UNDERSTANDING THE EXPERIENCE OF ADULTS COPING WITH CHAGAS DISEASE:

A GROUNDED THEORY STUDY

A DISSERTATION SUBMITTED TO THE FACULTY OF THE ADLER SCHOOL OF PROFESSIONAL PSYCHOLOGY

BY

NATHALIA BETANCOURT, M.A.

IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY

CHICAGO, IL June 18, 2013

ADLER SCHOOL OF PROFESSIONAL PSYCHOLOGY DISSERTATION COMMITTEE MEMBERS

Student's Name: Nathalia Betancourt

Dissertation Title: Understanding the Experience of Adults Coping with Chagas Disease: A Grounded Theory Study.

This dissertation has been defended and submitted for final submission

Certified by:

Name and Degree	Institution Affiliation
Nataka Moore, Psy.D Dissertation Chair	Adler School of Professional Psychology
Josefina Alvarez, Ph.D. Dissertation Reader	Adler School of Professional Psychology
Lynn Todman, Ph.D. Dissertation Reader	Adler School of Professional Psychology

Abstract

The present investigation was developed with the purpose of identifying how the social determinants of health impact individuals' ability to cope with Chagas disease. Identifying coping methods was also a goal of this investigation. Semi-structured interviews were conducted with 15 Latino patients between the ages of 30 and 65 who were being treated for Chagas disease at a university affiliated medical center.

The results of this investigation revealed that individuals infected with Chagas disease are impacted by structural, intermediary, and socio-political aspects that affect their living, and working conditions, and make more difficult for them to cope with their illness. Although, concerned professionals are addressing some of these social barriers, there are still many difficulties faced by the population due to lack of attention to the illness and the conditions that cause inequalities in society. Despite the social barriers that individuals with Chagas face, they still thrive by finding ways to cope with their particular situations.

Findings from the study revealed coping strategies used by the participants, some of these include relying on family for support, staying active, believing in God, remaining optimistic, and minimizing or using denial.

From the investigation, several recommendations for practitioners, advocates, and policy makers were developed, as well as recommendations for future studies. Some of the major recommendations are increasing awareness about the illness among policy makers and advocates in order to fully attend to the needs of the population. This would lead to doing more research, investing in the development of better drugs, and providing support to address some of the social needs of the people infected so they can cope better with the illness. Some of the recommendations for future research include increasing the sample size in order to investigate the impact of demographic variables as well as their particular stage of the illness in their ability to cope, and assessing the impact of social determinants using quantitative research methods.

Acknowledgments

I would like to thank my dissertation chair Dr. Moore for her support and guidance throughout this process. I also thank Dr. Todman for her valuable input and knowledge and for being the best role model of a socially responsible practitioner. I thank Dr. Alvarez for her commitment and contribution and Dr. Bridgeman for her dedication to helping in my development as a professional. I am ever grateful to Dr. Sheba Meymandi and Dr. Salvador Hernandez at Olive View - UCLA Medical Center for their support and collaboration in this project.

I would like to thank my mother because without her unconditional love and support I would not have been able to reach my professional and personal goals. I thank my father and brother for their emotional support and for believing in my capacity to fulfill my dreams. I thank my husband for his patience, encouragement, and help so that I would be able to finish this project.

This dissertation is dedicated to:

The participants in this research who were willing to share their stories in hope that one-day there will be more attention to the issues surrounding Chagas disease.

Curriculum Vitae
Nathalia Betancourt, MA.

EDUCATION

Adler School of Professional Psychology January 2008 - Present
APA accredited Program
Chicago, IL
Doctor of Clinical Psychology
Current GPA: 3.74

Adler School of Professional Psychology August 2009 - August 2011
Master of Arts in Counseling Psychology
Chicago, IL Term GPA: 3.91

Florida Atlantic University January 2005 - May 2007
Bachelor of Arts in Psychology
Boca Raton, FL
Psychology GPA: 3.73

Broward Community College August 2003 - December 2005
Associate of Arts
Davie, FL
GPA 3.57

LANGUAGE SKILLS

Fluent in spoken and written Spanish

CLINICAL TRAINING

Marin County Health and Human Services September 2013 – Present
Full time Intern
San Rafael, CA
Supervisor: Marisol Munoz-Kiehne, Ph. D.

Will County Health Department September 2011 - May 2012
Advanced Extern
Joliet, IL
Supervisor: Ja'net Seward, Psy.D.

Adler Community Health Services September 2010 – August 2011
Psychotherapy Extern
Chicago, IL
Supervisor: Mary Pfeiffer, Ph. D.

United Stand Counseling Center August 2009 – July 2010
Diagnostic Extern
Chicago, IL
Supervisor: Kim Mis, Psy.D.

PROFESSIONAL EXPERIENCE

United Stand Counseling Center September 2010 – June 2011
Peer supervisor and Psychotherapist
Chicago, IL
Supervisor: Kim Mis, Psy.D.

COMMUNITY ENGAGEMENT

Heartland Alliance, Refugee Immigrant Community Services
May - July 2010
Youth and Family Services Intern
Chicago, IL
Supervisor: Darwensi Clark

St. Mary's Center for Youth and Families
August 2009 - April 2010
Program Facilitator
Cicero, IL
Supervisor: Alicia Viera, Psy.D.

The Adler Institute on Social Exclusion May 2009
Simulation for Adler trustees
Chicago, IL

- Facilitated simulation about social barriers faced by incarcerated women.
- Participated in the discussion about how social and structural barriers affect individual's ability to cope effectively in their attempts to reintegrate successfully into society.

United Stand Family Center November - December 2008
Parenting Group Facilitator
Chicago, IL

Supervisor: Sharyl Trail, Psy.D.

RESEARCH EXPERIENCE

The Adler Institute on Social Exclusion May 2010 – December 2012
Research Assistant
Principal Investigator: Lynn Todman, Ph.D.

PRESENTATIONS

Betancourt, N. (2012, June). *Understanding the Experience of Adults Coping with Chagas Disease.* Poster presented at the Multifaceted Themes of Diversity Conference 2012, Adler School of Professional Psychology, Chicago, IL.

Betancourt, N. (2010, December). *Chagas: A Neglected Disease.* Oral presentation for Brown Bag Seminar Series, Adler School of Professional Psychology, Chicago, IL.

Betancourt, N. (2010, November). *Chagas: A Neglected Disease.* Oral presentation at Alivio Medical Center, Chicago, IL.

Betancourt, N. (2010, September). *Chagas: A Neglected Disease.* Poster presented at the Summit of Clinicians for Healthcare Justice, Washington, D.C.

Betancourt, N., Boyd, M., Fairless, L., Johnson, P., Kahn, S, Ph.D., Kirk, R., Soll, S., White, L. (2010, March). *Hypnosis for Anger Management, Theory, Application and Research.* Poster presented at the American Society of Clinical Hypnosis Annual Conference, Nashville, TN.

Betancourt, N. (2008, December). *The Challenge of Freedom: Reintegration Process of Ex-offenders.* Poster presented for the Community Service Practicum presentations, The Adler School of Professional Psychology, Chicago, IL

Betancourt, N (February, 2007). *Context Effects on Lexical Access in Bilingual Speakers*
Poster Presented at the Annual Psychology Fair, Florida Atlantic University, Davie, FL.

Table of Contents

LIST OF FIGURES

Understanding the Experience of Adults Coping with Chagas Disease: A Grounded Theory Study

Chapter I: Introduction

Chagas disease is one of the neglected tropical diseases (NTDs), also referred as Neglected Infections of Poverty (NIPs). Neglected infections have an impact on public health, child development, and worker productivity. These infections are parasitic and bacterial diseases that disproportionally affect poor populations living in the U.S., Africa, Asia, and Latin and Central America (Hotez, 2008).

Chagas disease is caused by the parasite Trypanosoma Cruzi. It is spread by infected bugs called triatomines also known as "kissing bugs". It is estimated that 20 to 25 million persons are infected throughout Mexico and Central and South America (Zuniga et al., 2008). Humans, domestic mammals and wild animals are at risk for contracting the disease; however, persons living in endemic regions are at higher risk (Meymandi, 2009).

Chagas disease is often referred to as a forgotten disease when in fact what has been forgotten is the population who suffers from this and other infections of poverty (Briseño-León & Méndez, 2007). Chagas and other neglected infections of poverty are closely linked to social, political, and economic factors referred to as the social determinants of health

(McDonald, 2009). The Social Determinants of Health (SDH) are the conditions in which people are born, live, work and age. These conditions are influenced by policy choices responsible for health inequities that lead to the distribution of money, power, and resources. The health outcomes and well-being of individuals infected with Chagas and other infections of poverty are impacted by their living and working conditions, and the unequal distribution of power, resources, access to health care, and education (Commission on Social Determinants of Heath, 2008).

Some examples of the social determinants that lead to transmission of Chagas in endemic regions are: residing in poorly-constructed homes in rural areas, residing in areas of dense vegetation, having inadequate sanitation infrastructure, inaccessibility to health care, and lack of awareness about the disease (Meymandi, 2009). Other indirectly related factors that lead to transmission are living in regions where climate conditions are conducive to the triatomine bugs and living with domestic animals (Meymandi, 2009). Of concern is the rate of transmission of the illness along the US-Mexico border where dogs, coyotes, rats, domestic cattle, horses, and sheep are common hosts of the vector. Texas is a state with a great number of infected vectors or hosts; therefore, people living in dwellings along the borderline region are at higher risk for transmission (Hotez, 2008).

In the U.S., it is estimated that over a million Hispanics are infected with Chagas disease (Hotez, 2008). A factor that has led to the great prevalence of the illness in the U.S. is related to immigration. There are approximately 50.5 million Hispanics living in the US as of 2010 (US Census Bureau, 2012). A great number of immigrants come from South and Central American countries where the virus is endemic (Schmunis, 2007). Immigration leads to other sources of transmission, such as by blood transfusion, organ donation, and congenital infection (Meymandi, 2009). The greatest number of blood donors more likely to harbor the virus are concentrated in California, New Mexico, and Texas; states with the greatest number of Hispanic immigrants (Schmunis, 2007). These numbers provide evidence for the potential increase of individuals infected by blood transfusion, organ donation, or congenital infection, which will require intervention and prevention in the U.S. from public health authorities (Briseño-León & Méndez, 2007).

Among the limitations that prevent adequate treatment for infected individuals in the U.S. are lack of awareness about the disease in the general and medical community and lack of recognition of its increasing prevalence in the U.S. In addition, there is lack of funding for control and prevention programs to assist infected individuals (Stimpert & Montgomery, 2010). Furthermore, language barriers, immigration issues, and limited health care access often confront patients, which prevent or complicate treatment (McDonald, 2009). Some of the limitations for those receiving treatment include: only two drugs have been developed to treat the condition, they are difficult to obtain, and they require close monitoring because of their strong chemotherapy-like side effects, many doctors are not familiar with the condition, and there is no testing done during routine doctor visits (Meymandi, 2009).

Other challenges that still prevail pertain to the need to develop a vaccine and the need to increase investigation and policy interventions that ultimately lead to addressing the social determinants of the illness. No literature has documented how the social determinants of the illness impair people's ability to cope effectively with their condition. There are also no investigations documented on how individuals use available resources and psychosocial aspects to cope with the illness and therefore, decrease the impact of health inequity.

There is very little research on how ethnically diverse populations cope with chronic illnesses (Tummala-Narra, 2007). It is important to address this issue because understanding the experience of marginalized populations coping with illness would help develop interventions that are culturally competent and that focus on promoting well-being and adjustment.

Statement of the Problem

Research about Chagas disease has focused on the description of the illness, investigation of the methods of eradication, prevalence, treatment, and description of the social, biological, and environmental aspects related to the condition. The focus on these areas has led to the recognition of the need for increasing awareness, the need for addressing the political conditions that make difficult the treatment of people infected with the disease, the need to find other approaches for the elimination of the vector, and the need for investigation of alternative drugs for treatment (McDonald, 2009; Meymandi, 2009). Others have focused on investigations to develop policy that aims to decrease the social barriers that maintain the high prevalence of the illness and make treatment difficult.

In order to understand how individuals infected with Chagas disease counteract some of the social determinants of the illness and find ways to cope with it, it is necessary to assess the social and individual factors these individuals identify as having a negative or positive impact on their psychological and physical health. Factors that promote resilience, or coping mechanisms also need to be understood. These mechanisms could be behaviors, attitudes, or other sources of support that allow individuals to thrive despite adversity.

Previous studies investigating how Latino and Latina individuals cope with adversity revealed several mechanisms used for coping. Family and community support, spirituality, religion, specific cognitive orientations and attitudes, and cultural beliefs and values, were among the commonly identified coping mechanisms described by the researchers investigating the Latino population (Abraido-Lanza, 2004; Dunn & O'Brien, 2009). However, the literature on how Latinos cope chronic, life-threatening illness is by no means extensive and there are no know studies of how individuals cope with Chagas.

Statement of Purpose

Given the increased prevalence of Chagas disease across the world, it is important to increase awareness of this serious condition. It is imperative to expand on the different areas of study related to the illness that have not been fully investigated. The current study was developed with the intention to help understand how aspects of the social, political, biological, behavioral, and psychosocial factors (Social Determinants) impact people's ability to cope with this complex disease. Equally important, this study aimed to identify factors that help individuals cope with the illness and promote well-being despite their adverse situation. As a result of this investigation, culturally competent interventions to address the psychological and social needs of patients infected with Chagas may be developed to help individuals in the U.S. and other countries where there is prevalence for Chagas.

Chronic illness is an important phenomenon to study in relation to psychological functioning, given that it is an event that threatens self-concept and requires the utilization of social support and coping skills to promote psychological thriving (Abraido-Lanza, Guier, & Colon, 1998). Given the nature of the population of study, their experience of coping was examined from a multicultural perspective. A multicultural perspective takes into account aspects of the individual development, the influence of their community, social barriers, family, social support networks, and cultural beliefs and values (Tummala-Narra, 2007).

By identifying factors that help individuals cope with the illness, some of the psychological and social needs of the immigrant adult population of individuals infected with Chagas were also identified. In addition, this investigation assessed how coping strategies help counteract the social determinants of health and well-being. The study led to developing recommendations for how to address the social determinants of health such as advocating for more accessibility to treatment and increasing attention to the needs of the population, thus decreasing the negative impact on health outcomes and well-being.

This study aimed to understand how the social determinants of health related to Chagas disease, impact individuals' ability to cope with the illness. The study also sought to assess the cultural and psychosocial factors that help counteract the impact of the social determinants of Chagas disease.

Research Questions

The following research questions guided participant selection, data collection, and data analysis for the current study:

- How do the Social Determinants of Health impact individuals' ability to cope with Chagas disease?
- How do participants' cultural and psychosocial characteristics help them cope, thus counteract the impact of some of the social determinants of the illness?

Assumptions and Limitations

A number of studies have reported gender differences on how individuals cope with chronic illness (Dunn & O'Brien, 2009; Hutton & Perkins, 2008; White, Hunter, & Holttum, 2007); therefore, one assumption in this study was that gender differences about how people perceive the impact of the social determinants on their ability to cope were going to be evident. Another assumption was that age-related differences would also influence people's perception of their limitations and the type of coping strategies they used. It was assumed that people may react differently to their condition and their ability to cope depending on the different stage of their illnesses. One of the limitations of this study is that gender and age differences in coping could not be explored.

Another limitation of the study was that the aforementioned social determinants influenced participation in the study. For example, aspects such as lacking transportation or having inadequate resources to take public transportation impaired some participant's ability to attend their scheduled appointment to be interviewed. Some participants were also concerned about losing their jobs for taking time off for doctor's appointments and this was another potential limitation that made the recruitment process difficult. Because the small number of participants and the qualitative nature of the study, it is not possible to generalize results to all Latinos coping with Chagas disease in the U.S.

Chapter II: Review of the Literature

Chagas Overview

Chagas disease is one of the identified neglected infections of poverty in the Americas (Hotez, 2008). Chagas is a chronic parasitic illness that produces cardiopathy or megaesophagus, also known as megacolon in 20 to 30 percent of infected individuals. Chagas disease represents the second highest burden among tropical diseases in the Americas. In addition, other poverty-related conditions coexist with Chagas, making it more complicated to treat (The World Health Organization, 2005).

Although the insect (triatomine) that transmits the parasite trypanosome cruzi, which causes Chagas disease, is found in the U.S., the majority of individuals infected in the U.S. acquire the disease in endemic regions. Nonetheless, transmission in the U.S. can also occur from organ transplantation, blood transfusion, or congenitally (National Alliance for Hispanic Health, 2008). It is estimated that approximately one million individuals are infected with the illness in the U.S. (Hotez, 2008).

Physician Carlos Chagas discovered the illness in 1909 (Coutinho, 1999). The Triatoma infestants are the vectors for the disease, the reservoirs are humans and domestic and wild mammals. The illness is transmitted when the bug sucks blood from a victim; the insect leaves feces on the victim's skin and when the person rubs or scratches the bite area, the feces, which contain the parasite, enter the bloodstream, and disrupt and infect the cells, causing colonization of muscle or neural tissue. Once inside the bloodstream, the virus needs to be treated promptly in order to prevent later complications (Meymandi, 2009).

The initial phase of the illness can last up to eight weeks after infection. At this stage, the patient can present with mild symptoms such as fever, headaches, enlarged lymph glands, muscle pain, difficulty in breathing, swelling around the bite area, and abdominal or chest pain. If treated with antiparasitic therapy at this stage, the cure rate is about 90 percent; unfortunately, Chagas is not usually diagnosed on time (Meymandi, 2009).

At the indeterminate stage of the illness, patients are asymptomatic because the parasite had become dormant in the tissue, and it is not detectable in the blood. This phase can last between 10 to 20 years. After that period of time, 40 to 50 percent of patients will develop chronic manifestations, such as enlargement of the heart, which eventually results in heart failure, enlargement of the esophagus or colon, or peripheral nerve damage. At this stage of the illness, treatment is ineffective and the disease is irreversible (Meymandi, 2009).

There is no vaccine to prevent the disease. Currently, there are two drugs available to treat the illness: Benznidazole and Nifurtimox; neither drug has been approved by the FDA. They can only be obtained with approval from the CDC to the treating provider. In addition, the drugs have strong chemotherapy–like side effects, which need close monitoring (World Health Organization, 2010).

For years, Chagas was thought of as a disease of Latin America. It has been ignored in the U.S. until very recently (Hotez, 2008). A study conducted by the National Alliance for Hispanic Health, found that Hispanic consumers and health care providers in the U.S. have not heard of Chagas disease or had very limited knowledge about it. Most health providers did not know about screening measures or available treatment (National Alliance for Hispanic Health, 2008).

Despite this illness being around for over a hundred years, it was just until 2007, that the FDA approved screening of donated blood (Hotez, 2008). The majority of infected people in the U.S. contracted the illness through blood transfusion or organ transplant; however, others at risk of contracting the illness are those who got infected in endemic regions, people exposed to infected vectors or reservoirs, children of infected mothers, transplant recipients, transfusion recipients, and those vulnerable to laboratory accidents. Increasing awareness, addressing other barriers to treatment, developing better drugs, and increasing research funding, are some of the areas of concern to be addressed in order to improve treatment and prevention of Chagas disease (Meymandi, 2009).

Social Determinants of Health

The Social Determinants of Health (SDH) are the conditions in which people are born, live, work, and age. These conditions are influenced by policy choices responsible for health inequities that lead to the distribution of money, power, and resources. The living and working conditions of individuals and communities, and the distribution of power and resources, such as access to health care and education, determine the health outcome and well-being of individuals in society (Commission on the Social Determinants of Health (CSDH) 2008).

The Commission on Social Determinants of Health developed a framework to identify the social determinants of inequalities in health, explain the interrelationship between the major determinants, explain the mechanisms by which the social determinants generate health inequities, facilitate the evaluation of the social determinants of health that are most important to address, and develop specific interventions and policy proposals for action (Figure 1) (Commission on Social Determinants of Health, 2007). There are three main components of the Social Determinants of Health: the socio-political context, the structural determinants and socioeconomic position, and the intermediary determinants.

Socio-political Component

The first element of the framework, the socio-political component, is referred to as the structural, cultural, and functional aspects of the social system that impact individuals' social stratification and health opportunities. The socio-political context is composed of the following elements: governance, macroeconomic policy, social policies, public policy, culture and societal values, and epidemiological conditions. These components influence aspects such as people's participation in society, the labor market, and the resources available to individuals and communities, such as education, medical care, water, and sanitation (Commission on the Social Determinants of Health (CSDH) 2007).

Structural Determinants

Structural determinants and socioeconomic position is the second element of the framework. These refer to the distribution of resources according to people's social class, occupational status, education achievement, and income level (CSDH, 2007). The socioeconomic position of individuals in society leads to income inequality. Income inequality results in social comparison, thus causing chronic stress leading to poorer health for those at the bottom of the hierarchy (CSDH, 2007).

Stress is experienced when the individual's coping skills are insufficient to respond to the environmental demands (Ray, 2004). Financial inequality creates stressful circumstances, which produce anxiety, low self-esteem, social isolation, lack of control, and inability to cope (Wilkinson & Marmot, 2003). Having little control over one's particular circumstances in relation to employment stability, as well as receiving inadequate reimbursement for the effort put into work, has been found to be associated with greater risk for illness development (Ray, 2004). In the case of individuals with Chagas disease, one of the factors affecting individuals' participation in treatment, is their fear of losing their job due to having to take days off to attend doctor appointments (Meymandi, 2009).

Individuals from low socioeconomic statuses in any society are more likely to suffer from diseases and to have shorter life expectancy than those with more financial accessibility (Wilkinson & Marmot, 2003). Refugees, ethnic minorities, disabled people, and homeless people are low in the socioeconomic scale, and are therefore at higher risk for premature death. In addition, the greater the length of time that people live in disadvantaged circumstances, the more likely they are to suffer from a range of health problems, particularly cardiovascular disease (Wilkinson & Marmot, 2003).

“Income inequality erodes social bonds that allow people to work together, decreases social resources, and results in less trust and civic participation, greater crime, and other unhealthy conditions” (CSDH, 2007, p. 22). Wilkinson and Marmot (2003) argued that having positive social relations and strong supportive networks increases well-being; while individuals with a lower sense of social cohesion and social support usually have greater risks for developing disease, reduced inability to trust, and increased levels of violence in the community.

Income inequality results in lessened ability to avoid risks and cure or prevent disease. It also impacts the ability to invest in safe housing, good schools, etc., necessary to promote health and well-being (CSDH, 2007). Inequalities in health result in inequalities in people’s ability to function; for example, poor health in childhood results in limited educational attendance, and predisposition to adult disease (CSDH, 2007).

The relationship between education and health outcomes was also addressed by Ray (2004); this author explained how lack of education or knowledge leads to decreased adaptability to cope with the environment. The more understanding the person has about her or his surroundings, the more control he or she can exercise over the environment. Ray also documented that the higher the level of education of a person, the lower her/his mortality rate.

Occupation is strongly related to income; therefore, it is also directly related to the material living standards that influence health outcomes. Ones' occupation reflects work based stress, control, and autonomy, therefore, impacting health through psychosocial processes (CSDH, 2007). People's occupation and social class determine their exposure to toxic environments and physical demands (CSDH, 2007). An example of this relationship was described by Wilkinson & Marmot (2003) who argued that the perceived or actual inability to cope with social and psychological circumstances can have long-term effects for our cardiovascular and immune systems.

Other important structural determinants of health are gender and ethnicity. Females and minority groups are often discriminated against (CSDH, 2007). Due to the systematic discrimination suffered by women and girls in many societies, their lack of access to power and prestige impacts their ability to obtain education, access adequate remunerated forms of employment, and exert control, which leads to greater exposure to health risks (CSDH, 2007). Along the same lines as gender, racial and ethnic differences are the basis for discrimination in many societies. People from marginalized ethnic groups often have worse health outcomes than those from privileged groups who have better status, opportunities, and resources throughout their life course (CSDH, 2007).

Intermediary Determinants

The third element of the framework on Social Determinants of Health is referred to as the intermediary determinants. These are individual-level influences such as health-related behaviors and physiological factors that antecede the social determinants of health (CSDH, 2007). More specifically, the categories of intermediary determinants of health are: material circumstances, psychosocial circumstances, behavioral and/or biological factors, and the health system.

Material circumstances such as housing, financial means to buy healthy food, adequate clothing, and the physical environment in which people live and work can contribute to health risks or positive health outcomes (CSDH, 2007). In addition, the sanitary conditions in which people live, such as the presence of damp and condensation and overcrowding have direct effects on health, as these conditions impact the transmission of infectious diseases. Material circumstances are one of the major determinants of transmission for Chagas disease, as risk of infection increases for people living in houses with inadequate infrastructure and sanitation (Meymandi, 2009).

Psychosocial circumstances include life stressors such as debt, negative life events, job strain, lack of social support, and coping styles. Resources available to people related to their socioeconomic position determine their exposure to stress and their ability to cope with their life situations (CSDH, 2007). Behavioral and biological factors include diet, alcohol consumption, smoking, and lack of exercise. Wilkinson and Marmot (2003) argued that individuals in marginalized communities are more prone to addictions, which in turn affects people's ability to cope effectively with their life circumstances. Environments determine people's behaviors and their coping strategies, which could be positive or negative. When the environment creates stress and unhealthy conditions, people often resort to alcohol consumption, tobacco, poor diets, and lack of physical activity (CSDH, 2007).

The above explained framework developed by the Commission on Social Determinants of Health explores how social, economic, and political mechanisms shape specific intermediary determinants, which in turn produce differences in exposure and vulnerability to health-compromising conditions (CSDH, 2007). Raising awareness of policy makers, advocates, social leaders, and the general public about these factors is an important and difficult task; nonetheless, it is necessary to address these differences and improve the lives of disadvantaged individuals and communities (Niederdeppe, Bu, Borah, Kindig, & Robert, 2008). In an effort to address the social determinants of health, which are responsible for health inequities across the world, the Commission on

Social Determinants of Health (CSDH) was created to promote global equity in the matter (CSDH, 2007).

Initiatives to address neglected infections of poverty have been put in place in the U.S. and Latin American countries. Governmental proposals such as the unification of civilian experts to address global social challenges, "civilian power" formulated by the United States Secretary of State in November and December 2010, attempts to create a team that attends among other problems, to the elimination and control of neglected tropical diseases. In collaboration with the United States Agency for International Development (USAID) and other international organizations, the "civilian power" intervention would help generate control measures, provide diagnostic, create vaccines, and develop drugs to treat neglected infection of poverty (Hotez, 2011).

In The United States, a group of professionals from different disciplines are united to bring awareness to the public and medical community about neglected infections of poverty (Hotez, 2011). Olive View-UCLA Medical Center is the center of excellence for the treatment of Chagas disease in the U.S. This center is committed to increasing awareness in the medical and general community about this disease. At Olive view-UCLA, a great number of identified patients are being treated with antiparasitic therapy for Chagas disease. The center performs screening and treatment for patients who developed idiopathic cardiomyopathy as a result of the illness (Meymandi, 2009). Several recommendations with implications for policy have been developed to address the underlying structural determinants of health inequity. One of the recommendations is to promote collaboration between the political sector and the community to address the macro and micro levels of the problem based on the model developed by the Commission on Social Determinants of Health (CSDH, 2007).

Efforts to eliminate Chagas in South and Central America and Mexico include vector control and housing improvement. In South America, organizations such as Iniciativa de Salud del Cono Sur (INCOSUR), have demonstrated efforts to eliminate Chagas and other diseases through vector control. The Global Network for Chagas Elimination has initiated control programs in Argentina, Belize, Ecuador, Haiti, Honduras, and Nicaragua (Hotez, Bottazzi, Franco-Paredes, Ault, & Periago, 2008). In 2007, other initiatives by the Proyecto de Control y Prevencion de la Enfermedad de Chagas (Project for Control and Prevention of Chagas Disease) in collaboration with international organizations and governmental institutions, have been taking place in the region of Intubuca, Honduras, one of the sectors with highest indices of Chagas disease in Central America. The initiative intended to integrate the community in an effort to promote awareness, increase the number of entomologic samples, educate the community about the disease, and improve life quality of Intubuca's inhabitants (Ardon & Mazariegos, 2007).

Coping

There is limited information available about how individuals infected with Chagas disease cope with the illness. In Honduras, there is a group of health care providers who have organized the community in order to provide education about the illness, its treatment, and prevention measures in order to increase awareness in the regions where the disease is more prevalent (Ardon & Mazariegos, 2007). Other programs in Honduras have promoted initiatives to encourage the community in an effort to eliminate the vector and prevent infections (The World Health Organization, 2005).

Currently, there is no information available in the literature on how individuals infected with Chagas cope with the illness. There is also no information about resources available to patients infected with the illness in the US. Nonetheless, aspects that have been identified in the literature as coping mechanisms that have helped Latino/a individuals cope with adversity are discussed in the remaining pages of the present review.

Several authors, have looked at how coping mechanisms such as family, availability and accessibility to resources, community support, and religion/spirituality, influence the individual's ability to cope and promote well-being. Dunn, and O'Brien's (2009) surveyed 179 immigrants from El Salvador about the influence of gender, perceived stress, social support, family and religious coping in relation to psychological health and life meaning. They found that lack of social support from a significant other, greater perceived stress by Latinas/Latinos, and negative religious coping were predictive of search for meaning in one's life. Kirmayer, Dandeneau, Marshall, Phillips, and Williamson (2011) conducted a study that consisted of observations of the Inuit, Metis, Mi'kmaq, and Mohawk indigenous communities in Canada. The authors were interested in looking at resilience from an indigenous perspectives and identifying social structural barriers to the expression of resilience. They used focus groups and semi-structured interviews to obtain information about the local understandings of oppression, well-being, and the contextual factors of resilience. The study concluded that other systemic, collective, and community factors play a part in the expression of resilience; for example, at the family and community level, some dimensions of resilience were associated with the durability of interpersonal relationships. They also found that aspects that help counteract the impact of social barriers on resilience were associated with active political activism, empowerment, and reconciliation, which led to the recognition of rights and identity and increased people's self-esteem, and mental wellbeing.

Similarly, Ungar (2010), collected information from a mixed methods investigation of resilience with 14 communities in five continents and over 1500 youth for a study about the culturally and contextually specific aspects of resilience in order to develop recommendations on interventions that were culturally relevant. From his study, he developed recommendations for mental health professionals to address the needs of marginalized communities and culturally diverse populations; the most relevant being the need to address the racial, ethnic, and religious identities of the individuals. Ungar (2010) suggested that the use of individual counseling, family-based interventions, school programs, and community mobilization would have a greater impact on the interventions used to help individuals use resources and create an impact on their ability to cope with their particular situations.

Some of the aspects that impact Latinos in the U.S. are related to their socially disadvantaged position. According to Duncan, Hotz, and Trejo (2006), some of the social disadvantages that Hispanics in the U.S. are exposed to at a higher degree compared to other ethnicities include: higher unemployment rates, working in more physically demanding jobs, experiencing higher levels of stress at work, working in low paying jobs, having lower levels of education, language barriers, and stressors and challenges associated with immigration status. Despite the mentioned adversities, the authors explained, Hispanics have shown to have better health outcomes than non-Hispanic Whites. This statement, however, is not consistent across studies as Gallo, Penedo, Espinosa de los Monteros, and Arguelles (2009) demonstrated in their study where they used information collected by the National Center for Health Statistics, 2008, to report that overall, even though Hispanics are less likely to experience mental health issues, they are disproportionally more vulnerable to other health conditions such as HIV, diabetes, and obesity. These authors also reported findings suggesting that Hispanics are believed to share a set of cultural values that help counteract the social barriers they are exposed to. Some of these include stronger social networks, allocentrism, familism, time orientation, and gender role, which positively impact their health outcomes and promote well-being (Gallo et al., 2009). Some of the cultural values that promote well-being in the Latino culture are also explained by Marin and Marin (1991). These include allocentrism and familism as values that reflect a collective view, where the needs of the family or group are placed over the needs of the individual. Family has also been identified by other authors, as explain below, as a particularly important aspect associated with coping and well-being in the Latino community.

Family and Social Support. Sabogal, Marin, Otero-Sabogal, Marin, and Perez-Stable (1987) referred to familism as a set of values expressed Latinos related to the family unit, putting emphasis on obligations, financial, and emotional support to the nuclear and extended family members. Gallo and colleagues (2009) identified familism as an important source of support that impacts people's well-being. Higher family support has been associated with better psychological well-being. With regards to physical well-being, the same authors explained that familial stability increases the likelihood of seeking medical attention. Similarly, a study of coping among breast cancer patients found that Hispanic patients were more likely to adopt positive health behaviors if they perceived that doing so benefited the whole family rather than only the individual (Ashing-Giwa, Padilla, Bohorquez, Tejero, & Garcia, 2006).

Other authors have focused on the relationship between social support and expressions of well-being. Dunn and O'Brien (2009) defined social support as embedded in interactions that provide individuals with love, care, assistance, and reliability. Family was found to be a natural social support system for Latino/as. In their study, the same authors also found a positive relationship between perceived social support and expressed meaning in one's life. They predicted that females would report higher degrees of social support compared to men. Contrary to their prediction, women and men reported the same degree of perceived social support from their families and significant others. Family also plays an important role in the development of spiritual beliefs that help develop protective factors (Tummala-Narra, 2007).

Spirituality and Religion. Spirituality and religiosity have been associated with better health outcomes in the Hispanic population. For example, Abraido-Lanza, Vasquez, and Echeverria (2004) found that religious coping, such as praying and seeking support from God was correlated with active coping. Additionally, both religious and active coping were related to positive mental and physical health. In the same study, Latinas suffering from arthritis reported that religious beliefs helped them fight the illness.

Trevino and associates (2007) conducted a study to explore the relationship between religious coping and psychological, physiological, social, and spiritual outcomes in patients with HIV/AIDS. For the purposes of their study, they differentiated between positive religious coping, such as seeking spiritual support, and patients trying to accept and understand their condition through God's plan, versus spiritual struggle, referred to as expressing anger at God, experiencing spiritual conflict, and having doubts regarding faith. They found that individuals who identified themselves as having positive religious coping reported better health outcomes compared to those who identified as experiencing spiritual struggle.

Religious practices were also associated with better health outcomes. Trevino and colleagues (2007) found that church attendance, being part of a religious group, and praying were associated with less distress, better quality of life, and greater compliance with medical care. They also found that higher frequency of praying and other religious practices resulted in the use of more adaptive coping strategies, as well as lower levels of depression and anxiety in HIV- infected men and women. Positive religious coping practices were also associated with greater perceived family support by patients with HIV.

In another study, Abraido-Lanza, Vasquez, and Echeverria (2004) found that religious coping enabled Hispanic individuals with arthritis to gain a sense of mastery, self-efficacy, and acceptance of their condition. In their study, self-efficacy and acceptance were associated with less depression and pain and greater psychological well-being. Investigators in the same study identified two types of coping for Hispanic patients with arthritis: active and passive coping. Active coping was defined as practicing strategies such as staying busy, diverting attention away from the pain, and functioning in spite of pain. On the other hand, passive coping practices included restricting activities because of pain, catastrophizing, or focusing on wishful thinking. The results of their study indicated a positive relationship between active coping and psychological well-being, while passive coping was associated with greater pain and negative adjustment.

Life meaning was defined by Seligman as “belonging to and serving to something that you believe is bigger than the self” (Seligman, 2011, p. 17). Meaning, Seligman explained, is an element of well-being achieved through our connections and relationships with other people. This statement was in line with Dunn and O’Brien’s (2009) findings in which reappraisal of God’s power and having a significant other as a source of support, were associated with having a sense of personal meaning, or sensing that life was meaningful.

Gender. Gender has also been discussed in the literature as playing a role in coping. Marin and Marin (1991) referred to the gender role value in Hispanic culture as the traditional tendency of men to be described as in control, strong, and as being the provider; while women are often described as submissive and lacking in power and influence. In looking at how gender influences coping, another study observed that certain types of support that did not violate the gender role norms were helpful to Latina women coping with chronic illness. For example, receiving support with household chores from their daughters was acceptable and appreciated; on the contrary, receiving support with household work from "role-inappropriate support providers" such as a spouse resulted in greater distress (Abraido-Lanza, 2004, p. 168). On examining the influence that gender identity has on mental and physical well-being in the Latino culture, Dunn and O'Brien (2009) argued that Latinos and Latinas respond differently to stress. They found that men who adhered to the traditional gender role were likely to suppress and somaticize emotional problems or neglect physical symptoms, while females who adhere to their gender roles were more likely to report higher levels of life satisfaction, social support, and overall better psychological health.

Cognitive Styles. Linley and Joseph (2004) conducted a review of 39 empirical studies about positive change following trauma and adversity. The review indicated that patients suffering from chronic illness, heart attacks, breast cancer, bone narrow transplant, HIV, and AIDS who reported having a problem-focused orientation, acceptance for ones' condition, adopting a positive reinterpretation of the adverse event, and being optimistic, experienced positive coping. Practicing a religion, using cognitive processing, and experiencing positive affect, were also associated with growth following trauma or adversity. Linley and Joseph (2004) explained that it is the subjective reaction to a particular event, rather than the event itself, what influences growth after adversity.

Linley and Joseph (2004) also found emotion-focused coping to be positively correlated with growth. Ironically, the adaptation of cognitive processing that includes rumination, intrusions, and avoidance was positively correlated with growth. This form of cognitive processing, the authors explained, is necessary for recovering after trauma. Interestingly other authors have found that cancer patients who used minimization as a coping strategy, expressed less negative impact in their social, work, and family life (Butow, Coates, & Dunn, 2000).

Along with the above-mentioned authors, Riegel and Carlson (2002) found that patients suffering from chronic heart failure would cope with the illness by ignoring it. Buetow, Goodyear-Smith, and Coster (2001) conducted interviews in 1999 with 62 patients suffering from chronic heart failure, in order to understand the impact of their condition on their lives and their ability to adapt psychologically to their condition. The study was developed as a way to make recommendations to improve clinical care. They found that patients who cope with their condition by dissociating from the detrimental effects of the illness, perceived their illness as less serious and threatening. In the same study, some patients use withdrawal as a coping mechanism; however, this strategy was identified as ineffective because it compromised their treatment and health outcome.

Persson and Ryden (2006) identified a number of cognitive processes that helped patients cope with chronic illnesses by minimizing the personal threat of their illness. Some of these cognitive mechanisms included focusing on positive aspects of their situation, focusing on hope, and comparing themselves with others who were more afflicted. Withdrawal strategies were described as passive coping strategies; which often did not help patients cope effectively with their condition; on the contrary, problem-focused coping, which includes active efforts to solve or relieve the source of stress, were associated with positive indices of well-being.

Kaltsouda, Skapinakis, Damigos, Lkonomou, Kalaitzidis, Mavreas, and Siamopoulos (2011) explained that people with physical diseases use psychological defenses to guard themselves from emotions such as anxiety, sadness, fear, and anger evoked by a physical disease. This study found that the use of denial was associated with depressive symptoms and poorer mental health due to the impediment to grieve; however, emotional defensiveness was a predictor of better physical health. The authors explained that the use of defensive coping may be facilitated by the specific characteristics of the disease. For example, patients suffering from chronic kidney disease did not manifest obvious signs of defensive coping until the end stage; therefore, the silent progress of the illness made it easy for patients to ignore the potential threat of the disease.

In a study about hospice decision among Central and South American cancer caregivers, Kreling, Selsky, Perret-Gentil, Huerta, and Mandelblatt (2010) found that denial and secrecy about prognosis were among the cultural values expressed by Latinos in relation to hospice decisions. Many Latino caregivers in this study reported preference for secrecy of prognosis and less information about the illness, as they experienced this as cruel to the family and harmful to the patient. Caregivers also expressed more denial and less openness to discussing death than White caregivers.

Another study looking at ethnic specific coping styles found that patients diagnosed with idiopathic chronic fatigue who were members of minority groups, relied more on religion, denial, and behavioral disengagement to cope with their condition (Jason et al., 2000). Major and Schmader (1998) offered a possible explanation for the use of this coping style, they suggests that in order to maintain self-esteem in the face of discrimination, stigmatization, and prejudice, members of minority groups can psychologically disengage. Another study suggests that one aspect that influences how coping skills are used by minority groups may be the lack of availability of resources and healthcare (Torres-Harding, Jason, & Taylor, 2002).

Njoku, Jason, and Torres-Harding (2005) suggests that the use of denial for individuals with no obvious signs of illness, serves as a protective factor from feelings of guilt and shame associated with not being able to fulfill family responsibilities. The same authors also suggest that it is also possible that the use of denial among Latinos is associated with negative attitudes about being sick, as illnesses are seen as a sign of personal weakness or moral failure. Finally, the authors also suggest that the use of denial in Latina women may serve to allow them to continue to perform their traditional gender roles.

Emotions play a part in how people cope. Gallo, Ghaed, and Bracken (2004) documented that hostile individuals report high levels of social stress and low social support, which could result in social experiences that reinforce their hostile cognitions and behaviors. In contrast, people who reported positive emotions and optimism perceived better social support and lower social conflict. Another study stated that an important determiner of life demands was the perception of the situation (Ray, 2004). Ray's finding revealed a positive correlation between emotions and posttraumatic outcome. He stated that the balance between the environmental demands and the person's coping skills is what determines the psychological adaptability of the person after adversity. In terms of personality traits, Linley and Joseph (2004) found that extraversion, agreeableness, openness to experience, and conscientiousness were positively associated with growth, while neuroticism was negatively associated with growth after adversity.

Synthesis of the Literature

Although Chagas disease is among the diseases with the highest mortality rate in Latin America, it is still a neglected infection of poverty and prevalence continues to increase across the globe (Hotez, 2008). The lack of attention to this global issue is closely related to a lack of awareness of the illness and neglect of the populations in which it prevails (Tummala-Narra, 2007). The neglect of the illness and the population is the number one reason for the need for more investigation and attention to this important issue that not only impacts the immigrant population in the U.S. but those getting blood transfusions infected with Chagas. Even though a group of activists and health care providers have united to disseminate information about the illness and draw attention of the community, in an effort to address the different aspects associated with the illness, the need to establish better treatments, open more clinics, conduct more research, develop better drugs, and attend to the psychological needs of the populations suffering from Chagas still prevails.

Chagas disease is linked to an extensive list of variables that contribute to its prevalence and lack of treatment; these factors have been identified as the social determinants of health. Not surprisingly, the social determinants develop as a result of discrimination, poverty, and stigmatization. In addition to having to deal with the physical and psychological effects of the illness, individuals infected with Chagas disease have to cope with other social barriers such as having limited or lack of accessibility to health care, lack of education, lack of resources, lack of social support, inadequate nutrition, language barriers, and issues related to their immigration status in the U.S. (Meymandi, 2009). Coping with the illness and its social determinants results in high levels of stress that could lead to negative health outcomes. This study was developed with the goal to understand the impact of social determinants on individuals infected with Chagas and learn about the coping strategies that help individuals to overcome and counteract the impact of the social determinants of Chagas disease.

Despite the levels of adversity and stress experienced by the Latino population in the U.S. a number of coping factors specific to that ethnic group have been identified as aspects that help them cope with trauma and adversity. Currently, there is no available literature that studies the experience of coping on individuals infected with Chagas disease;

however, there is some literature that explores coping among Latinos suffering from coronary heart disease, arthritis, trauma, and cancer. Some of the identified factors that have aided individuals with chronic illness to cope with their condition are: the family (including support from extended family, friends, and community), spirituality and or religion, cultural beliefs, attitudes, gender, and cognitive styles.

The evaluation of factors that help Latino/a individuals cope with adversity was approached from a social ecological model, which incorporates aspects of the social context and culture, along with the particular individual and collective characteristics that play a part in the way individuals and communities cope with adversity. It was expected that some or all of the factors identified as ways of coping in studies of Latino/a individuals coping with adversity and chronic illness were going to be identified by individuals infected with Chagas disease in the present study.

This investigation expands the available literature on Chagas disease, as well as the literature on the impact of social determinants on coping in Latino individuals suffering from a chronic condition. This investigation also promotes awareness about the illness and leads to the development of recommendations to address the social and psychological needs of this population.

Chapter III: Methodology

Sample

A sample of 15 individuals diagnosed with Chagas was recruited for this study. Participants were four males and eleven females between the ages of 34 and 66. The average age was 49.2. Seven participants were diagnosed with Chagas less than five years ago, eight were diagnosed more than ten years ago; therefore in the chronic stage of the illness. The study was designed to recruit twenty participants; however, four participants did not keep their scheduled interview appointments and one participant had to withdraw from the study because he reported having memory loss.

Ten participants were from Salvador, four were from Mexico, and one was from Guatemala. All of the participants have been living in the U.S. for more than ten years. Ten of the participants were married, one was divorced, three were single, and one was separated. All of the participants spoke Spanish as their first language, but two of them preferred to be interviewed in English.

None of the participants had health insurance and they were all receiving treatment for their condition at an urban, university-affiliated medical center. Nine participants reported making less than $10,000 a year, three were making between $10,000 and $20,000, and one was making between $20,000 and $30,000, two participants reported making more than $40,000 per year. Most of the participants (60%) resided with other family members in order to cover the living expenses. Eleven participants did not graduate from high school, one completed a GED and two graduated from college.

Instruments

Semi-structured interviews of approximately 45 to 60 minutes consisting of open-ended questions, followed by more specific open and closed questions were asked to obtain information about participant's background, their health condition, and their experience coping. A script of the interview introduction and guide questions can be found in Appendix A of this document. A voice recorder was used to record the interviews.

A demographic questionnaire, found in Appendix B, was developed for the study. It asked information about participants' age, gender, ethnicity, place of birth, education level, occupation, marital status, date of diagnosis, religious orientation, number of people living in the home, and number of years residing in the U.S., insurance information, and income range.

Interviews and demographic questionnaires were done in Spanish for all participants except two who preferred speaking English. Field notes were taken to organize the information collected during the interviews and to identify themes about the social determinants of health reported by participants and their ways of coping. A flyer was used to help in the recruitment process.

Procedure

This investigation was a collaboration between the principal investigator at Adler School of Professional Psychology and a physician at the medical center specialized in the treatment of Chagas. After the study was approved by the Adler School of Professional Psychology IRB and the Medical Center's IRB (Appendices C & D), the physician and her staff identified potential participants and asked them for permission to be contacted by the researcher.

Individuals who consented to being approached to be part of the study were contacted over the phone by the researcher. At the initial contact with participants, the researcher reviewed the purpose of the study and clarified any questions they had. Subsequently, participants were asked to sign a consent form, in which information regarding the nature of the study, the procedures to maintain confidentiality, the rights of the participants, compensation, and the possible risks and benefits of their participation were explained in detail.

The researcher traveled to the medical center to conduct the interviews over four weekdays during the month October 2012. A semi-structured interview format, using open-ended questions was used. Interviews were audio-recorded using a voice recorder and later transcribed by the researcher. Once the interviews were transcribed, they were transferred into a password-protected electronic document and the audio-recorded interviews were erased. Transcribed interviews did not contain identifying information; instead, interviews were assigned a number for identification.

Interviews lasted approximately 45 to 60 minutes. Interviews were face-to-face, 13 were administered in Spanish and two in English. Interviews started by asking participants details of their demographic information, then they were asked about their 'personal experience' before and after being diagnosed with Chagas disease. They were asked questions related to how they have managed to deal with and adapt to their condition and what factors could have increased their ability to cope more effectively.

At the end of the interview, participants were provided with information about how to obtain psychological services in their city in case they wished to seek these services. After all interviews were conducted, participants entered a lottery to win a $50 gift card. Once the winner was determined through random selection, the person was notified via phone and the card was mailed to her residence.

Chapter IV: Results

Data were analyzed using grounded theory. This methodology allows the researcher to understand the complexities of individuals' experiences. Grounded theory is a flexible, yet systematic method that uses comparative methods and assists in theory construction (Wertz et al., 2011). The first step to analyze data was open coding. Coding allows the researcher to summarize, synthesize, and sort data (Wertz et al., 2011). Coding involves line-by-line analysis of the transcript to identify the emerging themes and start to generate possible codes (Green & Thorogood, 2009). Then, emerging conceptual labels, which identify the phenomenon under investigation, were assigned a code for further analysis. The initial concepts were then subject to further questioning in order to identify their characteristics (properties) and the continua in which these properties could be arranged (dimensions). Similar categories derived from the open coding strategy were grouped as similar phenomena.

The next step of the analysis was axial coding; this refers to the analysis of core themes by categories or concepts in relation to each other. In this stage of the analysis, data was grouped in order to determine relationships between categories. Finally selective coding was applied to develop core categories that lead to the creation of substantive theory

(Green & Thorogood, 2009). All the coding process was done by the researcher in Spanish. Throughout the research process, memo writing was used to support the analysis of emergent categories. Because most of the interviews were conducted in Spanish, segments from the interviews to illustrate the categories that emerged were translated to English by the examiner.

In order to ensure credibility and validity of the findings, the identified codes were discussed and analyzed by one of the readers from the dissertation committee, the dissertation chair, and the treatment team at the Chagas clinic.

Two main categories emerged from the analysis: (1) Aspects that help people cope with their illness, and (2) Social, political, and psychological aspects that make coping very difficult, these categories will be explained as follow:

Coping Strategies

Denial and Minimizing. Denial and minimizing were the most common coping strategies reported by the participants. The majority of participants used denial and minimizing as a coping mechanism. Participants stated that not thinking about the illness or believing that they were in better condition than they actually were helped keep their minds busy with other things, which reduced the stress and anxiety often produced by thinking that they may get sick any day because of the illness. Despite being explained that the illness has no cure, many believed that they would be cured with the medication.

> Participant 1: *I don't take problems very serious because they resolve on their own sooner or later.*
>
> Participant 2: *If I don't hear about Chagas I forget about it.*
>
> Participant 3: *I talk to my family, but the illness is like if it didn't exist so I don't worry and I don't make them worry... I think they talk to each other, but they make sure I don't hear them.*

Family. Twelve participants out of fifteen (eighty percent) considered their families as their biggest source of support for coping with their condition. For many, having family members away in their countries of origin was unfortunate; however, keeping frequent communication with them was important to maintain closeness and receive emotional support. Participants often reported that because there are no community support groups, family members care for one another and provide support by taking participants to their doctors' appointments, taking care of them at home when they are sick, helping around the house, and providing emotional support. Some participants mentioned that continuing with their family roles helped them feel useful and important, participants who mentioned this, were more concerned with helping other family members than they were about taking care of their own illness.

> Participant 1: *My wife and my kids give me the strength to keep going...*
>
> Participant 2: *My son is my support, we keep active communication.*
>
> Participant 3: *The meaning of my life is my grandchildren, sharing with them is my life, is what keeps me going.*

Believing in God. Most participants (about eighty percent) mentioned God as one of their main coping mechanisms. The majority of those who used religion as a coping strategy used religious practices as part of their daily routines to help them cope with Chagas disease and with their lives in general. The following quotes illustrate this point:

> Participant 1: *I am Christian and God has helped me a lot, he is big and powerful and his mercy over me has opened the mind of doctors so they can help me.*
>
> Participant 2: *I've been catholic all my life, I go to church, I go to the festivities, if there is a praying, I go to it, all my life since I was little he has helped me, I ask him to cure me so I can continue living because my children need me.*

Optimism. The majority of participants expressed having hope about the future and keeping a positive attitude toward their situation. Optimism was a recurrent response throughout the study. Participants were hopeful about their health, they hope for a cure, and increased attention to the issues surrounding Chagas disease. They were also hopeful that more clinics would be open and that better drugs would be developed. Most participants expressed their optimism by mentioning that they thought positively in order to have strength to continue with their lives like before they were diagnosed. The following quotes illustrate this theme:

> Participant 1: *I want to stay healthy, I want to travel and enjoy life until my last breath.*
>
> Participant 2: *I come to the appointments because I have hope that I will never get worse from this.*

Financial Help. All the participants mentioned receiving some kind of financial help from the government or from the hospital to help pay their medical bills or medications. Some participants reported receiving free medical services from the county. Additionally, the hospital provided medications for all patients and some also received financial help for transportation. Other participants mentioned receiving help from their family members, as well as help from the medical center to attend doctor's appointments and pay for medical tests or medications.

> Participant 1: *I don't have health insurance, but I have Orsa (covers outpatient services and medication at the Department of Health Services facilities) to pay for services here, I had only come*

> *here for Chagas and have never had to pay for medications.*
>
> Participant 2: *I don't have health insurance but they give me the medications here.*
>
> Participant 3: *I have food stamps because my husband was laid off and I'm looking for a job.*

Staying Active. Ninety percent of participants talked about staying active as a helpful behavior to cope with their condition. Participants who were active continued working despite their illness, continued their pre-diagnosis activities such as household shores, and weekend activities such as visiting family members and attending church.

> Participant 1: *I am very active in church, I have been going to English and parenting classes for three years, so I stay busy and I don't have time to feel bad.*
>
> Participant 2: *I go out to walk three times a week I go to the garden to plant whatever we want. It makes me feel good.*

Trust in Medical Care. The majority of participants expressed their appreciation for the physicians at the medical center. Four out of ten participants expressed having faith that the medication would help their illness. These participants were thankful with the medical center and doctors, yet they were also disappointed that there is little attention paid to the illness and that there is only one medical center that treats the illness in the country.

Participant 1: *We are in the hands of God and the doctors. Thank God I met Salvador, the doctor who detected the illness.*

Participant 2: *Thanks to the doctors and medicines, thank God for the doctors here who have seen me since I came here and did all the exams on me.*

Participant 3: *I feel secure, first God, the doctors and the medicine, I feel that the staff in the hospital is very good, they don't let people die, I was dying and now here I stand.*

The following themes were not endorsed as often by participants; however, some are important to mention as they served as positive coping strategies, thus leading to recommendations to address the needs of the population of study:

Education. The majority of participants (eighty percent) did not graduate from high school, and only completed a few years of elementary school; however, the minority who completed high school or had some college education, and those who had learned English, or a technical skill, had a better understanding about their illness, treatment, and resources available to help them cope. Those participants who had more years of education knew how to use the Internet for finding information about the illness, seeking help, and being more resourceful and aware of their condition:

Participant 1: *When I found out about that, I basically educated*

> *myself, and I have always been diligent as long as I was financially able to go to the doctor and get extensive research done to make sure where I am at. I started reaching out and doing research because I like being informed.*
>
> Participant 2: *When I was diagnosed, I educated myself because everything is in the computer. I read and read; I know where it came from (the illness) why did they name it like that, and all that stuff.*

Helping Others. For about forty percent of participants, helping others allowed them to feel better about themselves. Two of the participants were advocates of Chagas by promoting awareness in the community. Others felt that helping others kept them busy, which allowed them to focus on other things.

> Participant 1: *I feel very good when I help my family, even if it is with little but I know it helps them.*
>
> Participant 2: *I am a coach of a soccer team, we practice twice a week, I like that. When I retire I want to help anyone who needs it, the neighbor or anybody I know.*
>
> Participant 3: *I like helping good people, animals, and the elderly. I see an animal on the street and I take it home because I feel sad... I already have six animals at home.*

Seeking Information. Seeking information was not a consistent behavior among participants; however, for about twenty percent of participants, actively seeking information about their condition, was a very helpful behavior. Being resourceful and taking the initiative to seek information to educate themselves about their condition, made people feel proactive about their condition, which improved their self-esteem.

> Participant 1: *Being resourceful is one thing that has helped me through this, there is nothing more better than to really know the truth, you know where you are standing, and the rest God knows when is going to come.*
>
> Participant 2: *I told my husband that if we as patients didn't talk, no one would do it for us, if we didn't dare to talk and ask for help nobody would do anything for us.*

Lack of Symptoms. For those participants who had been diagnosed recently having no symptoms helped them cope with the illness because not feeling sick made them forget about having the condition. Over fifty percent of participants did not report any symptoms form their condition. Having no symptoms helped participants to feel more active and energetic, which gave them hope about the future. This was a consistent theme throughout the study for those who were not yet at the chronic stage, as the following quotes illustrate:

> Participant 1: *My attitude is very positive right now, because I don't have symptoms, I don't feel sick, I feel healthy.*

> Participant 2: *I didn't know I had that illness because I never felt sick, I still feel good and I think that helps me.*

Being Independent. Independence was not a consistent theme throughout the study; however, a few participants stated that maintaining an independent life style helped them feel better about their condition and their lives in general.

> Participant 1: *I have been independent all my life and spend the money that I make. I don't like asking anybody for anything...*
>
> Participant 2: *Being independent has helped me a lot.*

Living in the Present. Living in the present was not a recurrent theme, but about thirty percent of participants indicated that living in the present was helpful because it took their minds away from worrying about what could happen to them in the future.

> Participant 1: *My grandchildren ask me what are we going to make tomorrow and I said to them we have to live today to know what we are doing tomorrow, is better to live in the present because we don't know if we'll be here tomorrow. Why think about tomorrow, is better to live in the present.*
>
> Participant 2: *There is no future because I don't have many years to live, but I ask God that I wake up ok, I thank God every day for another opportunity, I think the future doesn't exist, or it does but I just don't think about it.*

Barriers to Coping

Financial Limitations. All participants mentioned experiencing some kind of financial limitation. Despite receiving help from the government through food stamps, health care, medications, or help with transportation, most participants were poor, underpaid or unemployed, and declared having difficulties because of their financial situation. Lack of education was dependent of people's socio economic status; however, language barriers, discrimination, and lack of opportunity also played a part in people's financial situation. Because of financial limitations, other difficulties such as lack of health insurance, lack of transportation, and inadequate nutrition were also reported. Four out of fifteen participants were unable to attend routine appointments because of lack of money due to being unemployed. About forty percent of those who participated in the study stated being afraid of losing their jobs; therefore, they continued to go to work despite feeling very sick. Others mentioned being afraid of asking for time off to attend doctor's appointments fearing to get fired from their jobs. The following quotes illustrate this theme:

> Participant 1: *Is too hard to cover medical expenses, that is why I didn't want to go to the doctor, because I didn't have insurance…I ended up coming because it was serious and didn't have a choice.*
>
> Participant 2: *My job doesn't allow a person like me to do the Chagas treatment or get psychological help because of time. Most*

> *of the appointments are Monday to Friday and that is when I work. I got to take care of my job.*
>
> Participant 3: *The illness affected my job because I couldn't work…my friend gave me food and she told me that my health came first. They fired me from my job because I had a doctor's appointment and the lady I worked for said she could not give me more time off for doctor's appointments.*

Lack of Clarity about the Illness. Eighty percent of participants implied or indicated confusion or lack of understanding about their condition. Several participants reported being unsure about the way the illness affected them. Several did not know if the symptoms they experienced were the result of their condition or if they were due to something else. The majority of these participants did not have a clear understanding about the treatment. The lack of clarity about their illness seemed to create anxiety and uncertainty for many of these participants. It was evident that those participants with fewer years of education had greater difficulty understating their condition and treatment. The majority of participants only did a few years of elementary education in their countries of origin, and some were illiterate. Those who have completed high school or some college appeared to be more resourceful, and knowledgeable about their illness. The following quotes demonstrate this theme:

> Participant 1:*Every time I looked for information I found*

> *something different. I feel the information they gave me was not enough and they didn't explain it well.*
>
> Participant 2: *The doctor told me that my heart is very big but I don't know why.*
>
> Participant 3: *I did not know anything about Chagas, they gave me some information but I didn't understand because it was in English, honestly I forgot everything they told me, it was confusing.*

Language Barriers. Even though the clinic had a few physicians who spoke Spanish, the number of bilingual clinicians was small for the number of patients. The great majority of participants only spoke Spanish, for those who did not speak English; not being able to read or speak the language was a limitation because most of the written documentation on the illness was not available in Spanish.

> Participant 1: *They explained the illness to me…not knowing English is a barrier, the doctor only speaks English, I think it is a barrier.*
>
> Participant 2: *Not knowing English is a limitation in this country is necessary, I can't retain anything.*

Psychological Impact. Approximately seventy percent of participants indicated that the illness had a negative psychological impact on their lives. The illness caused stress, uncertainty, depression, and anxiety for many of them. The following excerpts demonstrate how some participants expressed the psychological impact of the illness:

> Participant 1: *Life changes so much because our countries are so poor, but then you run into these issues and it really changes the way you see things. When I found out what I had and realized there is no cure…you just kind of slow down… it is difficult.*
>
> Participant 2: *I remember that when I found out I was very stressed out because of the uncertainty of not knowing what it was. I was stressed, afraid, I had everything. Not knowing if my kids had it, I was feeling very bad, I was very afraid.*
>
> Participant 3: *At the beginning I was very afraid to be left alone. At the beginning it was only me and my husband, I didn't want him to go anywhere because I was afraid that I was going to get something, at night I couldn't sleep from thinking that I may get something. I used to say why me, why did this have to happen here.*

Lack of Better Medications. All participants except for one talked about the negative side effects of the medication and how difficult it made it for them to continue with their routines and their ability to cope with the illness. Some of the side effects included vomiting, diarrhea, loss of appetite, weight loss, memory loss, headaches, skin disorders, excessive tiredness, depression, and tingling of the feet and hands. Those who suffered severe side effects due to the strong medication that is usually prescribed for the condition, indicated that the medication seemed to be worse than the actual illness. Many had to discontinue treatment while others were given alternative medications.

> Participant 1: *The treatment was very difficult, the medicine attacks everything, not only what is wrong. Thank God that from all the possible side effects, I only had loss of appetite, I lost 25 pounds in three months, I could not eat, I used to forget things... but compared to others that started treatment at the same time I did, my effects were minimal.*
>
> Participant 2: *The treatment was awful, very strong. I would get dizzy, I got very thin, I didn't want to eat and I had to do it to take three pills a day, I had vomit and diarrhea sometimes, I became depressed, I could not sleep, I still can't sleep very well... at that time I lost my job.*

Lack of knowledge in the General and Medical Community. Ninety percent of participants expressed their concern and disappointment about the lack of knowledge about the illness in the community. None of them had heard of Chagas before they were diagnosed, and once diagnosed they were disappointed to find out that not many doctors knew about the existence of the illness. When diagnosed, most participants did not receive a lot of information about it, the majority were notified about their condition in writing or by phone; however, the notice they received gave them vague information about their diagnoses, or simply asked to seek further help or call the medical center that specializes on treating the condition to obtain more information. Some participants were frustrated to find out that doctors did not know how to treat the condition because many had never even heard of Chagas. There is only one medical center that specializes in treating the condition, and the lack of knowledge in the medical community results in limited medication to treat the illness, this medication is not FDA approved and needs to be obtained through the CDC and needs to be shipped from overseas, which often delays the treatment. The following quotes illustrate what participants expressed about this issue:

> Participant 1: *I wanted to bring a paper to my coworkers because I don't even know how to explain it. The illness has different names and they never heard of it. To be honest I don't know what to tell them.*
>
> Participant 2: *I made an appointment with my doctor and I asked her about the illness and she said that the only time she heard of that was in medical school, so she could not help me, she sent me to a CDC specialist to check me again, they didn't even know what exams to give me.*

Stigma. Stigma was not a recurrent theme mentioned in the study;

however, three of the participants expressed to have experienced discrimination due to their condition. The lack of knowledge and clarity about the condition causes some people to believe that it is contagious, which leads to stigma and discrimination. Some of these participants were also aware of the relationship between neglect of the illness and the population in which is prevalent. In other words, they were aware that the lack of effort from the medical community and the government to address Chagas was related to the fact that the Latino population, in which it prevails, is also neglected and marginalized.

> Participant 1: *They don't develop a better drug because we are a minority. It is considered an illness of the poor. Because the medicine would not make a lot of money, they don't invest in it.*
>
> Participant 2: *My life has changed because of the way I feel right now. I talked to my wife and my kids to clear things up...now everything that is my personal things are apart from everyone else (crying).*

Family Separation. This was not a recurrent theme; however, three participants who mentioned that they had family members in their countries of origin stated that this limited their main source of support. Some of these participants had to help their family members financially in other countries, which made even more difficult their financial situation in the U.S. The following is an excerpt of a participant who wished her children lived here with her.

> Participant 1: *The only thing I don't feel good about, because I don't feel complete is having my children away. I wish I could be with them, but I married this man who helped me come here, so I wish I could split in two so I can be here and there.*

Analysis of the Results

Results from this investigation revealed the impact of the social determinants of health on individuals coping with Chagas disease; the theory that emerged from this study explains some of the social determinants specific to Chagas disease and the way in which they impact individuals' ability to cope with this Illness.

The results of this study indicated that participants cope with the illness by using family and social support; however, due to the socio-economic and political aspect impacting coping, individuals infected with Chagas experience significant stress such as family separation due to immigration, lack of support in the community, and social isolation. These conditions make it more difficult for individuals to rely on their main source of support and participate in the community, or rely on ethnic cohesion to advocate for themselves and use more effective ways of coping.

Other social aspects that affect coping are related to their socioeconomic position; which impacts participant's level of education, occupation, and their income. The majority of participants were from low socio economic status, which overall, limits their accessibility to resources that would otherwise facilitate coping. Other factors reported by participants that make coping more difficult include living in segregated and unsafe neighborhoods, living in crowded conditions, which create stress and increase risks for contracting other illnesses, experiencing unstable and unsafe working conditions. In addition, many participants do not have access to healthy nutrition because their income does not make it possible for them to buy good quality food, and many experience discrimination due to the lack of information about the illness, and the stigma of having a chronic transmittable disease.

Some of the participant's behaviors that impact coping are based on their working and living circumstances, examples of these include: not attending doctor's visits due to fear of losing their jobs, going to work in spite of feeling sick, not following doctor's recommendations, and stopping the medication because of the negative side effects of the drugs to treat the condition.

Some of the biological factors include: genetic predisposition to illnesses, having comorbid illnesses, or having to deal with negative side effects of the medication. Finally, some of the identified psychological factors that impact coping are: Having to deal with stress, anxiety, depression, as a result of the illness, dealing with negative life events, such as having other sick family members, being separated from family members, having limited support, experiencing financial difficulties, and using negative coping strategies. In addition to all these limitations, there are no support groups or psychological services offered to individuals dealing with Chagas. All of the mentioned components have an impact on equity in health and the way people cope with the illness.

The second part of the theory resulting from this study describes the aspects related to coping, which highlight individual's resilience and the way in which they counteract the effects of the social determinants of health inequality. Most participants cope with Chagas by using denial and minimization; although this coping mechanisms may be counteractive for treatment outcome, given the social context in which individuals live and the limited resources offered to the population, the use of denial and minimizing allows individuals to focus their energy on other priorities such as working and taking care of their basic needs. It also helps them to focus their mental energy on other things, to remain physically active, and to be hopeful about the future. This aspect of the theory could be looked at from a bidirectional point of view based on the ecological model. Based on individual's responses, it was observed that individuals who had a positive attitude were more likely to seek treatment, comply with medication, attend appointments, and seek information, which in turn increased their awareness about the illness and facilitates communication between patients and providers to understand their needs and develop better services for the population. Some individuals with positive attitudes and motivation to seek information and increase awareness had participated in informational workshops as advocates and educators in the community to promote early detection. Another example of how these individuals impacted social systems was seen on those who took the initiative to obtain information about their condition. These behaviors increase awareness in the community and empower individuals to take control of the situation and improve their health outcomes.

Chagas' infected individuals from the interviewed sample encouraged family members to get tested, which increases awareness and allows for early detection of the illness, this is another example of how a part of the microsystem (the individual) positively influences the exosystem and macrosystem (the family and other communities). Some of the cultural values seen on the population at study were reliance on family, reliance on religious beliefs, and the use of denial; these coping strategies allowed individuals to maintain cohesion, remain hopeful, and be active contributors of society, thus reducing the impact of lack of health care, and other social barriers surrounding Chagas. Overall, even though social determinants impact the well-being of individuals infected with Chagas, individuals are also empowered to advocate and create changes that counteract the social determinants and lead to positive coping and well-being.

Researcher's Perspective on the Data Analysis

This study was approached based on previous research of the literature on the social determinants of health; knowing that the population of study suffers from discrimination, financial limitation, and general social disadvantage, it was expected to hear about some of these social barriers faced by participants in this study. It was still disheartening for me as a researcher to know how neglected they felt, how disempowered they were, and how many more difficulties besides Chagas they had to confront.

Many participants shared information about the psychological impact of their situation; however, given the setting and the nature of the interviews, there was very limited time to process any emotions, especially in those who reported depression, anxiety, and severe stress. Nonetheless, participants were referred to psychological services after the culmination of the interview. With regards to the emotional experience of the researcher, Hubbard, Backett-Milburn and Kemmer (2001) give recommendations for how to process the emotional impact of face-to-face interviews and still maintain neutrality for data collection and analysis. Hubbard and colleagues argued that emotions that arise as a result of conducting research may help the researcher empathize with the interviewed by understanding their distress; emotional distress, authors suggest, should be anticipated and accepted as an aspect of the research experience. The above mentioned authors also recommend the researcher to share the emotional burden with others members of the research team in order to avoid feeling personally responsible for the participants and to provide support for the researcher. I practiced this one and other recommendations by Hubbard and colleges, such as note writing, pacing the interviews and debriefing with the research staff, which provided validation and support during my research project.

Chapter V: Discussion

Discussion of Major Themes

This study aimed to develop a theory by investigating the impact of the social determinants of health on individual's ability to cope with Chagas disease. It was also intended to identify coping mechanism that Latinos infected with Chagas use to cope with the illness. Semi-structure interviews were conducted with 15 participants to explore their views on the issues they faced and coping strategies.

One of the most hopeful and positive aspects of the study was finding that participants were receiving some form of help from the medical center, the state, or the county to cover the Chagas treatment. Participants who did not have health insurance often received medical insurance from the state. A few participants were also receiving food stamps and/or a transportation pass.

On the other hand, because there is little attention to the illness in the U.S. (Hotez, 2008), there are no policies to protect or allow providing adequate services to individuals infected with Chagas. Because the illness predominantly affects marginalized communities, individuals do not have the same opportunities to participate in society to advocate for themselves as other more privileged communities. People infected are more concerned with keeping their jobs and surviving. The labor market for this population is limited and often underpaid; most participants worked labor jobs such as cleaning, landscaping, or construction. Most participants were underpaid and none had health insurance. Most participants were also uneducated and often lived in overcrowded conditions with other family members that help to pay rent.

The structural determinants of the social determinants of health; refer to the distribution of resources according to social class. Social class determines people's occupation and education level. The socioeconomic position of individuals in society leads to income inequality, which results in social comparison, thus causing chronic stress leading to poorer health for those at the bottom of the hierarchy (CSDH, 2007). Most participants in the study were considered low income, the majority did not complete high school or its equivalent, and the majority did not speak English. Few of the participants did not know how to read. Because the majority migrated to the U.S. more than ten years ago as refugees or illegal immigrants, the opportunities for education were limited or completely absent as individuals were more concerned with having basic resources to survive.

All participants declared experiencing stress due to their economic situation. This finding was consistent with the literature, which states that income inequality produces anxiety, stress, and inability to cope

(Wilkinson & Marmot 2003). According to the literature, Latinos are also more likely to hold lower paying jobs, they are more likely to lack basic skills, experience discrimination, and access information about job openings (Dunn & O'Brien, 2009). Nonetheless, despite participant's social situation, they were able to use the resources available to them and cope by other means such as by using the support of their families, using positive cognitive styles, and positive cultural beliefs.

Many participants stated fearing losing their jobs for having to take time off to attend doctor's appointments. Others expressed having lost their jobs due to the illness, while some were unemployed. According to Ray (2004) having little control over one's particular circumstances in relation to employment stability, as well as receiving inadequate reimbursement for the effort put into work, has been found to be associated with greater risk for illness development (Ray, 2004).

Because of the level of education of most participants, the majority did not know how to use a computer; therefore, many had very limited knowledge about their condition. This is also due to the fact that the illness is not very well known in the medical community. Participants were affected by the lack of knowledge about their condition; as Ray (2004) explained, that lack of education or knowledge leads to decreased adaptability to cope with the environment. The more understanding the person has about her or his surroundings, the more control he or she can exercise over the environment.

Material circumstances such as housing, financial means to buy healthy food, adequate clothing, and the physical environment in which people live and work are part of the intermediate determinants of health. Most participants lived in overcrowding conditions, and many did not have adequate financial means to buy healthy food; in addition, most participants worked at hard labor jobs, having to work overtime, and receiving inadequate payment for their work. All of these conditions contribute to health risks (CSDH, 2007).

Another part of the intermediate determinant of health is the psychosocial circumstances that affect people; these include life stressors such as debt, negative life events, job strain, lack of social support, and the use of negative coping styles. Many participants in the study declared experiencing great amounts of stress related to debt, anxiety due to lack of health insurance and inability to pay bills, negative life events such as having to take care of other sick family members, separating from children and other family members due to moving to the U.S., losing their jobs, and experiencing comorbid illnesses themselves. Many had limited support, as there are no support groups offered for individuals infected with Chagas; in addition, there is only one clinic that specializes in treating the condition in the U.S.

Behavioral, psychological, and biological factors are the last components of the intermediary determinants; these include diet, behaviors such as alcohol consumption, smoking, and lack of exercise, and vulnerability to illness (CSDH, 2007). Participant's exposure to stress and other barriers that make it difficult to effectively cope with their conditions results in psychological issues such as depression and anxiety, which adds another layer to the already complex situation individuals have to cope with. Only one of the participants stated to be eating better after his diagnosis, while the rest did not make any changes related to diet or exercise. Many declared not having time or energy to exercise. In addition to behavioral and biological factors, the majority of participants had to deal with the negative side effects of the medication, which further impacted their ability to cope effectively.

With regards to coping, participants indicated many disadvantages due to their social position, health condition, and ethnicity. Results of this investigation were supported by findings from Duncan et al. (2006), who stated Hispanics in the U.S. are exposed to social disadvantages such as higher unemployment rates, working in more physically demanding jobs, experiencing higher levels of stress at work, working in low paying jobs, having lower levels of education, language barriers, and facing stressors and challenges associated with immigration status.

However, many of the coping strategies used by Latinos with chronic conditions previously documented in the literature, were also mentioned in this study. Participants indicated high levels of family support, which often resulted on putting the needs of the group or family before the needs of the individual. Some of the participants were more concerned with the health of other family members. Others preferred not to tell about their illness to other family members not worry them. Thinking about other family members before the individual's needs goes along with secrecy about the illness. Kreling and colleagues (2010) found in their study that secrecy about prognosis among Latinos in relation to hospice decisions was preferred to protect other family members. This theme was consistent among participants in this study. Many participants stated that keeping the illness secret from their children or other members of the family helped them reduce worry and anxiety. On a different study about coping with comorbid illnesses, participants reduced the impact of their conditions by limiting information about the illness to other family members and taking medications in private (Collins & Reynolds, 2008).

Although the study could not determine if religious beliefs lead to better health outcome, many participants use religious beliefs as a coping mechanism. Trevino and colleagues (2007) found that church attendance, being part of a religious group, and praying were associated with less distress, better quality of life, and greater compliance with medical care. Many participants in the study reported praying to God to get cured or get better. Many thought that believing in God helped them stay positive and reduce stress. Abraido-Lanza et al. (2004) found that religious coping enabled Hispanic individuals with arthritis to gain a sense of mastery, self-efficacy, and acceptance of their condition. Dunn and O'Brien (2009) found that reappraisal of God's power and having a significant other as a source of support, were associated with having a sense of personal meaning, or sensing that life was meaningful. These findings were consistent with some participants in the study who stated that what gave meaning to their lives was having family members around and other sources of support.

A recurrent theme in the study was the participant's level of activity. Staying busy was often mentioned as a coping mechanism. Many participants mentioned that exercising; working, or staying active doing their regular activities helped them divert their attention from the illness. Active coping has been previously positively correlated with psychological well-being (Abraido-Lanza et al., 2004). On the other hand, those participants who restricted their activities after their diagnosis appeared to be struggling more with their condition.

Another one of the major themes for coping was minimization and denial. This theme was consistent with some of the literature, which found that patients suffering from chronic heart failure would cope with the illness by ignoring it (Riegel & Carlson 2002). The mentioned study conducted structured interviews with 26 individuals suffering from heart failure to understand the impact of their condition and their self-care strategies. Some participants in the study mentioned not thinking about the illness as a coping strategy, which was also used by family members who never mentioned the illness to the participants. Perhaps undermining, denying, or ignoring their condition, helps participants to feel less threatened by it. This was consistent with other study, in which patients coped with their condition by dissociating from the detrimental effects of the illness. This way of thinking allowed participants to perceive their illness as less serious and threatening (Buetow, Goodyear-Smith, & Coster, 2001). Another possible use of denial as a coping mechanism has to do with the lack of resources and health care available to minority populations. About fifty percent of participants stated that the reason they did not seek medical attention was in part because the illness was not considered to be as serious due to it being unrecognized in the community and among doctors.

Another reason that could have influenced the use of denial and minimization as a coping mechanism was the lack of symptoms that many participants experienced. Lack of symptoms could have led participants to believe that the illness was not serious or that they could have been misdiagnosed. Njoku, Jason and Torres-Harding (2005) suggests that the use of denial for individuals with no obvious signs of illness, serves as a protective factor from feelings of guilt and shame associated with not being able to fulfill family responsibilities.

All participants, except one, stated feeling optimistic about their future. Linley and Joseph (2004) found that being optimistic was associated with positive coping. Optimism was in line with having trust in doctors and the medication. Despite the negative side effects of the medication and lack of resources for adequate health care, participants were trustful, grateful, and hopeful. They expressed hope that their illnesses would improve with the treatment and that Chagas would get more attention from the government; they were concerned with increasing awareness in the community about this illness.

Overall the results of this investigation revealed many of the complexities interrelated to the issue of the social determinants of health. Marginalized communities that are affected by social barriers confront very complex difficulties that complicate their ability to cope with their illness. The social determinants of Chagas produce a snowballing effect on individuals suffering from this condition. The studied population already experience disadvantages such as discrimination and lack of opportunities because of their ethnicity and socio-economic status. These characteristics are often correlated with having limited education and low income, which leads to lack of health care, inadequate nutrition, greater levels of stress, and poorer health outcomes.

In addition to these barriers already experienced by the participants in the study, Chagas disease brings additional barriers such as limited healthcare centers, strong and strictly regulated medication that are difficult to attain, and lack knowledge from doctors to treat infected patients. Needless to say, there is very little support in the community to help people cope with their condition. Because the population lacks resources to cope, denial and minimization are probably the easiest and most effective coping mechanisms, perhaps decreasing the negative psychological, social, and physical effects of the condition and drifting attention away from the illness in order for patients to be able to continue to stay active and support their families. Because the lack of resources available, people rely on one another to cope and use positive cognitive styles and attitudes to remain hopeful in spite of their difficulties (Figure 2).

Despite the help received by patients at the clinic and the efforts of a small group of people who are trying to create awareness and better circumstances for individuals suffering from Chagas, many remain undiagnosed due to the limited attention to the illness in the U.S. Most participants found out about their diagnosis because they were blood donors; however, there is no testing done during routine visits and there are not enough medical centers or knowledgeable physicians to treat infected patients.

Limitations

Because the use of denial and minimization was the most recurrent theme in the study, it is possible that participants were withholding information, repressing psychological distress or minimizing the negative impact of the illness and social determinants of health during the interview. It is also possible that because interviews were conducted at the clinic, participants could have withheld or minimized negative information due to perceiving the interviewer as part of the staff at the medical center.

Even though interview questions were created in a format that would be easy for any individual from any education level to understand, it is possible that for those participants with only a few years of education or no formal education, some concepts such as coping, social barriers, etc. were difficult to understand; therefore, making communication less effective. In addition, given that the study was conducted at the only medical center that specializes in the treatment of Chagas in the country, results could not be generalized to other individuals infected with Chagas who are not being treated for the condition, or who do not have the same resources offered at the medical center. Perhaps individuals with fewer resources may report less effective coping strategies or greater physical, psychological, and social distress.

There were other limitations with regards to the characteristics of the sample. Because most participants were from El Salvador, it is possible that interviewing other people from other countries would result in finding other coping strategies or different perspectives on the impact of social determinants. Even though there was agreement among the participants on the major themes found in the study, the sample was small. It is possible that a larger, more diverse sample would yield more information about the impact of structural determinants and coping strategies. Lastly, the uneven number of males and female participants in the study impaired the ability to make comparisons about coping based on gender. In addition, comparisons based on age, income, education, and level of acculturation were not made in the current analysis.

Implications for Professional Practice

One of the contributions of this investigation was the attention paid to the individuals infected with Chagas and the illness in general. Given that Chagas is considered one of the neglected infections of poverty, an obvious need to address this issue is to increase awareness in the medical and general community and educate individuals about the illness (Hotez, 2008). Major changes would have to be done at the governmental level by putting policies in place that increase knowledge in the medical community in order to provide routine testing, open more clinics across the country, develop better drugs for treatment, and invest in research to develop a vaccine (Meymandi, 2009). However, more complex policies would need to be put in place in order to address the social determinants of health, such as unemployment, inadequate paid for people's jobs, lack of health care, discrimination, financial disparities that lead to overcrowding living conditions, among other socio-political aspects that produce social inequality and impact well-being.

Prior to this study there was no literature addressing coping strategies used by Latino adults infected with Chagas. The results of this study revealed some ways in which individuals cope with the illness. Some of these were similar to the way in which individuals with other chronic condition cope, while others coping strategies were more specific to Latino individuals coping with adversity, such as relying on family members and religious beliefs, and using denial and minimization. Some of the ways in which people would be able to counteract the impact of the social determinants of Chagas and thus cope more effectively with the illness would be by providing support to the families in a culturally appropriate way. For example, given that individuals prefer the use of secrecy, minimization, and denial, clinical staff should be trained to deliver diagnostic services in a culturally sensitive way. Asking patients about their preference to communicate to family members about the illness, and develop services such as support groups and educational workshops to increase individual's understanding of their condition and treatment. Another recommendation is to approach medical centers that offer health care to the Latino population and offer workshops about the illness, in order to increase awareness in the community. By educating individuals about the condition, they may become empowered to be advocates and promote early detection by encouraging others to get tested (Figure 3).

A recommendation for physicians is to create a safe and trusting relationship with the patients to make them feel secure about asking questions and answering any doubts they may have. A lot of times, participants avoid asking questions because of fear of being stigmatized or feeling embarrassed about their lack of understanding or because they see the doctor as an authority figure. Physicians should be aware of how these beliefs impact individuals' ability to understand the illness and comply with treatment.

Recommendations at the individual level include allowing individuals to make a decisions about the participation of family members in their treatment as sources of support and approaching religious communities to inform religious leaders so that they are informed about the illness and prepare to provide support to those who choose to seek emotional help from the church.

Another recommendation is to provide incentives to the individuals suffering from the condition to continue treatment. An example of how this could be done would be to allow those who have legal status to apply for disability, or receive a notice from the doctor so that they could take some days off from work during their treatment in order to cope better with the side effects of the medication.

The results of this study led to other recommendations, such as the need to offer psychological services to patients diagnosed with the condition. Given the collective nature of the Latino population, group therapy may be a particularly helpful strategy to address the psychological effects of the illness, as well as the impact of social barriers on these individuals. Mental health providers should act as advocates to address some of the social issues surrounding Chagas. Mental health providers could also act as intermediaries between the patients and the medical doctors to help patients to obtain referrals for social services and address some of their needs.

Recommendations for Future Research

Based on the results on the investigation, recommendations for future research are as follows:

(a) It would be important to conduct more qualitative and quantitative studies with individuals diagnosed with Chagas at the different stages of the illness in order to understand how the progression of the illness affects coping.

(b) Conduct a study with a larger sample that would compare individual's responses based on gender, age, education level, level of acculturation, and socio economic status could reveal interesting differences in the perception of the impact of the social determinants of Chagas and the use of coping strategies.

(c) It would also be important to measure the impact of social determinants of Chagas on individual's psychological well-being by using quantitative or qualitative measures of well-being.

(d) It would be important to investigate knowledge about Chagas disease in the medical community.

(e) Quantitative studies that investigate the different components of the social determinants of health and their impact on individual's health outcome could reveal important findings that would increase attention to the complexities surrounding Chagas and other neglected infections of poverty.

References

Abraido-Lanza, A. F. (2004). Social support and psychological adjustment among Latinas with arthritis: A test of a theoretical model. *The Society of Behavioral Medicine*, *27*, 162–171. doi:10.1207/s1532479abm2703_4

Abraido-Lanza, A. F., Guier, C., & Colon, R. M. (1998). Psychological thriving among Latinas with chronic illness. *Journal of Social Issues*, *54*, 405–424. doi:10.1111/j.1540-4560.1998.tb01227

Abraido-Lanza, A. F., Vasquez, E., & Echeverria, S. E. (2004). En las manos de Dios (In God's Hands): Religious and other forms of coping among Latinos with arthritis. *Journal of Consulting and Clinical Psychology 72*, 91–102. doi:10.1037/0022-006X.72.1.91

Ardon, L., & Mazariegos, L. (2007). *Control y prevención de la enfermedad de Chagas: Una experiencia de participación comunitaria para compartir. Proyecto de Control y Prevención de Chagas.* {Control and prevention of Chagas disease: An experience of community participation to share. control and Chagas prevention project}. San Francisco de Opalaca Intubuca, Honduras: Secretaria de Salud. Retrieved from: http://www.paho.org/hq/index.php?option=com_docman&task=doc_view&gid=15482&Itemid=1994&lang=es

Ashing-Giwa, K.T., Padilla, G.V., Bohorquez, D. E., Tejero, J.S., & Garcia, M.

(2006). Understanding the breast cancer experience of Latina women. Journal of *Psychosocial Oncology*, *24*, 19–52. doi:10.1300/J077v24n03_02

Briseño-León, R., & Méndez G, J. (2007). The social determinants of Chagas disease and the transformations of Latin America. *Mem Inst Oswaldo Cruz*, *102*, 109–112. doi:10.1590/50074.02762007.5000095

Buetow, S., Goodyear-Smith, F., & Coster, G. (2001). Coping strategies in the self-management of chronic heart failure. *Family Practice*, *18*, 117–122. doi:10.1093/fampra.

Butow, P. N., Coates, A.S., & Dunn, S. M. (2000). Psychological predictors of survival: Metastatic breast cancer. *Annals of Oncology*, *11*, 469–474. PMID: 10847468.

Commission on Social Determinants of Health (CSDH). (2007). *A conceptual framework for action on the social determinants of health. Discussion paper for the Commission on Social Determinants of Health.* World Health Organization. Retrieved from: http://www.who.int/social_determinants/resources/csdh_framework_action_05_07.pdf

Commission on Social Determinants of Health (CSDH). (2008). *Closing the gap in a generation: health equity through action on the social determinants of health. Final report of the Commission on Social Determinants of Health.*

Geneva, Switzerland: World Health Organization. Retrieved from: http://www.who.int/social_determinants/final_report/csdh_finalreport_2008.pdf

Collins, S., & Reynolds, F. (2008). How do adults with cystic fibrosis cope following a diagnosis of diabetes? *Journal of Advanced Nursing, 64*(5), 478-487. doi:10.1111/j.1365-26488.2008.04797.x

Coutinho, M. (1999). Ninety Years of Chagas Disease: A Success Story at the Periphery. *Social Studies of Science, 29*,4, 519–549. doi:10.1177/030631299029004003

Duncan, B., Hotz, V.J., & Trejo, S.J. (2006). Hispanics in the U.S. labor market. In National research Council (Ed.), *Hispanics and the future of America.* (pp. 228–290). Washington DC: *National Academies Press.*

Dunn, M. G., & O'Brien, K. M. (2009). Psychological health and meaning in life. Stress, social support, and coping in Latina/Latino immigrants. *Hispanic Journal of Behavioral Sciences, 31*, 204–227. doi:10.1177/0739986309334799

Gallo, L. C., Ghaed, S. G., & Bracken, W. S. (2004). Emotions and cognitions in coronary heart disease risk, resilience, and social context. *Cognitive Therapy and Research, 28*, 669–694. doi:10.1023/B:COTR.0000045571.11566.19

Gallo, L, C., Penedo, F. J., Espinosa de los Monteros, K., & Arguelles, W. (2009).

Resilience in the face of disadvantage: Do Hispanic cultural characteristics protect health outcomes? *Journal of Personality, 77*, 1708–1746. doi:10.1111/j.1467-6494

Green, J., & Thorogood, N. (2009). *Qualitative methods for health research.* Thousand Oaks, CA. Sage Publications, Inc.

Hotez, P. J. (2008). Neglected infections of poverty in the United States of America. *PLoS Neglected Tropical Diseases, 2*(6), e256. doi:10.1371/journal.pntd.0000256.

Hotez, P. J. (2011). Unleashing "Civilian Power": A new American diplomacy through neglected tropical disease control, elimination, research, and development. *PLoS Neglected Tropical Diseases, 5*(6), e1134. doi:10.1371/journal.pn td.0001134

Hotez, P.J., Bottazzi, M. E., Franco-Paredes, C., Ault, S. K., & Periago, M. R. (2008). The neglected tropical diseases of Latin America and the Caribbean: A review of disease burden and distribution and a roadmap for control and elimination. *PLoS Neglected Tropical Diseases, 2*(9), e300 doi:10.1371/journal.pntd.0000300

Hubbard, G., Backett-Milburn, K., & Kemmer, D. (2001). Working with emotion: issues for the researcher in fieldwork and teamwork. *Social Research Methodology, 4.* (2), 119–137 doi:10.1080/13645570116992

Hutton, J. M., & Perkins, S. J. (2008). A qualitative study of men's experience of myocardial infarction. *Psychology, Health, and Medicine, 13*, 87–97. doi:10.1080/13548500701294549

Jason, L.A., Taylor, R. R., Kennedy, C. L., Jordan, K., Song, S., Johnson, D. E., Torres, S. R. (2000). 'Chronic fatigue syndrome: sociodemographic subtypes in a community-based sample.' *Evaluation & the Health Professions, 23*, 243–263. doi:10.1177/01632780022034598

Kaltsouda, A., Skapinakis, P., Damigos, D., Ikonomou, M., Kalaitzidis, R., Mavreas, V., and Siamopoulos, K. C. (2011). Defensive coping and health-related quality of life in chronic kidney disease: a cross-sectional study. *BMC Nephrology, 12*, 12–28. doi:10. 1186/1471-2369-12-28

Kirmayer, J. L., Dandeneau, S., Marshall, E., Phillips, M., & Williamson, K, J. (2011). Rethinking resilience from an indigenous perspective. *The Canadian Journal of Psychiatry, 56*, 84–91. Retrieved form Pro Med website: http://www.ncbi.nlm.nih.gov/pubmed/21333035

Kreling, B., Selsky, C., Perret-Gentil, M., Huerta, E. E., Mandelblatt, J. S. (2010). 'The worst thing about hospice is that they talk about death': contrasting hospice decision and experience among immigrant Central and South American Latinos with US-born White, non-Latino cancer caregivers. *Palliative Medicine, 24*, 424–434. doi:10.1177/0269216310366605

Linley, A., Joseph, S. (2004). Positive change following trauma and adversity: A review. *Journal of Traumatic Stress, 17*, 11–21.

doi:10.1023/B:JOTS.0000014671..278567e

Major, B & Schmader, T (1998). Coping with stigma through psychological disengagement, in J .K. Swim & C.Stangor (Eds.), *Prejudice: The target's perspective. Academic Press* 219–241. doi:10.1016/B978-012679130-3/50045-4

Marin, G. & Marin, B.V. (1991). *Research with Hispanic populations*. Newbury Park, CA: Sage Publications.

McDonald, M. C. (2009, October) Identifying and addressing the social determinants of infectious diseases. Presentation at the National Summit on neglected infections of poverty in the United States, Washington, D.C.

Meymandi, S. (2009, October). Chagas disease: A community health perspective. Presentation at the National Summit on Neglected Infections of Poverty in the United States, Washington, D.C.

National Alliance for Hispanic Health (2008). Chagas disease initiative focus group report. Washington, DC: Doctors Without Borders. Retrieved from: http://www.doctorswithoutborders.org/events/symposiums/2009-dndi-treat-chagas/assets/files/NAHH_ChagasFinalReport.pdf.

Niederdeppe, J. Q., Bu. L., Borah, P., Kindig, D. A., & Robert, S. A. (2008). Message design strategies to raise public awareness of social determinants of health and population health disparities. *The Milbank Quarterly, 86*, 481–513. doi:10.1111/j.14680009.2008.00530.x

Njoku, M. G. C., , Jason, L. A. & Torres- Harding, S. R. (2005). The relationships among coping styles and fatigue in an ethnically diverse sample. *Ethnicity and Health,10*, 263–278. doi:10.1080/13557850500138613

Persson, L-O., & Ryden, A. (2006). Themes of effective coping in physical disability: an interview study of 26 persons who have learnt to live with their disability. *Scandinavian Journal of Caring Sciences, 20*, 355–363. doi:10.1111/j.1471-6712.2006.00418.x

Ray, O. (2004). How the mind hurts and heals the body. *American Psychological Association, 59*, 29–40. doi:10.1037/0003-066X.59.1.29

Riegel, B. & Carlson, B. (2002). Facilitators and barriers to heart failure self-care. *Patient Education and Counseling, 46,* 28 –295. doi:10.1016/S0738-399(01)00165-3

Sabogal F, Marin G, Otero-Sabogal R, Marin BV, Perez-Stable EJ. (1987). Hispanic familism and acculturation: What changes and what doesn't? *Hispanic Journal of Behavioral Sciences*, 9,397–412. doi: 10.1177/07399863870094003

Seligman, M. E. P. (2011). *Flourish. A visionary understanding of happiness and well-being*. New York, NY: Free Press.

Schmunis, G, A. (2007*).* Epidemiology of Chagas disease in non-endemic countries: The role of international migration. *Inst Oswaldo Cruz, 102, 75–85*. doi:10.1590/S0074-02762007005000093

Solar O, & Irwin A. (2010) A conceptual framework for action on the social determinants of health. Social Determinants of Health Discussion Paper 2 (Policy and Practice). Geneva: *World Health Organization.* Retrieved from:http://www.who.int/sdhconference/resources/Conceptualframeworkforactiononsdh_eng.pdf

Stimpert, K. K., & Montgomery, S. P. (2010). Physician awareness of Chagas disease, USA. *Emerging Infectious Diseases, 16*, 871–872. doi:10.3201/eid1605.091440

The World Health Organization. (2005). Reporte del grupo de trabajo científico sobre la enfermedad de Chagas. {Report of the scientific group about Chagas disease}. Buenos Aires, Argentina. Retrieved from: http://apps.who.int/tdr/svc/publications/tdr-research-publications/reporte-enfermedad-chagas.

The World Health Organization (2010). Neglected tropical diseases: Chagas Disease (American Trypanosomiasis). Retrieved from: hhttp://www.who.int/medicacentre/factsheets/fs340/en/index.html

Torres-Harding, S. R. Jason, L. A., & Taylor, R. R. (2002). 'Fatigue severity, attributions, medical utilization, and symptoms in person with chronic fatigue', *Journal of Behavioral Medicine, 25*, 99–133. doi:10.1023/A:10144850819995

Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, A., & Tsevat, J. (2007). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS and Behavior, 14*, 2, 379–389. doi:10.1007/s10461-007-9332-6

Tummala-Narra, P. (2007). Conceptualizing trauma and resilience across diverse contexts: A multicultural perspective. *Journal of Aggression, Maltreatment, and Trauma 14*, 2, 33–53. doi:10.1300/J146v14no1_03

Ungar, M. (2010). Families as navigators and negotiators: Facilitating culturally and contextually specific expressions of resilience. *Family Process, 49*, 421-435. doi: 10.1111/j.1545-5300.2010.01331.x

US Census Bureau. (2012). Statistical Abstract. Retrieved from: http://www.census.gov/newsroom/releases/archives/facts_for_features_special_editions/cb11-ff18.html.

Wertz, F. J., Charmaz, K., McMullen, L. M., Josselson, R., Anderson, R., & McSpadden, H. (2011). *Five ways of doing qualitative analysis. Phenomenological psychology, grounded theory, discourse analysis,* *narrative research, and intuitive inquiry*. New York, NY: The Guilford Press.

White, J., Hunter, M., & Holttum, S. (2007). How women experience myocardial infarction? A qualitative exploration of illness perceptions, adjustment and coping. *Psychology, Health, and Medicine, 12*(3), 278–288. doi:10.1080/13548500971288

Wilkinson, R., & Marmot, M. (2003). Social determinants of health: The solid facts. (2nd Ed). Copenhagen: Denmark. Retrieved from the World Health Organization. http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf

Zúñiga, C., Cury, D., Ponce, C., Sierra, M., de Margerie, G., Kojima, M.,...Gómez, J., (2008). Plan estratégico nacional de Chagas 2003-2007.{National strategic plan for Chagas 2003-2007}. *Dirección General de Salud. Programa Nacional de Control de la Enfermedad de Chagas*. Tegucigalpa: Republica de Honduras: Secretaria de Salud.

Figures

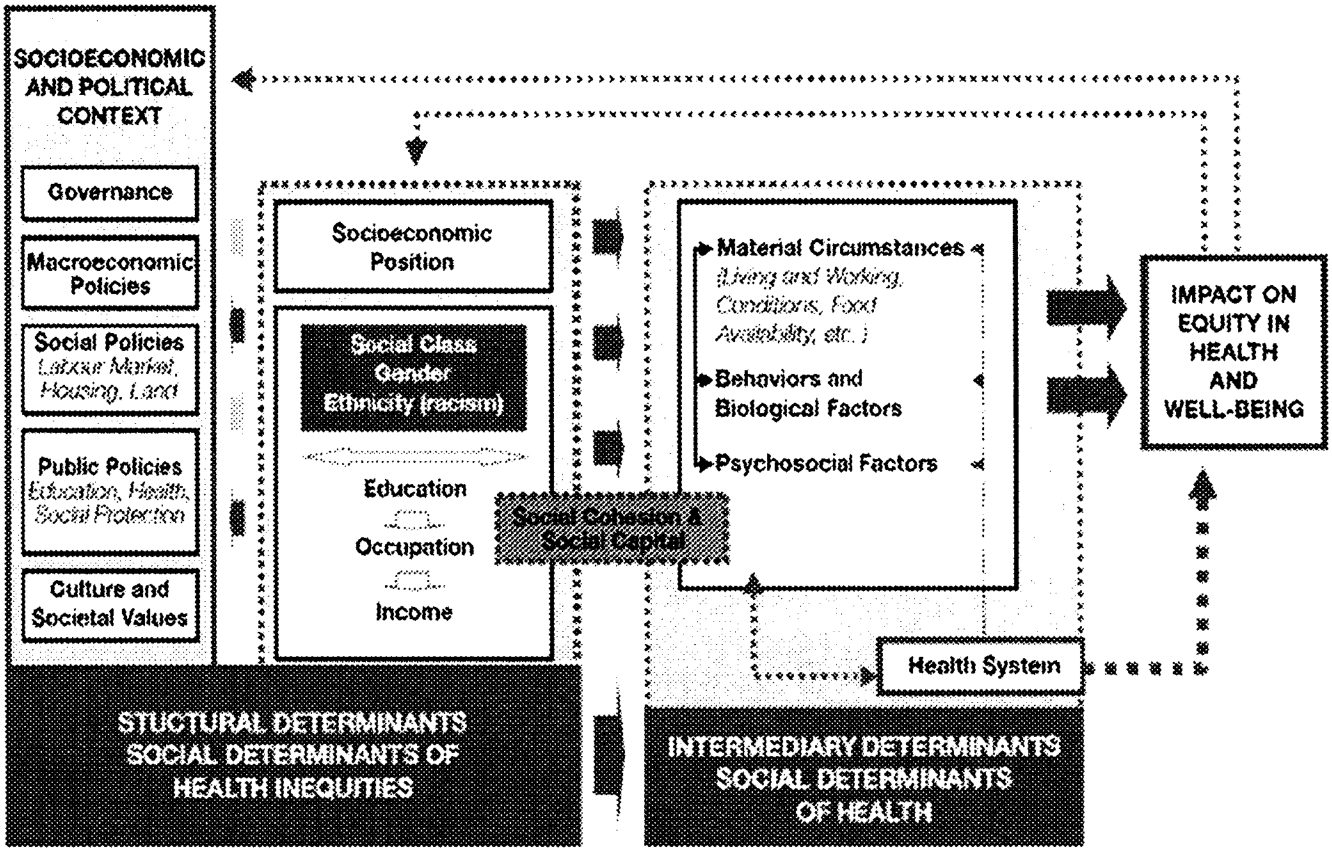

Figure 1. Social Determinants of Health Framework

Taken from: Conceptual framework for research and intervention to mitigate the impact of social determinants on health and well-being (Solar and Irwin, 2010). Published on the World Health Organization Website. Extracts of WHO information can be used for private study or for educational purposes without permission as stated in their website.

http://www.who.int/about/licensing/extracts/en/index.html

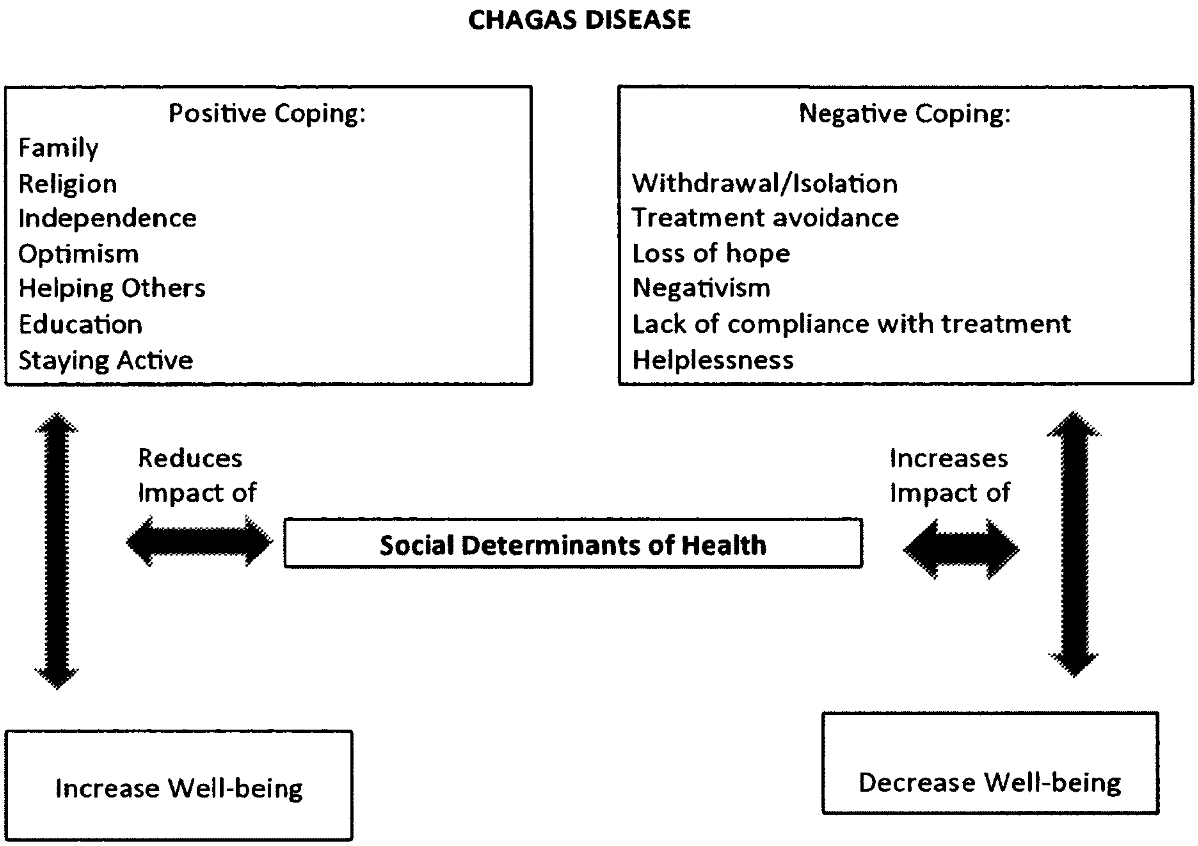

Figure 2. Social Determinants of Chagas Disease and their Impact on the Ability to Cope with the Illness in the U.S.

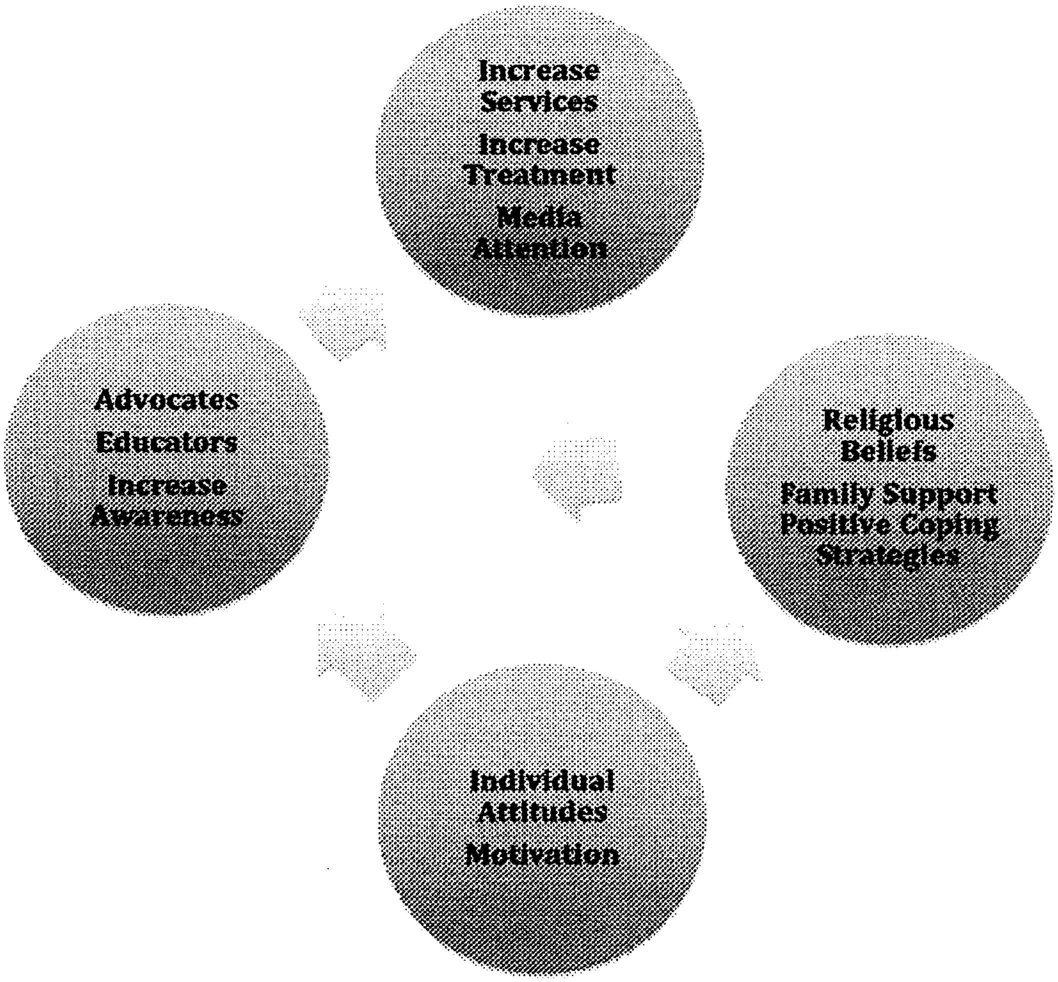

Figure 3. Impact of Coping on the Social Determinants of Chagas

Appendix A
Interview Script and Guide Questions

Introduction

Now that you have an understanding about the study, I would like to get to know you. Let's start by talking about your background.

About the Social Determinants of Health

Main question: Can you talk about you and your experience living in the U.S? Follow up questions may include those found in the demographic questionnaire. Other follow up questions may include:

Can you tell me about your job?
How is your schedule?
Do you believe you receive fair payment for your work?
Can you talk about how you live?
Can you tell me how do you get to work? (transportation access)
Could you talk about your diet?
How has your health been since you came to the U.S.?
In order to connect this information with the social impact I will ask:

How does your job, access to transportation, living conditions, diet, healthcare, etc. impacts your health?

About the Social Determinants of Chagas

Main question: Now can you tell me about how you contracted Chagas? How did you find out you have Chagas? What did you do after knowing you had that condition?

Follow up questions will include:
Can you tell me about how, when, and where you contracted the illness?
Can you describe your symptoms and your health in general?
What did you know about Chagas before you got infected?
What did you learn about Chagas after you sought medical help?
Did you seek help right away, if not, why did you wait?
Can you talk about how you access medical care when you found out that you had the illness?
Can you talk about your treatment? (Can they afford medications?)
Are you compliant with the medical treatment, if not what prevents you from following the doctor's recommendations?

What other things may affect negatively your ability to receive adequate medical care?

About Coping

Main questions: Can you talk about your experience coping with the illness? What have helped you cope with the illness?

Follow up questions may be:
Can you tell me in what ways has the illness affected your life? (What things are you able to do or not do as a result of the illness?)
What persons in your life have been of support to you?
What resources in the community do you have accesses to that have helped you cope with your condition?
What kinds of behaviors have helped you cope with the illness?

What aspects of your personal self, have helped you cope with Chagas?

What is your attitude about life?
What gives meaning to your life?
What is your attitude about the future?
In what ways do you think you have changed since you received the diagnosis?

As you think about going from day to day, what helps you?
(Cultural values, people, resources, religion?)

Do you have any other information that could help me understand your experience coping with the illness?

Thank you so much for your participation in this study, the information you provided is very valuable and it can help us assess and address the needs of individuals like you who have been dealing with this illness in the United States. Do you have any questions for me? Thank you very much.
Good bye.

Interview Script and Guide Questions Spanish

Introducción
Ya que usted ha entendido el propósito del estudio, me gustaría empezar a conocerlo/a. Empecemos hablando acerca de su información básica

Acerca de los Determinantes Sociales de Salud
Pregunta Principal: ¿Podría hablar acerca de usted y de su experiencia viviendo en los Estados Unidos?
Preguntas de seguimiento:

¿Podría hablarme acerca de su trabajo?
¿Cómo es su horario?
¿Cuál es su opinión acerca de su pago por el trabajo que hace?
¿Podría hablarme acerca de las condiciones en que usted vive?
¿Podría contarme como se transporta?
¿Podría hablarme acerca de su dieta?
¿Cómo ha sido su salud desde que llego a los estados Unidos?

Con el propósito de conectar esta información con el impacto social preguntare: ¿Cómo su trabajo, acceso a transporte, condiciones de vivienda, dieta, cuidado médico, etc. han impactado su salud?

Acerca de los Determinantes Sociales de Chagas
Pregunta Principal: ¿Ahora podría hablarme acerca de cómo contrajo la enfermedad? Como se enteró que tenía Chagas? ¿Que hizo después de que supo que tenía esta condición?
Preguntas de seguimiento:
¿Ahora podría contarme cómo, cuándo, y donde contrajo la enfermedad?
¿Podría describir sus síntomas y su salud en general?
¿Sabía algo acerca de Chagas antes de que contrajera la enfermedad?
¿Qué aprendió acerca de Chagas después de que busco ayuda médica?
¿Busco ayuda inmediatamente, si no, que lo/la hizo esperar?
¿Podría contarme acerca como acceso a cuidado médico cuando se enteró que tenía la enfermedad?
¿Podría hablar acerca de su tratamiento? (Puede usted cubrir los gastos de sus medicamentos?)
¿Sigue usted las recomendaciones de sus doctores acerca de su tratamiento, si no, que lo previene de seguir las recomendaciones de su médico?
¿Qué otras cosas afectan negativamente su capacidad de recibir el cuidado médico adecuado?

Acerca de Cómo Enfrenta la Enfermedad
Pregunta Principal: ¿Podría hablarme acerca de su experiencia enfrentando la enfermedad?
Preguntas de Seguimiento:
¿Podría decirme de que formas la enfermedad ha afectado su vida? (¿Qué cosas puede usted hacer o no hacer como resultado de la enfermedad?)
¿Qué le ha ayudado a enfrentar la enfermedad?
¿Qué personas en su vida le han sido de apoyo?
¿A qué recursos en la comunidad tiene usted acceso para ayudarle a enfrentar la enfermedad?
¿Qué tipo de comportamientos le han ayudado a luchar contra la enfermedad?

Que aspectos de su vida personal le han ayudado a enfrentar la enfermedad de Chagas?

¿Cuál es su actitud hacia la vida?
¿Qué le da significado a su vida?
¿Cuál es su actitud acerca del futuro?

¿Qué le ha ayudado en su día a día? (valores culturales, gente, recursos, religión)

¿Quiere compartir otra información que me pudiera ayudar a entender su experiencia enfrentando la enfermedad?

Muchas gracias por su participación en esta investigación, la información que nos compartió es muy valiosa y puede ayudarnos a evaluar y hacer algo al respecto de las necesidades de personas como usted quienes están luchando contra la enfermedad en los Estados Unidos.
¿Tiene alguna pregunta?
Muchas gracias.
Hasta luego.

Appendix B
Demographic Questionnaire

Please mark or fill in the blank the answer that best describes you.

Age______________

Gender ______________

Race/Ethnic Group______________

Country of Origin ______________

Marital Status: Single___________ Married_________ Divorced_________

Separated_________ Widowed, ____________Living with Partner_________

Number of people residing in the home____________________

Number of years residing in the United States _______________

Occupation:________________________

Religious____________ Non-Religious_____________

Education Level:
Never Attended School___________
Some Elementary Years___________
Completed Elementary Education _____________
Some High School _____________
Completed High School or GED _________
Some College___________________
College Graduate__________________
Post Graduate Degree (Masters or Doctorate)___________
Other, please specify: ____________________

Gross Income (Per Year):

Less than $10,000______ $10,000 to $20,000______ $20,000 to $30,000______

$30,000 to $40,000_______ More than $40,000_______

Insured___________________ Uninsured________________

Date of Diagnosis ___________________

Demographic Quetionnaire Spanish

Por favor marque o llene en la línea las respuestas que mejor lo describan.

Edad_______________

Genero _______________

Raza/Grupo Étnico_______________

País de Origen _______________

Estado Civil: Soltero____________, Casado__________, Divorciado_________,

Separado_________, Viudo _____________, Conviviendo con Pareja_________.

Número de personas viviendo con usted _____________

Número de años residiendo en Estados Unidos _______________

Ocupación: _________________________

Religioso_____________ No Religioso______________

Nivel de Educación: Nunca asistí a la escuela ____________
Algunos años de escuela elemental____________
Completo Escuela elemental (Primaria) _____________
Algunos años de Secundaria ______________
Completo la secundaria o GED __________
Algunos años de universidad___________________
Graduado Universitario __________________
Graduado de Postgrado (Maestría o Doctorado) ____________
Otro, por favor especifique _____________________

Ingreso Anual (Por año):

Menos de $10.000_______ $10.000 a $20.000______ $20.000 a $30.000_______

$30.000 a $40.000_______ Más de $40.000_______

Asegurado____________________Sin Seguro de Salud ________________

Año en que fue diagnosticado __________________

Appendix C
IRB Approval Letter

ADLER
SCHOOL

Nathalia Betancourt□Adler School of Professional Psychology 17 N.
Dearborn□Chicago, IL 60602

Dear Ms. Betancourt,

The Institutional Review Board evaluated the changes to your application, proposal **#12- 062**, *Understanding the Experience of Adults Coping with Chagas Disease*. Your application has now received **Full Approval**. This means that you may proceed with your plan of research as it is proposed in your application.

Please note that if you wish to make changes to your procedures or materials, you must provide written notification to the IRB in advance of the changes, co-signed by your Dissertation Chair, Dr. Moore. Such changes must be approved by the IRB prior to implementation. Good luck as you proceed with your research, and please feel free to contact myself or other IRB committee members should you have any questions.

Sincerely,

Catherine McNeilly, Psy.D., CADC□Core Faculty, Psy.D. Program in Clinical Psychology Chair, Institutional Review Board□Adler School of Professional Psychology

June 6, 2012

Catherine A. McNeilly, PsyD

17 N Dearborn Chicago, IL 60602

T 312-662-4000·**F** 312-662-4099 www.adler.edu

Appendix D
Consent Forms
Consent for Research Participation

Purpose

You have been invited to participate in a research study that aims to investigate the experience of individuals coping with Chagas disease. This investigation is part of a doctoral dissertation project conducted by the investigator Nathalia Betancourt from the Adler School of Professional Psychology and volunteer at Olive View-UCLA medical center. If you agree to participate, you will be asked to fill out a demographic questionnaire and participate in a 60 to 90 minute interview with the principal investigator.

Participant's Rights

Your participation in this study is completely voluntary. You do not have to answer any questions if you do not want to, and you can withdraw from the study at any point during the process. Regardless of your decision to participate, complete, or withdraw from the study, services you receive at Olive View-UCLA will not be affected. You also have the right to ask questions regarding the purpose of the study to the principal investigator, Nathalia Betancourt, or her dissertation Chair, Dr. Nataka Moore, or to Dr. Sheba Meymandi at Olive View-UCLA.

Confidentiality

All personal information obtained during the investigation will be kept confidential unless there is a risk to your safety or the safety of someone else, in which case the investigator will need to share the information with the appropriate authorities. Written documents, such as analysis or findings from the study will not contain identifiable information. As the principal researcher, Nathalia Betancourt is committed to privacy protection. Moreover, in order to protect the participant's privacy, HIPPA rules and regulations will be followed.

Procedures

During the interview, you will be asked to share your experience coping with Chagas disease. You will be asked questions about your life experience, working and living conditions, your beliefs, attitudes, cultural values, and support sources that have influenced or affected your ability to cope with the illness. The interview will be recorded and later transcribed with your permission. The interview can only be reviewed by Nathalia Betancourt or her dissertation chair, Dr. Nataka Moore. Translated documents and data obtained in Spanish will be reviewed by Dr. Alvarez and the principal investigator, Nathalia Betancourt. The documents filled out by you and the interview file will be kept in a safe place to protect your confidentiality. An ID number will be used to identify your information. The audio-recorded file will be erased after it has been transcribed, and the unidentifiable documents used for the analysis of the study will be kept for a period of seven years, as set forth by the American Psychological Association.

Possible Risks and Benefits

The only risk associated with your participation in this study is the possibility of psychological distress that may arise when recalling an emotional experience. There may not be a direct benefit from your participation in this study, but your participation will contribute to the knowledge of how individuals struggling with Chagas disease may perceive and cope with this condition. The information obtained in this study could promote better treatment for the patients infected with Chagas and greater attention to the personal, social, and psychological needs of individuals with the disease.

Compensation

By participating in this study, you will enter to win a 50 dollar Target gift card. A raffle will take place after all the interviews have been completed. ID numbers will be use to chose the winner and the researcher will match the ID number with the participant's name. The selected participant will be notified via phone, at which point the researcher will ask for his or her address. The card will be mail to the participant's mailing address.

Any questions about this study can be directed to Nathalia Betancourt at Nbetancourt@my.adler.edu 312-402-8160, Dr. Sheba Meymandi at Olive View-UCLA, Dr. Nataka Moore at Nmoore@adler.edu, or IRB Chair, Dr. Catherine McNeilly, 312-662-4347, cmcneilly@adler.edu.

By signing this form, I consent to voluntarily participate in this study, and I confirm that I understand the information above, and that I received a copy of this form.

Signature of the Participant	Date
Signature of the Investigator	Date
Signature of Dissertation Chair	Date

Consent Form (Spanish)
Consentimiento Para Participar en el Estudio de Investigación

Propósito
Usted ha sido invitado a participar en un estudio de investigación que tiene como objetivo investigar las experiencias de individuos con la enfermedad de Chagas. Esta investigación realizada por Nathalia Betancourt, voluntaria de Olive View-UCLA, es parte de un proyecto de grado para el programa de doctorado de Adler School of Professional Psychology. Si usted decide participar, se le pedirá que responda unas preguntas acerca de su experiencia de vida, y su información demográfica, y se le pedirá que participe en una entrevista con la investigadora que durara aproximadamente 60 a 90 minutos.

Derechos del Participante
Su participación en este estudio es completamente voluntaria. Usted no debe sentirse obligado a responder a ninguna pregunta si no desea hacerlo. Usted también se puede retirar del estudio en cualquier momento. Independientemente de su decisión de participar, completar, o retirarse del estudio los servicios que recibe en Olive View-UCLA no serán afectados. Usted también tiene derecho a preguntar cualquier duda sobre el propósito de la investigación a la investigadora principal Nathalia Betancourt o a su supervisora de tesis, la doctora Nataka Moore, o la doctora Sheba Meymandi en Olive View-UCLA.

Confidencialidad
Toda la información obtenida durante la investigación será confidencial a menos que haya un riesgo a su seguridad o la seguridad de otros. En tal caso, la información que usted comparta, tendrá que ser informada a las respectivas autoridades. Documentos escritos como los análisis o resultados de la investigación no contendrán información que lo pueda identificar. Como investigadora principal, Nathalia Betancourt está obligada y comprometida a garantizar la seguridad y confidencialidad de su información. Además para proteger su información, la investigadora seguirá las reglas y regulaciones establecidas por HIPPA.

Procedimientos
Durante la entrevista se le preguntara que comparta su experiencia enfrentando la enfermedad de Chagas. Se le harán preguntas acerca de experiencia de vida, sus creencias personales y culturales, sus actitudes, y fuentes de apoyo que han influenciado o afectado de forma positiva o negativa su habilidad para enfrentar la enfermedad. La entrevista será grabada y luego transcrita con su autorización. La entrevista solo podrá ser escuchada por Nathalia Betancourt o su supervisora de

tesis Dra. Nataka Moore. Los documentos que usted llene y el archivo que contiene la entrevista, serán guardados en un lugar seguro para proteger su confidencialidad. Los datos grabados en español o traducidos al español serán revisados por la investigadora principal Nathalia Betancourt o por la doctora Alvarez, miembro del comité. Un número de identificación será asignado para identificar su información. La grabación será borrada después de que haya sido transcrita, y los documentos utilizados para el análisis serán guardados por un periodo de siete años como es establecido por la Sociedad Americana de Psicología.

Posibles Riesgos y Beneficios
El único riesgo asociado con su participación en este estudio es la posible aflicción que pueda sentir al hablar de su enfermedad o recordar una experiencia emocional. Puede que no haya un beneficio directo como resultado de su participación en este estudio, pero su participación contribuirá al conocimiento acerca de como las personas infectadas con Chagas perciben y luchan contra la enfermedad. La información obtenida en esta investigación podría promover mejoramiento en el tratamiento de pacientes infectados con Chagas, y conseguir que se preste mayor atención a las necesidades personales, sociales, y psicológica de las personas que tienen esta enfermedad.

Compensación
Al participar en esta investigación usted entrara a participar en una rifa de tarjeta de regalo de 50 dólares de Target, la cual será enviada a la dirección del ganador después de haber sido seleccionado al azar. El número de identificación será utilizado para seleccionar el ganador y este será contactado por el investigador vía telefónica. El investigador solicitara la dirección del participante y la tarjeta será enviada a su dirección.

Cualquier pregunta acerca de esta investigación puede ser dirigida a Nathalia Betancourt, quien puede ser contactada en la siguiente dirección de correo electrónico Nbetancourt@my.adler.edu, o a la Dra. Sheba Meymandi en Olive View-UCLA, Dra. Nataka Moore, quien puede ser contactada en Nmoore@adler.edu, o la directora del comité de investigación, Dra. Catherine McNeilly 312-662-4347, cmcneilly@adler.edu.

Al firmar este documento, doy consentimiento de mi participación voluntaria en este estudio y confirmo que entendí la información explicada en este documento, y doy constancia de que recibí una copia del mismo.

______________________________ ______________

Firma del Participante Fecha

______________________________ ______________

Firma del Investigador Fecha

______________________________ ______________

Firma de la supervisora de Tesis Fecha