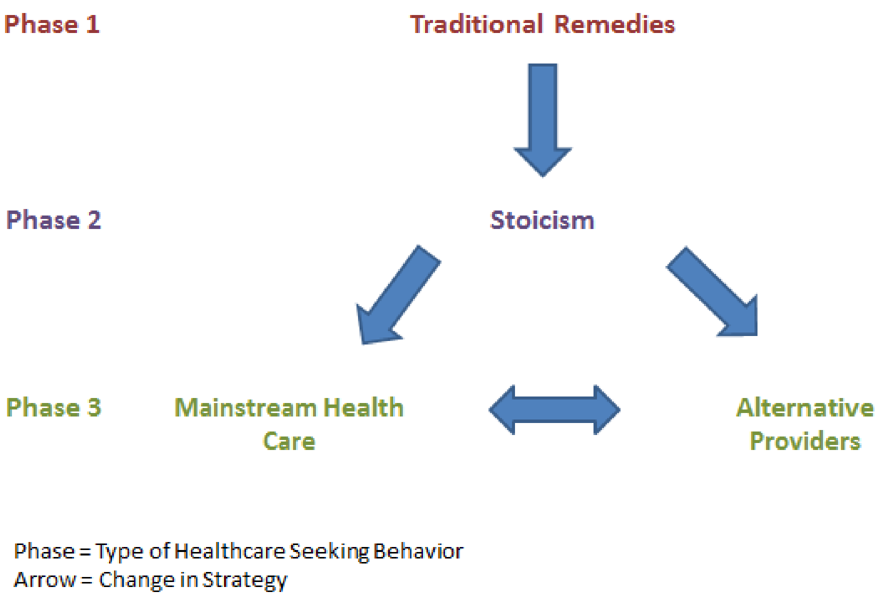


Figure 3. Process of seeking healthcare

Participants descriptions of the process of seeking healthcare, symptoms affecting their heart or stomach (areas most commonly affected by Chagas), highlighted three distinct stages: phase 1 involved the use of traditional remedies, phase 2 involved a period of stoicism, whereby no healthcare was sought, and phase 3 involved consulting a health provider, either mainstream healthcare or alternative (Fig. 3). The pathway through these stages differed by gender, area (rural men or urban men), and the gravity and familiarity with the health problem. Each of these stages is described below for the different types of participants.

Women

Female participants indicated that they and other Latino immigrants first used traditional remedies (Phase 1, Fig. 3), when confronted with familiar and less severe health problems such as colds or stomach aches. They described a variety of traditional remedies. Some traditional remedies were widely perceived as safe and effective, such as brewing various types of tea (e.g. lemon and cinnamon), or using certain herbs to make compresses to apply to various parts of the body, or making remedies out of certain insects. Other traditional practices used by Latinos were seen as outlandish, for example the use of tarot cards to treat heart disease and necklaces made of tomatoes to treat sore throats. In general, traditional remedies were used exclusively as the first recourse for illness, and were not used in conjunction with over the counter medicine from pharmacies.

While women recognized that often times these remedies were not effective and can be dangerous by causing them to delay seeking formal treatment, they continued to use traditional remedies as the first recourse for illness. The following quotes illustrate the common use of traditional remedies and the participants’ recognition of the danger of delaying care:

> *"For the most part, we treat ourselves with natural or homemade medicines, but if it doesn't cure us, one goes to the hospital, to the doctor, but first we treat with what we know."* (Female, Group 4, P1)

> *"This is the bad* [thing] *about us, Latinos. We decide to take the advice of the people that give it to us. For example, you say you have a pain,* [other Latinos say] *'do this, do that.' We self-prescribe, which is bad, but sometimes due to a lack of money* [we must]*."* (Female, Group 5, P6)

Women described using traditional remedies despite the risk they represent, for two reasons: the cultural tradition of their use and the lower cost of these treatments compared to mainstream providers. Women sought advice from family members in their home countries on how to use traditional remedies for illness, as they were considered more knowledgeable about traditional remedies due to the long history of their use in Latin America. When women were unable to find the herbs recommended by family members, they requested family members to mail herbs from their country of origin to the United States. The following extract demonstrates how female participants valued the advice of family members in their home countries about traditional remedies:

> *"Because they* [family in country of origin] *almost always cure themselves with natural medicines like an herb or something. They make them into tea. They know more, a little more than one* [here]*."* (Female, Group 4, P2)

In addition to the custom of using traditional remedies, women also preferred to use them because they cost less than mainstream healthcare providers. If the traditional remedies cured their maladies, they saved money, but if they failed, the women recognized that it was both dangerous and often more expensive. The following quote demonstrates their preference for traditional remedies due to their lower cost:

> *"You call* [your family] *on the phone and you say to them, 'my stomach hurts, what can I take?* [They say] *take this, take this.' If it works you save* [the money for] *the doctor, but if it doesn't work, that's the bad part. It doesn't save you* [money]*."* (Female, Group 5, P6)

If traditional remedies did not cure the illness or if women were unaware of any traditional remedy for the illness, they described a second phase of health treatment as "aguantando" (waiting stoically) (Phase 2, Fig.1), which involved postponing caring for their illnesses, with the hope that the illness would cure itself. Women described four reasons for not seeking healthcare and waiting stoically. First, the lack of economic resources or lack of time to seek medical care led women to wait for the symptoms to disappear on their own. For example:

> *P7: "We wait. When the pain is strong and we can't* [wait] *anymore, then* we [go to the doctor]." *Moderator: "Why do you wait?"P8: "Because of the same* [reason], *because there is no money."* (Female, Group 5, P7-P8)
>
> *"At times, also because of the time* [as well as the money] *we can't go to the doctor and it's better for one to wait until it's so late that one cannot wait any more and has to go* [to the doctor]*."* (Female, Group 4, P2)

Second, women reported the fear of being diagnosed with a grave, untreatable or expensive illness as reasons for waiting to seek healthcare. Women described how some Latinos prefer not to know if they were ill, even at the cost of not caring for themselves and stopping the spread of infection, because they believe they will die anyway due to a lack of resources. For example,

> *"Because many times, we, I have friends that I tell* [them] '*let's go get a checkup' and they say 'no, I won't because if I have some problem, I am scared and prefer not to know…because if I have something severe, I don't have any money and will die sooner than before my time.'"* (Female, Group 4, P1)

Third, some women stated that they waited stoically because they lacked trust in mainstream healthcare providers in the United States. These women described how some doctors are more interested in charging them than curing them and cite examples of receiving a large number of tests before being treated with providers unwilling to use previous test results from other clinics, and being charged for consultations without being told anything new about their illness. The following extract demonstrates these issues when consulting mainstream healthcare in the United States:

> *"When you go to the doctor, they say 'I have to do an exam for this,' but sometimes you say 'this is just to get my money.' Yes, because sometimes you already went to another clinic and they did a blood test, but in the other clinic* [the new one] *they repeat the same test to get information that you knew from the beginning. When they do it and you ask why,* [they say] *I can't prescribe anything if I don't do the exam to know what you have.' Because of this, sometimes I trust* [Mexican doctors] *more because in Mexico, no, in Mexico it is cheaper because they say 'Where does it hurt?' 'Here,' and they touch you and* [say] *'It is probably this' and they give you something."* (Female, Group 5, P6)

The fourth reason that women give for waiting rather than seeking healthcare is because their health is not a priority for them. They described Latinos as "descuidados" or careless with their health. Women portrayed people who were too lazy or irresponsible to seek healthcare, even if they had the resources to do so. One woman described how she forgets her own check-ups:

> *"Speaking for myself, instead of going to get a pap smear every year, sometimes I forget and say 'well it has been almost two years, it might as well be two.'"* (Female, Group 3, P1)

If symptoms became insufferable, women entered into the third phase of the process of seeking healthcare (Phase 3, Fig. 3), which involved either consulting alternative health providers or mainstream healthcare providers depending on their available resources.

Alternative providers included stores that provide prescription medications (e.g. antibiotics) without a prescription, natural doctors/herbalists who had no medical licenses and doctors in their country of origin who would post prescriptions to the United States. Typically, women who do not have the financial resources to pay for mainstream healthcare (i.e. licensed clinics, hospitals and medical providers) used these alternative providers. Women also described using alternative providers when they knew what medicines they needed or when they had strong relationships with family members and physicians in their home countries. For example, when describing why they used alternative providers instead of seeking mainstream healthcare some women responded:

> *"I buy* [prescription medicines] *because they are cheaper than [going to a] doctor. Let's say, for example that you have a sore throat, an infection, that won't go away with pharmacy cough syrup. It won't go away with pills because the infection is very strong. What do we do? We find antibiotics in the Latin stores. We find an injection of penicillin and we inject ourselves with penicillin. Amoxicillin. Pills. And with this, two shots of penicillin it's over. Sixty dollars and we will cure ourselves."* (Female, Group 5, P8)

> *"I suffered a lot from my ears, and I went to a, well I went with him* [a doctor] *and he charged me about $200…and from then on when we had a problem, we had a doctor in Guatemala where I used to go and I would call him and tell him 'I feel like this' and he would tell me what to do and my family would try to send it* [medicine] *to me."* (Female, Group 4, P3)

Some women chose to use mainstream healthcare rather than alternative providers when waiting became intolerable (Phase 3, Fig. 3). Women primarily chose to use mainstream providers if they had sufficient financial resources to pay for healthcare, or if they had very grave illnesses.

Yet, within the category of mainstream healthcare, various factors were used to select providers, the most important, across focus groups, was cost. For those eligible, acceptance of Medicare/Medicaid was the first requirement when searching for doctors. Those who were ineligible for government aid described asking for recommendations from acquaintances in order to find the most economic option when selecting mainstream providers. Other women described selecting providers who offered payment plans and sliding scales (e.g. St. Joseph's Mercy Care). One woman described how she selected her provider based on affordability:

> *"It depends on your situation, the situation, what you feel, the symptoms… according to me I had problems in my breast, this breast, and I was thinking, it took me almost two months thinking 'where, where, where will it be the cheapest?'"* (Female, Group 3, P4)

In addition to cost, some women described selecting healthcare providers who spoke Spanish, because they felt that interpreters could not correctly communicate their concerns. They worried that interpreters might try to correct or change the meaning of what they said. One woman gave an example of her distrust for interpreters:

> *"If I say my stomach hurts, and then the interpreter might say, 'well it could be the belly, it can't be the stomach' and he tells the doctor something I don't actually feel."* (Female, Group 2, P4)

If women who, after waiting stoically and first chose mainstream healthcare over alternative providers, found that these mainstream healthcare failed to cure them, they described turning to alternative providers. Women cited experiences (either personal or from acquaintances) where the doctors failed to cure their illnesses either by being too expensive or ineffective. They turned to alternative providers such as "natural doctors" or herbalists or having their doctor from their country of origin send a prescription through the mail (Phase 3, Fig. 3). One woman described how a friend of hers had various visits, tests and treatments from mainstream healthcare providers, but her health did not improve so she tried an alternative provider:

> *"There is a woman who went to different doctors, even American doctors, and all to see if* [her illness] *changed but no,* [it stayed] *the same. Her daughter went to a natural doctor here in Atlanta…she is taking some herbs, some plants that he recommended and is better and can move her leg and arm."* (Female, Group 2, P3)

Children

Women considered the health of their children to be a priority, therefore, when a child was ill, women would directly seek mainstream healthcare, thereby skipping Phase 1-2 and moving straight to Phase 3 in Figure. 1. When their children were ill, they did not use traditional remedies (Phase 1), wait stoically by making their children wait (Phase 2), or seek alternative providers. One woman cited that even though she knew what was wrong with her child, she would take her child to the doctor:

> *"Even though* [it is just a fever] *one goes to the doctor if they have a fever or something and the only thing they* [the doctor] *tells you is to give them aspirin and it's over. And if you have to pay* [no Medicaid] *they charge you for the consult and everything."* (Female, Group 4, P2)

Often children had Medicaid so mainstream healthcare was less costly, but even when they did not have Medicaid and it was hard to find time, women made an effort to take children to mainstream providers. One woman stated that seeking healthcare for her children is a priority.

> *"Yes, even if they* [children] *do not have health insurance, you do what you can to pay. You have to go."* (Female, Group 4)

Men

In contrast to women, all the men (both urban and rural) described their first action when ill to be “aguantando” or waiting stoically, rather than attempting to treat their illnesses with traditional remedies. Therefore men entered the process of seeking healthcare at Phase 2 in Figure 3 by waiting until the illness cured itself.

Men cited the same reasons as women for waiting rather than seeking healthcare, including a lack of financial resources to pay for healthcare and fear of being diagnosed with a grave, fatal or expensive illness. The following are examples of how Latino men dreaded going to the doctor:

> *“We* [Latino men] *are much more careless with ourselves. Going to the doctor doesn’t matter to us, we dread going to the doctor, we are always afraid of that they will tell us that we have this thing or the other.”* (Male, Group Urban Men, P4)
>
> *“I think getting sick is a problem for Latinos here in the United States because it costs us a lot. This is the biggest problem there is for one* [Latinos]. *If you get gravely ill, they* [doctors] *won’t see you because it is so expensive for one* [Latinos]. *It* [healthcare] *is mostly for people from the United States.”* (Male, Group Rural Men 1)

Men, similarly to women, criticized Latinos for being irresponsible with their health, but the men attributed this negligence to a culture of machismo, in which men felt that they should not acknowledge illness in order to maintain their masculinity. Participants described machismo as affecting Latino men by making them avoid seeking healthcare:

> P1: *“We are careless* [with our health]. *Why? Because of machismo, how can we acknowledge it* [that we are ill]*?* [Men say] *‘How could it be? The doctor is mistaken.’”*
> Moderator: *“So you think it* [the carelessness] *is due to machismo?”*
> P1: *“Some, but also, I don’t know if it is the mentality of every individual or human being. For me, I will not let the illness advance if there is a cure for it.”* (Male, Group Urban Men, P1)

While criticizing men in the Latino community for waiting for illnesses to resolve themselves and not seeking healthcare, men excluded themselves from these reproaches by claiming that their health was a priority for them. When asked what they would do if they found out they were infected with Chagas, most say that they would find a way to cure it, because they valued their health. The following are responses of male participants when asked what they would do if they found they were positive for Chagas disease that demonstrate the importance they attached to their health:

> *"I wouldn't wait, I swear not even a day. I am a person who is always responsible with my body and I wouldn't let this illness* [Chagas Disease] *advance, even if I didn't have money, I would search for alternatives to be able to eliminate it."* (Male, Group Urban Men, P4)
>
> *"*[I would take] *the treatment* [for Chagas]. *I know it is expensive, but I would find the money, if I didn't have it to do the treatment. Because to leave it* [untreated] *is like not loving yourself. Because if you love yourself and you love your body, logically you will do what's right for it, right? But, many say, 'no, it will go away, it will go away' but it doesn't.* (Male, Group Urban Men, P1)

When symptoms became intolerable, men entered Phase 3 in the process of seeking healthcare (Fig.1), but Phase 3 varied by the area where the men lived (urban vs. rural). Urban men used both alternative providers and mainstream providers, but rural men only used mainstream providers.

Urban Men:

When waiting became intolerable, urban male participants either sought care using mainstream healthcare providers such as hospital emergency rooms or clinics or alternative providers (Phase 3, Fig. 3). Despite being more expensive, mainstream healthcare was preferred over alternative providers; those urban men who had sufficient funds to pay for care would seek mainstream healthcare.

Urban men expressed concern over the quality of healthcare they received from mainstream providers, while preferred to alternative providers, and cited personal stories about how mainstream healthcare providers had failed to cure their illnesses. When such failures occurred, urban men sought care from other mainstream, and not alternative, providers.

Those urban men who did not have the financial resources to pay for mainstream healthcare used alternative providers (Phase 3, Fig. 3). The alternative providers described by urban men included Hispanic or Asian stores that sold prescription drugs without prescriptions as well as unlicensed dentists and doctors in Georgia who would treat them at a lower cost. Urban men recognized the risks of using these alternative providers and expressed concern over their effectiveness and safety. However despite their unease, they used alternative providers if they could not afford mainstream healthcare. If alternative health providers failed to cure them, they described using mainstream healthcare providers. The following demonstrates their lack of confidence and their acknowledgment in the risk of delaying care:

> *"The people will tell you anything. They are not prescriptions of doctors; rather they are prescriptions of the people. You go to the pharmacy, Chinese or Hispanic; in the Hispanic stores around here they will give you a 'mejoral,' an aspirin, all that, and if it doesn't work you have to go to the doctor, but your condition is already serious."* (Male, Group Urban Men, P2)

There were three differences in Phase 3 of Figure 3 between urban men and women. The first difference is that unlike women, urban men did not cite language as a priority when selecting mainstream providers. Secondly, the alternative providers, used by those urban men who did not have financial resources to use mainstream healthcare, differed from those used by women. Women described seeking care from physicians in their home countries while urban men described using unlicensed providers in Georgia. Finally, when alternative providers or mainstream providers first failed to cure them, all urban men sought different mainstream providers. Unlike women, after mainstream providers failed to cure them, no urban men described turning to alternative providers.

Rural Men:

Rural men, similar to urban men, began the process of seeking healthcare directly in Phase 2 of Figure 3 by waiting stoically, yet their reason for waiting was a reluctance to take time off from work. Since they came to the United States to earn money and were hired on a temporary basis, rural men were unwilling to seek healthcare unless it was absolutely urgent because taking time off from work meant lost earnings. They preferred to wait and then seek care in Mexico in order to avoid losing time off work and to ensure continuity of care. For example, when rural men were asked if they would be tested or complete the three month treatment for Chagas Disease, they responded that in Mexico they would, but not in the United States because they would not earn as much money. The following quotes exemplify their reluctance to seek care:

> *"In order not to lose a day* [of work], *to maintain a relationship with the boss, you have to work. Economically, economically you have to work. This is what we*

> *know. You have to take care of yourself, that's how it is."* (Male, Group Rural Men 1)
>
> *"We don't have enough money to do long treatments…it is not a good idea for us…we would like to do checkups here but there is not enough time, and to lose a day for a checkup, we can't."* (Male, Group Rural Men 1)

When waiting became intolerable, rural men entered Phase 3 of Figure 3, but rural men only sought care with mainstream health providers. Rural men made no mention of using any type of alternative providers. When selecting mainstream providers, rural men described choosing based on convenience, in order to avoid losing more time at work.

There were four major differences in the healthcare seeking strategy of rural men compared to women and urban men. The first difference was that the primary reason for waiting to seek care for rural men (Phase 2, Fig. 3) was a reluctance to take time off of work. Urban men and women described waiting for a variety of reasons and the most important reason was a lack of financial resources. The second difference was that, no rural men described using any type of alternative provider; they only used mainstream healthcare providers (Phase 3, Fig. 3). Women and urban men described using both alternative providers and mainstream providers. The third difference was that when choosing mainstream providers, rural men chose them based on convenience. Women and urban men described choosing mainstream providers based on cost, rather than convenience. The final difference was that, unlike women and urban men, no rural men expressed concern over the quality of care they would receive from mainstream providers.

Discussion

The goal of this study was to identify barriers to testing and treatment of Chagas disease amongst Latino Immigrants in Georgia and to understand the process of seeking healthcare by Latino immigrants from which to develop effective treatment interventions. Five barriers to being tested and treated for Chagas disease were reported by study participants. The first barrier was a lack of awareness of the disease. The majority of participants had never heard of Chagas disease, despite some being able to identify the vector, thus they had no motivation to be tested. The second barrier to seeking mainstream care for Chagas disease was fear of being diagnosed with a fatal disease or an illness requiring expensive treatment. The third barrier identified were reservations about the quality of care they would receive from mainstream healthcare providers. The fourth barrier was economic limitations to accessing mainstream healthcare. Women and urban men described being unable to pay for care and their subsequent use of lower cost alternative providers instead of mainstream providers for healthcare. Rural men described an unwillingness to miss work and lose subsequent earnings as the reason they did not seek care from mainstream providers, but did not cite using alternative providers. Finally, women described seeking mainstream healthcare immediately if their children became ill, thus no barriers were found to treating Chagas disease among children.

The Process of Seeking Healthcare:

A conceptual framework was developed to understand the process of seeking healthcare by Latino immigrants (Figure 3) and to understand the context to the barriers to testing and treatment for Chagas disease that were identified by participants. Latino immigrants described seeking mainstream healthcare only when they could no longer tolerate the illness symptoms. Therefore, the lack of definitive symptoms and long asymptomatic period associated with Chagas disease, means that Latino immigrants would not seek care until they enter the clinically evident stage of the disease (e.g. cardiomyopathy, achalasia, and megacolon). Based on our model, if a female Latina immigrant in Georgia was infected with Chagas disease, they would attempt to treat themselves with traditional remedies once they entered into the clinically evident stage. When traditional remedies failed, they would wait until the symptoms were unbearable, and then seek care from either mainstream providers or alternative providers depending on their financial resources. Both urban and rural male Latino immigrants infected with Chagas disease would follow the same process as a female, except that when they entered the clinically evident stage they would not use traditional remedies to treat themselves, rather they would wait for symptoms to disappear or become unbearable. When symptoms were intolerable their processes of seeking care would differ because urban men would seek care either with mainstream or alternative providers depending on their resources, but rural men would only seek care from the closest mainstream provider. Finally, if a Latino child was infected, they most likely would not enter the clinically evident stage of Chagas until they were adults, and thus may follow the process described above depending on their gender and location of residence. According to the women's descriptions of seeking care on behalf of their children, if the mother of the infected child was aware of any symptoms the child had, they would immediately take the child to a mainstream provider.

Lack of Knowledge of Chagas disease:

One of the prominent findings of this study was that the lack of awareness of Chagas disease was a significant barrier to testing. Currently, the authors are unaware of any studies measuring awareness of Chagas disease among Latino immigrants in the United States. However, a qualitative study in Spain among at-risk immigrants also showed their lack of knowledge about the disease, as well as many fears and false beliefs about Chagas [60]. This lack of knowledge may be due to the low prevalence of Chagas disease in the United States hence few immigrants have been diagnosed with Chagas (previous studies have documented seroprevalence rates ranging from 0.4% to 4.9%) [20-22]. Additionally, knowledge of Chagas disease is limited among medical providers in the United States; 68.2% of American College of Obstetricians and Gynecologists surveyed described their knowledge level about Chagas disease as "very limited" [61]. Yet, in areas where the disease is endemic, such as Argentina, there have been high rates of public participation in vector control campaigns which indicate an awareness of risk of Chagas disease [62].

The lack of awareness of Chagas disease documented in this study suggests a need for increased education, about the risks of Chagas disease in order to increase testing for this disease among Latino immigrants in the United States. Based on the results of this study, the need for education encompasses both Latin America and the United States due to the tendency of women to consult their families and physicians in Latin America regarding remedies and the growth of the immigrant population in the United States. As indicated by our results, education should focus on risk factors for contracting the disease and the need for testing due to a lack of definitive symptoms and an extended asymptomatic period. Previous campaigns to stop the spread of Chagas disease have been concentrated on controlling transmission by triatomine vectors in Latin America, but recently there have been new efforts at educating at-risk populations and their medical providers. The majority of campaigns conducted throughout Latin America were focused on vector control rather than education and implemented by governments with limited public participation [reviewed in [6, 27, 62, 63]]. More recently, strategies encouraging community participation have been used, but they are still focused on vector eradication rather than education [62, 64-66]. There is only one educational campaign aimed educating at Latino immigrants in the United States about Chagas disease. This campaign is run by Center of Excellence for the Diagnosis and Treatment of Chagas Disease in the Olive View University of California Los Angeles Medical Center and consists of using health promoters to encourage and test for Chagas disease by educating immigrant populations about their risk [67]. While this campaign has a limited scope, their approach has been successful and could be more widespread. One successful example of an education campaign for at-risk populations that could be applied to the U.S. occurred in Spain. Spain, second only to the United States in the number of Latino immigrants [23], has instituted a successful educational program for at-risk immigrants to increase knowledge and decrease fears about Chagas disease and to encourage testing [60]. The program was community based and culturally tailored for female migrants of child-bearing age from Latin America. It consisted of community education and screenings for Chagas disease. The educational component of the program included developing leaflets about Chagas disease and informational sessions in non-clinical settings and use of media and social events to inform migrants about Chagas disease. In addition to education, the program included free screenings for Chagas disease. This campaign has been very successful, in the year of its initiation (2007) the number of consultations for Chagas disease doubled [60]. Finally, new efforts have been made to increase knowledge among medical providers regarding Chagas disease as well as at-risk populations. The Centers for Disease Control and Prevention in the United States has created a training module to educate medical providers about Chagas disease to combat the documented lack of knowledge among medical providers [68].

Economic Limitations:

Educational campaigns could also increase testing and treatment by allaying the fear of being diagnosed with a fatal or expensive illness. Educational campaigns emphasizing the availability of treatment (gratuitous through the Centers for Disease Control and Prevention) have the potential to diminish the fear described by participants as a reason for not seeking care when they are ill. Based on our results, one of the reasons that immigrants self-medicate when ill, wait for illness to subside or use alternative providers before seeking mainstream healthcare was due to a fear of being diagnosed with a fatal illness. Other studies have also shown that female Latina immigrants delay treatment seeking due to a fear of being diagnosed with a serious illness, particularly cancer [69, 70]. In addition, our study highlighted that mainstream healthcare was not sought because of the cost of treatment if they were diagnosed with a serious illness. This economic barrier has also been shown in other studies whereby Latinos avoid seeking care because of the cost either due to lower incomes or lack of health insurance [33, 71]. Increased education concerning the availability of free treatment may allay the fear described by participants and encourage testing.

The economic limitations cited by participants as a reason to avoid seeking mainstream healthcare differed; women and urban men described their inability to pay for care and rural men described an unwillingness to lose time at work and subsequent earnings. The inability to pay for care was one of the most important reasons for self-medicating, waiting and using alternative providers instead of seeking mainstream healthcare among women and urban men. This result is supported by previous studies that have shown how the cost of care, along with other structural barriers (e.g. lack of health insurance and legal status), limit access to healthcare for Latino immigrants [33]. The use of alternative providers including folk healers, homeopathic practitioners, physicians in countries of origin and prescription medications is common among Latino immigrants in order to overcome these structural barriers associated with mainstream care [33, 56, 69]. This denotes the need for more low cost or free services as well as other forms of support such as medical insurance for immigrants, particularly those living in urban areas. Increasing free services has been shown to be an effective way to increase access to healthcare among uninsured Latino immigrants [72].

The primary structural barrier for seeking care for rural men was not cost as described by urban participants but losing time at work and subsequent earnings. The disincentives associated with losing time at work for farmworkers have been shown to act as a deterrent for accessing care among migrant farmworkers [73]. In rural areas, offering screenings, education and preventative care in mobile clinics after work hours has been shown to increase access to mainstream healthcare for rural male immigrants [74, 75]. The focus group discussions with rural men were conducted in conjunction with one such mobile clinic called the Farmworker Family Health Program that went to farms after work hours and offered free screenings and blood tests as well as other services [76]. Utilization of the clinic by farmworkers was high, which indicates that efforts to increase care by offering care after work hours and at farms could be effective in increasing access to healthcare among rural men.

Quality of Care:

A further barrier to testing and treatment seeking for Chagas disease were reservations about the quality of care they would receive from mainstream healthcare providers. Latinos' belief that they receive lower quality care than other races has been previously documented. Often, Latinos fear the cost, potential for deportation, long waits, and discrimination that they associate with accessing healthcare [33]. Most Latinos state that they think that they would receive better care if they were not Hispanic [77]. Latinos, particularly Spanish dominant Latinos, consistently rate their experiences with medical staff more poorly than non-Hispanic whites [55]. This result suggests that a network of mainstream healthcare providers where Latinos could share information and rate their experiences of mainstream healthcare providers, particularly those in urban areas, could be valuable for this population. By being able to rate and read other Latinos' ratings, Latinos may be able to choose providers where they feel they will receive higher quality of care, which may make them more likely to seek mainstream healthcare for testing and treatment for Chagas disease.

Concerns regarding quality of care also indicate a need for educating mainstream providers about the expectations of Latino immigrants and ways to increase cultural sensitivity within their practices. Some of these beliefs and disparities in satisfaction with health care are due to differences in cultural values between Latinos and their healthcare providers. By educating providers about values held by Latinos, and culturally appropriate ways to interact with Latinos as patients, we can improve the quality of healthcare received by Latino immigrants. There are some resources already available to healthcare providers to educate them with respect to providing culturally appropriate care including the *National Standards for Culturally and Linguistically Appropriate Services in Health Care* [78] and *Quality Health Services for Hispanics: the Cultural Competency Component* [79]. An educational DVD, *Sowing the Seeds of Health: a Program for Latinas* [80] shown to medical providers was proven to increase overall knowledge and confidence in Latino cultural beliefs related to healthcare [81]. Educational programs for providers may therefore increase cultural sensitivity and the quality of care that Latino immigrants receive.

Use of Alternative Providers:

Due to their inability to pay for care, urban participants described using a variety of alternative providers due to the lower cost associated with these providers. Some of the alternative providers used by these participants were forms of complementary and alternative medicines (homeopathic healers and herbalists). There has been an increase in incorporating some forms of alternative medicine including herbs and homeopathic remedies into mainstream practice [82-84], and providers of these types of complementary and alternative medicine have been shown to be amenable to working with mainstream providers [85]. By encouraging mainstream healthcare providers to work in conjunction with those alternative providers who can offer safe and effective remedies, we may increase preventative care and effective treatments among urban Latino immigrants. Because of their utilization of these providers rather than mainstream healthcare providers, working with mainstream healthcare providers to ensure that the treatment they receive is both safe and effective may improve their health. Yet, forming partnerships with some of the alternative providers identified (e.g. stores that sell prescription medications without prescriptions and physicians without licenses), is not feasible due to the lack of safety and the illegal nature of their practices. Thus, educating Latino immigrants about the risks associated with using unlicensed physicians and prescription medications may encourage them to use mainstream providers.

No rural men described using alternative providers in order to bypass the barriers of seeking mainstream care. All the rural male participants were in Georgia on H-2A visas, which are temporary visas in which farmers hire, transport and house immigrants during the agricultural growing season, usually February to September, and then return them to their home countries [86]. Given the temporary and restricted nature of the farmworkers' time in Georgia, it is possible that they have less access to transportation, very few had cars and there was minimal public transportation, which could limit their ability to access alternative providers. Additionally, farmworkers might have been less aware of alternative providers, because their time in Georgia was limited and they were often housed together on a farm limiting their knowledge of and access to locally available health resources. The dependence of rural men on mainstream healthcare providers is an opportunity to increase preventative care for this population, because when they are ill and can no longer wait, they all seek care with licensed medical providers who could treat their immediate illnesses as well as provide other care and education concurrently.

Finally, the practice of immediately taking ill children to mainstream healthcare providers creates a window of opportunity to educate and encourage the women who bring their children to providers to seek care for themselves and the rest of their families. The practice of seeking immediate care for children, described in the results, is in contrast to previous studies which show that very few Latina mothers seek care for their children in a timely and appropriate manner. Previous studies depict procrastination by mothers when children are ill due to the same structural and belief barriers that affect their personal care seeking behaviors (e.g. lack of insurance, cost of treatment, and reservations about the quality of care) [87]. One study found that 21% of Latino children were brought to emergency departments for routine sick visits [88]. The process of immediately seeking mainstream healthcare for children found in this study may be a new opportunity to increase access to healthcare for women. The authors are currently unaware of any programs aimed at integrating care for Latina mothers and their children in the United States. Yet, integrating care has been shown to be effective in a variety of settings and for a variety of preventative practices [89-91]. For example in Togo, Africa, the use of referral messages linking family planning to childhood immunizations increased awareness and use of family planning services [92]. Thus, programs focused on providing simultaneous care for children and their mothers may increase access to care and among Latino immigrants, which in turn may increase awareness, testing and treatment for Chagas disease by mainstream healthcare providers.

Strengths and Limitations:

The qualitative approach used in this study allowed a more comprehensive understanding of the perceptions of Chagas disease and the process of seeking healthcare among Latino immigrants. The inclusion of both Latino day laborers and farmworkers, who are often difficult to reach due to the mobile nature of these populations, is unique to this study and allows for these often underserved and underrepresented groups to voice their experiences. Further research should include other groups of Latino immigrants, particularly urban males with documentation, in order to allow for comparisons. Additionally, the process of seeking healthcare for recent Latino immigrants may differ from those who are better established, thus an effort to compare these groups should be made.

Conclusion:

This study provides an in-depth understanding of the barriers regarding testing and treatment for Chagas disease among Latino immigrants by describing their processes of seeking healthcare, the motivations for using these processes and the pathways between them. Latino immigrants tend to wait until they are gravely ill before seeking care due to belief barriers and economic limitations and the process that Latinos use to seek care is primarily determined by financial resources. Educational campaigns on Chagas disease need to be implemented based on these treatment seeking pathways in order to increase testing and treatment. More low cost and free services or health insurance need to be made available for Latino immigrants in order to increase access to preventative care.

Public Health Implications

- Lack of awareness surrounding Chagas disease indicates a need for increased education about Chagas disease in Latin America and among Latino immigrants in the United States.

- As indicated by concerns of participants, educational campaigns should focus on the risk factors for contracting the disease, the need for testing due to a lack of definitive symptoms and an extended asymptomatic period, and the availability of treatment.

- The concerns regarding quality of mainstream healthcare among participants suggests that a network of resources where Latinos could share information and rate their experiences of mainstream healthcare providers, particularly those in urban areas, could be valuable for this population.

- The concerns regarding the quality of mainstream healthcare also indicate that there is need for educational programs for mainstream providers in order to increase cultural sensitivity within the practice of healthcare.

- The inability of women and urban men to pay for mainstream healthcare denotes the need for more low cost or free services as well as other forms of support such as medical insurance for immigrants, particularly those living in urban areas.

- The use of alternative providers by women and urban men imply that by working in conjunction with those alternative providers who can offer safe and effective remedies, and educating Latino immigrants about the risks associated with using unlicensed physicians and prescription medications, access to healthcare and the quality of care may be improved for Latino women and urban men.

- The loss of earnings associated with seeking mainstream healthcare among rural men indicate that in rural areas, offering screenings, education and preventative care in mobile clinics after work hours may increase access to mainstream healthcare for rural male immigrant.

- The practice of immediately taking ill children to mainstream healthcare providers creates a window of opportunity to educate and encourage the women who bring their children to providers to seek care for themselves and the rest of their families.

Appendix A: Focus Group Discussion Guide (Spanish)

Buenas! Me gustaría agradecerles hoy por tenernos aquí. Mi nombre es ________ y trabajo con la Universidad de Emory. Estamos realizando un estudio para conocer sobre el conocimiento y actitudes relacionadas a enfermedades parasitarias que afectan a los latinos/as en los Georgia, y la discusión tomará alrededor de una hora. Después de terminar la discusión, se le dará información sobre estas enfermedades y usted tendrá la oportunidad de hacernos preguntarme sobre ellas. Durante las siguientes semanas, nuestro equipo de investigación estará hablando con grupos de hombres y mujeres latinas como Uds. para entender lo más posible sobre sus conocimientos, experiencias y perspectivas.

Su participación hoy en día es voluntaria y si no quieren participar se pueden ir. Toda la información que usted comparta conmigo permanecerá confidencial, aunque no le podemos garantizar que otros miembros del grupo no compartirán la información. Vamos a grabar la discusión de grupo hoy y borraremos la grabación después de transcribirla anónimamente para proteger su identidad. La información que colectamos hoy será utilizada solo para la investigación. Será guardado en una manera segura para que solo el equipo de la investigación la pueda utilizar. Les pedimos que respeten a la privacidad y la confidencialidad de sus compañeros, y que no repitan cualquieras cosas dicho en confianza después de que se vayan.

No queremos perder las opiniones de nadie, por tanto es importante que sólo una persona hable a la vez. Recuerden que no todos van a estar de acuerdo, y estamos interesados en escuchar a todos entonces por favor se sienten libres de compartir sus opiniones.

Nos gustaría pasar 60 minutos con Uds. hoy. Por favor sírvanse refrescos antes de comenzar. ¿Tiene preguntas antes de comenzar? ¿Todos quieren participar? ¿Están de acuerdo que grabamos la discusión?

Bueno, gracias por su participación. Por favor, para empezar comparten su nombre y su comida favorita.

ACCESS

¿Cuáles consideran ustedes son los problemas más importantes de salud que afecta a la comunidad Latina?
Probes: parásitos, acceso al cuidado de salud

¿A dónde irías si tuvieras problemas del corazón o del estómago?
Probes: sala de emergencias, clínicas, tu familia

¿Por qué irías allí?
Probes: $, conveniencia, confianza, idioma, seguro de salud (seguranza).

KNOWLEDGE

¿Conocen enfermedades transmitidas por insectos?

¿Qué saben sobre Malaria (paludismo)?
Probes: transmisión, síntomas, áreas de mayor riesgo, tratamiento, alguien cercano que ha tenido Malaria, de dónde escucharon la información- Dengue si no saben sobre malaria

Hasta ahora, hemos hablado un poco sobre la salud en general. Ahora me gustaría ser un poco más específico y hablar sobre una enfermedad que se llama la enfermedad de Chagas.

¿Han escuchado de la enfermedad de Chagas? Cuéntenme lo que han escuchado sobre la enfermedad de Chagas.
Probes: transmisión, síntomas, áreas de mayor riesgo, tratamiento, alguien cercano que ha tenido Chagas, de dónde escucharon la información

¿Qué grupos de personas tienen mayor riesgo para la enfermedad de Chagas?
Probes: Áreas

¿Alguna vez han visto este insecto? (show pictures of the Chagas triatomine vector and if possible the real bug as you ask the question)
Probes: nombres, lo han visto, enfermedades, vive, tiene un olor desagradable, alimenta (After asking if they recognize it, provide Spanish names here: vinchuca, chinche, pito, chinche caballo, chichorro, barbeiro, chipón)

LA ENFERMEDAD DE CHAGAS

La enfermedad de Chagas es causada por un parásito y generalmente se propaga por los insectos que les mostré hace poco. La mayoría de las personas que se enferman de Chagas viven en América Latina, generalmente en casas de adobe o con techos de paja donde los insectos viven. La mayoría de las personas que tienen Chagas no lo saben porque no hay síntomas, pero la enfermedad es muy peligrosa porque puede causar problemas muy serios en el corazón y el estómago muchos años después que una persona ha sido infectada. La enfermedad de Chagas puede ser propagada por transfusiones sanguíneas o de madres a sus hijos durante el embarazo. Aunque esto es más común en los Estados Unidos, porque las personas vienen ya infectadas a los Estados Unidos y no lo saben. Los médicos pueden hacer pruebas de sangre y dar tratamiento, pero muchas personas que tienen la enfermedad no se hacen las pruebas. El tratamiento dura por 3 meses y consiste en unos medicamentos anti-parasitarios.

¿Quién debería hacerse las pruebas de sangre para Chagas?

¿Qué motivaría a las personas para hacerse la prueba?

¿Qué prevendría a las personas hacerse la prueba?
Probes: dificultad, vergüenza

¿Si te enteraras que estás infectado/a con la enfermedad de Chagas, que harías?
Probes: hablar con alguien, hacer una prueba

¿Qué prevendría a las personas para seguir un tratamiento?
Probes: dinero, tiempo, niños, idioma, documentos, vergüenza, desconfianza, transporte, efectos secundarios, trata no cura, actitud sobre tomar medicamentos

¿Qué piensan sobre donar sangre y órganos?
Probes: Frecuencia, Razones, Diferencias en sus países/US, Donadores de órganos, miedo, engorda

OUTREACH

Parte de este estudio es preguntarles su opinión acerca de la mejor forma de informar a personas como ustedes sobre la importancia de Chagas.

¿De dónde reciben información en cuanto a temas de salud?
Probes: internet (Facebook- health groups, tweeter, Google, Wikipedia, chatrooms), TV, radio, texting, periódicos, revistas, iglesia, folletos, eventos de salud, escuela de los niños, familia, amigos, reuniones

¿En qué fuentes confía más?

¿Qué tipo de información les gustaría recibir sobre la enfermedad de Chagas?

¿Cuál sería la forma más útil/efectiva de recibir información sobre Chagas?
Probes: método, fuente, donde, idioma

CLOSING

La discusión casi se terminó pero hay unas preguntas más que quiero hacer:
¿Si vas a contar un amigo o pariente sobre Chagas qué le dirías?

¿Hay algo más que les gustaría compartir sobre lo que hemos hablado hoy?
Gracias por venir hoy. La conversación que hemos tenido aquí es muy importante y ustedes nos han ayudado a explorar las mejores formas de llegar a personas como ustedes con información sobre la enfermedad de Chagas. Esta información podrá mejorar la salud de personas con Chagas en el futuro.

Appendix B: Focus Group Discussion Guide (English)

Good morning/afternoon. I would like to thank all of you for coming here today. My name is ____________ from Emory University. We are conducting a study to understand the knowledge and attitudes related to parasitic diseases that affect the Latino community here in Georgia. The discussions will take approximately an hour. After the discussion, you will be given information on these diseases and have the opportunity to ask me questions. During the next few weeks our research team will be talking to groups of women and men like you about these diseases so we can find out as much as possible about your views, knowledge and experiences.

Your participation in this group is completely voluntary, and if you don't want to participate you can leave. The information that we discuss today will remain confidential, although we cannot guarantee that other members of the group will not share the information. We will be recording the group discussion, and after it will be transcribed anonymously to protect your identity. The information gathered here today will be used only for research purposes. It will be securely stored so that nobody outside the research team can access it. We ask that you respect the privacy and confidentiality of your companions and do not repeat anything said in confidence after this is over.

We don't want to miss anything that is said, so it is very important that everyone takes turns talking. Remember that not everyone will agree and we are interested in hearing everything so please feel free to share your opinions.

We would like to spend about 60 minutes with you today. Please also help yourselves to the refreshments provided during our discussion. Are there any questions before we start? Does everyone agree to participate? Does everyone agree to record the discussion?

Why don't we start by going around and telling each other our first names and our favorite food?

Community/Health Care Access

What do you think are the most important health problems affecting the Latin American community?
(Probes: *parasites, access to care****)***

Where would you go if you had heart problems or problems with your stomach?
(***Probes:*** *ER, clinic, family)*

Why do you go there?
(Probes:*$, convenience, trust, language, health insurance****)***

Knowledge

Have you ever heard of any diseases spread by insects?

What do you know about Malaria?
(Probes:** transmission, symptoms, high risk areas, treatment, someone you know has it, where did you hear this-if don't know about Malaria ask about Dengue**)
So far we have been talking about health in general, now I would like to be a little more specific and talk about a certain disease, called Chagas Disease.

Does anyone know anything about Chagas disease? Tell me what you have heard about Chagas disease.
(Probes:** transmission, symptoms, high risk areas, treatment, someone you know has it, where did you hear this**)

Who do you think is most likely to get Chagas disease?
(Probes: areas)

What do you know about this bug? (show pictures of the Chagas triatomine vector)
(Probes: names, seen it, diseases, live, smell, diet)
After asking if they recognize it, provide Spanish names here: vinchuca, chinche, pito, chinche caballo, chichorro, barbeiro, chipón

Chagas Disease

Chagas disease is caused by a parasite and is usually spread by the bugs that we just showed you. Most people who get Chagas disease live Latin America, usually in adobe or thatched roofed houses where the bugs live. Many people have Chagas disease and do not know it because there are no signs, but the disease is very dangerous because it can cause serious heart and stomach problems many years after a person gets it. Chagas disease can also be spread by blood transfusions and from mothers to their babies during pregnancy. However, these are more common in the United States because people come to the United States infected and do not know it. Doctors can test blood for the disease and treat people, but many people who have Chagas disease do not get tested. The treatment consists of anti-parasitic drugs and lasts for three months.

Who do you think should be tested for Chagas disease?

What would motivate people to get tested?

What would prevent people from getting tested?
(Probes:** difficulty, embarrassment**)

If you were told that you have been infected with Chagas, what would you do?
(Probes:** talk to someone, test**)

What would prevent people from getting treatment?

(***Probes:*** money, time, kids, transportation, language, documents, shame, distrust, secondary effect, treat not cure, attitude towards medication**)**

What are your thoughts and feelings about donating blood to a blood bank?
(Probes: frequency, reasons, differences in their country vs. US, organ donors, fear, weight gain**)**
Outreach

Part of why we are here is to ask your opinion on the best way to reach people like you about the importance of learning about Chagas. We want to create a better understanding among community members about Chagas. So let's imagine we're doing an ad campaign:

Where do you normally get health information?
(Probes: *internet*-Facebook, tweeter, Google, Wikipedia, chat rooms), TV, radio, texting, newspapers, magazines, family, friends, churches, brochures, health events, school for children, meetings***)***

Which methods do you trust the most?

What kind of information would you like to receive about Chagas?

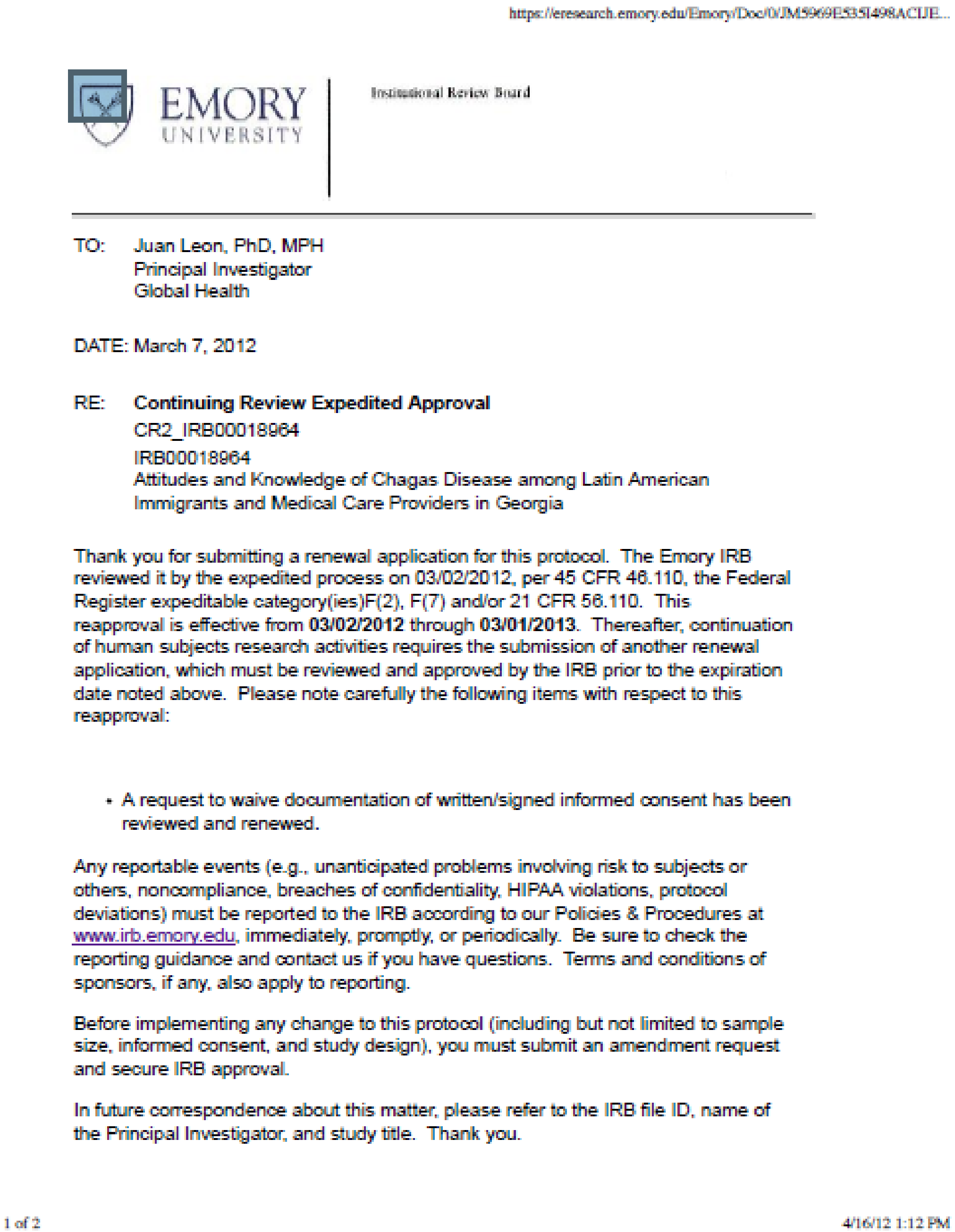
What would be the most useful way to receive information about Chagas?
(Probes: *method, source, where, language)*

Closing
Our discussion time is almost over, but there are just a few more questions I would like to discuss with you before we finish.
If you were to tell a friend or family member about Chagas disease, what would you tell them?

Do you have anything else that you would like to share with us about what we talked about today?

Thank you for coming today, we really appreciate it. The work that we've done here today is very important. You have helped us explore the best ways to reach people like yourselves with information about Chagas disease. This may help us improve the health of people with Chagas disease in the future.

Appendix C: Emory Internal Review Board Approval



https://eresearch.emory.edu/Emory/Doc/0/JM5969E535I498ACIJE...

EMORY
UNIVERSITY

Institutional Review Board

TO: Juan Leon, PhD, MPH
Principal Investigator
Global Health

DATE: March 7, 2012

RE: **Continuing Review Expedited Approval**
CR2_IRB00018964
IRB00018964
Attitudes and Knowledge of Chagas Disease among Latin American
Immigrants and Medical Care Providers in Georgia

Thank you for submitting a renewal application for this protocol. The Emory IRB reviewed it by the expedited process on 03/02/2012, per 45 CFR 46.110, the Federal Register expeditable category(ies)F(2), F(7) and/or 21 CFR 56.110. This reapproval is effective from **03/02/2012** through **03/01/2013**. Thereafter, continuation of human subjects research activities requires the submission of another renewal application, which must be reviewed and approved by the IRB prior to the expiration date noted above. Please note carefully the following items with respect to this reapproval:

- A request to waive documentation of written/signed informed consent has been reviewed and renewed.

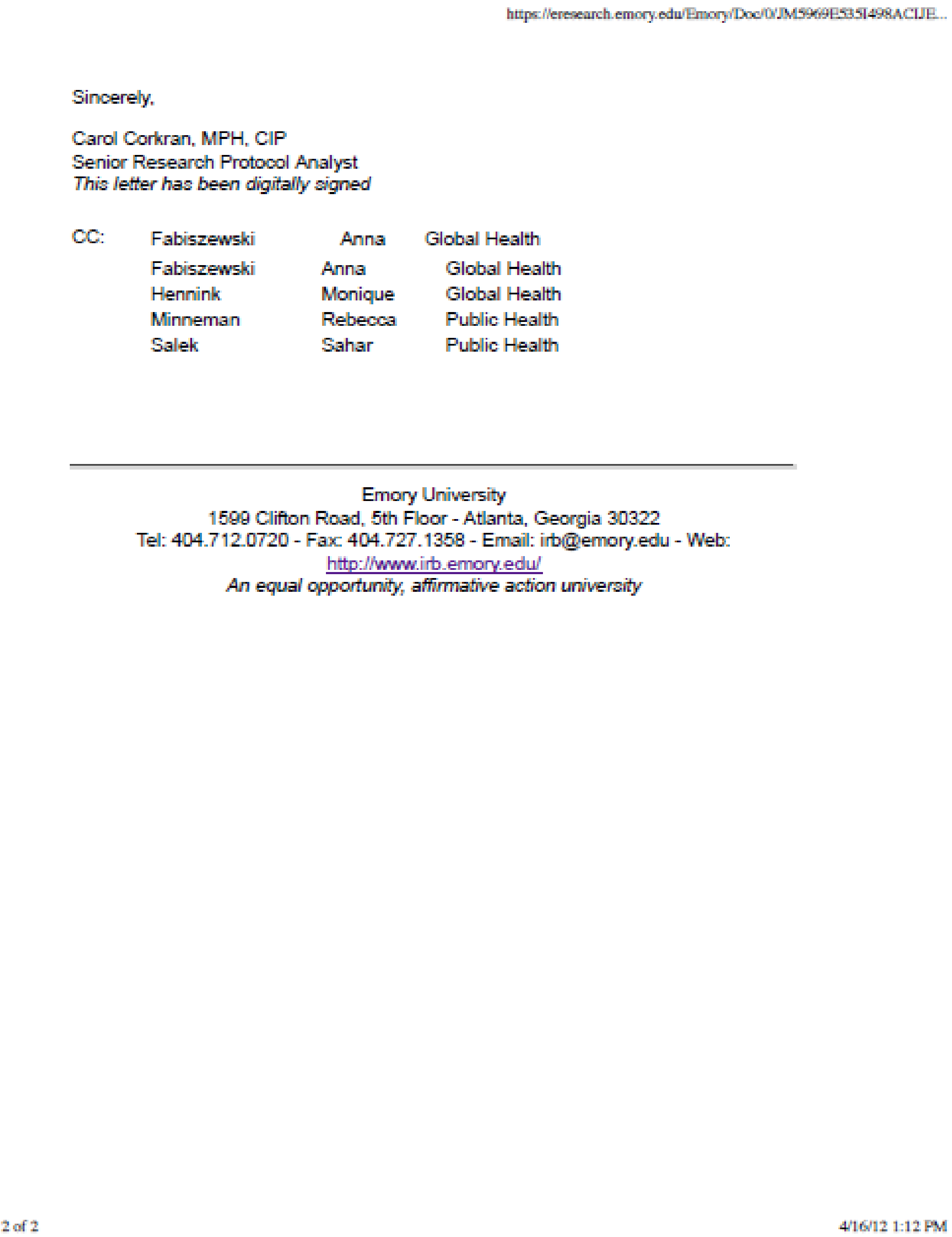
Any reportable events (e.g., unanticipated problems involving risk to subjects or others, noncompliance, breaches of confidentiality, HIPAA violations, protocol deviations) must be reported to the IRB according to our Policies & Procedures at www.irb.emory.edu, immediately, promptly, or periodically. Be sure to check the reporting guidance and contact us if you have questions. Terms and conditions of sponsors, if any, also apply to reporting.

Before implementing any change to this protocol (including but not limited to sample size, informed consent, and study design), you must submit an amendment request and secure IRB approval.

In future correspondence about this matter, please refer to the IRB file ID, name of the Principal Investigator, and study title. Thank you.

1 of 2

4/16/12 1:12 PM



Sincerely,

Carol Corkran, MPH, CIP
Senior Research Protocol Analyst
This letter has been digitally signed

CC:	Fabiszewski	Anna	Global Health
	Fabiszewski	Anna	Global Health
	Hennink	Monique	Global Health
	Minneman	Rebecca	Public Health
	Salek	Sahar	Public Health

Emory University
1599 Clifton Road, 5th Floor - Atlanta, Georgia 30322
Tel: 404.712.0720 - Fax: 404.727.1358 - Email: irb@emory.edu - Web: http://www.irb.emory.edu/
An equal opportunity, affirmative action university

References

1. Munoz, M.J., L. Murcia, and M. Segovia, *The urgent need to develop new drugs and tools for the treatment of Chagas disease.* Expert Rev Anti Infect Ther, 2011. **9**(1): p. 5-7.
2. Clayton, J., *The promise of T. cruzi genomics.* Nature, 2010. **465**(7301): p. S16-7.
3. Dias, J.C. and V. Amato Neto, *[Prevention concerning the different alternative routes for transmission of Trypanosoma cruzi in Brazil].* Rev Soc Bras Med Trop, 2011. **44 Suppl 2**: p. 68-72.
4. Dias, J.C., V. Amato Neto, and E.J. Luna, *[Alternative transmission mechanisms of Trypanosoma cruzi in Brazil and proposals for their prevention.].* Rev Soc Bras Med Trop, 2011.
5. Martins, L.P., et al., *Incidence of Trypanosoma cruzi transmission through breastfeeding during acute experimental Chagas disease.* Braz J Infect Dis, 2011. **15**(2): p. 116-8.
6. Remme, J.H.F., et al., *Tropical Diseases Targeted for Elimination: Chagas Disease, Lymphatic Filariasis, Onchocerciasis, and Leprosy.* 2006.
7. Apt, W., et al., *Vertical transmission of Trypanosoma cruzi in the Province of Choapa, IV Region, Chile: Preliminary Report (2005-2008).* Biol Res, 2010. **43**(3): p. 269-74.
8. Bern, C., et al., *Evaluation and Treatment of Chagas Disease in the United States.* JAMA: The Journal of the American Medical Association, 2007. **298**(18): p. 2171-2181.
9. Dias, E., et al., *Chagas' disease; a clinical, epidemiologic, and pathologic study.* Circulation, 1956. **14**(6): p. 1035-60.
10. Apt, W., *Current and developing therapeutic agents in the treatment of Chagas disease.* Drug Des Devel Ther, 2010. **4**: p. 243-53.
11. Pinazo, M.J., et al., *Tolerance of benznidazole in treatment of Chagas' disease in adults.* Antimicrob Agents Chemother, 2010. **54**(11): p. 4896-9.
12. Barbu, C., E. Dumonteil, and S. Gourbiere, *Evaluation of Spatially Targeted Strategies to Control Non-Domiciliated Triatoma dimidiata Vector of Chagas Disease.* PLoS Negl Trop Dis, 2011. **5**(5): p. e1045.
13. Oliveira, B.G., et al., *Health-related quality of life in patients with Chagas disease.* Rev Soc Bras Med Trop, 2011. **44**(2): p. 150-6.
14. Moraes-Souza, H. and M.M. Ferreira-Silva, *[Control of transfusional transmission].* Rev Soc Bras Med Trop, 2011. **44 Suppl 2**: p. 64-7.
15. Moncayo, A., F. Guhl, and C. Stein *Global burden of Chagas' disease in the year 2000.*
16. Norman, F.F., et al., *Neglected tropical diseases outside the tropics.* PLoS Negl Trop Dis, 2010. **4**(7): p. e762.
17. Bern, C. and S.P. Montgomery, *An estimate of the burden of Chagas disease in the United States.* Clin Infect Dis, 2009. **49**(5): p. e52-4.
18. Dorn, P.L., et al., *Autochthonous transmission of Trypanosoma cruzi, Louisiana.* Emerg Infect Dis, 2007. **13**(4): p. 605-7.
19. Sarkar, S., et al., *Chagas disease risk in Texas.* PLoS Negl Trop Dis, 2010. **4**(10).

20. Kirchhoff, L.V., A.A. Gam, and F.C. Gilliam, *American trypanosomiasis (Chagas' disease) in Central American immigrants.* Am J Med, 1987. **82**(5): p. 915-20.
21. Arena, R., et al., *Prevalence of antibody to Trypanosoma cruzi in Hispanic-surnamed patients seen at Parkland Health & Hospital System, Dallas, Texas.* BMC Res Notes, 2011. **4**: p. 132.
22. Ciesielski, S., et al., *The seroprevalence of cysticercosis, malaria, and Trypanosoma cruzi among North Carolina migrant farmworkers.* Public Health Rep, 1993. **108**(6): p. 736-41.
23. Field, V., et al., *Travel and migration associated infectious diseases morbidity in Europe, 2008.* BMC Infect Dis, 2010. **10**: p. 330.
24. Piron, M., et al., *Seroprevalence of Trypanosoma cruzi infection in at-risk blood donors in Catalonia (Spain).* Transfusion, 2008. **48**(9): p. 1862-8.
25. Schmunis, G.A., *Epidemiology of Chagas disease in non-endemic countries: the role of international migration.* Mem Inst Oswaldo Cruz, 2007. **102 Suppl 1**: p. 75-85.
26. Tanowitz, H.B., L.M. Weiss, and S.P. Montgomery, *Chagas disease has now gone global.* PLoS Negl Trop Dis, 2011. **5**(4): p. e1136.
27. Dias, J.C., *[The beginning of Chagas disease control (homage to Dr. Emmanuel Dias, the pioneer of Chagas disease control, in the year of his birth centenary)].* Rev Soc Bras Med Trop, 2011. **44 Suppl 2**: p. 12-8.
28. Lee, B.Y., et al., *The potential economic value of a Trypanosoma cruzi (Chagas disease) vaccine in Latin America.* PLoS Negl Trop Dis, 2010. **4**(12): p. e916.
29. Delgado, S., et al., *A history of chagas disease transmission, control, and re-emergence in peri-rural La Joya, Peru.* PLoS Negl Trop Dis, 2011. **5**(2): p. e970.
30. Ferreira-Silva, M.M., et al., *Socioepidemiological screening of serologically ineligible blood donors due to Chagas disease for the definition of inconclusive cases.* Mem Inst Oswaldo Cruz, 2010. **105**(6): p. 800-5.
31. AABB. *Chagas' Biovigilance Network.* 2011 [cited 2011 July 6]; Available from: http://www.aabb.org/programs/biovigilance/Pages/chagas.aspx.
32. Askim-Lovseth, M.K. and A. Aldana, *Looking beyond "affordable" health care: cultural understanding and sensitivity-necessities in addressing the health care disparities of the U.S. Hispanic population.* Health Mark Q, 2010. **27**(4): p. 354-87.
33. Ransford, H.E., F.R. Carrillo, and Y. Rivera, *Health care-seeking among Latino immigrants: blocked access, use of traditional medicine, and the role of religion.* J Health Care Poor Underserved, 2010. **21**(3): p. 862-78.
34. Morales, L.S., et al., *Are Latinos Less Satisfied with Communicaiton by Health Care Providers?* J Gen Intern Med, 1999. **14**: p. 409-417.
35. Huerta, E.E. and E. Macario, *Communicating health risk to ethnic groups: reaching Hispanics as a case study.* J Natl Cancer Inst Monogr, 1999(25): p. 23-6.
36. Marin, G., *AIDS Prevention Among Hispanics: Needs, Risk Behaviors, and Cultural Values.* Public Health Reports, 1989. **104**(5): p. 411-415.
37. Elder, J.P., *Reaching Out to America's Immigrants: Community Health Advisors and Health Communication.* American Journal of Health Behavior, 2003. **27**(3): p. 197-205.

38. Viswanath, K. and L.K. Ackerson, *Race, ethnicity, language, social class, and health communication inequalities: a nationally-representative cross-sectional study.* PLoS One, 2011. **6**(1): p. e14550.
39. Clayman, M.L., et al., *Providing health messages to Hispanics/Latinos: understanding the importance of language, trust in health information sources, and media use.* J Health Commun, 2010. **15 Suppl 3**: p. 252-63.
40. Pena-Purcell, N., *Hispanics' use of Internet health information: an exploratory study.* J Med Libr Assoc, 2008. **96**(2): p. 101-107.
41. Elder, J.P., et al., *Health Communication in the Latino Community: Issues and Approaches.* Annu. Rev. Public Health, 2009. **30**: p. 227-251.
42. Delorme, D.E., J. Huh, and L.N. Reid, *Evaluation, use, and usefulness of prescription drug information sources among Anglo and Hispanic Americans.* J Health Commun, 2010. **15**(1): p. 18-38.
43. Carter-Pokras, O., R.E.M. Zambrana, Sonia E., and K.A. Aaby, *Emergency Preparedness: Knowledge and Perceptions of Latin American Immigrants.* Journal of Health Care for the Poor and Underserved, 2007. **18**: p. 465-481.
44. U.S. Census Bureau, *American FactFinder*. 2010.
45. National Council de la Raza (2005) *Latinos in Georgia: a Closer Look*. **Statistical Brief No. 7**.
46. Odem, M. and I. Browne, *Migration and Health: Transforming Race, Transforming Place.* 2011, Emory University: Atlanta, GA.
47. Huskey, C. and L. Sullivan, *Portions of Gov. Deal's HB87 Blocked*, in *Loganville-Grayson Patch*. 2011.
48. Montgomery, S., *Chagas Disease in your backyard: blood donors and Trypanosoma cruzi. Presentation ed.* Presentation, 2009.: Atlanta.
49. Schmunis, G.A. and Z.E. Yadon, *Chagas disease: a Latin American health problem becoming a world health problem.* Acta Trop, 2010. **115**(1-2): p. 14-21.
50. Munoz, J., et al., *Congenital Trypanosoma cruzi infection in a non-endemic area.* Trans R Soc Trop Med Hyg, 2007. **101**(11): p. 1161-2.
51. Riera, C., et al., *Congenital transmission of Trypanosoma cruzi in Europe (Spain): a case report.* Am J Trop Med Hyg, 2006. **75**(6): p. 1078-81.
52. Jackson, Y., et al., *Congenital transmission of Chagas disease in Latin American immigrants in Switzerland.* Emerg Infect Dis, 2009. **15**(4): p. 601-3.
53. Benjamin, R.J., et al., *Trypanosoma cruzi infection in North America and Spain: evidence in support of transfusion transmission.* Transfusion, 2012.
54. Hoffman, C., et al., *The uninsured, a primer: Key facts about Americans without health insurance*. 2008, The Henry J. Kaiser Family Foundation: Menlo Park,.
55. Morales, L.S., et al., *Are Latinos Less Satisfied with Communication by Health Care Providers?* J Gen Intern Med, 1999. **14**: p. 409-417.
56. Jennifer H. Lee, M.S.G., E. Richard Brown and Rachel Ballard-Barbash, *How Does Acculturation Affect the Use of Complementary and Alternative Medicine Providers Among Mexican- and Asian- Americans?* Journal of Immigrant and Minority Health, 2010. **12**(3): p. 302-309.
57. Hennink, M., I. Hutter, and A. Bailey, *Qualitative Research Methods*. 2011, London: SAGE publications.

58. Glaser, B. and A. Stauss, *The Discovery of Grounded Theory: Strategies for Qualitative Research*. 1967, New York: Aldine de Gruyter.
59. Vetter, R., *Kissing bugs (triatoma) and the skin.* Dermatology Online Journal, 2001. **7**(1): p. 6.
60. M Navarro, et al., *Targeted screening and health education for Chagas disease tailored to at-risk migrants in Spain, 2007 to 2010.* Eurosurveillance, 2011. **16**(38).
61. Verani, J.R., et al., *Survey of obstetrician-gynecologists in the United States about Chagas disease.* Am J Trop Med Hyg, 2010. **83**(4): p. 891-5.
62. Llovet, I., G. Dinardi, and F.G.D. Maio, *Mitigating social and health inequities: Community participation and Chagas disease in rural Argentina.* Global Public Health: An International Journal for Research, Policy and Practice, 2011 **6**(4): p. 371-384.
63. Oliver Yun, M.A.L., Tom Ellman, Wilma Chambi, Sandra Castillo, Laurence Flevaud, Paul Roddy, Fernando Parreño, Pedro Albajar Viñas, Pedro Pablo Palma, *Feasibility, Drug Safety, and Effectiveness of Etiological Treatment Programs for Chagas Disease in Honduras, Guatemala, and Bolivia: 10-Year Experience of Médecins Sans Frontières.* PLoS Medicine, 2009. **3**(7).
64. Monroy C, B.D., Pineda S, Rodas A, Castro X, Ayala V, Quiñónes J, Moguel B., *House improvements and community participation in the control of Triatoma dimidiata re-infestation in Jutiapa, Guatemala.* Cadernos de Saúde Pública, 2009. **25**(1).
65. Dumonteil E, R.-S.M., Ferral J, Euan-Garcia M, Chavez-Nuñez L., *Usefulness of community participation for the fine temporal monitoring of house infestation by non-domiciliated triatomines.* J Parasitol, 2009. **95**(2): p. 469-471.
66. Cardinal MV, L.M., Marcet PL, Orozco MM, Kitron U, Gürtler RE., *Impact of community-based vector control on house infestation and Trypanosoma cruzi infection in Triatoma infestans, dogs and cats in the Argentine Chaco.* Acta Trop, 2007. **103**(3): p. 201-211.
67. Petherick, A., *Campaigning for Chagas disease.* Nature, 2010. **465**(7301): p. S21-S22.
68. Centers for Disease Control and Prevention, *Chagas Disease: What U.S. Clinicians Need to Know*. 2010.
69. Garcés, I.C., I.C. Scarinci, and L. Harrison, *An examination of sociocultural factors associated with health and health care seeking among latina immigrants.* Journal of Immigrant and Minority Health, 2006. **8**(4): p. 377-385.
70. Moreland, S., et al., *Papanicolaou testing among Native American and Hispanic populations.* Ethn Dis, 2006. **16**(1): p. 223-7.
71. Hargraves, J.L. and J. Hadley, *The contribution of insurance coverage and community resources to reducing racial/ethnic disparities in access to care.* Health Serv Res, 2003. **38**(3): p. 809-29.
72. Salman Khan, V.V., Craig O'Connor, Rachel E. Simon, and Annie S. De Groot, *Health Care Access, Utilization, and Needs in a Predominantly Latino Immigrant Community in Providence, Rhode Island.* Medicine & Health/Rhode Island, 2011. **94**(10): p. 284-287.
73. Meister, J.S., *The health of migrant farm workers.* Occup Med, 1991. **6**(3): p. 503-18.

74. Stein, L.M., *Health care delivery to farmworkers in the Southwest: an innovative nursing clinic.* J Am Acad Nurse Pract, 1993. **5**(3): p. 119-24.
75. Heuer, L., C.W. Hess, and M.G. Klug, *Meeting the health care needs of a rural Hispanic migrant population with diabetes.* J Rural Health, 2004. **20**(3): p. 265-70.
76. Connor, A., L. Layne, and K. Thomisee, *Providing care for migrant farm worker families in their unique sociocultural context and environment.* J Transcult Nurs, 2010. **21**(2): p. 159-66.
77. Johnson, R.L., et al., *Racial and ethnic differences in patient perceptions of bias and cultural competence in health care.* J Gen Intern Med, 2004. **19**(2): p. 101-10.
78. *National Standards for Culturally and Linguistically Appropriate Services in Health Care*. 2001, U.S. Department of Health and Human Services Office of Minority Health: Washington D.C.
79. National Alliance for Hispanic Health, *Quality Health Services for Hispanics: the Cultural Competency Component*, L.G. Epstein, Editor. 2001, Department of Health and Human Services, Health Resources and Services Administration: Bureau of Primary Health Care, Office of Minority Health, Substance Abuse and Mental Health Services Administration.
80. University of Alabama at Birmingham: School of Medicine, *Sowing the Seeds of Health: A Program for Latinas*. 2007.
81. Allison A. McGuire, I.C.G.e.-P., Isabel C. Scarinci,, *A Successful Guide in Understanding Latino Immigrant Patients: An Aid for Health Care Professionals.* Fam Community Health, 2012. **35**(1): p. 76-84.
82. Rakel, D.P., et al., *CAM education: promoting a salutogenic focus in health care.* J Altern Complement Med, 2008. **14**(1): p. 87-93.
83. Miriam S. Wetzel, D.M.E., Ted J. Kaptchuk, , *Courses involving complementary and alternative medicine at U.S. medical schools.* JAMA: The Journal of the American Medical Association, 1998. **280**(9): p. 784-787.
84. Frenkel, M. and L. Cohen, *Incorporating complementary and integrative medicine in a comprehensive cancer center.* Hematol Oncol Clin North Am, 2008. **22**(4): p. 727-36, ix.
85. Barrett, B., et al., *What complementary and alternative medicine practitioners say about health and health care.* Ann Fam Med, 2004. **2**(3): p. 253-9.
86. Commission for Labor Cooperation *Guide to the H-2A Visa Program in the United States*.
87. Zambrana, R.E., et al., *The relationship between psychosocial status of immigrant Latino mothers and use of emergency pediatric services.* Health Soc Work, 1994. **19**(2): p. 93-102.
88. Flores, G., et al., *Access barriers to health care for Latino children.* Arch Pediatr Adolesc Med, 1998. **152**(11): p. 1119-25.
89. Mark, K.E., et al., *Contraception among HIV concordant and discordant couples in Zambia: a randomized controlled trial.* J Womens Health (Larchmt), 2007. **16**(8): p. 1200-10.
90. Pope, D.S., et al., *A cluster-randomized trial of provider-initiated (opt-out) HIV counseling and testing of tuberculosis patients in South Africa.* J Acquir Immune Defic Syndr, 2008. **48**(2): p. 190-5.

91. Dodds, S., et al., *Integrating mental health services into primary care for HIV-infected pregnant and non-pregnant women: Whole Life--a theoretically derived model for clinical care and outcomes assessment.* Gen Hosp Psychiatry, 2000. **22**(4): p. 251-60.
92. Huntington, D. and A. Aplogan, *The integration of family planning and childhood immunization services in Togo.* Stud Fam Plann, 1994. **25**(3): p. 176-83.

Figures:

Fig. 1: Center for Disease Control, *Parasites - American Trypanosomiais (also known as Chagas Disease).* http://www.cdc.gov/chagas/
Fig. 2: *Chagas Disease: Diagnostic Breakthrough.* http://www.macroevolution.net/images/chagasdisease-map-300-349-8.jpg