LATINA IMMIGRANTS, HIV, AND THEIR EXPERIENCES WITH HEALTHCARE PROVIDERS IN THE U.S. AND THEIR HOME COUNTRY

by

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The intersection of factors associated with immigration in the Latina population and available culturally sensitive health care has not been well examined. There is a scarcity of research available that examines factors specific to the Latina population that contribute to HIV/AIDS education, screening, and care, despite the vulnerable state of Latinas for contracting HIV/AIDS. For the Latina immigrant population, perceptions of U.S. providers of patients in relation to encounters with providers from their countries of origin are important, and may influence subsequent patient and healthcare provider interactions, including potential for screening, education, and care in the U.S. Two articles were completed for this study: (a) a systematic review of literature presented on the efficacy for using Latino community-based organizations as a more culturally appropriate and effective way to raise the awareness of need for HIV information and screenings with Latinas, and (b) a community-based participatory research study, pertaining to sexual health education and screening of Latina immigrants. Based on these findings, recommendations are made for researchers, healthcare providers, and policymakers who work with Latina immigrants seeking or in need of HIV/AIDS education, screening, or health care.

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DEDICATION

This I dedicate to you, my beloved Terry, my greatest sustenance. Since our destined meeting, so many years ago, we have been one another's secure base, that safe place to explore from. Our roots, grown and nourished in North Carolina clay-loam and sand, give us definition. My love of everything North Carolinian, I see in us: you, the dredger, coming from the docks, from the tiny tug-boat with your daddy, sun-drenched and needing sleep; and me, climbing down from those little tractors, covered in field dust, red from the sun, tired but sustained.

This large work, these pages that lay ahead, is a product of the pieces that are represented here: our North Carolina home; the edifying nature of our spiritual upbringing; the courageous, adventurous spirit and curiosity of immigrant people; the resolute instruction from this eastern North Carolina university that has been so kindly shared with me; and a large dose of determination that you encouraged and maintained in me throughout this process.

With you, my beloved, I share my home, my memories, children and grandchildren, and the days that still lay ahead. To you I dedicate this work, and say thank you, because without you it would have never begun.

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I would also like to express my large indebtedness to Juvencio Rocha-Peralta, executive director of the Association of Mexicans in North Carolina, Inc. (AMEXCAN), the Promotoras y Promotores for Social Justice, and the many members of the AMEXCAN organization who helped with this project in many and varied ways. Juvencio has been my dear friend for many years, has served as my mentor, and more recently served as my research collaborator. His persistent dedication to eastern North Carolina communities extends beyond the Latino community. Juvencio, the Promotoras/es, and the AMEXCAN members remind me that when we work together, we can make great and beautiful things happen.

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Finally, I am especially grateful to the women who gave their time and their stories, and placed their trust in me and in this research team. Their stories give us a closer look at how sexual health care is experienced by Latina immigrants, and through their efforts they help us improve health care for so many others.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

PREFACE

I have grown up in eastern North Carolina (N.C.), and have lived in various eastern N.C. counties for all of my life. I grew up primarily in the rural poverty of Vance County, and have seen many people suffer from health disparities due to a lack of resources, or barriers to resources. My father was diagnosed with paranoid schizophrenia when I was an adolescent. Few people were aware of this type of mental illness in my community, and resources for screening and treatment were scarce. My father displayed paranoia, as well as symptoms of dissociating. When he would dissociate and become paranoid, and his thoughts become disordered, he would act as though he were a different person, often becoming violent. I, and my mother and siblings, feared for our lives. While no one in our community recognized the mental illness my father lived with, or understood the dangers we faced, we were provided with no support. We were initially ostracized from family and others in the community; no one could accept our explanations of his mental illness. Eventually, things changed and people began to acknowledge his illness, giving us limited support in getting him help. However, the scars of the prejudices and essential abandonment stayed with me.

I now feel a deep sense of empathy for others who are ostracized by a community; and I appreciate the determination that it takes a person to overcome unusual hardships in order to make their life, as well as their relationships with family better. Many of the Latinos that I have grown to know, share with me their own stories of danger in their home communities, and discuss with me their determination to move forward and provide a safe and nurturing place for their children. While I am not Latino and have not directly experienced many of the challenges that they have shared with me, I understand the feelings associated with fear, a lack of safety, a need for a caring community, and a desire for a sense of belonging.

I have seen poverty. I have experienced fear for my own safety and the safety of my family. I have experienced a great sadness watching my father become more lost in the depths of his mental illness due to barriers in accessing health care in the rural community we lived in, and I understand from personal experience the feelings of isolation and pain that is encountered when a community essentially discards you. Furthermore, and perhaps more importantly, I recognize the strength of spirit and character that comes with such adversity. I appreciate these things that I see in the Latino immigrant population that I have encountered.

It has been my own personal experiences that have given me the drive and determination to seek education, first in marriage and family therapy, and now in the field of Medical Family Therapy. I believe that we all have a right to health care, and that good health is the product of the integration of biological, psychological, sociological, and spiritual wellbeing. My interest in working with the Latino population is primarily from admiration for people who have faced hardships and found strength through adversity in order to make a better life for themselves and their family. It is all of these things that add to my desire to conduct research, write grants, promote clinical services, and offer international collaborations with this group in addressing healthcare needs.

CHAPTER 1: INTRODUCTION

Precis

During the past half century, communities have experienced a variety of epidemics, but few diseases have had the devastating impact on morbidity and mortality as the human immunodeficiency virus (HIV). The global transmission of this disease has been perpetuated, in part, by the ease of long distance travel and migration (Decosas, Kane, Anarfi, Sodji, & Wagner, 1995; Magis-Rodriguez et al., 2004; Xu, Zu, Zheng, Xu, & Liu., 2014). Researchers have provided evidence that Mexican migrants who come to the United States (U.S.) to live and work are at a higher risk for contracting HIV, than Mexicans who live and work in their homeland (Magis-Rodriguez et al., 2009). When surveillance data was initially collected in Mexico in 1983, all HIV positive cases that were recorded in Mexico were individuals who had at some point lived in the U.S. (Magis-Rodriguez et al., 2009), suggesting a link between HIV transmission and the migratory process. Throughout the 35 years since the virus was first identified, the disease course of HIV changed from a terminal diagnosis to that of a chronic disease for those who were able to access treatment. Given the increase in migration from Mexico to the U.S., as well as the increase in risks of HIV for the Latino migrant populations, this community-based participatory research study will focus mostly on changes, concerns, and strengths pertaining to the screening and treatment for HIV among Latino immigrants. Additionally, because the presence of a sexually transmitted infection (STI) correlates with an increased likelihood to become infected with HIV, which is itself an STI (CDC, 2015), discussions will in some cases include information pertaining to STIs as well. However, the main focus of this research will be on HIV. The term “migrant” is used in this dissertation to refer to individuals who have moved from Mexico, or a country in Central or South America, to live and/or work in the U.S. for a limited or undefined period; and the term “immigrant” is used to refer to any individual who has moved from their country of origin and settled permanently in the U.S. In this chapter, a brief overview of the dissertation is provided along with highlights from past research, in order to demonstrate a unified purpose for the dissertation study. Subsequent recommendations are also provided in order to address gaps in the literature.

Changing Migration/Immigration Patterns

The U.S. was built as a consequence of the endeavors and labor of individuals representing many immigrant cultures during the colonial period and the years of reconstruction that followed the Civil War. During the period of reconstruction, the southern region of the country aggressively pursued the hiring of an immigrant labor force (Berthoff, 1951). Few immigrants, however, moved to the southern area of the country as permanent residents (Berthoff, 1951), primarily due to a lack of economic opportunity at that time (Bankston, 2007). In fact, during the period when the U.S. experienced massive waves of immigration (1880-1920) only 2.5% of foreign born individuals resided in the South (Bankston, 2007), compared to 13% to 15% of immigrants who lived in the U.S. as a whole (Terrazas & Batalova, 2010). Immigration in the U.S. and other countries waxed and waned in accordance with economic circumstances. As conditions deteriorated in some areas of the world, and American labor needs increased, immigration provided a convenient and timely answer to a dynamic situation (Bankston, 2007).

By the late 1930's, the economic situation in Mexico was worsening and employment in that country was difficult to secure (American Experience, n.d.). When the U.S. entered World War II in 1942, another call came from the American agricultural industry for immigrant laborers (American Experience, n.d.). This call initiated the Bracero Program which offered the contract employment of Mexican men and laborers by U.S. farmers and became the precursor to later Mexico-U.S. migration policy (Philip, 2006; Vialet, 1980).

Latinos who immigrated to the U.S. did not come exclusively from Mexico. Some individuals migrated from countries south of the Mexican border (e.g., El Salvador, Guatemala, Honduras) and entered the U.S. illegally, although they were presumed to have entered the U.S. through Mexico (Bankston, 2007) and thus assumed to be authorized to enter the country through the Bracero Program. When the program officially ended in 1964, many of the migrant workers remained in the U.S. in an unauthorized status (Philip, 2006).

Increasingly, Latinos have been migrating to the southern region of the country (Mather & Pollard, 2007). Whereas the fastest growth has occurred in large metropolitan areas, large numbers of Latinos are now settling in small towns and rural areas (Mather & Pollard, 2007). By early 2000, many Latino immigrants had become residents of North Carolina (N.C.) (Weeks, Weeks, & Weeks, 2007; Torres et al., 2003), with the Latino population in N.C. increasing by more than 111% during the decade of 2000 to 2010 (Passel, Cohn, & Lopez, 2011). Reportedly, the highest percentage of Latinos living in N.C. are in small towns and rural areas (Chesser, 2012), areas that are known to suffer a shortage of resources, such as health care (North Carolina Department of Health and Human Services [NCDHHS], 2013). In 2013, Latino and Hispanic populations were estimated to comprise about 8.9% of the N.C. state population (U.S. Census). Some cities within N.C. reported growth in the Latino population as high as 1180%, with most of this growth occurring between 1990 and 2000 (Weeks et al., 2007). In fact, Weeks et al. (2007) reported that three of the four "hypergrowth" (p. 51) Latino destination cities were located in the state of N.C. These new patterns of immigration and subsequent increase of Latino residents in N.C. found the state unprepared to meet the healthcare needs of the immigrant communities (Weeks et al., 2007), particularly in relation to HIV infections among Latinos.

HIV Infection Concerns for Latinas

Patterns of immigration have not been the only thing to change. Patterns of HIV incidence rates have also been changing with time. It is estimated that there are more than one million people in the U.S. who are living with HIV (CDC, 2012). With the establishment in 1995 of highly active anti-retroviral treatment (HAART) for people living with HIV, mortality rates between 1995 and 2002 from acquired immunodeficiency syndrome (AIDS), the most advanced stage of HIV, have declined (Holtgrave, 2005). The estimated incidence of HIV within the U.S. has been relatively stable since this time, but changes have occurred in HIV incidence within and between diverse sub-populations in the U.S. (AIDS.gov, 2009).

Between racial categories (Black, White, Latino/Hispanic), the greatest affliction continues to be among Blacks. Representing only 12% of the total U.S. population, Blacks represent an estimated 44% of all new infections (CDC, 2014). The highest rates of new infection in men across all three racial categories are among men who have sex with men (MSM), however, new infection rates among women across all three racial categories are primarily among heterosexuals, with 84% of new infections attributed to heterosexual contact and 16% attributed to injection drug use (CDC, 2014). While Blacks continue to bear the largest number of infection rates among racial and ethnic groups, HIV infection rates among Latinos are gaining increasing attention.

Latinos comprise nearly 17% of the U.S. population; yet disproportionately represent 21% of all new HIV diagnoses (U.S. Census, 2015). There has recently been an 8% increase in Latinos living with an HIV diagnosis, compared to a 7% increase among Blacks, and a 5% increase among Whites (Kaiser Family Foundation, 2014). The CDC estimates that 79% of new HIV infections in the Latino or Hispanic population occur in MSM (CDC, 2013). Many Latino migrant men identify as heterosexual, but resort to sexual relations with other men due to loneliness, isolation, and lack of access to female partners (Magis-Rodriguez et al., 2004), thus making their or other female partners especially vulnerable to the likelihood for infection upon intercourse or reunification with a male migrant or seasonal working partner.

Not only do HIV disparities exist among various racial and ethnic groups, but regional differences and differences between sexes also occur among those who are infected with HIV (CDC, 2012). Both the number of individuals diagnosed with HIV, as well as the rate of HIV diagnoses are highest in southern U.S. states (CDC, 2014). According to the CDC (2012), incidence rates as well as the risk factors that are attributed to diagnosed HIV infections among Latinos, vary from region to region. Traditionally, the "U.S. South" comprises 17 states situated in the south and southeastern region of the U.S. (Zhang, McGoy, Dawes, Fransua, Rust, & Satcher, 2014). In 2010, 46% of all new HIV diagnoses were in the South, despite the fact that this region represents only 37% of the U.S. population (Zhang et al., 2014). In the 46 states reported on by the CDC (2012), the greatest percentage of Latinos with new HIV diagnoses resided in the South, compared to other regions of the US. Furthermore, researchers have noted that Latinos who resided in rural areas as opposed to urban areas had a shorter HIV to AIDS interval, suggesting less access to and /or differing qualities of health care (Espinoza, Hall, & Xiaohong, 2012). While male to male sexual contact is the main mode of transmission of HIV infection, and the predominate mode of transmission within the Latino population living in the South (CDC, 2013), Latino women remain especially vulnerable to HIV transmission via heterosexual contact (CDC, 2010).

Within the U.S., the rates of infection for Latinas are more than four times that of White non-Hispanic women (CDC, 2015). According to the 2012 N.C. epidemiologic profile, Latina immigrants living in N.C. had the highest proportion (40.9%) of HIV infection and presented late for treatment (5 to 7 years after infection) (NCDHHS, 2012). According to CDC reports (2011), Latinas are among the fastest growing population for developing AIDS in the U.S., yet the complex dynamics that put or keep Latinas at risk remains unclear.

In summary, the impact of the HIV/AIDS epidemic has been influenced by changing patterns of immigration (Decosas et al., 1995; Magis-Rodriguez et al., 2004). Though there has been recent progress in combating the disease, with incidence rates in the U.S., stable, regional and sex differences have become a concern (CDC, 2013; Magis-Rodriguez et al., 2004; Zhang et al., 2014). The recent inflation of Latino immigration in N.C. has stressed limited resources (NCDHHS, 2013; Weeks et al., 2007), and has become cause for concern due to a variety of factors that increase the risk of HIV infection within the Latino population (Hirsch, Higgins, Bentley, & Nathanson, 2002; Magis-Rodriguez et al., 2004; Magis-Rodriguez et al., 2009). There is a scarcity of research available that examines factors specific to the Latina population that could contribute to HIV infection rates in this vulnerable population. The intersection of factors associated with immigration by the Latina population in N.C. and the availability of culturally sensitive health care generally and HIV care specifically has not been well examined. Given the infectious nature of HIV, changing patterns of immigration, and patterns associated with HIV infection rates within the Latina population, this study will provide a closer look at potential barriers to sexual health care, HIV prevention screenings, and treatment within the Latina population. Specifically, patient and provider interactions will be explored for relevance to Latinas' access to sexual health care including HIV education and screenings. When addressing the biological realities of an HIV infection, or when considering the biological potential for an STI, it is imperative to include greater systemic views that go beyond the biological (i.e., the psychological, sociological, and spiritual) (Engel, 1980; von Bertalanffy, 1973; Wright, Watson, & Bell, 1996). Given that the Latina population is an immigrant population, perceptions of previous experiences that have occurred between patient and provider from country of origin, as well as country of immigration are important, and may influence subsequent patient-healthcare provider interactions.

Purpose

The purpose of this research is to explore Latina immigrants' experiences with completing a screening and/or assessment with healthcare providers in their home country and the U.S., particularly regarding sexually transmitted infections or diseases. An additional objective is to cultivate a broader awareness of how the immigration process contributes to HIV infection risks for Latinas, and to promote a greater understanding of how cultural experiences influence Latinas' decisions regarding HIV prevention and treatment. I also strive to share this learning process with the Latino community members in order to foster a co-learning environment, and empower the community through the research process to have the capacity to act independently in matters of their own health. It is through a review of the literature, a systematic review, and a community-based participatory qualitative research study that these objectives will be pursued. This dissertation captures the three-year journey of a research partnership that began in September of 2012 with the identification of HIV as the health issue to be investigated, and continued through September of 2015 with the dissemination of results and a call to action for addressing issues that emerged from the qualitative study.

In starting a doctoral program in Medical Family Therapy, my vision was to commit my time and knowledge to the health and health care of underserved populations. My initial passion for research was to better understand the healthcare needs of immigrant communities who straddle two countries, two cultures, and two systems of health. However, over time I learned through my medical family therapy research and policy training and through hundreds of hours embedded in underserved communities, how to develop research that makes a direct impact on a community of interest (e.g., in this case Latina's experiences with healthcare providers in relation to their sexual health). My training and experiences have allowed me the opportunity to develop this dissertation in collaboration with community leaders, health ambassadors, and Latinos and Lantinas who became directly and indirectly involved in the development, implementation, and dissemination of the research from this dissertation. As such, the term "we" is used throughout the dissertation, to convey the representation of the community partnership (i.e., the collaboration between university researchers and community partbers) utilized in this dissertation.

In Chapter 2, an in-depth review of the literature is provided regarding the history of immigration between the U.S. and Latin America, the history of HIV/AIDS in the U.S., and the intersection of the migration process with HIV/AIDS. Critical theory is described in this chapter as a useful lens in understanding the relationship between the immigration process and healthcare experiences in relation to HIV and other STIs. Specifically, critical theory, embraced by Habermas, emphasizes a moral argument based on reason (Habermas, 1987). Habermas, sociologist and philosopher, argued that human beings are capable of reasoning, and possess the communicative competence to develop mutual understanding, arriving at a more humane, just, and equalitarian society (Habermas, 1987). From this perspective, society is able to "unmask the institutionally anchored distortions" and its people "from all ideological delusions" (McCarthy, 1989, p. 88). Given the relevance of these theoretical elements (i.e., human reasoning that aims to develop a more humane, equalitarian society) to HIV and other STI screenings for Latinas, critical theory is employed to guide the reader through this research, and bring attention to the social and economic structures that impede progress toward eliminating health disparities in HIV/AIDS.

In Chapter 3 of this dissertation a systematic review is provided as an overview of the effectiveness of Latino community-based organizations in reaching the target population to increase access and adherence to sexual health care that addresses prevention and treatment of HIV within the Latino community. Eight studies meeting inclusion and exclusion criteria are compared and contrasted. Strengths and limitations of community-based research are discussed. This chapter concludes with recommendations to researchers, as well as healthcare providers, regarding HIV research that uses a community-based participatory research approach with Latinos.

Chapter 4 includes the methodology for this qualitative study. A community-based participatory research (CBPR) framework (Israel, Eng, Schulz, & Parker, 2013) was employed to explore the research question: *What are Latina immigrants' experiences with healthcare providers in their home country and the United States?* It should be noted that this question was intended to be broad enough to capture the lived experiences of Latina immigrants who had received health care in their home country and the U.S., however it was also presumed that most experiences would be in the context of obstetric or gynecologic health care given that these health matters are what most commonly bring Latina's to healthcare contexts and providers. Members of the CBPR research team (consisting of bi-lingual researchers who received training from the principal investigator [PI]) recruited participants from the community and conducted individual in-depth interviews, which were transcribed verbatim by an independent professional. In collaboration with trained team members, transcripts were analyzed using Giorgi's phenomenological method of analysis (Giorgi, 2009). The research process closely followed the tenets of CBPR (Israel et al., 2013).

Chapter 5 is a manuscript that extends the results of a CBPR study, using a phenomenological design, with a sample of Latina immigrant women. This study was based on the sample's experiences with healthcare providers in the U.S. and their home country, particularly in relation to sexual health needs, including HIV screening and treatment. The PI and CBPR team coded the interview transcripts using Giorgi's method of analysis (Giorgi, 2009). Seven revelatory themes were identified and discussed. The research team closely followed the CBPR core concepts throughout the study. Qualitative results, as well as clinical, research, and policy recommendations were offered at the conclusion of this study.

The dissertation concludes with a policy brief (Chapter 6) that offers research informed recommendations, based on the findings from Chapter 5, guiding a call-to-action for establishing a code of ethics for healthcare interpreters. Multiple comments were given throughout the interviews in Chapter 5 that eluded to concerns pertaining to ethical dilemmas when interpreters or promotoras de salud were used as part of the healthcare visit. These responses were so compelling, that a call to action was constructed. This call to action provides support for healthcare systems (who are federally mandated) to offer ethical language services from competent promotoras, in order to aid healthcare providers in extending quality health care to Latino patients. Grounded in the philosophical underpinnings of critical theory (McCarthy, 1989), as well as the philosophy of CBPR (Israel et al., 2013), recommendations are provided for researchers, providers, and communities to build an infrastructure, whereby clinical patients (as well as research participants) are not exploited by hierarchical differences in health care or research systems. Nor is their confidentiality or anonymity at risk when engaging in necessary healthcare visits or potentially beneficial research studies.

Through the commitment of a community of citizens and a community of scholars, this dissertation serves as a reminder to patients, providers, researchers, and policy makers that culturally informed care can be co-constructed, practiced, researched, analyzed, and then reported back to the communities of interest. Together these communities can reduce the needless disparities that exist between Latinas and other populations in relation to sexual health care, HIV screenings, and HIV treatment.

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CHAPTER 2: A HISTORY OF IMMIGRATION AND HIV

"*We live in a completely interdependent world, which simply means we cannot escape each other. How we respond to AIDS depends, in part, on whether we understand this interdependence.*"

~Bill Clinton, former U.S. President

"*Recognize yourself in he and she who are not like you and me.*"

~Carlos Fuentes, Mexican writer

As international interactions become more common place, and boundaries between societies more porous, the containment of infectious diseases becomes more exigent. The infectious nature of one such disease, the human immunodeficiency virus (HIV), has proven to be obstinate and challenging due to a variety of factors (CDC, 2013), including the ease of travel and migration of people who are likely unknowing carriers (Wilson, 1995). Throughout history, people have migrated within and between various communities in pursuit of employment, education, and other opportunities; however, this mobility further complicates attempts to end or at least contain health risks such as HIV (Wilson, 1995). With this in mind, it is important that we have a clear understanding of the risks and vulnerabilities that emerge via the process of migration, particularly attending to factors that can further complicate matters of health and illness. As such, the purpose of this chapter is to provide (a) an overview of critical theory, a foundational lens to unveiling the social and economic inequalities that exist for today's immigrants, (b) a history on the process of immigration from Latin America to the U.S., (c) a description of the health disparities for Latinos in the U.S., (d) common barriers to prevention and treatment for HIV among Latinos, and (e) recommendations for future researchers and clinicians. However, operational definitions and prevalence trends are provided first, to set the stage for the review of this literature.

Historically considered to be a country of immigrants (Agnew, 2013), the United States (U.S.), not surprisingly, has more foreign-born residents than any other country, at 45.7 million (United Nations, 2013). The United Nations Educational, Scientic and Cultural Organization (UNESCO, n.d.) defines *migrant* as "any person who lives temporarily or permanently in a country where he or she was not born, and has acquired some significant social ties to this country. *Immigrant* is defined by the Office of Economic Co-operation and Development (OECD, 2003) as an individual who is “foreign born”; and *immigration* as “movements of people into…a specific country or countries (OECD, 2013). As such, immigration is a multi-faceted process involving movement between societies and cultures. It is a process that can bewilder established social structures and tax limited resources, particularly within the health care arena (Okie, 2007; Weeks, Weeks, & Weeks, 2007). Traditional infrastructures become inadequate when a population increases suddenly and unexpectedly, which is currently happening in some areas of the southern U.S. since early 1990s (Passel, Cohn, & Lopez, 2011). Challenges are further complicated when the language of the immigrant population is underrepresented in health care (Flores, 2006). In fact, researchers have found that language is a barrier to health care within the Latino immigrant population (Branch, Harvey, Zukoski, & Warren, 2010). Here we use the term *Latino* to depict a person of Latin American descent “of South Ameircan, Central America, Mexico, Cuba, the Dominican Republic, or Puerto Rico” (Foster, 2009). It has also been documented that Latino immigrants who are in the U.S. without authorization use the healthcare system less frequently than their non-Latino counterparts (Ortega et al., 2007; Stimpson, Wilson, & Eschbach, 2010). Consequently, not seeking health care often translates to late diagnoses for diseases such as HIV, a potential contributor to health disparities (CDC, 2011; Dennis, Napravnik, Seña, & Eron, 2011).

While 35.3 million people are living worldwide with HIV, an estimated 220,000 HIV positive Latinos live in the U.S. (CDC, 2013). The disparity in HIV rates of infection between Latinos and Whites in the U.S. has been researched and documented (CDC, 2015), and has been attributed in part to barriers blocking access to health care (e.g., language, transportation, documentation status, lack of insurance) (Branch et al., 2010; North Carolina Rural Communities Assistance Project, Inc. (NCRCAP), 2002). Additionally, researchers exploring costs associated with HIV or acquired immunodeficiency syndrome (AIDS) in the U.S. have found more medical costs incurred by Whites than any other racial group, yet productivity losses (e.g., missed days of work due to illness) were highest for Latinos (Hutchinson et al., 2006), further highlighting the disparities. Researchers attributed these disparities to late diagnoses, delays getting into care, and not having access to antiretroviral (ART) treatment (Hutchinson et al., 2006). Furthermore, recent shifts in the immigration patterns from traditional states (e.g., Texas, Arizona, California) toward the southeastern region of the U.S. has created new challenges for some of the South (Dennis et al., 2011; Weeks et al., 2007).

Traditionally, the U.S. South is recognized as consisting of 17 states situated in the south and southeastern regions of the U.S. (Zhang, McGoy, Dawes, Fransua, Rust, & Satcher, 2014). In 2010, 46% of all new HIV diagnoses were in the South, despite the fact that this region only represents 37% of the U.S. population (Zhang et al., 2014). According to the CDC (2012), the greatest percentage of new diagnoses among Hispanics/Latinos was in the South. Recently, North Carolina (N.C.) has experienced changes in immigration patterns. From 2000 to 2010, N.C. has seen an increase in the Latino population of more than 111% (Passel, Cohn, & Lopez, 2011). The dynamics that make up this percentage are continuously shifting because of new and emerging phenomena regarding migration patterns (Weeks et al., 2007). More specifically, in the past, men would leave their family or community to find work (Weeks et al., 2007). Now, it is more common to find *Latinas* (the feminine form of Latinos) migrating to follow their partners or entire families immigrating together (Ayers, 2013). At the same time, the incidence rate for HIV/AIDS cases increased as well, from 1% of Hispanics/Latinos in N.C. reported in 1995 (North Carolina Department of Health and Human Services [NCDHHS], 2000) to 8% of Hispanics/Latinos in N.C. in 2009 (NCDHHS, 2010). Researchers have only begun to look at these new patterns, but the emerging picture is one that highlights Latinas as being particularly vulnerable to contracting HIV, given risk factors associated with her partner or experiences of assault and rape during or after her immigration process (Peragallo, Deforge, Khoury, Rivero, & Talashek, 2002; Persichino & Ibarra, 2012).

As such, the remainder of this chapter is intended to highlight the interdependency between the U.S. and Latin America regarding the immigration process, to emphasize how immigration and HIV/AIDS interface, and to punctuate ineffective social structures (e.g., healthcare systems) that have been taxed with meeting the healthcare needs of Latino immigrants in the South, specifically in N.C. While much of the existing literature on immigration and HIV/AIDS between Latin America and the U.S. addresses Latinos as a homogenous population, this chapter will culminate with a specific emphasis on the vulnerable state of Latinas. Also, this review will address the healthcare needs specific to Latina immigrants and punctuate the need to explore other factors that might add to our understanding of barriers to health care and poor rates of adherence to treatment in this population. Additionally, critical theory will be employed to highlight existing social and economic inequalities given the history of immigration between Latin America and the U.S. This theory will also aid in emphasizing the need for liberating endeavors.

Critical Theory

The historical context that the U.S. shares with the countries of Latin America is extensive (Chambers, Grew, Herlihy, Rabb, & Woloch, 1987; Fernandez-Armesto, 2014; Goldfield et al., 2004) and riddled with outcomes (e.g., colonization and enslaving of indigenous peoples) that seem principally unjustified (Chambers et al., 1987; Fernandez-Armesto, 2014). Early American history began with powerful ethnic groups dominating land mass and exerting control over less powerful ethnic groups (Chambers et al., 1987; Fernandez-Armesto, 2014; Goldfield et al., 2004). The resulting societal structures and social positions continued to support the dominant race, while holding stagnant and less empowered the state of minority cultures and ethnicities (Fernandez-Armesto, 2014; Habermas, 1981, 1984), . Critical theory (Habermas, 1981, 1984) provides us with a lens that highlights unjust power structures, and brings attention to the need for emancipatory endeavors (e.g., advocacy toward political movement) (McCarthy, 1989).

According to the critical theory of Habermas (1981, 1984), *emancipatory knowledge* is self-reflection that produces a liberation from such social forces as institutions or environmental forces that stand to limit the control we have over our own lives. Critical theory, as espoused by Habermas, is rooted in Kantian ideas, which become evident through Kant's thoughts on Enlightenment:

> Enlightenment is man's release from his self-incurred tutelage. Tutelage is man's inability to make use of his understanding without direction from another. Self-incurred is this tutelage when its cause lies not in lack of reason but in the lack of resolution and courage to use it without direction from another. *Sapere aude!* 'Have courage to use your own reason!'—that is the motto of enlightenment (Kant, 1784, 1963, p. 3).

This self-reflection leads to critical self-awareness, which leads to emancipation from forces that limit options and rational control over one's own life (Habermas, 1981, 1984). Critical theory was used as the guiding framework of this compilation of literature in order to highlight the historical factors that set dominant cultures in positions of power while other cultures are subjugated. As scholars, we are required to question power dynamics, and design research studies that will not further subjugate already vulnerable populations. Critical theory will provide us with an appropriate lens to view this literature, under the premise of empowering both majority and minority cultures to work together toward better health outcomes for Latinos, and more specifically Latinas at risk for acquiring or who have been diagnosed with HIV.

Background

The History of Immigration between Latin America and the U.S.

The U.S. is a country of immigrants (Agnew, 2013; Hipsman & Meissner, 2013). Various groups of immigrant cultures have settled the land at differing points in history and though immigration has occurred all throughout the country's development, immigration typically followed specific patterns by region and ethnic group (Hipsman & Meissner, 2013). Not surprisingly, each period of heightened immigration came at a time of economic transformation (Bankston, 2007; Hipsman & Meissner, 2013). The processes of movement throughout and between Latin America and the U.S. (for example) were particularly influenced by governmental agreements made between countries, such as the Bracero Act, a bilateral agreement between Mexico and the U.S., which laid the groundwork for further U.S.-Mexico migration (Martin, 2003).

Historical Patterns of Immigration in the United States

There have been four distinct periods of immigration in the U.S. over the roughly five hundred year timeline of settlement (Hipsman & Meissner, 2013). These include the first wave, which was the period of colonization beginning in the late 15th and early 16th centuries, and stretching to the early 19th century; the second wave of immigration that occurred in the mid-19th century (1820s to 1880s) due to the country's westward expansion; the third wave at the turn of the 20th century that was due to industrial development, which created enticing economic opportunities; and the most recent wave that began in the 1970s and continues to present time (Diner, 2008; Hipsman & Meissner, 2013). Whereas conquest of the Americas actually began with the Spanish invasion in Puerto Rico in the late 15th and early 16th centuries (i.e., early in the first wave of immigration) (Fernandez-Armesto, 2014), a long stretch of immigration by the English, French, Dutch, and Scottish followed (Gidmark, 2000; Goldfield et al., 2004) and eventually other European groups began immigrating as well (Berthoff, 1951), many as indentured servants (Fernandez-Arnesto, 2014). During these early years of European settlement, arguments and battles over land were not uncommon (Fernandez-Armesto, 2014; Goldfield et al., 2004). Two relevant historical accounts of Spanish settlement in America are the Treaty of San Lorenzo, signed in 1795, which allowed English settlers to trade goods into Spanish claimed territory past the Mississippi border; and the Transcontinental Treaty, signed in 1819 (i.e., launching the second wave of immigration), which established the Spanish-English territorial border at Louisiana (Fernandez-Armesto, 2014). At that time, Spain was in possession of Texas, California, and New Mexico (Fernandez-Armesto, 2014). A push for Midwest settlement further encouraged immigration, as did new prospects of industrial development, which would ultimately launch the third and most impressive wave of immigration (Diner, 2008). Land battles between the Spanish, English, and French ultimately caused the loss of more Spanish territory, and the expansion of U.S. territory (Fernandez-Armesto, 2014; Goldfield et al., 2004). As U.S. territory expanded, so did favorable conditions for immigration.

Conditions for Immigration

The third wave of immigration began toward the end of the 19th and beginning of the 20th centuries as a result of several factors, including the improvement in travel (Diner, 2008; Goldfield et al., 2004; McKeown, 2004), as well as developing economic opportunities within the country, and deteriorating economic conditions in other parts of the world (e.g., Ireland; Cuba; Mexico) (Bankston, 2007). Most of the immigrants in this wave came from Europe, likely given the development of technology that lead to the ease of oceanic travel (Diner, 2008). Twenty-five million Europeans were recorded as immigrating to the U.S. during this wave (Diver, 2008). They mostly settled in urban areas, taking on industrial jobs (Diner, 2008), despite enticement by southerners to secure immigrant laborers for their own labor needs (Berthoff, 1951).

With the end of slavery, southern plantation owners were in need of cheap labor; thus began a movement, led by plantation owners, to bring in some of these new immigrants to southern regions of the U.S. (Berthoff, 1951). This met with little success; and in fact, from 1850 to 1970, the South had a smaller percentage of immigrants than any of the other regions in the country (Bankston, 2007). However, the need for cheap laborers was nationwide and thus an increased desire for immigrant laborers emerged (Bankston, 2007).

The need for laborers was further exacerbated by the onset of World War II, whereby many industries (e.g., agriculture and ranch farmers, and the railroad industry) were in need of help, because young American men were being called to fight in the war (Bankston, 2007). This initiated the Bracero program in 1942, an agreement between the U.S. and Mexico's government that allowed importation of Latino laborers into the U.S., contracted to provide temporary work.

The Bracero Act

Due to the large demand for labor that was created when the U.S. entered WWII and many American men leaving for active duty, the Bracero program was initiated to quench labor demands for U.S. industries and provide economic opportunity for Mexican and other Latin American communities (Martin, 2003). There were actually two Bracero programs initiated, the first in 1917 that ran through 1921, the later in 1942 that ran through 1964. The first program was terminated by the Mexican government due to the experiences of discrimination and extortion that the Braceros encountered from their employers (Martin, 2003). The second program came with demands by the Mexican government for the U.S. to guarantee the contracts that were made between the farmers and the Braceros, as well as other ethical demands (Martin, 2003). The program officially ran for twenty-two years (1942-1964); however, termination of the program did not end the demands by U.S. farmers for efficient, cheap labor, or the Braceros' dependency on the wages provided by the established work opportunities (Durand, Massey, & Charvet, 2000; Martin, 2003).

With the end of the wartime Bracero program in 1947, farmers were given the opportunity to seek Braceros through approved channels, but there were also undocumented Braceros available, which was attractive to farmers wanting to avoid their responsibility of the transportation costs for the Braceros (Martin, 2003). The Bracero program laid the foundation for continued Mexico-U.S. migration, as well as the surge of undocumented Latino immigrants (Martin, 2003). Historically, the pattern for immigration was toward a few key states in the Southwest (Durand et al., 2000); but economic opportunities grew in the Southeast after the 1970s and provided the motive that began the shift of Latino immigrants from the well-established gateway states (e.g., New Mexico, Texas, California) toward the southeastern states (e.g., Georgia, Virginia, North Carolina) (Bankston, 2007; Marrow, 2009).

Latino Immigrants in the South: The New Destination

Immigrants from Latin America have typically settled in the following six U.S. states: New York, New Jersey, Texas, Florida, California, and Illinois (Hipsman & Meissner, 2013). However, these patterns have recently changed (Crowley, Lichter, & Qian, 2006; Durand et al., 2000; Weeks et al., 2007), in part due to growing anti-immigrant attitudes (Durand et al., 2000). The negative attitudes regarding immigrants resulted in such actions as California's Proposition

187 (Durand et al., 2000). Proposition 187 was the 1994 California ballot initiative that required state employees to report undocumented individuals who apply for benefits unlawfully (Eig, n.d.). Proposition 187 was a direct contradiction to the earlier Immigration Reform and Control Act (IRCA) of 1986, that created the opportunity for undocumented immigrants to gain appropriate documentation, thus allowing them the freedom to pursue economic opportunities elsewhere in the U.S. (Durand et al., 2000).

Currently, there is a new trend of Latino immigrants bypassing the traditional gateway states (Durand et al., 2000), and coming directly to the southeast, a region that has historically seen little immigrant activity (Bankston, 2007; Berthoff, 1951). According to Durand and colleagues (2000), the geographical map of migration in the U.S. changed most radically with the passage of IRCA, thus populating the southeast U.S. with immigrants which potentially had the greatest influence on present day destinations for Latin American immigrants.

IRCA was passed in 1986 in order to deter further illegal immigration to the U.S. (U.S. Department of Homeland Security, n.d.). With the passage of this reform act, a multitude of previously undocumented immigrants were given the opportunity to legalize their residential status. There were two immediate results that came from this colossal legalization of immigrants. The first major consequence was the flooding of the legal labor market in areas of California, which subsequently drove down wages, as most of the undocumented Latino immigrants resided in California at the time (Durand et al., 2000; Orrenius & Zavodny, 2012). The second major effect was that many formerly undocumented immigrants now had the liberty to migrate throughout other areas of the U.S. to pursue other economic opportunities (Durant et al., 2000). This began a radical change to the demographics of the U.S., and gave way to a more diverse spread of immigrants, particularly from Latin America, across the country (Durand et al., 2000). Furthermore, illegal immigration did not slow as had been expected, but in fact increased; and followed the economic opportunities that were developing in the southeast, thus creating challenges for receiving cities and states who served as the new homes for undocumented immigrants (Kochhar, Suro, & Tafoya, 2005; Weeks et al., 2007).

Undocumented in the South

There was an additional, major and unexpected outcome with the passage of IRCA. What was intended to deter undocumented immigration actually had a contrary effect, creating a substantial increase of undocumented immigrants in the country (Weeks et al., 2007). Furthermore, as Durand and colleagues (2000) reported, immigration patterns of the 1990s diverted from traditional gateway states to non-traditional states, primarily to the southeast region of the U.S. The rate of migration toward non-gateway states during the 1990s rose from 13% to 31% (Durand et al., 2000), a transformation that some of the receiving states were ill prepared for (Weeks et al., 2007). According to 2012 estimates from the Department of Homeland Security, three of the top ten states where undocumented immigrants presently reside in the Southeast were: Georgia, Florida, and North Carolina (U.S. Department of Homeland Security, 2013).

According to Pew Hispanic reports, during the 1990s, North Carolina had experienced the highest growth rate in the U.S. of immigrants (274%), and the second highest growth rate in the U.S. of children living with immigrant parents (224%) (Passel, Cohn, & Gonzalez-Barrera, 2013). In fact, in 1990, the percentage of the population in N.C. that was foreign born was 1.7%, compared with 2000 statistics of 5.3%, an increase of 3.6% (Passel et al., 2013). Statistics from 2012 (7.7%) indicated that the surge in undocumented immigrants is slowing somewhat (Passel et al., 2013); however, approximately 42% of Latinos living in N.C. are undocumented (Passel & Cohn, 2011). With such an explosive growth rate of immigrants, as well as representation of a large segment of the undocumented population (U.S. Department of Homeland Security, 2013), the southeastern states, particularly N.C., faced unfamiliar challenges in providing quality health care to meet the needs of the Latino immigrant community, thus resulting in a chasm for health disparities.

Health Disparities of Latino Immigrants in the U.S.

According to Link and Phelan (1995), difficult social and economic factors were thought to be fundamental contributors to illness and disease, influencing access to important resources, thus affecting overall health outcomes. The rise in the number of undocumented Latinos living in the U.S. (i.e., patients who may not have access to care because of lack of documentation or fear of deportation) met with increasing rates of poverty (i.e. patients who cannot afford services) (Crowley et al., 2006; Durand et al., 2000); the two intertwining elements greatly influenced access to health care for this population (NCRCAP, 2002; Nisbet & Rogers, 2013; Vargas Bustamante et al., 2012). When researchers Nisbet and Rogers (2013) compared the wage earnings from 2002 to 2009 of documented and undocumented farmworkers in the U.S., they found that those immigrants who were documented reported making 13.1% to 15.2% higher wages than their undocumented counterparts. Branch and colleagues (2010) reported that one in four Latinos lives in poverty and that Latinos living in rural communities were less likely than their urban counterparts to have health insurance. As immigration patterns for Latinos have shifted to southern states (Durand et al., 2000; Marrow, 2011), and because conditions of poverty have been linked to health disparities (Andrulis, 1998), the conditions for poverty among Latino immigrants living in the south have only worsened (Kandel, 2008). This point was most recently highlighted in the Migration Policy Institute report (2014), which stated that 48% of the foreign born population in N.C. does not have health insurance coverage, compared to 13.9% of the U.S. born population. This statistic is even more concerning when considering the needs of patients who struggle with chronic or communicable medical conditions, such as HIV and AIDS.

HIV, and the subsequent onset of AIDS, was virtually unheard of until the 1980s, with the first case of AIDS identified in the U.S. in 1981 (National Institutes of Health [NIH], 2011). Shortly thereafter, in 1983, the first diagnosed case of AIDS was identified in Mexico, likely as a result of Mexican migrant workers who were infected in the U.S. and then returned to their home communities and infected their partners (Magis-Rodriguez et al., 2004). Today in the U.S., the estimated number of people living with HIV is greater than 1.1 million, and it is further estimated that 220,000 are Hispanics/Latinos (CDC, 2013). Even though the number of new HIV infections among the Hispanic/Latino population in the U.S. peaked during the late 1980s, it has since declined, holding at 9,800 in 2010 (CDC, 2012). The severity of the impact of HIV in the Latino population is notable when considering the disparity that exists between Latinos and Whites (i.e., incidence rates in 2010 were three times greater for Hispanics/Latinos than Whites [CDC, 2015]), some of which may be due to barriers to care.

Barriers to Care

While the exact prevalence rate of HIV within the Latino immigrant community is unknown, estimated rates for the U.S. Latino migrant community is thought to be somewhere between 3.5% and 13% (Organista, Organista, & Soloff, 1998; Persichino & Ibarra, 2012). The large gap between these estimates underscores the challenge that exists in HIV treatment for this population. As for incidence rates, Hispanic/Latino men are estimated to have two and a half times the rates of infection as white men; and rates of infection for *Latinas* are more than four times that of white women (CDC, 2011). There was an increase of 8% between 2008 and 2010 among the Latina population living with an HIV diagnosis, whereas a 7% increase was noted in Blacks, and a 5% increase in Whites (CDC, 2013). Access to prevention and treatment in this population is critical, but significant barriers make this challenging (Branch et al., 2010).

In a 2002 survey that investigated the health of Hispanics/Latinos living in rural eastern N.C., participants were asked if they had sought medical care for identified health problems (NCRCAP, 2002). Only 11.8% of documented participants reported seeking medical attention, and those individuals without documentation were noted to access medical care at a much lower rate (5.4%). A number of access to care barriers identified include: high cost of services, lack of health insurance, questions regarding legal status, fear of discrimination, and lack of transportation (Branch et al, 2010; NCRCAP, 2002). English language comprehension was reportedly low among the survey participants mentioned earlier (NCRCAP, 2002), and was also identified as a barrier (NCRCAP, 2002), resulting in a plethora of unmet needs.

Reports from various states (e.g., Texas, Michigan, North Carolina) have revealed a higher proportion of unmet needs (defined as diagnosed HIV positive, but not in treatment) associated with the Hispanic/Latino population in comparison to other ethnic groups throughout the U.S. The state of Texas, for example, reported that the average statewide percentage of unmet needs for Hispanic/Latino individuals living with HIV is 41%, above the state average (Texas Department of State Health Services, 2012). In the state of Michigan, Hispanics/Latinos represent only 5% of all persons living with HIV/AIDS; however, the unmet need in this population represents the highest proportion in the state at 47% (Michigan Department of Community Health, 2012). North Carolina also reported that the highest proportion of unmet needs in the state was among the Hispanic/Latino population, at 40.9%, compared to 24.3% Whites and 25.8% Blacks (NCDHHS, 2013). In fact, the proportion of Hispanics/Latinos with unmet needs has steadily increased over the last five years, representing a 43.7% relative increase (NCDHHS, 2013). A similar increase in unmet needs in the Hispanic/Latino population exists for people living with AIDS, at 44.7% relative increase over the last five years (NCDHHS, 2013). Furthermore, Latina immigrants living in N.C. had the highest proportion (40.9%) for

HIV infections presenting late for treatment (5 to 7 years after infection) (CDC, 2011), punctuating the likelihood for barriers to care and perhaps unique vulnerabilities experienced by Latina immigrants.

Vulnerabilities of Latinas

The primary way for transmission of HIV to *Latinas* is by heterosexual contact; often with a man who engages in injection drug use, has sex with multiple partners, does not use condoms, and/or has sex with other men (CDC, 2005; Peragallo et al., 2002). Furthermore, cited in the 4th global report from the Joint United Nations Program on HIV/AIDS, 50% of new infections are now occurring between spouses, calling this a move toward a "feminization of HIV/AIDS" (UNAIDS, 2004, p. 8). These statistics emphasize not only health disparities among the Latino population, but the vulnerability of *Latinas* to HIV infection.

Latinas are among the fastest growing population for contracting AIDS in the U.S. (CDC, 2011), and as such, it is important to understand what contributes to this population's vulnerability to HIV infection. It has been noted that traditional cultural values play at least some role in Latinas' agency (i.e., ability to voice choices or concerns) within a relationship, highlighting a lack of autonomy that Latinas have over their own sexual health (Galanti, 2003; Parrado, Flippen, & McQuiston, 2005; Persichino & Ibarra, 2012; U.S. Department of Health and Human Services, 2012; Viadro & Earp, 2000). For example *machismo,* which is an exaggerated demonstration of masculine characteristics, dictates that women be submissive to their partners, as well as to other men in the family (Hargreaves, Hidalgo, Byrd, Bagchi, & Kim, 2010; U.S. Department of Health and Human Services, 2012). Thus, negotiating safe sexual practice with their partner can be very difficult, and quite often not possible (Hargreaves et al., 2010; Parrado et al., 2005). Galanti (2003) also reported that gender roles are seen to constrain sexual negotiations among Latinas with their partners, and suggested that traditional religious influences supported values of female modesty and male dominance that make it less likely for women to ask their partners to use a condom during sex. Furthermore, Latinas are expected to put the needs of their family before their own, a cultural value known as *familismo,* which has been indicated as a contributor for Latina dropout rates in relation to treatment (Hargreaves et al., 2010). In addition to these, Latinos often have a belief in *fatalism,* which is the view that God enacts certain events to occur, and as such, HIV infection is seen as a judgment delivered by God (Hargreaves et al., 2010).

In addition to cultural beliefs about the role of women in relationships or the perspective about how illness emerges, the sexual behaviors of Latinas' partners contribute to vulnerabilities and risks for HIV. In a study conducted by Persichino and Ibarra (2012), the researchers concluded that the only risk factor for women in border and rural areas of northern Mexico to contract HIV is through sex with a male partner who had traveled to the U.S. Additionally, Viadro and Earp (2000) conducted a study investigating sex between male Latino migrants and females who are not sex workers. The researchers reported that 42% of the men who identified as married had had extramarital sex at some point in time, 21% reported having had two or more sex partners in the last year, and 21% reported twenty or more sex partners in their lifetime. It stands to reason that a Latina's risk of HIV infection is tied to the risk behavior of her partner, and given these high risk statistics, Latina immigrants are at a potentially high risk for infection.

Barriers to Prevention and Treatment for Latina Immigrants

In addition to vulnerability to HIV infection, barriers that prevent access to testing and staying in care are also of concern. Researchers have found implications that Latinas may not be accessing testing for HIV infection outside of prenatal care (Torrone, Wright, Leone, & Hightow-Weidman, 2010); or to have their HIV tests confirmed, (Ganguli et al., 2013; Liddicoat, Losina, Kang, Freedberg, & Walensky, 2006; Parra, Doran, Ivy, Arnada, & Hernandez, 2001).

Also, researchers have noted Latinas are less likely to receive antiretroviral therapy (ART) medication during pregnancy when diagnosed HIV positive compared to other groups (Zhang, Senteio, Felizzola, & Rust, 2013). Receiving ART medication during pregnancy is instrumental in preventing transmission of HIV from mother to infant (Zhang et al., 2013), thus magnifying that barriers to treatment could ultimately risk two lives at once.

Researchers have concluded that simply improving access to HIV testing and ART may not be enough. Patient-provider relationships have been identified in research to be a potential issue in health care for Latinos (Schuster et al., 2005). Factors that have been noted in the literature as potential determinants to adherence include perceptions related to health care (Infante et al., 2006; Schuster et al., 2005), and patient-provider interactions (Beach et al., 2010; Lazcano-Ponce et al., 2004; Saha et al., 2013).

A study conducted in Mexico with providers from three Mexican states found discriminatory attitudes from providers by HIV infected patients (Infante et al., 2006) which undoubtedly influenced perceptions related to health care. The researchers reported a concern for unethical behavior, and called for a debate regarding discrimination in HIV health care among providers. In this study, the researchers found providers' persistent attitudes about patients were that they were *hopeless*; and despite 75% of providers reporting training in HIV/AIDS, providers demonstrated a lack of knowledge relating to types of transmission. Twenty-three percent stated that they would not buy food from a person diagnosed with HIV/AIDS, and 38% stated that they felt employers and administrators have the right to be aware of a person's HIV/AIDS status. The researchers also found that "isolation [isolating the HIV positive patient] notes in clinical histories pointing to HIV, obligatory testing, and delays in surgeries for people living with HIV/AIDS were constant practices" (Infante et al., 2006, p. 141).

The authors of several investigations have also noted potential concerns for patient-provider interactions that could be relevant to Latina patients' decisions for seeking health care. Kendall (2009) documented several cases of Latinas' personal experiences with their healthcare providers during training on sexual and reproductive rights. After obtaining permission from the participants to analyze and publish their cases, Kendall reported blatant violations of several participants' reproductive rights. Included in the cases reported, one Latina participant described being verbally insulted by her Mexican healthcare provider (Kendall, 2009). Several of the participants in these case stories described various discriminatory interactions initiated by their healthcare providers that included verbal insults and humiliation (Kendall, 2009).

In another study conducted in Mexico researchers investigated ethics and patient-provider communication. Lazcano-Ponce and colleagues (2004) identified physicians as exercising "power and authority over patients" (p. 66), and that in many cases physicians did not allow for their patients' autonomy. There has also been research conducted in the U.S. that has looked at patient-provider communication and cultural competence. Beach et al. (2010) conducted a mixed-methods study with 19 HIV providers and 113 of their patients. The researchers found that visits by providers to Latino patients were significantly less patient-centered than with White patients, and that there was less psychosocial talk, despite whether the patient spoke Spanish or English.

Identifying potential barriers to HIV prevention and health care in the Latina immigrant population requires that our discussions include the new immigration trends to the Southeast, and the socio-economic factors that exist in this region. We must also explore other factors that might add to our understanding of barriers to health care and poor rates of adherence to treatment in this population. Such factors as patients' perceptions of health care, and patient-provider interactions related to sexual health should continue to be investigated.

Discussion

In the present global environment of infectious diseases such as HIV/AIDS, understanding the context of a disease within a particular population is imperative. N.C. is a state situated in the southeastern region of the U.S. that has been caught unprepared to meet the healthcare needs of the Latino immigrant population (Weeks et al., 2007); a population that is largely undocumented (Passel & Cohn, 2011), living in poverty (Kaiser Family Foundation, 2011), and vulnerable to many healthcare concerns due to socioeconomic factors (Branch et al., 2010; Kandel, 2008; Link & Phelan, 1995). In the wake of this dynamic environment, there is a new phenomenon emerging. Latinas are immigrating along with their partners and family; and in some cases even immigrating alone (Ayers, 2013; Weeks et al., 2007).

Latinas are recognized to be among the fastest growing population for developing AIDS in the country (CDC, 2011). Despite this, little is known about this population and the barriers they encounter in health care. There has been a dearth of research conducted with the Latina migrant population, particularly concerning experiences with healthcare providers. Latina immigrants' perspectives about health-related care between the U.S. and their country of origin has not been previously explored.

N.C. has experienced an exponential growth of the Latino community since the early 1990s, being labeled one of the new destination states (Marrow, 2009; Passel, Cohn, & Gonzalez-Barrera, 2013). With steadily increasing numbers of Hispanics/Latinos with an HIV diagnosis, not in continuous care (NCDHHS, 2013), it seems that the present healthcare infrastructure is insufficient to meet the HIV/AIDS healthcare needs of this growing population. This is the interface of Latino immigration and HIV/AIDS.

Racial and ethnic inequalities in health are common and have been widely recognized for many years (Bahls, 2011; Stryer, Weinick, & Clancy, 2002; Warnecke et al., 2008); and are known to occur across a spectrum of diseases (Evans, Whitehead, Diderichsen, Bhuiya, & Wirth, 2001). Yet there are also health *inequities* that exist that have a “moral and ethical dimension” and “refers to differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust” (Whitehead, 1992, p. 219). Health inequities, then, can potentially be preventable (Evans et al., 2001). Addressing racial and ethnic inequities can help to eliminate health disparities (CDC, 2014), such as the disparities between Latinas and majority populations in relation to HIV/AIDS (CDC, 2014). Thus, the following recommendations are provided for researchers and clinicians.

Critical theory is a philosophy that is employed by those who are concerned by the power imbalance and inequitable resource distribution that occur in societies today (McCarthy, 1989). The emphasis is placed on emancipation, and Habermas declares that self-knowledge and reflection can liberate individuals from the circumstances that originate out of social institutions (McCarthy, 1989), and that reflection and subsequent action are required to overcome any unjustified power of societal systems (Habermas, 1962, 1989). Using this as a guide, researchers are called to reflect on the many barriers that have already been identified, recognize that current social structures do not meet the HIV/AIDS healthcare needs of Latinos living in the U.S., discern what HIV healthcare programs and practices offer clinically and statistically significant outcomes (e.g., the Promotores model), and further evaluate culturally appropriate programs with rigor in order to produce evidence for widespread implementation for a culturally relevant model.

In particular, evidence is mounting for community-based participatory research (CBPR) as a more culturally appropriate and effective way to close the gap in health disparities research in comparison to traditional methods and designs (Minkler, Vasquez, Chang, & Miller, 2008; Viswanathan et al., 2005). Though there continues to be a need for rigorous studies, evidence for the effectiveness of CBPR on health outcomes is materializing (Salimi et al., 2012; Swider, 2002). CBPR combines rigorous research methods with strategies that strive to empower the voices of the people within a community, which strengthens the community's ability to advocate for choices and raises concerns relevant to its people (Israel, Eng, Schulz, & Parker, 2013). Researchers utilizing a CBPR approach pay particular attention to power dynamics, and aim for equality between all partners throughout the research process (Israel et al., 2013), thus helping to liberate individuals from the circumstances that originate out of social institutions (Habermas, 1962, 1989). As such, researchers must give significant attention to building, maintaining, and sustaining partnerships throughout the research process. This is a critical element to community-based participatory research, as it builds trust among team members, allows for conflict resolution, and gives space for development and sharing of knowledge and skills as the team moves forward through the process (Israel et al., 2013), building a solid framework for the production of quality research and effective outcomes. Furthermore, few CBPR studies have used rigorous random control trial (RCT) research designs. In order to have a clear understanding of how effective CBPR is with the Latino population, researchers must include rigorous designs into their projects and programs. When publishing study results, researchers must also include discussion on the participatory research process, and include a report on the process of evaluating the partnership in order to better promote accountability, rigor, and fidelity to a model. CBPR requires that the research findings are disseminated at the community level, as well as through professional publications and presentations. Disseminating results at the community level will ensure clinicians have more timely information to guide clinical work, and therefore identify best practices. Finally, CBPR requires the research to result in action, whether this be in the form of program development, advocacy, or policy.

Identifying the best clinical practices for healthcare interventions with the Latina population may contribute to closing the health disparity gap in HIV related health concerns and honoring the emancipatory knowledge that can be moved forward through research and policy to become a purposeful emancipatory movement. Specifically, clinicians need to recognize the inadequacy of current healthcare structures for this population, and thus consider new models of health care. The Promotores Model has been implemented in a number of studies, and shows promise for overcoming barriers of access to care and potential results for positive health outcomes with Latinos across various health concerns (Twombly, Holtz, & Stringer, 2012). In addition, language barriers continue to be an issue for Latinos. Clinicians must be aware of the current best practices for interpretation services (National Council on Interpreting in Health Care [NCIHC], 2005) and strive to meet these standards.

Conclusion

This literature review has provided an overview of the various intersecting factors that have been associated with HIV infection rates with the Latino immigrant community in the U.S. Critical theory has provided the lens that stimulates a critical analysis of developed social structures that limit the power of minority cultures. Infectious diseases such as HIV/AIDS within minority communities must be studied in the context of the environment, which includes the dynamics of the immigration process, in order to better understand the barriers to prevention and healthcare.

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CHAPTER 3: HIV HEALTH OUTCOMES FOR LATINO IMMIGRANTS: A SYSTEMATIC REVIEW

It is estimated that there are more than one million people in the United States (U.S.) who are living with the human immunodeficiency virus (HIV) (Center for Disease Control and Prevention [CDC], 2014). Research regarding trends in HIV infections continues to reveal that new HIV infections are highest among men who have sex with men (MSM) (AIDS.gov, 2014; Henry Kaiser Family Foundation [KFF], 2014). MSM represent only 4% of the U.S. population, but they represent 78% of new infections in males, and 63% of all new infections within the U.S. (CDC, 2014; KFF, 2014). However, with the number of new cases in the U.S. estimated at 29,800 (CDC, 2014) it is important to look more closely at the incidence rates of other populations beyond MSM. For example, new infection rates among women are primarily among heterosexuals, with 84% of new infections in women attributed to heterosexual contact and 16% attributed to injection drug use (AIDS.gov, 2014; CDC, 2014). Between White, Black, and Hispanic/Latino racial categories, the greatest affliction continues to be among Blacks (AIDS.gov, 2014; KFF, 2014). Representing only 12% of the total U.S. population, Blacks represent an estimated 44% of new infections (CDC, 2014). Though Blacks continue to bear the highest number of infection rates among these three racial and ethnic groups, HIV infection rates among Latinos are becoming a greater concern due to the increasing infection rates that also coincide with barriers to treatment (CDC, 2015).

Latinos are the largest growing ethnic minority in the U.S. and comprise 16% of the country’s population; however, this population has a disproportionate representation of all new HIV diagnoses (i.e., 21% of all new diagnoses) (AIDS.gov, 2014; CDC, 2014). Within the U.S., the rates of infection for Latino males are 2.9 times the rate of White non-Hispanic males, and Latinas’ (female gender) rates for infection are more than four times that of White non-Hispanic women (CDC, 2014). According to reports from the CDC (2011), Latinas are also among the fastest growing population for developing acquired immune deficiency syndrome (AIDS) in the U.S. Researchers have demonstrated that Latinos (male and female) are at a greater risk for complications from HIV and AIDS, due to late diagnosis and thus lack of adherence to treatment recommendations in comparison to their White counterparts (Chen, Gallant, & Page, 2012).

Though traditionally considered to be an urban disease (CDC, 2015), nearly half of all new HIV infections in the U.S. are in the rural South, where there is a scarcity of resources available to effectively fight the epidemic (Vega, Klukas, Valera, & Montenegro, 2015). Coincidentally, this is also an area of the U.S. that has experienced a considerable growth in the Latino population. The presence of Latino communities is rising across the U.S. and most notably in the South (Vega et al., 2015), but often in areas that already suffer from an inadequate healthcare infrastructure (Vega et al., 2015), placing many Latinos at risk for numerous health disparities.

Unfortunately, reports from some states within the U.S. South (e.g., Texas, North Carolina) revealed a higher proportion of disparities among Latinos with regard to unmet needs (defined as diagnosed HIV positive, but not in treatment) in comparison to other ethnic groups. Researchers in the state of Texas, for example, reported that the average statewide percentage of unmet need for Latinos living with HIV is 41%, above the state average of 33% (Texas Department of State Health Services, 2012). In North Carolina (N.C.), researchers found that the highest proportion of unmet need in the state was among the Latino population, at 34% (North Carolina Division of Human Health Services [NCDHHS], 2013). Furthermore, the proportion of Hispanics/Latinos with unmet needs in N.C. has steadily increased over the last five years, from 2009 to 2013 (NCDHHS, 2013).

As a response to the concerns about late diagnosis and treatment adherence for all ethnic groups at risk for HIV, Guidelines for the Prevention and Treatment of Opportunistic Infections in HIV-Infected Adults and Adolescents were published with a mandate to include antiretroviral therapy (ART) at all stages of the disease process, thus emphasizing the need for early diagnosis and adherence to care (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2015). Since Hispanic/Latino communities have an increased prevalence rate, and they tend to have sex partners from within their own racial and ethnic group, they are at a greater risk of HIV infection (CDC, 2015). This coinciding with concerns of late HIV diagnoses and lack of treatment adherence in this population warrants our attention to the healthcare needs of Latinos regarding culturally appropriate HIV prevention and treatment. Thus, a new direction to prevention and treatment for Latinos seems necessary, one that is informed by and responsive to their unique cultural needs. In reply to this reality, more researchers are utilizing a community-based, action research approach which has been embraced by national and international health organizations (Mendenhall, Berge, & Doherty, 2014) and particularly relevant toward reducing health disparities with Latinos (Israel, Eng, Schulz, & Parker, 2013).

Around the same time that ART was becoming available as a treatment program (i.e., 1995), a new approach to research was also emerging (i.e., Community-Based Participatory Research [CBPR]) (AIDS.gov, 2009; Israel, Eng, Schulz, & Parker, 2013). CBPR is currently used among healthcare researchers to respond to concerns pertaining to health disparities via community-based organizations as a way to improve the quality of the research pertaining to health outcomes in minority populations (e.g., with Latinos at risk for HIV) (Israel et al., 2013). Furthermore, CBPR requires that the research findings are disseminated at the community level in addition to professional publications and presentations. Disseminating results at the community level will ensure clinicians have more timely information to guide clinical work, and therefore identify best practices. Troubling to many researchers and clinicians is that it currently takes an average of 17 years for clinical research findings to be fully implemented (Balas & Boren, 2000). Also unique to CBPR is that it uses a collaborative and equitable partnership between community members and researchers in all phases of the research to empower minority groups (Green et al., 1995; Israel, 2013). CBPR is defined by Israel and colleagues (2013) as:

> A partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision making ownership. The aim of CBPR is to increase knowledge and understanding of a given phenomenon and integrate the knowledge gained with interventions, policy, and social change to improve the health and quality of life of community members (p. 6).

Based on an extensive review of literature investigating core components of CBPR, Israel and colleagues (2013) offered guiding principles and core components for community-based research to support partnership approaches in public health research, toward the purpose of eliminating health inequities. Important to CBPR are the seven core components that are used in conducting this type of research (Israel et al., 2013). The core components speak to the phases of research, and what aspects of the research take place in each phase (Israel et al., 2013). These core components are: "(a) forming a CBPR partnership, (b) assessing community strengths and dynamics, (c) identifying priority health concerns and research questions, (d) designing and conducting etiologic intervention and/or policy research, (e) feeding back and interpreting research findings, (f) disseminating and translating research findings, and (g) maintaining, sustaining, and evaluating CBPR partnerships" (Israel et al., 2013, pp. 12-13). These phases of research are somewhat sequential, however this is a circular process and not a linear one (Israel et al., 2013). Some components may actually begin at the onset of a study and continue throughout the research process (e.g., maintaining, sustaining, and evaluating the CBPR partnerships) (Israel et al., 2013).

In order to better understand the success of community-based programs or initiatives that exist for Latinos, a systematic review is conducted to answer the following research question: *Are Latino community-based organizations effective in reaching the target population (Latinos), improving HIV knowledge, and/or improving HIV screening rates?* Given this research question, the purpose of this article is to: (a) provide a theoretical foundation for research with vulnerable populations, (b) unveil the health disparities connected to HIV infections for Latinos within the U.S., (c) provide the evidence on culturally relevant community based programs with Latino or Latina populations diagnosed with HIV, and (d) offer research and policy implications for future research and program initiatives with Latinos.

Theoretical Framework

As scholars, we are required to question power dynamics and design research studies that will not further subjugate already vulnerable populations. However, historically there is evidence of minorities who have been abused through research processes (Lawrence, 2000; Park, 2012; Presidential Commission for the Study of Bioethical Issues, 2011), neglected from the sample in culturally relevant research (Beauvais 1998; Duran & Duran, 1995; Lagaspi & Orr, 2007; Novins et al., 2011), or abandoned as a community (i.e., exploited for the purpose of research) after a project has ended (Minkler, 2004, 2005). In our commitment to ethical research, as a team invested and embedded in the Latino community, and to ensure inclusion of an often neglected minority group, we grounded this research in critical theory (Habermas, 1981, 1984).

Critical theory places an emphasis on liberating people from the circumstances in life that restrain them (McCarty, 1989). Habermas, a sociologist and philosopher, argued that human beings are capable of reasoning, and possess the communicative competence to develop mutual understanding, arriving at a more humane, just, and equalitarian society (Habermas, 1981, 1984). Based on this perspective, society is able to "unmask the institutionally anchored distortions" and its people "from all ideological delusions" (McCarthy, 1989, p. 88). Given the relevance of these theoretical elements (i.e., human reasoning and communicative competence) to the health (e.g., HIV) of minority populations (e.g., Latinos), critical theory is implemented as a foundation to bring attention to the social and economic structures that impede progress toward eliminating health disparities in HIV/AIDS. Critical theory will provide us with an appropriate lens to view this research, under the premise of empowering both majority and minority cultures to work together toward better health outcomes for Latinos, and more specifically for those at risk for acquiring or who have been diagnosed with HIV.

Background

Health Disparities of Latinos

According to the CDC (2015), the most common way to contract HIV for Latinos who live in the U.S. is through heterosexual contact. Latino immigrants are especially vulnerable regarding sexual health disparities, particularly when it comes to exposure to and screening for HIV infections (Webber, 2007) within the U.S. According to a 2002 national survey, approximately 63% of Latinos in the U.S. are foreign born (Brodie, Steffenson, Valdez, Levin, & Suro, 2009). Interestingly, foreign born heterosexual Latinos seem to be disproportionately affected by rates of HIV compared to their U.S. born counterparts (Chen, Enbelding, Yeh, & Page, 2010; Kelvens, Diaz, Fleming, Mays, & Frey, 1999).

More recently the attention of public health administration and policy makers has turned toward the sexual health risks for Latinas (Amaro, Raj, Reed, & Ulibarri, 2011). After all, the 4th global report from the Joint United Nations Program on HIV/AIDS, stated that 50% of all new infections have been occurring between spouses, calling the risk for women “a move toward a feminization of HIV/AIDS” (UNAIDS, 2004, p. 8). A large study of 6,000 participants by Chen and colleagues (2010) further confirmed these concerns, suggesting that Latina study participants were less likely to have been screened for HIV, than their male counterparts. It has been noted that Latinas’ greatest risk factors are those associated with her partner (e.g., partner’s HIV status; partner is a migrant worker; partner is suspected of being unfaithful) (Johri et al., 2010). These risk factors may be further exacerbated by cultural values that influence her decision-making about sexual health.

Values. Traditional cultural values play a role in Latinos’ relationships and particularly with regard to Latinas’ agency (i.e., ability to voice choices or concerns) within a relationship, highlighting a lack of autonomy that Latinas have over their own sexual health (Galanti, 2003; Parrado, Flippen, & McQuiston, 2005; Persichino & Ibarra, 2012; Viadro & Earp, 2000). For example machismo, which is a demonstration of masculine characteristics, implies that women are to be submissive to their partners, as well as to other men in the family (Hargreaves, Hidalgo, Byrd, Bagchi, & Kim, 2010). Thus, negotiating safe sexual practice with their partner can be very difficult and quite often not possible (Hargreaves et al., 2010; Parrado et al., 2005). Galanti (2003) also reported that gender roles are seen to constrain sexual negotiations among Latinas with their partners, and suggested that traditional religious values influence support for female modesty and male dominance that make it less likely for women to ask their partners to use a condom during sex, thus increasing their vulnerability toward HIV. Furthermore, Latinas are often expected to put the needs of their family before their own, a cultural value known as familismo, which has been indicated as a contributor for Latina dropout rates in relation to HIV care (Hargreaves et al., 2010). While these values may appear to place Latinas at a greater risk for infection, other factors may influence both Latinos and Latinas likelihood to get screened for

HIV, such as stigma, which can also decrease their adherence to care and increase the likelihood toward mortality due to the symptoms and diagnosis.

Stigma. HIV/AIDS remains highly stigmatized within the Latino culture due to the stigma associated with the infection (e.g., MSM and drug use) (VanOss-Marín, 2003). Participants in one study indicated feeling a sense of shame, isolation, and loneliness due to their HIV infection status (VanOss-Marín, 2003). Other researchers have found lower levels of disclosure of HIV infection reported by Spanish speaking Latinas compared to other ethnic groups (e.g., English speaking Latinas, Anglos and African Americans) (Simoni et al.,1995). It has been noted in the literature that stigma experienced by African Americans and Latinos, as well as other barriers, are influential and a strong deterrent to getting tested for HIV (Giordano et al., 2010). In fact, in a review of the literature that discussed cultural competency of healthcare providers with Latino patients regarding HIV/AIDS, Acevedo (2008) found that adherence patterns were influenced by patients' traditional values (e.g., reliance on a health model that encourages use of herbs and other natural remedies), and attribution of the cause for disease, such as the perspective that a diagnosis of HIV is punishment for living a socially unacceptable life. This cultural perspective, known as fatalism, is the view that God enacts certain events to occur, and as such, HIV infection is seen as a judgment delivered by God (Hargreaves et al., 2010) further propelling stigma associated with HIV. According to Acevedo (2008), the health model that is predominating in the culture is a *folk* medical model. This model emphasizes cause of disease to be attributed to unethical behavior, and can interfere with screening for HIV (Acevedo, 2008) thus further promoting health disparities among this sub-culture. As suggested in this segment, traditional values and stigma do not just influence Latinas' vulnerability toward contracting HIV, but also her likelihood to get screened for the diagnosis.

Access to screening. Screening behaviors for HIV within the Latino population vary across subgroups. For example, in a study that investigated screening behaviors for MSM, screening was found to be associated with the individual having seen a healthcare provider and disclosing male to male attraction (Oster et al., 2013). According to another study of a large sample of migrant Latino day laborers, HIV intentions to screen were associated with having a higher risk of infection from sexual encounters with female partners, having attended high school or beyond, and reported use of a condom with casual female partners (Ehrlich & Organista, 2007). Unfortunately, most Latinos do not get screened for HIV and in fact Latinas do not typically access testing for HIV outside of prenatal care (Chen et al., 2010; Torrone, Wright, Leone, & Hightow-Weidman, 2010). They have also been less likely than other groups to receive antiretroviral (ARV) medication during pregnancy when diagnosed HIV positive (Zhang, Senteio, Felizzola, & Rust, 2013). Zhang and colleagues investigated a large sample of 3259 HIV positive pregnant women receiving Medicaid, of which Latinas in the study had 3.89 times the risk of not receiving ARV medication as their White counterparts. Researchers suggested that this might be due to Medicaid restrictions for Latinas compared with White participants (Zhang et al., 2013) For example, there are some states' whose Medicaid eligibility rules effect Latinas more than other groups (i.e., "emergency Medicaid eligibility" to women whose immigration status would otherwise disqualify her as a recipient) (Zhang et al., 2012). This disparity must be resolved given that receiving ARV medication during pregnancy is instrumental in preventing transmission of HIV from mother to infant (Zhang et al., 2013). Attending to these concerns are not just an issue to reduce future health disparities among Latinos and Latinas, but also a community issue that can help raise awareness about healthcare needs and treatment options.

Collectivist culture. Some researchers (e.g., Giordano and colleagues, 2010) believe that access to testing is not enough to reduce the disparities among minority groups, and other studies support this (Ganguli et al., 2013; Liddicoat, Losina, Kang, Freedberg, & Walensky, 2006; Parra, Doran, Ivy, Arnada, & Hernandez, 2001). According to the CDC (n.d.), culture is central to the health habits of Latinos/Hispanics. The collectivist values of the Latino culture underscore a tendency for Latinos to rely on their social networks to help guide the decision-making process (CDC, n.d.). This reliance on social networks integrates Latino/Hispanic native and traditional immigrant values into that of the mainstream culture across the U.S. (CDC, n.d.). Given the complexity of Latino's vulnerability to HIV and disparities in screening, culturally appropriate programs from within the Latino community must be reviewed in order to better understand ways to reduce stigma while honoring cultural values.

CBPR- A Culturally Appropriate Method

It is increasingly noted in the literature that collaboration among healthcare researchers, community partners (which include the target minority population), and other interested organizations lead to action at the community level that serves to minimize health disparities, while also increasing empowerment of community members (Mendenhall et al., 2014; Salimi et al., 2012). However, it has also been noted that within the U.S., Hispanics/Latinos are difficult to recruit as participants in clinical trials due to such barriers as language, legal status, and cultural views regarding health care (McGill, 2013). Interestingly, the National Institutes of Health (NIH) report that minorities make up only 30% of those enrolled in clinical trials (McGill, 2013). In addition, Hispanics/Latinos make up only 7.6% of clinical trial participants, while Blacks represent 15% of participants (McGill, 2013). Utilizing a culturally appropriate method of research and program development (i.e., CBPR) could potentially address issues of low participant recruitment and attrition of participants during research studies, as well as improve

HIV healthcare outcomes. This systematic review will investigate the literature for studies that consist of collaborative partnerships designed to improve HIV outcomes for Latinos, and compare and contrast chosen articles for evidence of best practices.

Method

Cooper's *Research Synthesis and Meta-Analysis* (2010) guidelines were used in order to answer the systematic review research question: *Are Latino Community-based organizations effective in reaching the target population (Latinos), improving HIV knowledge, and/or improving HIV screening rates?* In May of 2015 a search of the literature was conducted through the following four search engines: CINAHAL, PubMed via Medline, PsycINFO, and Google Scholar.

Justification for Search Terms

Several search terms were selected in order to identify the literature most relevant to the subject matter and sample for this article. Most specifically that: (a) Latinos disproportionately represent new HIV diagnoses in the U.S. (AIDS.gov, 2014; CDC, 2014), are known for late diagnoses (Chen et al., 2012), and are increasingly settling into areas of the country that lack adequate infrastructure to accommodate their healthcare needs (Vega et al., 2015), and (b) that CBPR has been identified as a viable means to meet the healthcare needs of this population (Green et al., 1995; Israel et al., 2013; Mendenhall et al., 2014).

A variety of terminologies have been identified by researchers that are similar to the concept 'community-based approach' (e.g., participatory research; participatory action research; critical action research; collaborative inquiry; development leadership teams in action; cooperative inquiry; and appreciative inquiry) (Mendenhall et al., 2014). More specific to the field of public health, the community-based partnership approaches have taken on the terms "community-based participatory," "community-involved," "collaborative," and "community-centered-research"

(Israel et al., 2013). In order to be most comprehensive, the terms “community” and “participatory” were selected as search terms for this systematic review. In addition, the term “Latino” was chosen along with “Latina” due to the fact that “Latino” is an all-inclusive term for Latino men and/or women and thus Latinas may also be captured in research with Latino samples. The article review and selection process is depicted in detail in Figure 1.

Search Terms

1. Operationalization and/or clarification of search terms used:
    a. Latino, Latina, or Hispanic:
        i. The term *Latino* is defined as “all persons whose origins can be traced to the Spanish-speaking regions of Latin America, including the Caribbean, Mexico, Central America, and South America” (Flores, 2000, pp. 14-15). *Latino* is more inclusive of indigenous and African cultures than the term *Hispanic* (Flores, 2000), though *Hispanic* is the official term used by the government when indicating these groups (Flores, 2000). These terms overlap haphazardly in U.S. literature, thus both are included as search terms.
        ii. The term Latina is used when referring to “a woman or girl of Latin American origin or descent” (Oxford Dictionary, n.d.).
    b. Screening or testing:
        i. The term “screening” is typically used to suggest a strategy to identify a possible presence of a disease , whereas the term “testing” is designed to identify a disease (PACHA, 2011);
        ii. and given that there are a variety of HIV tests that can be administered (CDC, 2015), any reference to an HIV test is considered.

c. HIV or AIDS or STD or STI:
    i. HIV- refers to the human immunodeficiency virus: (i.e., affects specific cells (CD4 cells, T cells) of the immune system. If not treated, HIV can lead to AIDS (AIDS.gov, 2014)).
    ii. AIDS- refers to the acquired immune deficiency syndrome: (i.e., the final stage of HIV infections (AIDS.gov, 2014)).
    iii. STD- refers to sexually transmitted diseases: (i.e., a variety of clinical infections that cause bodily function impairment caused by pathogens that can be acquired and transmitted through sexual activity (CDC, 2015)).
    iv. STI- sexually transmitted infections, (i.e., growth of a specific group of pathogenic microorganisms in the body that can be acquired and transmitted through sexual activity (CDC, 2015)).

d. Community-based or participatory or collaborative:
    i. The community is considered a "unit of identity," which is defined by Israel et al. (2013) as "entities in which people have membership...a family, social network, or geographical neighborhood" (p. 8-9) .
    ii. Participatory or collaborative in the sense that Latinos participated/collaborated with the researchers in an equitable partnership in the research/project to the extent possible (Israel et al., 2013).

Search Process

Search limits included all peer-reviewed articles from 1995 to 2015. The year of 1995 was chosen because the more extensive antiretroviral medications that were approved for clinical use in the United States were introduced in 1995 (Warnke, Barreto, & Temesgen, 2007). Search engines and citation tracking were used to identify articles that emerged from search terms.

Titles and abstracts from results were searched, and these research articles, as well as subsequent articles, were stored in Ebscohost.

A search was first conducted through the CINAHL search engine, producing a total of 15 articles. Of these, six met the initial search criteria, and were stored in Ebscohost. The remaining articles were dismissed from title or abstract information that clearly did not fit the criterion set (e.g., community partners or CBOs excluded Latinos; participants did not include Latinos; study was conducted outside of U.S.; etc.). A subsequent search was made through PubMed that produced an additional 46 articles. Of these, 10 articles were chosen from abstracts and stored in Ebscohost. PsycINFO was then searched and produced 26 articles. Further examination from titles and abstracts resulted in seven articles from this search, which were then stored in Ebscohost. Additionally, a random search in Google Scholar was used to further search the literature. This search produced 164 relevant articles, bringing the total of articles from all initial searches to 251. Subsequent examination of titles and abstracts resulted in no new articles added from Google Scholar.

The researcher's review of titles and abstracts of the initial 251 articles reduced the number of articles selected to a total of 23 relevant articles. References and citations were inspected from these 23 identified articles, with two additional articles emerging, bringing the total to 25 articles. A second reviewer, trained by the first reviewer (the PI), was consulted throughout the process. The second reviewer performed a random check of the 251 articles.

The first and second reviewers applied the inclusion and exclusion criteria to the 25 chosen articles independently of one another. Inclusion criteria pertained to studies that: a) included Latino samples; b) utilized a community-based research approach involving Latinos as community partners; c) was published from 1995 to present. Exclusion criteria pertained to: a) participants who were commercial sex workers; b) community-based organizations that were a religious institution (only); c) studies conducted outside of the US. A coding sheet developed by the first reviewer was followed by both reviewers to guide the process and ensure accuracy of the searches. This lead to the selection of eight final articles (out of the 25). There were no discrepancies between reviewers.

Results

In conducting this systematic review, we looked at how researchers integrated core components of CBPR into their studies, specifically those with Latino samples. Based on an extensive review of literature conducted by Israel and colleagues (2013), nine priniciples are acknowledge as important guides to CBPR. From these priniciples, seven broad core components were identified (Israel et al., 2013) and serve here in this review as a measure to compare and contrast the eight identified studies. Other areas of interest for this review included the studies' designs, the development and maintenance of partnerships/relationships (i.e., the systemic support available to promotoras/es) and how partnerships/relationships affect retention and attrition of research participants, and change in participants' behavioral health outcomes.

Study Design

The eight final articles that met the inclusion and exclusion criteria for this systematic review were all implemented through community-based organizations that specifically reached out to the Latino population and partnered with researchers in order to carry out HIV prevention education and/or HIV screenings. All studies included a quantitative method. Of the eight articles, four employed an experimental design that used random assignment of participants into intervention groups or alternative/control groups (Flaskerud, Nyamathi, & Uman, 1997; Rhodes et al., 2009; Rhodes et al., 2011; Sanchez et al., 2013), and each of these four groups of researchers reported employing all seven components of CBPR as well. Two groups of researchers reported using a quasi-experimental design with pre and post test data collection

(Harper et al., 2009; Rios-Ellis et al., 2010). While Harper et al. (2009) employed all seven CBPR components, Rios-Ellis et al. (2010) employed only the first four. The remaining two groups of researchers used a descriptive design: (a) adapting and implementing a previously piloted program (Martinez et al., 2014), and (b) conducting a door-to-door survey and HIV rapid tests (Seña et al., 2010); neither employed all CBPR components.

All studies had a large sample of participants (i.e., ranging from 142 to 508 individuals). Five groups of researchers reported including a convenience sample (Flaskerud et al., 1997; Harper et al., 2009; Martinez et al., 2014; Rios-Ellis et al., 2010; Seña et al., 2010), and of these, three employed all seven CBPR components and two employed four of the components. Researchers conducting three of the studies reported using a randomized control trial method (RCT) (i.e., the gold standard) (Rhodes et al., 2009; Rhodes et al., 2011; Sanchez et al. 2013). These three sets of researchers employed all seven components of CBPR in their studies, maximizing CBPR collaboration from the study's start to finish.

The design comparisons mentioned above highlight that researchers employing all seven components of CBPR typically have more sophisticated study designs, including three that used random control trials, which is considered to be the highest standard for research trials. Furthermore, all eight research teams were able to include large sample sizes of their target population, strengthening the likelihood for generalization of findings.

CBPR Partnerships

Forming and maintaining relationships between community members and university researchers are key to fostering productive health outcomes within a community, according to the core components of CBPR (core component 1) (Israel et al., 2013). All but one article (Seña et al., 2013) provided information regarding partnerships; and researchers from five of the eight articles reported employing all seven core components of CBPR (i.e., emphasizing the importance of community partnership across the development and implementation of the project) (Flaskerud et al., 1997; Harper et al., 2009; Rhodes et al., 2009; Rhodes et al., 2011; Sanchez et al., 2013). Yet more importantly, these same five research teams also either referenced prior articles or produced additional articles that reported on the process of developing and maintaining the CBPR partnerships, highlighting the time intensive nature of the community networking and trust building process. Two studies employed only the first four of the core components (Martinez et al., 2014; Rios-Ellis et al., 2010), and one (Seña et al., 2013) did not employ any of the core components described by Israel et al. (2013).

Of these studies, Martinez et al. (2014) included some especially unique findings. The first four components were implemented to establish a connection with the local community, and collect data in a culturally sensitive way. What made this project unique, is that these researchers partnered with a local Latino community based organization (CBO), and the researchers stated that this organization continued to sustain elements of the program beyond the research study's conclusion, thereby helping HIV positive participants remain in care, as well as sustaining the outreach program that was implemented.

What is noteworthy from the overall collection of research, regarding CBPR partnerships, is that the partnerships were oftentimes well developed. The three research groups that had developed RCTs described an extensive amount of time dedicated to the development of their partner relationships. Rhodes et al. (2009) and Rhodes et al., (2011), developed their community partnerships during an eight month networking and trust building endeavor, attending community events, shopping at local tiendas (grocery stores), and eating at local tacquerias. Sanchez et al. (2013) reported fourteen months of partnership building for their four year study. It is important to note as well, that all of these studies received funding, which may be necessary for the time intensive work of building the relationships. Additionally, the Martinez et al. (2014)

article informed us that a key element to establishing partnerships was to work with a well-developed Latino CBO that could continue sharing the developed knowledge with the community beyond the conclusion of the research or grant funding.

Participant Recruitment and Retention

Recruitment of research participants often proves to be a challenge for many researchers (Patel, Doku, & Tennakoon, 2003). Patel and colleagues (2003) stated that the two main goals of recruitment for research are: 1) to be sufficient in size to meet the power requirements of the study, and 2) to produce a sample of a target population that is adequately representative of that population. All studies in our systematic review reported a large participant sample size, with intervention group numbers ranging from 142 to 508. The populations targeted in these eight studies varied within the Latino population. For example, Flaskerud et al. (1997) reported recruiting 508 low-income Latina women from the Public Health Service nutrition program for women, infants and children (WIC) in Los Angeles. The comparison group sample (n = 51) was recruited from the same setting. These researchers were interested in the effects of an HIV Program with low-income Los Angeles Latina women. Another group of researchers (Harper and colleagues, 2009) reported recruiting a sample of 378 Mexican-American adolescent girls from the local community. These participants were recruited from local community venues, through a street and community outreach effort. Others included Martinez et al. (2014), reporting recruitment of Latino men from a soccer league in the Midwest U.S. Rios-Ellis et al. (2010) recruited 461 Latinos who were primarily Mexican or Mexican-American, from two locations in California, one of which was a town that borders the U.S.-Mexico line. Seña et al. (2010) reported recruiting a sample of 228 Latinos. Rhodes et al. (2009) collected data from 222 male soccer teammates from intervention and control groups. Rhodes et al. (2011) reported recruitment of 142 Latino immigrant males. Sanchez et al. (2013) recruited 278 Latino migrant workers noted to be at high-risk for HIV, seeking their participants from different neighborhoods and camps within a Florida city area. As is demonstrated here, each of these researchers describe high numbers of recruitment within their targeted populations. Attendance and retention were also demonstrated in several of the studies.

Four of the eight articles reported participant attendance and retention (Flaskerud et al., 1997; Rhodes et al., 2011; Rios-Ellis et al., 2010; Sanchez et al., 2013). Of these four articles, three reported high levels of participation and retention at follow up. Potentially noteworthy, Rios-Ellis and colleagues were the only researchers to report significant attrition at follow up (only 21.5% retained) and missing baseline data that resulted in issues with posttest data. Rios-Ellis and colleagues discussed some of the issues with participants, such as invalid contact information, disconnected telephones, or that they had moved away from the area. Furthermore, the Rios-Ellis group conducted a multivariate logistic regression to determine variables that would help to explain attrition. Of the variables looked at (gender, marital status, years in the U.S., educational attainment, HIV knowledge, comfort level and stigma, safer sex and HIV testing intentions, and site location), attrition differed significantly by site location only, with the greater proportion of the participants lost to follow-up coming from the border region of California (i.e., from San Isidro border region) than from the alternative site location in Long Beach.

Recruiting and retaining Latino participants in clinical research studies lag behind recruitment from other ethnic and racial groups, often due to Latinos' cultural views about health care and lack of trust for researchers (McGill, 2013). It has been noted that the U.S. healthcare culture is more oriented toward preventive care than Latino cultures (Galanti, 2008), for example screenings (McMullen, De Alba, Chevez, & Hubbell, 2005) which include screenings for HIV or other STIs. Furthermore, researchers have noted that Latinos may discontinue treatment when there are no symptoms (Zea, Quezada, & Belgrave, 1994), again highlighting a lack of perceived need for preventive care. Recruiting efforts, as well as attrition and retention, may be even more challenging when it comes to research that includes potentially embarrassing or vulnerable topics, including research on STIs or HIV. The CBPR design (and strong community partnerships) may have been a key to the success in the large sample sizes in these studies that then resulted in helpful information pertaining to changes in behavioral health (e.g., consent to HIV testing and outcomes related to HIV knowledge and condom use).

Change in Behavioral Health

The goal for behavioral health research is to move the health field forward by identifying psychosocial and environmental factors that influence health, therefore generating new knowledge that will guide interventions and produce better health outcomes (Israel et al., 2013). Each of the studies in this review included some type of intervention that sought either to produce behavior change, or to identify factors that affect behavior change (i.e., factors that influence acceptance of HIV testing). Significant outcomes were reported in all of the studies that sought behavior change (Flaskerud et al., 1997; Harper et al., 2009; Rhodes et al., 2009; Rhodes et al., 2011; Rios-Ellis et al., 2010, Sanchez et al., 2013). The two studies that sought to identify factors that influence acceptance of HIV testing (Martinez et al., 2014; Seña et al., 2010) showcased success as well. Martinez et al. (2014) demonstrated that engaging Latino men within soccer leagues served as a natural system whereby Latino men are accessible for successful HIV and STI outreach testing. Seña and colleagues (2010) identified “no previous reporting of HIV testing” to be a predicting variable to acceptance of an HIV test in door-to-door rapid HIV testing interventions.

Five studies measured HIV screening or testing rates (Flaskerud et al., 1997; Martinez et al., 2014; Rhodes et al., 2009; Rhodes et al., 2011; Seña et al., 2010). Rhodes et al., (2009) and

Rhodes et al., (2011) both reported that participants in the intervention groups, compared to control groups, were more likely to report consent for HIV testing (p<.001 in both cases). Seña and colleagues (2010) reported rates of consent to HIV testing (55.2%) that were comparable to those reported by Martinez and colleagues (2014) (54%). Flaskerud et al. (1997) reported high rates of participants who were still involved at the one year HIV follow up retest (i.e., 38% returned). What was especially encouraging, was that of the participants in the Martinez and colleagues study (2014) who tested positive for HIV or another STI and were thus referred for follow up care, all individuals remained in care at the end of one year. This study highlights the personal touch that a CBPR study provide when offering a warm handoff and follow up process between place of testing and follow up to care.

Engaging researchers and communities in the production of knowledge is a key element of CBPR (Israel et al., Stoecker, 2009) that adds to the quality of results that are produced in CBPR projects. To this point, what was most noteworthy in these studies was the expertise of culture that the community members offered to researchers that ultimately helped produce best research results. For example, Flaskerud and colleagues (1997) demonstrated that condom use improved significantly after their intervention, but this was not due to increase in HIV knowledge, instead change was attributed to participants wanting to avoid pregnancy. Therefore, the researchers noted that an increase in knowledge did not influence HIV protection behaviors in this case. The researchers noted a similar issue when they measured increase in knowledge in "sharing needles and using bleach to prevent HIV transmission" (p. 100). This increase in knowledge did influence sharing and cleaning of needles for illicit drug use, but not sharing and cleaning needles for purposes of injecting home medications and vitamins. Participants did not apply the increase in knowledge from sharing and cleaning drug injecting needles to sharing and cleaning vitamin injecting needles. This was an important discovery that may not have come to light if conversations about culture had not taken place with the community members.

Discussion

In this study we set out to (a) provide a theoretical foundation for research with vulnerable populations, (b) unveil the health disparities connected to HIV infections for Latinos within the U.S., (c) provide the evidence on culturally relevant community based programs with Latino or Latina populations diagnosed with HIV, and (d) offer research and policy implications for future research and program initiatives with Latinos. Following is a discussion based in these objectives.

Theoretical Foundation

This study was grounded in critical theory, under the premise of empowering both majority and minority cultures to work together toward better health outcomes for Latinos, and more specifically for those at risk for acquiring or who have been diagnosed with HIV. With critical theory as our theoretical foundation, we look at non-traditional social structures for health research and education where clinical patients as well as research participants are not exploited by hierarchical differences in health care or research systems (i.e., CBPR with Latinos). In so doing, we highlight alternative structures that could be an avenue for bypassing barriers to HIV health care, and demonstrate their effectiveness in reaching the target population. Engaging with Latino community-based partners in order to address HIV health disparities provides a co-learning atmosphere between researchers and participants, empowers the Latino community through the research process, and provides a promising avenue for future health research and education.

HIV Health Disparities in Latino Population

Representing nearly 21% of all new HIV diagnoses while comprising only 17% of the U.S. population, Latinos disproportionately represent HIV infection rates in this country (CDC, 2011). Latino men are estimated to have two and a half times the rates of infection as White men; and rates of infection for Latinas are more than four times that of White women (CDC, 2011). Furthermore, foreign born heterosexual Latinos are recognized to be disproportionately affected by rates of HIV compared to Latinos who were born in the U.S. (Chen et al., 2010). In addition to these disparities, Latinas are noted to be less likely than their male counterparts to have been screened for HIV (Chen et al., 2010), and they tend to enter treatment later than their White counterparts (Chen, Gallant, & Page, 2012). Identifying the disparities in HIV rates of infection between racial and ethnic groups is a first step. Identifying ways to reduce the disparities requires that we identify and highlight best practices for culturally appropriate health care.

Culturally Relevant Community Based Programs: The Evidence

We have contributed to the literature by providing a systematic review of the CBPR HIV intervention studies conducted with Latino community-based partners, demonstrating the overall effectiveness of the CBPR approach on HIV risk behavior change and HIV testing rates. Some of the most encouraging results from our systematic review were the number of studies that used RCT (i.e., three of the eight studies [Rhodes et al., 2009; Rhodes et al., 2011; Sanchez et al., 2013]). Also impressive, was the realization that every study in our review that measured change in HIV knowledge and condom use demonstrated statistical significance on at least one outcome (e.g., increased consistency of condom use; increase of HIV transmission knowledge). Furthermore, rates of reported consent to HIV testing were significantly increased in two of the five studies measuring HIV testing (Rhodes et al., 2009; Rhodes et al., 2011), while rates were increased at lower levels in the remaining three studies (Flaskerud, et al.1997; Martinez et al., 2014; Seña et al., 2010). In addition, there were impressive rates of participant attendance and retention through several of the cited studies (Flaskerud et al., 1997; Rhodes et al., 2011; Sanchez et al., 2013), with the exception of the Rios-Ellis et al. study (2010). Also emerging as a significant outcome from the CBPR partnership process was the sharing of knowledge that was highlighted in the Flaskerud et al. (1997) study. The contribution of the community members' involvement and input provides valuable guidance for researchers that could ultimately produce higher quality research that can be translated into better healthcare practices or outcomes for Latinos. A notable mention from this review was the extensive investment of time for community partnership networking and building that went into studies employing more advanced experimental RCT designs, and the funding that was contributed to the process.

Research and Policy Implications

The community-based participatory research approach could be an effective way to reach Latinos for providing HIV and other STI healthcare education and research, as well as an effective approach for HIV and STI screening and testing. Local health departments might be successful in reaching the Latino population for HIV education and testing services through outreach partnering with a local Latino CBO. It will be necessary to identify and build partnerships with local Latino serving CBOs, and to maintain these relationships, which will likely require a significant time investment. However, this investment will be small given the potential to close the gap on HIV infection disparity rates. Creative efforts between research universities and community partners should be explored in order to produce quality research. For example, utilizing an internship program that places graduate research assistants in community-based organizations for the purpose of community-based participatory research could help maintain the relationships, as well as provide an avenue for steady, ongoing research.

Limitations

The search through this systematic review may not have captured all possible publications pertaining to CBPR. For example, we did not seek out unpublished documents, articles written in other languages, or dissertations. A second limitation of this systematic review are the inconsistent operational definitions developed for CBPR. Israel et al. (2013) reminds researchers that not all core components are to be strictly followed when a partnership decides it is not needed, thus descriptions of what is essential to a partnership may not be consistent across CBPR projects.

Recommendations

Based on the findings from this systematic review, researchers should begin cultivating community relationships that can be sustained. The more advanced research designs that were identified obliged extensive relationship building, requiring greater commitments of time. The most crucial elements identified to CBPR work is the development and maintenance of partner relationships (Israel et al., 2013). Additionally, sustained relationships create relational opportunities for further research and health related interventions. Researchers endeavoring to employ more advanced research designs should seek to identify and connect with the community leaders or gatekeepers of Latino community-based organizations, as researchers in this review did. They should invest time in attending community events and activities that are specific to the Latino community. Specifically, they should attend Latino community events, shop at local *tiendas*, and eat at local *taquerias* (Mexican restaurants), and consider volunteering at Latino community events when the opportunity presents. There may also be the need to seek funding due to the intensive time investment.

Community members should recognize community research universities as a resource, and potential avenue for building capacity. Latino gate keepers should connect with researchers specializing in fields of study that could be a resource for addressing known health concerns of the Latino community. Community healthcare providers should form partnerships with local Latino community organizations and offer information workshops and HIV testing opportunities via identified gatekeepers. Latinos are known to encounter both implicit and explicit barriers to health care (CDC, 2015; Giordano et al., 2010; Hargreaves et al., 2010). However, this review provides evidence that Latino community-based organizations are successful avenues for connecting Latinos to health care and healthcare research.

While not every research project will require a CBPR approach, health researchers who seek culturally appropriate methods that translate to better health outcomes for Latinos should embrace community collaborative research. These projects are particularly time intensive, requiring funding to allow for this. Research universities should train faculty in CBPR and culturally sensitive research designs, and develop strong relationships with identified community-based organizations and target populations that can be sustainable. This could come in the form of research graduate assistantship placements positioned in community-based organizations that would serve to bridge the research work between faculty and target populations over long periods of time, building capacity in Latino community organizations, strengthening and sustaining the relationships via collaborative community based initiatives, or through the provision of services through community-based organizations. As relationships are built and maintained between community organizations and research universities in this way, initial funding is replaced by the capacity that has been built, thus making projects sustainable.

Summary

There has been an increasing interest in CBPR as a means to provide a more comprehensive approach to research and interventions (De Las Nueces, Hacker, DiGirolamo, & Hicks, 2012; Israel et al., 2013; Stoecker, 2009; Viswanathan et al., 2005). The CBPR method, or approach to research, can be part of the solution that challenges the power dynamics which have historically subjugated vulnerable populations. If, through the avenues of CBPR, researchers are able to partner with Latino community organizations and community members in research, to be co-producers of knowledge, and exchange knowledge for the sake of improving community health outcomes, we can also affect present social structures that may inadvertently impede access to HIV care for Latinos. How we practice CBPR (i.e., how we develop and maintain partnerships, and include Latino community members in as much of the research process as feasible) will determine the quality of outcomes.

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Table 1: Synthesis of Intervention Studies with Latinos using a Latino Community-based Organization

	Author	*Year*	*Type of CBO/Partners*	*Participants*	*Core Components*	*Design*
1.	Flaskerud & Nyamathi	1997	Nurse researchers; Latina* CHWs from community; WIC program community setting	n=508 Latina* women n=51 comparison grp	1,2,3,4,5,6,7	Longitudinal 2 yr program; pre/post-test/re-test; Quasi-experimental design; convenience sample of low-income; comparison grp from same setting; focus grp; 2 stages
2.	Harper, Bangi, Sanchez, Doll, & Pedraza	2009	Latino-focused CBO, diverse; university researchers; Mexican-American females from local community	n=378 Mexican-American adolescent females	1,2,3,4,5,6,7	Quasi-experimental evaluation of SHERO program; pre/post-test/re-test; convenience sampling; participants participated in either 9 session intervention, or single session information only HIV prevention intervention, no random assignment
3.	Rhodes, Hergenrather, Bloom, Leichliter, & Montaño	2009	Partnership: university researchers; local health & Latino-serving CBOs; religious/AIDS/public health dept	n=222 Latino* men	1,2,3,4,5,6,7	RCT experimental; purposeful sample; pilot study; data collected baseline/18 month post
4.	Rios-Ellis, Espinoza, Bird, Garcia, D'Anna, Bellamy, & Scolari	2010	Staff; promotores (3 bi-lingual, bi-cultural health promotores); university researchers	n=461 Latinos* n=44 in focus grp	1,2,3,4	Quasi- experimental; 4 stages (needs assessment; intervention developed; implementation; evaluation) Convenience sampling; pre/post-test/re-test
5.	Seña, Hammer, Wilson, Zeveloff, & Gamble	2010	Promotores from local Latino community; university researchers	n=228 Latinos*	N/A	Convenience sampling; survey demographics/HIV rapid test offer
6.	Rhodes, McCoy, Vissman, DiClemente, Duck, Hergenrather, … & Eng	2011	Partnership: university researchers; local health & Latino-serving CBOs; religious/AIDS/public health dept	n=142 Latino* men	1,2,3,4,5,6,7	Experimental, RCT pre/post-test, purposeful sampling, participants randomized into HIV prevention intervention grp or a cancer education intervention.
7.	Sánchez, De La Rosa, & Serna	2013	Community health workers (CHWs); Office of Farmworkers Assoc. of Florida (FWAF); university researchers	n=278 high risk Latino* migrant workers	1,2,3,4,5,6,7	RCT experimental; pre/post-test/re-test; purposeful sampling; 4 year study
8.	Martinez, Roth, Kelle, Downs, & Rhodes	2014	Staff from a CBO serving Latino community; academic researchers; public health providers; representatives from local men's Latino soccer leagues	270 Latino* men	1,2,3,4	1 yr program; convenience sampling; adaptation & implementation of HoMBReS training modules; descriptive design

**Unspecified*

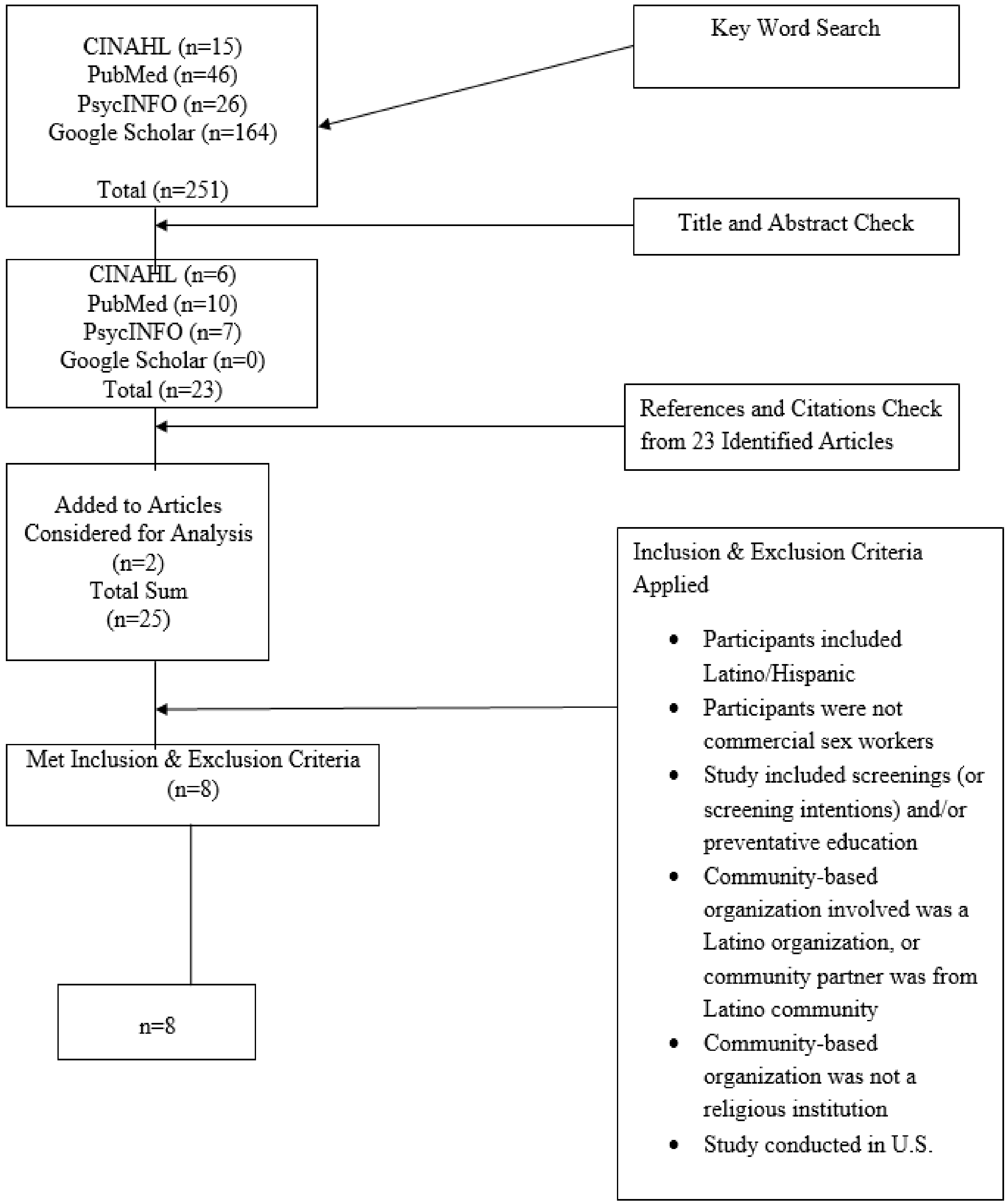
Table 1. Synthesis of Intervention Studies with Latinos using a Latino Community-based Organization

Author	*Intervention*	*Measures*	*Analysis*
1. Flaskerud & Nyamathi (1997)	HIV psychoeducation; counseling; antibody testing	Change in AIDS knowledge; condom use; change in risk behaviors; program assessment	Pearson product moment correlations at pre/post/re-test; one-way repeated measures ANOVA; independent t-tests; two-way repeated measures ANOVA; multiple regression analyses; & content analyses (Corbin & Strauss)
2. Harper et al. (2009)	Condom use education; HIV education; HIV risk reduction skills specific to culture	Psychosocial outcome variables; Condom Attitudes Scale; HIV-related Peer Norms Measure; Sexual Beliefs Scale; Token Refusal Subscale; Health Protective Sexual Communication Scale; Kirby's Behavior Inventory	Pearson chi-squares; ANCOVA repeated measures mixed model ANOVAs
3. Rhodes et al. (2009)	Condom use education; HIV testing; HIV education	18 true/false HIV knowledge assessment; risk behaviors measure; acculturation	t-tests; chi-square; multivariate logistic regression w/GL mixed modeling
4. Rios-Ellis et al. (2010)	HIV/AIDS education; condom use education	HIV knowledge; safer sex & HIV testing intentions; comfort level & stigma	Paired t-tests; multivariate logistic regression
5. Seña et al. (2010)	HIV testing; HIV/AIDS education	Surveys; rapid HIV test	Self-reports; bivariate analysis; multiple logistic regression
6. Rhodes et al. (2011)	Condom use education; HIV testing; HIV education	Self-report questionnaire; acculturation measure using Short Acculturation Scale for Hispanics; 18 true/false HIV assessment; Xhosa & Afrikaans scale	t-tests or Wilcoxon rank sum tests; chi-square or Fisher's exact tests; logistic regression; multivariable modeling; MICE
7. Sánchez et al. (2013)	Condom use education; HIV education	Self-reports; psychometrics; gender roles scale	t-tests; chi-square tests; logistic regression; linear regression
8. Martinez et al. (2014)	Condom use education; HIV testing; HIV/STI education, HoMBReS program	Rapid HIV test; urine STI screening; did not measure for change in behavioral factors	N/A

Table 1. Synthesis of Intervention Studies with Latinos using a Latino Community-based Organization

Author	*Results*
1. Flaskerud & Nyamathi (1997)	Significant improvement in HIV knowledge at post-test; significant improvement in HIV risk behaviors; significant increase in use of condoms; No significant change was found for comparison group.
2. Harper et al. (2009)	All eight psychosocial outcomes were significant across pre, post, and follow up tests: Self-Esteem; Perceived peer norms; Sexual communication; Condom attitudes; Leading on justifies force; Token refusal of sex; HIV/AIDSs knowledge; STI knowledge
3. Rhodes et al. (2009	Significance reported in pre and post intervention tests among participants' use of condoms; HIV testing was significant, as well as increase in HIV knowledge
4. Rios-Ellis et al. (2010)	An increase in comfort level with suggesting a partner be HIV tested, however, self-willing to take HIV test was less significant; participants' HIV knowledge increased significantly. Safer sex and HIV testing intentions were significant at the post test
5. Seña et al. (2010)	The only variable predicting HIV test acceptance was if participants reported never testing for HIV before
6. Rhodes et al. (2011)	Participants in the HIV prevention intervention were more likely to report consistent condom use, and more likely to report receiving an HIV test
7. Sánchez et al. (2013)	Participants showed higher HIV knowledge than alternative intervention participants, and reported fewer perceived barriers to condom use, and greater condom use self-efficacy
8. Martinez et al. (2014)	Percentage of participants consenting to an HIV test was 54%, and 70% consented to an STI screening. Those testing positive were referred for follow up care, and 100% remained in care at the end of year one.

Figure 1: Methodology for Articles Retrieved



CHAPTER 4: METHODOLOGY

Racial and ethnic inequalities in health are common and have been widely recognized for many years (Bahls, 2011; Stryer, D.G., Weinick, R.M, & Clancy, C.M. 2002).These inequalities cut across a spectrum of diseases, including those identified as epidemics, such as human immunodeficiency virus (HIV) (Evans, Whitehead, Diderichsen, Bhuiya, & Wirth, 2001). While health *inequality* refers to the differences in health between and within nations (Evans et al., 2001), health *inequity* refers to a subgroup of inequalities that have been judged as unfair (Evans et al., 2001). According to Whitehead (1992), the term has a “moral and ethical dimension” and “refers to differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust” (p. 219). Addressing racial and ethnic inequities can help to eliminate health disparities (Centers for Disease Control (CDC, 2014)), such as those for Latinas who are at risk for or have been diagnosed with HIV or acquired immune deficiency syndrome (AIDS) (CDC, 2014).

Latina immigrants are exceptionally vulnerable to sexual health disparities, particularly when it comes to exposure to and screening for HIV infections (Webber, 2007). According to the CDC (2010), the most common way to contract HIV for Latinas who live in the U.S. is through heterosexual contact. It has also been noted that Latinas’ greatest risk factors are those associated with her partner (e.g., partner’s HIV status; partner is a migrant worker; partner is suspected of being unfaithful) (Johri et al., 2010), a trusted person that she wouldn’t likely suspect of putting her at risk for transmission of the disease. Other factors, such as traditional cultural values (Galanti, 2003; Parrado, Flippen, & McQuiston, 2005; Persichino & Ibarra, 2012; Viadro & Earp, 2000) and stigma (Infante et al., 2006) also contribute to Latinas’ vulnerability to HIV infection while adherence to care influences her mortality from the diagnosis, and thus are necessary to continuously assess.

While issues related to vulnerability and subsequent HIV treatment adherence exist across the U.S., these issues become even more complicated based on current incidence rates in particular regions of the U.S., such as the South. For example, in 2010 46% of all new HIV diagnoses were reportedly in the South, despite the fact that this region only represents 37% of the U.S. population (Zhang et al., 2014). In addition, the greatest percentage of new diagnoses among Hispanics/Latinos was in the South (CDC, 2012). And recently, from 2000 to 2010, North Carolina (N.C.) had seen an increase in the Latino population of more than 111% (Passel, Cohn, & Lopez, 2011). Furthermore the proportion of Latinos with an HIV diagnosis in N.C. that are not in treatment (i.e., unmet need) are higher than any other racial/ethnic group, and has steadily been increasing over the past five years (a 43.7% increase) (North Carolina Department of Health and Human Services [NCDHHS], 2013). The culmination of growing incidence and growing healthcare needs for Latina's extended into the purpose for this study.

Purpose

To better understand and address HIV infections within the Latina community in this country, a qualitative research study (Hennink, Hutter, & Bailey, 2011) was developed to explore the question: *What are Latina immigrants' experiences with healthcare providers in their home country and the United States?* This research question was constructed through a qualitative research design that integrated the research team's (i.e., researchers from East Carolina University and community ambassadors from AMEXCAN- all of whom will be described in greater detail below) chosen philosophical position, strategy of inquiry, and research method.

It should be noted that this question was intended to be broad enough to capture the lived experiences of Latina immigrants who had received health care in their home country and the U.S., however it was also presumed that most questions would be answered in the context of obstetric or gynecologic health care given that Latinos have a higher fertility rate than any other racial or ethnic group in the U.S., (Passel, Livingston, & Cohn, 2012) and that Latina's are more likely to receive health care in relation to pregnancy or gynecological care than any other time in their life.

The research team included the community-based organization (AMEXCAN-Association of Mexicans living in North Carolina), a grassroots Latino organization in eastern North Carolina; the primary investigator (PI); and three research assistants from East Carolina University (ECU): (1) A male, Mexican-American 2nd year Medical Family Therapy PhD student, (2) a white non-Hispanic American woman 2nd year Medical Family Therapy PhD student, and (3) a female, Mexican-American undergraduate Hispanic Studies student who is also a member of the AMEXCAN organization. All three research assistants were bi-lingual, Health Insurance Portability and Accountability (HIPAA) trained and IRB approved, and assisted the PI in areas of interviewing and transcribing. All research team members engaged in data collection and analyses (i.e., ECU researchers and one member from AMEXCAN) were trained by the PI in proper procedures and chosen method of analysis. This study was approved by the East Carolina University Internal Review Board (see Appendix A).

The PI has been a volunteer of the AMEXCAN organization since its inception in 2001, and has worked closely with the Executive Director and the Latino community in eastern N.C. since this time. It has been through this work that a long term, collaborative relationship between the PI and the AMEXCAN organization has been developed and maintained. Before beginning this research project, the PI approached the organization's Executive Director in the fall of 2012 and asked what health issues the Latino community were most concerned about. This question resulted in numerous conversations that ultimately became the development of the study described through this dissertation. Since fall 2012, the PI has increased her active membership in the organization's community activities, and has been a consistent attendee of the promotores' community meetings, which have been held regularly in two counties of eastern N.C. The PI participated in several opportunities offered by the Executive Director to speak with Latino community members regarding the progress of the research study.

Study Design

A "distinctive feature of qualitative research is that the approach allows you to identify issues from the perspective of your study participants, and understand the meanings and interpretations that they give to behavior, events, or objects" (Hennick, et al., 2011, p. 9). Furthermore, while some qualitative research designs emphasize an understanding of an individual's lived experience (Hennick et al., 2011), some researchers argue that qualitative research should also advocate for the oppressed and advance a social justice agenda (Denzin & Lincoln, 2005). According to Creswell (2009), a research design encompasses three components that intersect and provide the point of reference from where the researcher begins. These intertwined components include: (a) the researcher's philosophical /theoretical position, (b) strategies of inquiry, and (c) the specific method employed (Creswell, 2009). These components provide the framework for the selection of the sample, procedures, and rigorous method that has the capacity to translate into positive outcomes with and for a community (Creswell, 2009).

Philosophical and Theoretical Position

Critical Theory. The research team (i.e., the university researchers and those from the grassroots organization, AMEXCAN) chose critical theory (Habermas, 1962, 1989) as the theoretical foundation to ground this study. Critical theory emphasizes emancipation (i.e., freedom from circumstances that hold people down in life), and Habermas declared that self-knowledge and reflection (via communication) can liberate individuals from the circumstances that originate out of social institutions (1962, 1989). Critical theory is employed by those who are concerned by a power imbalance and inequitable resource distribution that occur in societies today (McCarthy, 1989), making it especially relevant to this research study related to the health concerns of Latinas in the U.S.

Community-Based Participatory Research. In addition to critical theory, a community-based participatory research framework (Israel, Eng, Schulz, & Parker, 2013), was interwoven into the development of the research design for this study. The research team chose to unite the tenants of critical theory with a research framework that honors the voice of the community through action research (i.e., community-based participatory research [CBPR]) to further support their philosophical position.

CBPR focuses on an equitable collaboration between community organizations and university researchers in an effort to improve public health and health outcomes within a community (Israel et al., 2013). There is a growing appreciation for the use of CBPR as a vehicle to explore ways to better understand health outcomes, specifically within minority populations (De Las Nueces, Hacker, DiGirolamo, & Hicks, 2012; Viswanathan et al., 2005). While attending to power differentials and validating voices within the targeted research sample is important, CBPR researchers are ultimately charged with the production of quality data via a rigorous method.

Principles of CBPR. Though there is not one set of principles that fit for every CBPR partnership, there are principles that helped when creating the collaborative partnership and process that resulted in co-developed research questions, recruitment for the interviews, and ensuring that CBPR was used through the data collection and analysis procedures. According to Israel et al. (2013), there are nine principles that guide the CBPR process, CBPR:

> “(a) acknowledges community as a unit of identity (i.e., individuals identify as members of a particular social network, emotionally connected to others by values, shared interests, etc.), (b) builds on strengths and resources within the community, (c) facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power sharing process that attends to social inequalities, (d) fosters co-learning and capacity building among all partners, (e) integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners, (f) focuses on the local relevance of public health problems and ecological perspectives that attend to the multiple determinants of health, (g) involves systems development using a cyclical and iterative process, (h) disseminates results to all partners and involves them in the wider dissemination of results, and (i) involves a long-term process and commitment to sustainability” (Israel et al, 2013, pp. 8-9).

These principles are not strict in the sense that a study cannot be considered CBPR if all nine are not present (Israel et al., 2013), In fact, Israel and colleagues (2013) emphasize that it is more important to remain flexible to ensure that the community’s needs are not second to staying faithful to all nine principles. With critical theory (Habermas, 1962, 1989) as a guide for the research team, our emphasis was on a collaborative partnership, sharing knowledge, and empowering the community throughout the entire research process.

Core Components of CBPR. Also important to CBPR are the seven core components that are used in conducting CBPR (Israel et al., 2013). While the principles of CBPR have more to do with what a CBPR partnership is and guides the partnership process, (Israel et al., 2013), the core components speak to the phases of research, and what aspects of the research take place in each phase (Israes et al., 2013). These core components are:

> “(a) forming a CBPR partnership, (b) assessing community strengths and dynamics, (c) identifying priority health concerns and research questions, (d) designing and conducting etiologic intervention and/or policy research, (e) feeding back and interpreting research findings, (f) disseminating and translating research findings, and (g) maintaining, sustaining, and evaluating CBPR partnerships” (Israel et al., 2013, pp. 12-13).

The implications that are derived from these seven core components are that relationships between community members and university researchers are key to fostering productive outcomes. As in this study, trusting relationships are important to quality data collection (Viswanathan et al., 2005). The relationships between the PI and AMEXCAN members have taken many years to build, and energy to maintain. Furthermore, forming relationships and then maintaining these relationships over time supports the weight that critical theory places on an equitable balance of power and distribution of resources (McCarthy, 1989).

Examples of these principles and core components at work in this study include, (a) the Executive Director of AMEXCAN was involved in identifying the health concern to be investigated (i.e., HIV in the Latino community), and was present for numerous meetings with the PI and other research team members to discuss the research process. He was also involved in the review of the literature regarding the study, and has been consulted on potential policy initiatives to be pursued based on the findings; (b) One research team member is a Latina, and a member of AMEXCAN, and has been involved in every part of the research process, including: HIPAA training, reviewing the literature, inviting participants to be interviewed, interpreting for the PI during the interviews, training in the method of analysis, and discussions with the Latino community during community forums about the CBPR process; (c) The PI has been actively involved in numerous promotores' meetings, as well as other Latino community events; and (d) Every participant interviewed was introduced to CBPR, and explained the importance of an equitable, collaborative partnership.

Strategy of Inquiry

A culturally appropriate strategy. Within the CBPR framework the research team chose to use a strategy of inquiry known as phenomenology (Groenewald, 2004) in order to explore Latina immigrants’ experiences with completing a screening and/or assessment with health care providers in their home country and the United States regarding sexually transmitted infections or diseases. Using an appropriate philosophical approach was important for understanding Latina immigrants’ experiences. Otherwise, there would be the potential for continued or increased health disparities if screening and assessments for sexually transmitted diagnoses, such as HIV, were not attended to in a culturally appropriate way by healthcare providers, or not received in a way that Latina immigrants understand the need for screening (Galanti, 2003; Parrado et al., 2005; Persichino & Ibarra, 2012; Viadro & Earp, 2000).

Phenomenology. As stated previously, the philosophical position of the research team was critical theory (Habermas, 1962, 1989) set within a CBPR framework (Israel et al., 2013). In order to answer the research question: *What are Latina immigrants’ experiences with healthcare providers in their home country and the United States?* , the research team used phenomenology (Husserl, 1960) as the strategy of inquiry. Phenomenology was used to explore particular phenomena through the eyes of the participant and how the experience was interpreted by the participant (Husserl, 1960). This strategy of inquiry has been suggested to be more of a method of questioning than a method of answering (Van Manen, 2014); and originates from the writings of Kant, Hegel, and more recently, Husserl (Groenewald, 2004). Phenomenology is an appropriate strategy of inquiry for this study, as it is in line with the core components and principles of CBPR (Israel et al., 2013), and promotes self-knowledge and reflection that is advocated for by critical theory (Habermas, 1962, 1989).

Method

Participants (Co-Researchers)

The research team focused on Latina immigrants as participants for the study, using a purposeful sampling procedure. Referring to participants as co-researchers keeps in line with the nine principles of CBPR (Israel et al., 2013). A total of 11 individual in-depth interviews were conducted (Creswell, 2007). The interviews continued until the point of saturation (i.e., the point where the interviewer no longer heard new information that was already stated by the previous participants (Creswell, 2007).

Recruitment of Participants

Flyers were developed by the research team for the purpose of advertisement for the study (see Appendix B). These flyers were placed in local area health clinics, including clinics in departments of infectious diseases. Specifically, flyers were placed in health departments and health clinics throughout the eastern counties of N.C. that are represented by AMEXCAN. Area health clinics included Kinston Community Health Center; and the Public Health Departments of Pitt and Greene counties. Flyers were also placed in the Division of Infectious Diseases at the Department of Internal Medicine in Pitt County. The flyers listed AMEXCAN's Executive Director, Mr. Juvencio Rocha-Peralta, as a contact person. The PI (Roberta Bellamy) (ECU Medical Family Therapy student; AMEXCAN volunteer member) was also listed as a contact person on all flyers, as well as a female member of AMEXCAN. The flyers also listed the AMEXCAN general phone number, a confidential number for individuals who wish to participate in the study.

The first three interviewees were recruited from one of the area healthcare clinics by the clinic's outreach worker. None of the interviewees answered the flyers, but contacted the PI directly at various AMEXCAN community events that were attended. Mr. Rocha-Peralta explained the study to those attending the events, and explained inclusion and exclusion criteria. Most interviewees scheduled their interview appointment with the PI in this way, while some were contacted later by Ms. Flores, the interpreter for the interviews.

At the start of all phone calls related to participating in study, each person received an explanation of the study (see Appendix C) and how confidentiality would be protected. Interested participants were screened for inclusion and exclusion criteria at this time. Inclusion criteria for the study were, that the participant: (a) identified as 1st generation Latina immigrant; (b) had at least one previous medical appointment with a healthcare provider (i.e., been seen by a medical provider in the U.S. or their home country); (c) had been asked to answer questions about her sexual history as part of a medical visit; and (d) was at least 18 years of age. Exclusion criteria for the study were that the participant: (a) had never received health care (i.e., had never been seen by a medical provider) and (b) had never been asked questions about her sexual history as part of a medical visit.

Setting

Each interviewee was asked where she might want the interview to take place (e.g., at the AMEXCAN office or in her home) and if she would need child care. Seven interviews took place in the interviewee's home, the remaining four took place at the AMEXCAN office. At each individual face to face interview, interviews were asked to sign a formal written consent agreement, as was standard with all interviewees. Interviewees were provided information pertaining to the research study, including reassurance that they would not be required or influenced to remain in the study (i.e., were able to stop the interview at any time or refuse to answer any question within the interview protocol). They were also informed about their rights to confidentiality. After reviewing all elements of the study, participants were asked to review and sign (if interested) the informed consent. Participants were each mailed a $25 gift card to compensate for their participation in the interview.

Procedures

Given that this study used a CBPR framework the term "we" was used when speaking about the community partners (i.e., researchers and community members) involved in the research procedures, emphasizing a collaborative effort. To further honor the importance of equitable collaboration, a "role of the CBPR team member" document was written by each major contributor involved in the development of the study and was shared with one another (CBPR core component 2) (Israel et al., 2013) (see Appendix D).

Development of the research team. Due to the unique nature of a CBPR study design, the procedures of the research study began with a collaboration meeting among the community members and research partners (CBPR core component 1) (Israel et al., 2013). The members of the CBPR team from the AMEXCAN Latino organization were invited to participate as co-researchers (www.amexcannc.org). The research team included the PI from a university in eastern North Carolina. Three research assistants were involved in the study as well: (1) A male, Mexican-American 2nd year Medical Family Therapy PhD student, (2) a white non-Hispanic American woman 2nd year Medical Family Therapy PhD student, and (3) a female, Mexican-American undergraduate Hispanic Studies student who is also a member of the AMEXCAN organization. All three research assistants were bi-lingual, Health Insurance Portability and Accountability (HIPAA) trained and IRB approved, and assisted the PI in areas of recruitment, interviewing, transcribing, coding, and analyzing data.

In keeping with the principles and core components of CBPR (Israel et al., 2013), there was community-dialogue held at the AMEXCAN office in Pitt County. The community-dialogue was conducted with AMEXCAN promotores (i.e., lay Latino community members who have received specialized training in basic health education) who had been active in this community for a number of years. The dialogue was facilitated by the PI and a female research assistant from AMEXCAN and the N.C. Latina community. The researchers provided introductory information pertaining to the study and talked with the promotores about the research questions developed and ways to reduce any possibilities for exploitation or discomfort among Latina immigrants who would be invited to participate in the study (CBPR core component 3 and 4) (Israel et al., 2013). This group worked together to review the interview protocol that was used for the in-depth interviews, as well as reviewed flyers for recruitment of participants.

Data collection: In-depth interviews. This qualitative study consisted of one on one in-depth interviews with individuals meeting the inclusion/exclusion criteria described above. Semi-structured, open-ended questions (see Appendix E) were developed by the CBPR team members (PI and Mr. Rocha-Peralta) involved in this research study in collaboration with study investigators from East Carolina University and AMEXCAN's promotores (i.e., the lay leaders from the AMEXCAN community organization). Interviews were conducted in the participant's home or at the AMEXCAN office. Following the interview, all interviewees were asked to fill out a demographic questionnaire, developed by the PI and AMEXCAN's Executive Director (see Appendix F). Each interviewee either had the demographic questionnaire read out to them by the bi-lingual research assistant, and asked to answer orally, or were given the questionnaire to fill out with bi-lingual research assistant seated next to her, available to answer any questions that arose.

The in-depth, semi-structured interviews consisted of questions that were asked of each interviewee and followed with probing questions, as indicated by the interviewee's response (Israel et al., 2013). The interviews followed an interview protocol to ensure that the procedures were addressed with all participants (Creswell, 2009). Steps of the protocol included: a greeting, review of the informed consent (see Appendix G), the interview questions (including probing questions), time to complete the demographic questionnaire, and a closing statement about the researcher's next steps (i.e., review of the audiotapes and transcription).

These interviews were conducted by the PI and research assistant interpreter. A *back translation* method (Harkness & Schoua-Glusberg, 1998) was utilized by the PI and research assistant interpreter to ensure for triangulation (i.e., a source for data collecting in addition to the primary data collection method) (Creswell, 2009). Back translation involved research questions posed by PI in the source language (i.e., English) and translated for the participant into the target language (i.e., Spanish), and then back into the source language for the PI (Harkness & Schoua-Glusberg, 1998). All interviews were audio recorded to assist in the facilitation of transcription and back translation processes. The interpreter recorded her English translation into a separate recorder as she translated the interview into Spanish for the PI. This process provided two recorded translations of the interview in order to protect the integrity of the participant's responses and the meaning attributed to those responses (Creswell, 2009).

The research assistant (in accordance with CBPR processes) was paid according to the rate indicated by the Bureau of Labor Statistics for translating services in eastern North Carolina (Bureau of Labor Statistics, 2014). Interviewees were asked to choose for themselves a fictitious name, beginning with a letter assigned by the PI (e.g., the 1st participant chose a name beginning with A, the second participant chose a name beginning with B, etc). The fictitious name was used in the audio recording, and written on the transcript. PI numbered the informed consent forms in order of interviews (e.g., 1st participant was assigned a 1 on her informed consent, etc.). PI was aware of which transcript matched which interview participant by looking at the first letter of participant's name, and matching this to the number on the corresponding informed consent. All recording devices and signed consent forms were placed into a portable file box with a key lock and locked before leaving the interview site. The locked box was taken directly to the Redditt House: Medical Family Therapy Research Academy and secured within the building under double lock and key. After the data had been collected, interview material was then analyzed.

Method of Analysis

Interview data was transcribed verbatim by a professional transcriptionist from the English recordings of the interviews. No identifying information was represented in any of the recordings in order to ensure anonymity with the transcriptionist. The primary investigator was assisted by a second researcher, who listened to the Spanish version of the interviews and verified that the English transcription was accurate. The research assistant was paid according to the rate indicated by the Bureau of Labor Statistics for translating services in eastern North Carolina. Providing a reasonable wage for translation services to a community member further supports the importance of the principles of CBPR (Israel et al., 2013).

The transcripts were coded by the PI and other members of the CBPR research team via Giorgi's method. Giorgi uses an easy to follow, yet rigorous, approach for analyzing qualitative data (Giorgi, 2009). Also of importance, Giorgi was influenced by Husserlian philosophy

(Giorgi, 2009). He modified Husserl's phenomenology to fit within a psychological framework (Giorgi, 2009), yet closely followed Husserl's writings, maintaining that "the object of phenomenological description is achieved 'solely' through a direct grasping (intuiting) of the essential structure of phenomena as they show in consciousness" (Dowling, 2007, p. 135). Due to this approach, Giorgi does not require that the researcher return to the participants to verify the resulting descriptions of the researcher with the experiences of the participant, which some have suggested involves interpretation, counter to Husserl's phenomenology (Dowling, 2007).

Giorgi also developed practical steps for applying a phenomenological method of analysis. An easy to follow approach to analysis is particularly helpful for this study, given that CBPR supports the inclusion of the community members of interest (i.e., Latinas) in all aspects of the research process (Israel et al., 2013). Giorgi's method of analysis uses four stages of deconstructing the transcribed data (Giorgi, 1975). The first stage calls for reading through the entire transcript. The PI and one other co-researcher, read through the transcriptions completely, making no judgment of the material (i.e., bracketing all presuppositions) (Husserl, 1960), to get a feel of the entire interview in a single reading (Giorgi, 1975). The second stage is where the researcher will discern "units of meaning" expressed within the larger text (Giorgi, 1975). This is where the PI and co-researcher, separately, looked to identify areas within the transcript that related to the participant's experience of the phenomena under study. From this point, at stage three, the PI and co-researcher reviewed these units of meaning in order to get a feel of how each related to the purpose of the study (Giorgi, 1975). It was in this stage that the themes were looked at for relevance to the phenomena under study. There was no conflict in agreement between the PI and co-researcher. In the final stage of the analysis, themes were identified and connected in such a way as to develop a concise description of the themes that were vital to the interpretation (Giorgi, 1975).

Using this phenomenological approach, the CBPR research team made sense of the phenomena being studied. Employing phenomenology allowed the research team to explore the research question through the eyes of the participant, to better understand how the experience was interpreted by the participant. Using critical theory as our philosophical position within the CBPR framework further emphasized the importance of the participant's voice, and honored a more equitable approach throughout data collection. Having AMEXCAN involved in the research process allowed for the opportunity for the Latino community to reflect on the meaning of the results and to ensure that they were consistent with the messages intended by the participants.

Verification Strategies

Quantitative research depends on objective, empirical data, where human interpretation is mostly eliminated (Holman, 1993). Quantitative researchers may look to reductionistic techniques to understand variables, and hence achieve objectivity (Holman, 1993). Therefore terms of reliability and validity are particularly relevant for quantitative research. Qualitative research, however, emphasizes the human interpretation; therefore warranting terms for reliability and validity that are specific to qualitative work (Holman, 1993). Over the last twenty years, the terms "reliability" and "validity" have slowly been challenged as irrelevant to qualitative research, and subsequently replaced with terms more relevant to qualitative inquiry (Lincoln & Guba, 1985). A comparable concept is that of "trustworthiness," which includes aspects of "credibility, transferability, dependability, and confirmability" (Lincoln & Guba, 1985).

Credibility and Transferability

For a qualitative study to be considered rigorous, the researcher should describe how she is actually measuring what she states she is measuring, and that the results are "credible" and "transferable" (Lincoln & Guba, 1985). In the case of this study, the research team went through several steps to help ensure that what was being measured was the participants' experiences, and not the researchers' judgments or assumptions about the participants' experiences. To establish qualitative credibility and transferability, three specific methods were used: (a) epoche (bracketing), (b) triangulation, and (c) reflexivity.

Epoche. The CBPR research team employed the concept of an epoche (or bracketing), introduced by Husserl (1960). Husserl believed that, though difficult, it is not impossible for researchers to set aside their own personal experiences in order to take on the unmarked experience of the study participant. According to Husserl, this can be done through bracketing or suspending judgment of one's personal opinion, (i.e., suspending judgment of our past knowledge about the phenomenon being studied) (1960). In order to suspend judgment of personal opinions, we must first acknowledge our own biases. Given the nature of our research question, it was important that we acknowledged our biases, thus the research team members each offered a "role of the CBPR team member" bias statement (see Appendix D). Writing a bias statement gave the research team members the opportunity to reflect on previous experiences with the subject matter, and thus bracket these personal experiences (Husserl, 1960).

Triangulation. The CBPR research team used triangulation by incorporating multiple layers of researchers (e.g., from AMEXCAN, from university researchers), and used a *back translation* process. Researcher triangulation involves using more than two researchers at any phase of the study, involving multiple interviewers or analysts (Denzin, 1978). Two researchers were present during the interview process (the PI as well as the research assistant who served as the interpreter). The PI asked the research question in English, which was then translated by the research assistant into Spanish. The participant answered in Spanish, which was then translated into English by the research assistant. Two recordings were made, one in each language, through this process. The English version was transcribed, and this English transcription was then verified by a second bilingual and bicultural research assistant against the Spanish recording.

Reflexivity. To further ensure accuracy, the PI used a reflexive process throughout the study to show transparency of how decisions were made along the way (Hennink et al., 2011). Specifically, the PI used an audit trail that consisted of a research log (to record activity and decision points during the study); field notes (taken during and immediately after the interview, and throughout the data collection process); and a reflexive journal (dated entries that keep track of the PI's reactions, assumptions, and biases). This process helped to ensure that the PI kept a continuous awareness of her actions and role as researcher throughout the research process, thus demonstrating how she has managed subjectivity (Hennink et al., 2011).

In addition to these indicators of rigor, Lincoln and Guba (1985) suggested that the researcher should spend a prolonged amount of time in the setting. This means that the researcher(s) should have an established rapport with the community or participants. This required the researcher to spend time with the participants in their community environment. In this case, the PI is a native and lifetime resident of eastern N.C., a member of AMEXCAN since the organization was established in 2001, and has worked directly with the Latino community for 15 years.

Confirmability and Dependability

The intent of confirmability and dependability is to maximize the opportunity for the same or similar outcomes if the same or other researchers followed the researcher's design and procedure. Qualitative researchers look to establish "confirmability" and "dependability" through efforts specific to the qualitative research process (Lincoln & Guba, 1985). The PI achieved this by documenting each step of the research process along with journaling unique outcomes or experiences throughout the study (Lincoln & Guba, 1985). Furthermore, the PI reviewed all transcripts for any obvious, notable mistakes (Lincoln & Guba, 1985) such as issues that could occur between translating Spanish into English (i.e., sentences are not fluid). The PI brought all concerns to another research assistant (bilingual, bicultural, Mexican-American PhD student) for discussion and verification. The research assistant listened to the entire audio recordings in Spanish and verified these against the transcripts, as well as the coded "units of meaning." No discrepancies were identified.

Conclusion

A research study design should encompass three components that intersect, establishing a point of reference from where a researcher views the study (Creswell, 2009). Critical theory was established as the research team's philosophical position, while emphasizing community-based participatory research to be the best avenue for enforcing this philosophy. CBPR has served as a guide throughout the development of this dissertation, providing core components that helped the research team stay true to the tenants of critical theory. The team's choice to do a qualitative research design, and chosen phenomenological strategy of inquiry (the data collection, analysis, and interpretive processes via transcendental phenomenology of Husserl) has fit well with the team's ontological perspective, viewing reality via the meanings one gives to their own lived experiences (Hennink et al, 2011; Creswell, 2009). As has been stated by Hennick and colleagues (2011), a “distinctive feature of qualitative research is that the approach allows you to identify issues from the perspective of your study participants, and understand the meanings and interpretations that they give to behavior, events, or objects.” It is from this framework, and within the parameters that we have set forth in the methods, that we set out to better understand and address the experiences surrounding HIV screening and diagnoses among Latinas. Furthermore, the avenue for research that the team is devoted to (i.e., CBPR), contributes more to the Latina community than simply the results from the research study; but contributes to the empowerment of this vulnerable population.

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CHAPTER 5: LATINA IMMIGRANTS' EXPERIENCES WITH SEXUAL HEALTH CARE IN U.S. AND COUNTRY OF ORIGIN: A COMMUNITY-BASED PARTICIPATORY RESEARCH STUDY

Introduction

The early challenge posed by the initial human immunodeficiency virus (HIV) epidemic of the 80s, was that people viewed it as a stigmatizing terminal disease that significantly shortened one's life span; but over time it has steadily evolved into a chronic, yet manageable chronic health condition for those who have access to consistent and quality care (World Health Organization (WHO), 2014). In order to reach the population who needed the necessary indicated treatments for HIV (and other sexually transmitted infections (STIs)) and best possible health outcomes, public health providers and community organizations worked together to generate a strong united effort that included dismantling structural barriers to accessing services (WHO, 2014). This united front has required the untangling of societal, cultural, and health inequities that ultimately influenced communities, large and small.

While barriers to care still exist today, disparities are particularly noticeable when comparing between various ethnic and racial groups (Center for Disease Control [CDC], 2014), meaning that some population s (e.g., African Americans and Latinos) experience a higher burden of infection or disease relative to other populations (e.g., White non-Hispanics) (Kaiser Family Foundation [KFF], 2012). Forms of disparities emerge through health *inequalities,* which refers to the differences in health between and within nations (Evans, Whitehead, Diderichsen, Bhuiya, & Wirth, 2001), and health *inequities,* which refers to a subgroup of inequalities that have been judged as unfair (Evans et al., 2001), and avoidable (Whitehead, 1992). According to experts commissioned by the Institute of Medicine of the National Academy of Sciences (NAS) (Smedley, Sith, & Nelson, 2003), basic factors such as barriers to care, mistrust of healthcare systems, and racial biases, result in health inequities and have been identified as macro-social conditions that affect health outcomes and disparities in minority populations. Addressing racial and ethnic inequities in relation to health and health care means tackling the discrimination and stigma associated with some infectious diseases, such as the human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS) (Earnshaw, Bogart, Dovidio &Williams, 2013) and improving the way in which patients are cared for within health care contexts, as well as the way in which messages about care and health are communicated back to patients' communities (i.e., through respect and without exploitation of vulnerable populations). The challenges regarding HIV and AIDS within the Latino population will likewise require attending to the variables that are specific to this population.

Review of Literature

More than one million people in the United States are estimated to be living with HIV (CDC, 2014). Of these, an estimated 220,000 HIV positive individuals are Latinos (KFF, 2014a). Though the groups most heavily affected by the disease are men who have sex with men (MSM) and the African American community (CDC, 2014), rates of HIV, as well as other STIs, disproportionately affect the Latino population (CDC, 2014; KFF, 2014a). According to the CDC (2015), Hispanics/Latinos rank third in STI rates in the country. Among the Latino population in North Carolina (N.C.), rates for Gonorrhea are 2.2 times higher than the rate for the White population; Chlamydia rates are three times higher than the rate for Whites (a 4.4% increase from the previous year); and Syphilis rates are 2.2 times higher for Latinos than for Whites (a 9.5% increase) (CDC, 2010). This is important, because the presence of an STI correlates with an increased likelihood to become infected with HIV (CDC, 2015). Noteworthy to the disparities regarding STIs and HIV in the Latina population are issues of culture, late diagnoses and treatment, and patient-provider interactions regarding culturally competent health care.

Influence of culture. Latino women (Latinas), in particular, are recognized as vulnerable to STIs and HIV infections, due in part to cultural issues such as established gender roles (i.e., machismo, familismo) (Galanti, 2008; Hargreaves, Hidalgo, Byrd, Bagchi, & Kim, 2010; Tung, 2012) and stigma (i.e., cultural emphasis on female modesty) (Galanti, 2003; Giordano et al., 2010; Infante et al., 2006; VanOss-Marín, 2003), as well as migratory patterns (i.e., the association between HIV risk for Latinas and having a sex partner who has traveled to the U.S.) (Magis-Rodriguez et al., 2004; Magis-Rodriguez et al., 2009, Persichino & Ibarra, 2012), all of which further health inequities and disparities experienced by this population. Researchers have noted that traditional gender roles play at least some role in Latinas' feeling able to voice concerns about their own sexual health within a relationship (Galanti, 2003; Parrado, Flippen, & McQuiston, 2005; Persichino & Ibarra, 2012; Viadro & Earp, 2000). For example *machismo,* which is an exaggerated demonstration of masculine characteristics, dictates that women be submissive to their partners (Hargreaves et al., 2010), making safe sexual practice very difficult to negotiate (Hargreaves et al., 2010; Parrado et al., 2005). Furthermore, Latinas are expected to put the needs of their family before their own, a cultural value known as *familismo,* which has been indicated as a contributor for Latina dropout rates in relation to treatment (Hargreaves et al., 2010). Additionally, HIV remains a highly stigmatized topic for Latinas due to gender roles that emphasize female modesty (Galanti, 2003). Acording to Galanti (2003), the traditional gender roles of Latinas are ones of wife and mother, and in these roles Latinas are expected to defer to the authority of their husbands, thus relinquishing reproductive rights and responsibilities.

Another concern that highlights Latinas' vulnerability to HIV is that researchers have identified migration to the U.S. to likely be the source of the first cases of HIV in Mexico (Magis-Rodriguez et al., 2004; Magis-Rodriguez et al., 2009). Other researchers demonstrated that along the U.S. and Mexico border regions, Latinas' only risk factor for the infection is having a sexual partner who has migrated to the U.S. (Persichino & Ibarra, 2012). These factors together strengthen already highlighted concerns for Latinas' vulnerability to HIV infection. In fact, according to the KFF (2014b), Latinas are four times more likely to have an HIV diagnosis than White women (i.e., 8.0 versus 1.9 per 100,000, respectively).

Late diagnosis and treatment. Researchers have demonstrated that Latinas are at a significantly greater risk for HIV because they do not tend to get tested or seek out the results from their HIV tests (i.e., late diagnosis). Furthermore, they tend to enter treatment later than their White counterparts (i.e., late treatment) (Chen, Gallant, & Page, 2012). These health inequalities between Latina and White non-Hispanic women reflect the likelihood for disparities, in both seeking out care and receiving appropriate treatment (Chen et al., 2012).

Researchers have recognized Latinas' vulnerability to HIV infections for a number of years (Webber, 2007), including reports of health outcomes aligned with heterosexual contact as primary transmission mode (CDC, 2012). In addition, researchers have focused on the role of traditional gender roles that influence Latinas' view of agency (i.e., negotiating gender roles in sexual health issues) and autonomy, as well as their ability to make decisions about their sexual health (Galanti, 2003; Hargreaves et al., 2010; Parrado, Flippen, & McQuiston, 2005; Persichino & Ibarra, 2012; Viadro & Earp, 2000). The concerns related to Latina's vulnerabilities to HIV and subsequent health inequities include real or perceived barriers that prevent Latinas from gaining access to testing, staying in care (Torrone, Wright, Leone, & Hightow-Weidman, 2010), having HIV tests confirmed (Ganguli et al., 2013; Liddicoat, Losina, Kang, Freedberg, &

Walensky, 2006; Parra, Doran, Ivy, Arnada, & Hernandez, 2001), and access to or adherence with antiretroviral therapy medication during pregnancy (Zhang, Senteio, Felizzola, & Rust, 2013) and other times across their lifespan (Chen et al., 2012). Furthermore, the relationships between Latina patients and their providers may create barriers to seeking health care as well (Beach et al., 2010;; Lazcano-Ponce et al., 2004; Saha et al., 2013; Schuster et al., 2005).

Patient-provider interactions. In addition to Latinas' vulnerabilities and reluctance to seek health care, researchers have recognized that patient-provider relationships and interactions once treatment has been sought out, may create barriers to future care (Beach et al., 2010;; Lazcano-Ponce et al., 2004; Saha et al., 2013; Schuster et al., 2005), as well as patients' generalized perceptions of healthcare providers (Infante et al., 2006; Schuster et al., 2005). Patient-provider interactions that include Latino cultural values such as *personalismo* (i.e., a friendly, peronsal connection) is noted to be important regarding clinical care for Latinos (Jucket, 2013). It has been further recognized that providers' levels of cultural competence (i.e., providers' effectiveness in treating patients from diverse cultural backgrounds) is associated with equitable treatment and quality of care (Saha et al., 2013), and associated with barriers to health care for Latinos (Jucket, 2013).

According to Barr (2011), "Barriers generally stem from forces within the organizational environment of the healthcare delivery system or within the broader social system itself" (p. 273). Barriers to health care that Latinas experience may include not only those associated with health care and social systems in the United States (U.S.), but also health care and social system experiences that were associated with her countries of origin. As researchers have noted, the migration experience for many Latinas has led to a complicated intersection of health care and social system factors that are known to influence sexual health risk factors (Magis-Rodriguez et al., 2009), perhaps further exacerbating disparities between Latinas and other populations.

Presently, there is scant research available regarding Latina immigrants' experiences with healthcare providers in the U.S. and their country of origin, in relation to sexually transmitted infections, HIV, and related health disparities. Therefore, the purpose of this study is to employ a culturally sensitive research method for understanding the intersection of health care and social system experiences of Latinas (Mendenhall, Berge, & Doherty, 2014). This research particularly attends to Latinas' experiences with healthcare providers regarding sexual health care, with the aim of understanding how risks for HIV infection intersect with the migration experience. This research and subsequent discussion will be guided by critical theory (Habermas, 1984), an appropriate theoretical lens for this study.

Theoretical Orientation

Researchers understand that health education and behavior requires the amalgamation of research, theory, and practice working in unison to produce the best outcomes (Glanz, Rimer, & Viswanath, 2008). Theory is often grounded in the real time experiences of clinical work, and a good theory will drive research as well as clinical practice (Glanz et al., 2008). With this in mind, this research uses critical theory (Habermas, 1984) as an appropriate lens to guide the research and discussion. Critical theory promotes self-reflection, which is deemed to be necessary for freeing those individuals who are otherwise limited by socially constructed conditions of life (McCarthy, 1989). Important constructs to this theory that will guide our research include purposive-rational action (i.e., strategic action), and research that takes an emancipatory approach (Habermas, 1984). Habermas (1984) considers that individuals are shaped by certain consensual norms (or the rules by which society operates), and that these consensual norms are assumed, or taken for granted, as how it should be. Habermas (1984) proposed that self-reflection leads to critical self-awareness, which then leads to emancipation from forces that limit options and rational control in an individual's life. Researchers who employ critical theory will critique traditionally accepted research methods, and opt for a research design that brings forward the voices of individuals, and explores the relationship between individual and social spheres (i.e., individuals and the societies in which they live) (Habermas, 1984; Kemmis & McTaggart, 2005). Therefore, using critical theory as a lens, the purpose of this study is to better understand the healthcare experiences of Latina immigrants regarding healthcare visits pertaining to sexual health, and to answer the research question "*What are Latina immigrants' experiences with healthcare providers in their home country and the United States?*"

Method

This study was a community-based participatory research study (Israel, Eng, Schulz, & Parker, 2013) and therefore employed a collaborative and participatory approach with a local grassroots Latino organization in eastern North Carolina (N.C.). The research team included the Latino community-based organization (AMEXCAN- Association of Mexicans living in North Carolina); the primary investigator (PI), a white non-Hispanic American woman with limited Spanish fluency; and three research assistants from East Carolina University (ECU): (1) A male, Mexican-American Medical Family Therapy PhD candidate, bilingual (2) a white non-Hispanic American woman Medical Family Therapy PhD candidate, bilingual, and (3) a female, Mexican-American undergraduate Hispanic Studies student, bilingual, who is also a member of the AMEXCAN organization. All three research assistants were Health Insurance Portability and Accountability (HIPAA) trained and IRB approved, and assisted the PI in areas of interviewing and transcribing. Research team members that engaged in data collection and analyses (i.e., ECU researchers and one member from AMEXCAN) were trained by the PI in proper procedures and chosen method of analysis.

The PI and research team employed a qualitative method for understanding the experiences of Latina immigrants with healthcare providers regarding sexual health care, with the purpose of developing a clearer understanding of how risk for and knowledge of HIV infection intersects with the immigration experience. Consistant with qualitative design, our study allowed for the phenomenon, in this case how Latina immigrants experience sexual health assessments from healthcare providers, to be explored from the perspective of each participant. Each step of the design process honored a strong collaboration between healthcare researchers and community members, as well as other interested stake holders (i.e., ECU medical family therapy researchers, Latino community residents of eastern N.C., Latino members of AMEXCAN) (Mendenhall et al., 2014; Salimi et al., 2012).

Collaborating with community members (i.e., PI collaborating with executive director and other AMEXCAN members) prior to implementing our health related research helped to address design concerns that commonly result in low-Latino participant recruitment. We were able to discuss common challenges and possible solutions to overcome potential barriers. Recruitment is often difficult for health related studies with Latinos, due to factors such as language barriers, low literacy, inaccuracies in or lack of translators, perceptions related to Latinos' legal status, and Latinos' cultural views regarding health care (McGill, 2013). To overcome these barriers in our study, the PI accompanied the executive director to many community meetings and events over the course of three years, beginning in the fall of 2012 through the fall of 2015. This process assisted in developing trusting relationships among community members, strengthened the PI's cultural knowledge as well as Spanish language skills. Furthermore, utilizing a collaborative approach between researchers and community partners allowed for a more effective way to disseminate results. Troubling to many researchers and clinicians is the time lag between healthcare research implementation and the dissemination of the results (Balas & Boren, 2000). For this reason, we employed a collaborative research design throughout our study.

Our team chose to conduct a qualitative study using a community-based participatory research (CBPR) approach, involving members of the Latino community in all aspects of the research process (Israel et al., 2013). CBPR focuses on an equitable collaboration between community organizations and university researchers in an effort to improve public health and health outcomes within a community (Israel et al., 2013). CBPR emphasizes equal, reciprocated sharing of knowledge and skills among all partners, and promotes empowerment of community members (Israel et al., 2013). While some qualitative research designs emphasize an understanding of an individual's lived experience (Hennick, Hutter, & Baily, 2011), some researchers argue that qualitative research should also advocate for the oppressed and advance a social justice agenda (Denzin & Lincoln, 2005). As such, CBPR was selected as the best approach to research with this sample.

A CBPR Orientation

Given the disparities in HIV infections, a new approach to prevention and treatment for Latinos should be considered, one that takes a culturally sensitive direction. Community-based, action oriented research (aka CBPR) has been recognized by various national and international health organizations as an effective and culturally appropriate form of research that is particularly relevant in reducing health disparities with Latinos (Bishai, Ghaffar, Kelley, & Kieny, 2015; National Institutes of Health (NIH), 2015). Researchers employing a CBPR strategy attend to the power dynamics that occur throughout the research process, and aim for leveling hierarchical relational structures that would likely otherwise emerge (Israel et al., 213). A substantial emphasis is placed on developing, maintaining, and sustaining partnerships throughout the research process. This is critical to CBPR, as it builds trust among team members, allows for conflict resolution, and gives a place for developing and sharing knowledge and skills among partners (Israel et al., 2013), which in turn builds a solid framework for the production of quality research and effective outcomes.

A core component of CBPR is the "identification of priority health concerns and research questions" (Israel et al., 2013, p. 12). In this study, the PI approached the executive director of the AMEXCAN organization to discuss the health concerns that had the highest priority for the Latino community in eastern N.C. (eNC). The executive director, along with AMEXCAN's *Promotoras y Promotores for Social Justice* (an established group of Latino community health promotors within the AMEXCAN organization) identified HIV as the top health concern to be addressed by the research team. Following the identification of HIV as the health priority, the PI conducted a review of the literature to identify gaps in research. It was through this process (along with collaborative reviews of these articles with the executive director) that a study fully emerged (i.e., the focus on Latina immigrants and their experiences with healthcare providers concerning sexual health issues, including HIV and other STIs in Mexico and the U.S.)

Another essential aspect of this study was to honor a second core component of CBPR, "maintaining, sustaining, and evaluating CBPR partnerships" (Israel et al., 2013, pp. 12-13). Throughout this research study, beginning in September of 2012 and continuing to September of 2015, the PI maintained strong connections with the AMEXCAN organization, attending bi-monthly meetings and community events, as well as serving as a mentor to some of the community members. Community members shared with the PI their concerns about working with university researchers, only to find these individuals leave after the study has been completed, and the community members often do not experience advantages for their personal investment. This PI offered many opportunities for community members to engage in the research process; for example, sharing information about qualitative research methods, as well as demonstrating the use of statistical software. These experiences often provided a new skill set to community members that helped them to further their professional abilities, while also strengthening their connection to this research. Two AMEXCAN members were trained by the PI in qualitative and quantitative analyses, and participated in this process. Furthermore, the PI has served as an advisor to the organization’s executive director regarding the many facets of a research process.

Procedures

Our CBPR study was approved by the Internal Review Board (IRB) of East Carolina University in December of 2014. Recruitment of participants took place through the AMEXCAN organization, as well as through flyers provided to local healthcare clinics. Throughout this study, the PI communicated with the executive director of AMEXCAN at each step. The research team was established early in the study; however, due to the nature of CBPR, the PI was required to be flexible to changing situations and schedules (e.g., there were some changes in staff over time). The original bilingual interpreter (i.e., the white non-Hispanic Ameircan woman) trained to aid the PI with interviews was unable to arrange her schedule with those of our participants. Therefore when data collection began, it became necessary for the PI to prepare a second research assistant (i.e., the female, Mexican-American undergraduate from the AMEXCAN organization) to serve as the interpreter, who then went through the proper IRB qualifying process in order to ensure that a bilingual and bicultural community member was involved in data collection and analysis.

Sample. Interviews continued to the point of saturation (i.e., when there was no new information being added or new themes emerging from what had already been collected from previous interviews) (Creswell, 2007). This study consisted of 11 interviews with Latina immigrants ranging in age from 31 to 64, with an average age of 46. These women selfidentified as potential participants for this study, based on meeting the following inclusion criteria: (a) being foreign born, and (b) a Latina immigrant who has experienced health care both in the U.S. and in her country of origin. Participants were excluded from the study if they were younger than 18 years of age, had never been seen by a healthcare provider, or had never been asked questions about her medical history as part of a medical visit. Ten of the participants reported Mexico as country of origin, while one reported being a native of Honduras. All participants resided in eNC, with 15 years representing the average number of years in N.C. (range: 1 to 21 years) (see Appendix G).

Setting. Of the 11 face to face interviews conducted, seven interviews took place in participants' homes and four took place at the AMEXCAN office at participants' requests. The AMEXCAN office is a location that is used for regular meetings specific to Latino issues, and is thus considered a safe environment for Latinos. The interviews were conducted, together, by the PI and the bilingual, bicultural research assistant.

Measures. This study consisted of one on one in-depth interviews. Semi-structured, open-ended questions (see Appendix E) were developed by the CBPR partnership (the PI and AMEXCAN executive director) involved in this research study in collaboration with study investigators from East Carolina University (i.e., the three bilingual research team members) and AMEXCAN's promotores (i.e., the promotoras y promotores for social justice, from the AMEXCAN community organization). Participants were offered the option to be interviewed in their home or at the AMEXCAN office. In addition to the interviews, each participant filled out a questionnaire that requested demographic information, such as: age, marital status, educational level, health insurance, time residing in U.S. and N.C., experience providing health care to Latinos (to determine if there were healthcare providers, educators, or promotoras in the sample), perceived quality of visits with healthcare providers, and preferred characteristics associated with healthcare providers. The PI and two AMEXCAN research assistants entered responses from questionnaires into SPSS (a statistical software program) to explore demographics and possible correlations of variables.

Phenomenological coding analysis. The responses from the interviews were analyzed using Giorgi's method (Giorgi, 1975) for phenomenological analysis. Influenced by Husserl's philosophy, Giorgi modified Husserl's phenomenology analysis to fit within a psychological framework. He closely followed Husserl's writings, maintaining that "the object of phenomenological description is achieved 'solely' through a direct grasping (intuiting) of the essential structure of phenomena as they show in consciousness" (Dowling, 2007, p. 135). Due to this approach, the researcher is not required to return to the participants to verify the resulting descriptions of the researcher with the experiences of the participant, which some have suggested involves interpretation, counter to Husserl's phenomenology (Dowling, 2007). However, because this study included a bilingual component throughout the interview process (i.e., the questions were read in English, then translated to Spanish, then translated back into English) and were therefore time intensive, four of the participants were contacted at a later time for the opportunity to add to their original interview or provide clarity to earlier responses. Two participants added additional information. A third individual was unavailable, and the fourth was unable to be reached through the contact information she provided.

The PI and two research assistants coded the 11 transcripts using Giorgi's four-step process (Giorgi, 1975). In addition to the PI and the research assistant who served as interpreter during the interviews, a third AMEXCAN member (non-bilingual, white American woman) was recruited to aid in the coding and analyses process. First, these three researchers (the PI, the PI's research assistant who interpreted for PI, and the non-bilingual AMEXCAN member) read through the entire transcript without making judgement of the material (i.e., bracketing all presuppositions) (Husserl, 1960). The second step involved isolating the material into units of meaning (Giorgi, 2007, pp. 139-166). In other words, the researchers separated each transcript into smaller segments of dialogue, in order to capture the participant's point in a concise way. Through these smaller segments, we were able to more quickly identify areas within the transcript that related to the participant's experience of the phenomena under study. The third step consisted of reviewing these units of meaning in order to get a sense of how each unit related to the purpose of the study (Giorgi, 1975). The PI also consulted her field notes taken during the interview process in order not to miss any relevant information. It was during this third step that initial themes were developed by the three researchers, and their relevance to the phenomena under study was considered and discussed. Initial themes began to appear, with some of these themes overlapping in ways that did not make sense to the PI, or to the non-bilingual research assistant, who then suspected culturally relevant information to be emerging. In several of the transcripts, participants would report having an emotional reaction to sexual health assessment questions by their doctor. This would be followed with an explanation that Latinas were not use to preventive care, and then would include a discussion of how HIV was not a topic to be discussed by Latinas. The PI then consulted literature regarding healthcare cultures (Galanti, 2008), and discussed this information with the non-bilingual research assistant. Both researchers agreed that the participants could be describing experiences related to *time orientation,* a concept that identifies how a society's focus regarding time might affect their views on health care (Galanti, 2008). This prompted a new category (time orientation) that included differences in the medical cultures of the U.S. and Mexico (i.e., preventive care in U.S. vs treatment of symptoms in Mexico). Consistent with the principles of CBPR, the PI and the non-bilingual research assistant then consulted with the male Mexican-American member of the research team (Israel et al., 2013) and a faculty researcher to verify identified themes as they related to the purpose of the study.

Since new, culturally relevant information was identified during the coding process, the team discussed the codebook and then clarified and re-coded the transcripts. This process is in line with methods of qualitative anaylsis and resulted in the renaming of seven culturally senstive themes (by the team) (MacQueen, McLellan, Kay, & Milstein, 1998). The PI and non-bilingual research assistant discussed and agreed upon all seven new themes (see Table 1), and the corresponding codebook (MacQueen et al., 1998). Themes were subsequently discussed with five AMEXCAN Latino community members to further verify that these themes made sense (Israel et al., 2013). The PI and non-bilingual research assistant completed the recoding separately, and then came together to discuss any disagreements, which were settled by referring back to the research question as indicated by Giorgi (2009). To ensure credibility and transferability, the PI maintained an audit trail consisting of a research log and journal throughout the interview and analysis process to record field notes during the interviews, and to record the PI's reflections of her own reactions during the process; all to ensure trustworthiness of the results (Hennick, Hutter, & Bailey, 2011). In the final stage of the analysis (step four), the identified themes were consolidated in order to showcase a concise description of the analysis (Giorgi, 1975). This final description is presented in the summary paragraph concluding the results section.

Results and Discussion

Clinical Characteristics

A total of 11 interviews were completed. Interviews stopped when no new information developed (i.e., the point of saturation) (Creswell, 2009). A 12th interview was begun, but discontinued due to the participant's emotional reaction during the interview process. This interview was not included for analysis, but followed ethical procedures and IRB protocol. One interview was conducted in English at the participant's request, and all others were conducted in Spanish. Each participant was instructed to choose a pseudonym for herself before the interview began, and was referred to by her pseudonym throughout the process of analysis, as well as in this manuscript. Of the interviews included for analysis, six of the participants reported being married, while four reported being single or "other," and one reported being divorced. While two participants reported some higher education (< 2 yrs university), seven reported having a high school diploma or GED, and two reported a primary school level of education. Regarding healthcare coverage, five participants reported having insurance through their employer, and one reported government assistance (e.g., Medicaid or Medicare), while five reported having no healthcare insurance. The percentage of participants reporting no healthcare insurance (45.5%) was much lower than the state's average for foreign born Hispanics/Latinos (71%) (Pew Research Center, 2015).

Identified Themes

There was a total of 293 meaning units identified by the PI and non-bilingual research assistant. A total of 266 unique meaning units that were identified as relevant to the research question were coded from the eleven transcripts (i.e., 100% coded). Giorgi makes note that some meaning units may not be of interest to the researcher's purpose, and therefore not coded (Giorgi, 1975, 2009; Whiting, 2001). The PI and non-bilingual research assistant agreed that 27 meaning units were not relevant to the research question, and were therefore not included for coding. Examples of a meaning unit that was deemed not relevant to the research question includes a sentence where Angel elaborated about her nephew's use of the internet for information, and her concerns that much of the information could be immoral (Angel, line 292); and Gabriella's fear of technology (Gabriella, line 32). Seven themes resulted from these meaning units and are expanded on in the following paragraphs. A discussion with implications and recommendations follows.

Communication style. Cultural concepts such as personalismo (e.g., importance of establishing relationship with healthcare provider) and directive vs. nondirective communication is described under this category. The most frequently coded theme was communication style, at 21% of all meaning units. Two aspects of communication style were noted from the interviews, both having a cultural basis. First, the concept of *personalismo* was identified across the majority of interviews. Personalismo is a cultural value shared among Latinos that emphasizes the importance of establishing a personal relationship with a healthcare provider before pursuing treatment (Galanti, 2008), and is noted in previous research to be an important cultural value that effects treatment adherence (Antshel, 2002). Participants in our study told us that it was important to them that their provider listen to them first, and show care about them as a person before beginning more difficult conversations about their sexual health. Some of the comments emphasized the rushed healthcare experience in the U.S., and how they needed to feel cared about by their doctor: *"If many think that the doctor just doesn't really care, isn't really pressed about the issue or cares about the patient, then one is much less likely to want to share anything" (Isabela, L80).* When asked what the most important characteristics of a healthcare provider were to her, Flora answered: *"…a doctor that will actively listen and take into consideration what I am saying about my health. So somebody I can feel safe talking to" (Flora, L125).*

The second aspect of communication style that emerged was the *directive vs non-directive* style of the provider. The U.S. medical cultue has begun to focuse on a shared decision making process between patient and healthcare provider (i.e., non-directive) (Galanti, 2008). However, not all cultures share this approach. In fact, Galanti (2008) noted that some researchers have shown that Mexican born patients rely on a directive communication style from their provider when seeking treatment (Browner et al., 2003). Our participants expressed this concept, indicating a desire for "clear" and "direct" communication from their healthcare provider. Hortencia told us that in Mexico ... *[doctors] give you the advice straightforward…" (Hortencia, L147)* and *"It's pretty direct and it's pretty much assured that you're going to, that they're treating what you have. Whereas here it's more ambiguous, in the United States" (L148). "Sometimes the doctor explained things, but not how people want them to be known or to be told" (L17).*

A crucial element in seeking health care is being able to communicate with the provider (i.e., the provider understands the patient, and the patient understands the provider). However, effective communication involves more than language alone. It extends to the style and manner in which information is put forward. Latinas need to feel that their healthcare providers are concerned about their health before they can feel safe talking to him, particularly about sexual health concerns. What was especially interesting to the PI and research assistant, was the finding that Latinas tend to identy directive communication from their healthcare provider as a higher level of care from the provider in relation to her health. Cultural differences between the doctor and patient, in the U.S. and Latin American countries, add to the confusion that the Latinas in our study have described.

Capacity of healthcare system (CHS). The capacity of a healthcare system to assess for sexual health and to resolve healthcare concerns is described under this category. This category was the second most frequently coded (21%), and included reports of whether the healthcare provider assessed for HIV or other STIs, and the participants' concerns about the ability of the healthcare system to meet their healthcare needs. The majority (eight) of our participants reported receiving a sexual health assessment by their U.S. healthcare provider during their last visit; and four of our participants reported having a sexual health assessment when at their last visit in their country of origin. Three participants reported no sexual health assessment at their last U.S. healthcare visit, and one reported that she initiated the request for a sexual health assessment with her U.S. provider. Across all the interviews, participants reported that more sexual health assessments take place in the U.S. than in their own country of origin. *"In [US], where they ask you more questions about it, it's much more normal here that you go to a clinic and they ask you more questions about it…" (Danielle, L22).*

Several participants described healthcare visits where their concerns were left unresolved. For example, Karla gave this account of a sexual health assessment: *"Once my pap smear came out irregular, when they did a biopsy, they didn't tell me anything. I went the next year and did a pap smear and everything was good. But I asked them what went wrong with the last exam. They didn't tell me anything. They just told me they were going to go and check, and that was it. And my husband also got really upset because they were supposed to send a letter, but they didn't. And then they brushed me off by saying that, 'If you didn't get information, it's because you're OK'" (Karla, L231).*

Esperanza told us about her last U.S. healthcare experience: *"[I] did not like the treatment because before I had my daughter, and they told me that they removed my uterus. And when I went to this appointment, they told me that I did have [my uterus]. They said they were going to contact the other hospital to make sure that it was still there…" "They did not tell me anything, they have not resolved anything, and since that last time I don't know anything. So I have yet to come back" (Esperanza, L15).*

Another participant described her last healthcare visit in the U.S. as being unresolved as well. She told us that *"…they kept rescheduling appointments, and they just kept going around with the information" (Borjan, L36).* Eventually she opted to go back to Mexico for her health care. *"...it's easier over in the other country, in Mexico, because here there is a lot of running around and making appointments and just so much information that nothing is being done" (Borjan, L37).*

Whether due to misunderstandings related to language and culture, or to the shortage of resources that is frequently experienced by some rural healthcare agencies (Vega, Klukas, Valera, & Montenegro, 2015), it is concerning that several of our participants indicated they had given up trying to access health care here in the U.S. Researchers have noted Latinos residing in rural areas as opposed to urban areas may have less access and/or differing qualities of health care (Espinoza, Hall, & Xiaohong, 2012). Furthermore, researchers have demonstrated that when Latinos are unable to receive the health care that they expect, and when their healthcare concerns are left unresolved, they may give up trying to access health care (Gannotti, Lawrence, Handwerker, & Groce, 2004). In order to address HIV disparities, Latinas need to feel that their healthcare needs will be met when seeking healthcare attention.

Access to care. Barriers to accessing health care are described under this category. Barriers that prevent access to testing and staying in care are also of concern and have been implicated as an issue for Latinas not accessing testing for HIV (Torrone, Wright, Leone, & Hightow-Weidman, 2010). Of the total number of meaning units, 18% were coded as access to care. This category included: (1) long wait times; (2) not having enough doctors available; (3) distance to healthcare provider; (4) high cost of services; (5) lack of health insurance, and (6) language barriers (i.e., doctors not speaking or understanding Spanish) and use of interpreters (i.e., not having qualified interpreters when needed, or interpreters were seen as a hindrance to health care) most of which are well documented by previous researchers as barriers to healthcare access for Latinos (Branch et al., 2010; Escarce & Kapur, 2006; Flores, Abreu, Olivar, & Kastner, 2011; NCRCAP, 2002).

Participants described various situations that barred their access to health care with their provider. Gabriela highlighted the long wait times she would encounter due to not having enough doctors: *"I really didn't like it there…They charged me a lot for every visit that I went and they took WAY too long – two hours – for me to be seen" and "…there were no doctors" (Gabriela, L49).* .Leyla and Danielle described concerns about travel distance to a healthcare center: *"…it's very uncomfortable there for me, to have to mobilize myself to go to a consult there, because it's long, it's far for me" (Leyla, L15),* and *"…over there [in Mexico], the reason I went to that doctor was because that was the most reachable" (Danielle, L30).* Some participants expressed barriers pertaining to cost, or lack of insurance: *"…your insurance, you money-wise, because that had a lot to do with it."* And *"Money do a lot with how you take care of yourself, because if you find something, you might find something that is going on with you and you don't have neither the insurance or the money to pay for it" (Angel, L93).* Though researchers from a previous study found that Latinas with Medicaid insurance did not access medical services as often as non-Latinas (regardless of insurance status (Habak, Coonrod, Brady, Bay & Mills, 2003)), it was none-the-less interesting to us that the frequency of accessing health care per our participants did not depend on their having healthcare insurance (see Figure 2).

Language barriers were expressed in terms of needing an interpreter, but not having one: *"…if for some reason you can't get an interpreter, it's you trying to speak to the doctor and there's no way. How do you tell them what's going on with you?" (Flora, L105);* as well as having interpreters who were unable to adequately interpret the full content of the dialogue: *"I understand little English, but I felt what the doctor would tell [the interpreter] something, I felt that it wasn't being interpreted right, like she wouldn't be able to tell me exactly, or here she would not be able to tell me exactly what the doctor said" (Hortencia, L38).*

Surprisingly, what surfaced as a major barrier to sexual health care for our participants was the *involvement* of medical interpreters. Of the eleven participants, seven discussed their experiences with medical interpreters. Experiences with interpreters were brought up by these participants in 23 of the 49 meaning units that constitute this category. Of these 23, two meaning units consisted of positive comments, expressing experiences of helpfulness and trust. Three meaning units were mixed, expressing the interpreter's presence as helpful, but also as a barrier. Alarmingly, 18 meaning units consisted of negative comments expressing participants' discomfort with interpreters being present.

Participants described language as a barrier to health care: "*What happens is here, is that you need the language, you need English" (Esperanza, L26), and "…because of the language barrier. For example, going here you would need an interpreter" (Danielle, L135)*; and also described experiences with interpreters as necessary, but embarrassing and uncomfortable, and expressed their concern with issues of confidentiality. One particularly poignant comment by a participant vividly described the significance of the interpreter being part of the sexual healthcare visit: *"...when you go to a doctor, a counsel with a doctor that it's like going to confession. And the fact of having an interpreter there, it's like they know everything about you; they're listening and they're a part of it" (Leyla, L76).* This discomfort may be tied to the fact that these Latinas lived in rural communities, which are often small, and the interpreters are often well known members of the Latino community. This idea is highlighted in Danielle's statement: *"And if the interpreter – I've had occasions where they know me very well, and so it's much harder for me to be able to tell the doctor everything because I'm talking to the interpreter, because the interpreter belongs to the community" (Danielle, L145).* One participant suggested a lack of feeling safe with an interpreter in the room, stating: *"... in one's own country, it's a safe environment because it's just you and the doctor speaking personally, whereas here in the*

United States ... there's an interpreter in the room" (Flora, L105). Another participant stated that she might not feel she is able to ask questions of her healthcare provider if there was an interpreter present: *"If there's an interpreter in the room, then [I] would hold back on questions that [I] may have for the doctor" (Lelya, L87).*

What was most surprising to us from the findings through this theme was our participants' concerns with medical interpreters in the room during a sexual healthcare assessment. Other researchers have noted Latino men's concerns with confidentiality in seeking sexual health assessments at local health departments as well as their concerns about the quality of interpreter services (Rhodes et al., 2007), but to our knowledge this is the first study to identify medical interpreters to be barriers to sexual health assessments for Latina immigrants. The literature is clear that using qualified medical interpreters in healthcare settings is associated with better health related outcomes (Flores, 2005; Karliner, Jacobs, Chen, & Mutha, 2007). However, it is clear from our findings that interpreters may also negatively influence Latina's health experiences and sexual health assessments may warrant a unique consideration concerning interpreters in the room.

Time orientation. Present time orientation (e.g., accessing health care only when there is a problem or symptoms) vs. future time orientation (e.g., accessing health care for preventive care) is described under this category. Occurring as a theme in 15% of the total number of meaning units, time orientation was coded when participants expressed what the researchers identified as a conflict between the time orientation of a participant's culture of origin and that of the U.S. healthcare provider. Galanti (2008) described time orientation as having a cultural relevance, and states that the healthcare culture in the U.S. tends to be oriented toward the future, thus operates from a future time orientation. Examples of this in the healthcare setting are preventive care, such as screenings (McMullen, De Alba, Chavez, & Hubbell, 2005), and continuing treatment even when there are no symptoms (Zea, Quezada, & Belgrave, 1994). In contrast to this, individuals from many developing cultures (Galanti, 2008) or a collectivist culture (Zea et al., 1994) tend to have a present time orientation. Thus, preventive care is not the norm. Throughout the interviews our participants described experiences with time that emerged as cultural in nature, and that were fairly consistent across interviews.

When we asked the participants in our study to describe a recent healthcare visit, several women described their experience as eliciting an emotional reaction, using words such as *"nervous, uncomfortable, difficult,* or *embarrassed."* Gabriella described her experience during a sexual health assessment with a healthcare provider: *"He did ask questions that were very strong, that I felt that they were like asking about my personal life. And it was really embarrassing to answer them because they were very hard questions and they were strong." "I get concerned when I am with a doctor, if he's checking in the vaginal area, and not knowing what he's thinking and what's going through his mind" (Gabriella, L17).* In describing her sexual health assessment, Gabriella indicated that she felt her provider was asking about her personal life, and she indicated that she was concerned about what the doctor was thinking while he was checking her vaginal area. From a future time orientation, where health screenings are a part of many healthcare visits, sexual health screenings would not necessarily warrant such a strong reaction. However, from a present time orientation, patients are left wondering about actions taken or comments made by the provider.

Many of the women stated that in their country of origin, preventive care and assessments were not normal. *"…it's pretty much non-existent, to have these regular checkups and preventative care" (Karla, L119).* Furthermore, participants discussed their thoughts following offers for STI or HIV testing by healthcare providers: *"...when I got pregnant, I was asked if I* *wanted the AIDS test and I was thinking that maybe he thought that I was sleeping around" (Karla, L100).* Karla further commented: *"…we don't have the capacity to understand what a disease is, that you're not going to be judged, 'Where did you get it from?' or 'How did you get it?'' (Karla, L95).* She told us that more than anything she is thinking *"What are they going to think about me?" (Karla, L97).* Another participant told us that Latinas would take offense to being asked if she wanted to be screened for STIs or HIV because she would receive the comment as an insult, insinuating that she is promiscuous: *"[Latinas] get very offended at even the thought of the questions" (Esperanza, L115).*

The women in our study described health care in their home country as something that one accesses only when one has symptoms, thus healthcare providers are only assessing and treating the suspected health issue, which is demonstrative of a present time orientation. This is consistent with previous research regarding the importance of experiencing symptoms before Latinas seek health care (Borrayo & Jenkins, 2001; McMullin et al., 2005). When confronted with HIV or STI assessments by U.S. healthcare providers operating in a future time orientation, some of our participants described feeling judged by the healthcare provider. When providers do not have an understanding of time orientation, they may unknowingly be contributing to stigma associated with HIV screening. To our knowledge, this is the first study to identify time orientation as a potential deterrent for sexual health screenings.

Stigma. The community's perception of HIV / STIs as a taboo topic, and not normal to discuss, is described under this category. Researchers have identified stigma as a substantial barrier for HIV testing and communication pertaining to STIs within the Latino population (Acevedo, 2008; Hargreaves et al., 2010). Our participants' statements supported this; identifying stigma as a concern in 13% of the total number of meaning units. Several of the participants talked about their experiences regarding stigma with their healthcare providers in

Mexico. Participants noted that healthcare visits in general were not an opportunity to discuss sexual healthcare questions: *"[In Mexico,] when you would go to doctors mostly for pregnancy checkups, all they would check for was to make sure that you were OK, your pregnancy was good... it was not a safe place to actually continue to ask questions about other health questions" (Esperanza, L79).* Participants also reported feeling that the subject of HIV/STIs was stigmatized by healthcare providers. Isabela demonstrated this idea in a story about her sister: *"[I have] a sister whose husband was a womanizer...she got infected, but she never told anyone. And so when she had her child… the child's eyes got infected. ... it was a venereal disease that [child's mother] was carrying, but the doctor never, ever mentioned anything for treatment for [child's mother]" (Isabela, L109).* When we asked another participant what concerns, if any, she would have when talking with her doctor about STIs, Borjan replied: *"If I was in Mexico, I would stay quiet" (Borjan, L103).*

Participants also discussed experiences with healthcare providers in the U.S. When asked what health problems were the most difficult to discuss with a doctor, Isabela replied that for both men and women, sexual health problems would be the most difficult to talk about: *"The doctors will say 'Look at these, because all they want is sex, sex, sex.' The people think that the doctors will tell them that these are just degenerates, sexual beings. Because [I've] heard many people say that" (Isabela, L53).*

Familismo. The cultural practice of Latinos placing needs of family before those of the individual and seeking advice of family for healthcare concerns is described under this category. The concept of familismo was demonstrated in 7% of the total number of meaning units. According to Galanti (2008), this concept highlights the importance of the family system in Latino culture, and is essential to understanding this culture. One participant told us that she would likely talk more freely about sexual health issues with family members, particularly her mother, than with the doctor. *"I tell my mom what's going on with me, first with my mom, because with doctors, one doesn't feel comfortable" (Karla, L116).* Researchers have noted the importance of familismo in treatment adherence in the Latino population (Antshel, 2002). Ruiz-Beltran & Kamau (2001) note that Mexican patients will often include a family member or friend in their healthcare visit. Karla substantiated this attitude when we asked her what she thought would make a discussion about STIs or HIV with her doctor go best: *"That he didn't tell me alone, that maybe he would tell me maybe with three other friends…" (Karla, L132).*

Other aspects of familismo that emerged was the importance of the family's needs coming before a Latina's healthcare needs. *"Everything comes before health. …the children…to make food, her job; she can't miss work. So yeah, it looks like everything comes before [the women]" (Karla, L125).* Several of our participants described a woman's motivation for HIV testing to be for the sake of her child: *"... [Latinas] would think to go to the clinics and get a test, because later if they do get something… then they will leave their children alone" (Isabela, L150).*

These cultural aspects, highlighted by the participants, greatly influence their willingness to seek out sexual health care. Some comments demonstrate familismo to be a barrier to health care; however, other comments made by our participants demonstrate that providers could recognize and take advantage of familismo in its strength-based form. The family unit is described as a powerful motivator for Latinas to attend to their health and thus could reduce the role of stigma in relation to screening for HIV and other STIs.

Perception of risk. Recognizing (or not recognizing) factors associated with HIV that could be applicable to oneself is described as perception of risk, and is discussed under this category. The theme that came up the least number of times in our sample was perception of risk for HIV, involving 5% of meaning units. In a previous study where perception of HIV and other STI risks for Mexican Latinas were analyzed, researchers found that the women in their study understood that there was a clear connection between men who migrated to the U.S. to work and returned to Mexico, and the subsequent infection of their partners, yet did not apply this to their own circumstances or perceive themselves to be at risk (Hirsch, Higgins, Bentley, & Nathanson, 2002). Our participants echoed a similar message, as demonstrated by participants' statements: *"A lot of people think because they are married and they have their spouse that they are safe, that it can't happen to them" (Flora, L82),* and *"[Latinas] need to understand that just because you have your partner, it can happen- it doesn't mean it can't happen to you" (Danielle, L133).* Isabela responded similarly, noting that Latino men migrate to the U.S. and become infected with HIV, and then return home and unintentionally infect their partners: *"He definitely got sick in the United States, and then when he came back to Mexico, he didn't last very long and then he died. And he left his wife with the infection, (Isabela, L130)"* and *"...many women, regardless, think in their head, when it comes time to being checked, they think, 'No, well, this isn't going to happen to me. Why do I need to get checked?" (Isabela, L120).* Isabela also told us that Latinas would rely on their religious beliefs for protection: *"God is not going to let them get any diseases and if He does, then He'll cure them" (Isabela, L132).*

In addition to acknowledging Latinas' lack of perceived risk, participants pointed to a lack of knowledge regarding HIV and STIs, as well as a lack of understanding about one's own body, as a barrier contributing to the lack of perceived risk. Researchers conducting previous HIV studies have pointed to the lack of information as a problem for Latinas as well (Giménez-García, Ballester-Arnal, Gil-Llario, Cardenas-Lopez, & Duran-Baca, 2003). In our study, when asked what they thought would improve Latinas' chances of talking with a doctor about STIs or HIV, or getting tested, several participants expressed a need for more information. "*It's a very* *hard subject to talk about, that [Latinas] would need more information to be able to talk about this" (Danielle, L154)* and *"It's a question about more information" (Danielle, L133). "The diseases that we know, we've heard about, but we don't really know what they are or what they're about" (Carmen, L103).*

Psychological Structure of Experience (Giorgi's Fourth Step)

The Latina immigrants in our study encountered health care in a way that is unique to a bicultural immigrant experience. Access to sexual health care for Latina immigrants was limited due to explicit barriers (e.g., long wait times, insufficient number of doctors, travel distance, language barriers, cost, and lack of health insurance), as well as concerns regarding confidentiality. Interpreters were often needed to help Latinas' navigate their health care, and assessments of sexual health, but often resulted in highly stigmatized communication, creating a strong cause for concerns about confidentiality for Latinas. When there is an interpreter in the room, Latinas did not feel safe and held back questions they had for their provider, or may even avoided accessing HIV health care and information. Furthermore, the medical culture in the U.S. is based on a future time orientation, thus measures such as preventative assessments are normal in the U.S., but not typical for Latina immigrants. Latinas' previous experiences from their native culture do not include preventive care, thus sexual health assessments are not typical. When a healthcare provider asks screening questions, particularly if he/she does not take time to build a rapport with the patient, Latinas often become uncomfortable, wondering if the provider is making a moral judgment of her character, or even wondering if the provider suspects she may actually have the HIV infection. They experience health care as confusing, not able to directly communicate with their provider, and sometimes not understanding fully what their diagnoses are. In not accessing HIV information, whether due to language barriers or a deliberate avoidance due to the stigma, Latina immigrants do not have a clear understanding of HIV, nor the ability to ask the questions that are necessary. Latinas would feel more comfortable with HIV screening that is offered to them in groups, so that they are not singled out; and to have HIV information given to them routinely, in order to normalize the otherwise taboo topic.

Summary

This CBPR study contributes to the literature by providing a look at the experiences of Latina immigrants with sexual healthcare experiences from both the US and the Latina's home country. Previous researchers have explored Latinos' sexual health care from the providers' perspectives (Branch et al. 2010; Infante et al., 2006), and looked at sexual health behaviors within the Latino male population (Rhodes et al., 2006; Rhodes et al., 2007; Viadro & Earp, 2000). Additionally, researchers have looked at culturally specific needs for AIDS prevention among Latinas (Hirsch et al., 2002; Peragallo, DeForge, Rivero, Khoury, & Talashek, 2002), and Enriquez et al. (2010), explored health needs of HIV infected Latina immigrants; but these were not CBPR studies, nor were Latinas' experiences with healthcare providers examined. This study extends the research, by employing CBPR to explore Latina immigrants' experiences with healthcare providers regarding sexual health, in the context of immigration between the U.S. and country of origin. When reviewing these results, it should be kept in mind that there are several limitations to our study which are discussed below. Recommendations are provided in accordance with the results, and implications are noted in closing, based on aforementioned findings.

Limitations

There are several limitations to this study. First, the PI is not fluent in Spanish, and using an interpreter creates an extra level that the interview dialogue had to go through. However, the results of the analyses were taken back to the AMEXCAN organization and presented to a small group of Latinas to verify that these results made sense to them and also reviewed with a faculty researcher to insure that the data collection and analysis included a process with integrity, rigor, and accuracy. Second, the women in this study all live in eNC, therefore these results may have been different for Latina populations who live in urban areas in N.C. or in other states.

Recommendations

The experiences of the Latina immigrants in our study are unique to bicultural considerations. First, their experiences are influenced by explicit barriers that directly affect their healthcare access; however, there were implicit barriers that emerged. Latinas discussed significant discomfort with medical interpreters being in the room during a sexual healthcare visit with the doctor, highlighting medical interpreters as an implicit barrier to accessing care. Additionally, Latinas' sexual healthcare experiences are influenced by the conflicting medical healthcare cultures from two countries. Differences between the time orientations and communicative styles within healthcare settings were revealed to cause major conflicts for Latinas seeking sexual health care. Below are recommendations from this study that flowed from our research findings, followed by implications for future research.

RECOMMENDATION 1: An interesting factor to emerge from our study was the style of communication used by the provider. Our participants told us that it was important to them that they develop a relationship with their provider before beginning treatment or assessments, a cultural concept known as personalismo. The women expressed how important it was that the provider interact with them in a warm and caring way before initiating treatment, particularly sexual health assessments (i.e., providing culturally appropriate care). Furthermore, the women expressed a desire for clear and direct information from their provider. Given the cultural differences between health care in the U.S., and health care in our participants' native countries, Latinas could potentially misinterpret the patient-centered approach of U.S. healthcare providers to suggest that a lower level of importance be placed on the provider's advice. We recommend providers take some initial time with Latina patients to establish the relationship, and then use clear, direct language when discussing issues of sexual health. For example, providers could take initial moments during the healthcare encounter to ask about her family; and demonstrate active listening when she talks (i.e., give clear and direct feedback to patient during the exam), in order to demonstrate their attention to what she tells them.

RECOMMENDATION 2: Experiences of unresolved healthcare concerns were highlighted by some participants and associated with their discontinuation of healthcare services in the U.S. Participants described experiencing confusion in many of their interactions with various healthcare personnel in scheduling appointments, receiving results from healthcare visits, and receiving treatment advice from providers. This could be the result of language barriers, not having medical interpreters available, or utilizing interpreters who have not been trained in medical terminology. It has been noted in the literature that community health centers often use staff who may be bilingual, but do not have knowledge of diverse dialects. In addition, their ability to translate medical terminology into the target language may not accurate (Riddick, 1998). Developing a set of core competencies for all medical interpreters, including metrics for assessing the language services provided in healthcare settings, could alleviate confusion resulting from using two languages, help providers feel more confident in the communication they are delivering and receiving, increase patient satisfaction, and likely improve health outcomes .

RECOMMENDATION 3: Another surprising factor that emerged as a potentially strong deterrent to sexual health screening was the conflict of time orientations. The women we interviewed expressed having emotional reactions to sexual health assessments by their U.S. providers, and explained that they are not accustomed to preventive care. From their perspective, the provider only assesses for what he or she thinks is potentially a problem. Thus, the women expressed concerns of what their provider might have been thinking of them (i.e., that she was sleeping around), and concerns that the provider must be thinking she is infected with a life threatening, highly stigmatized, HIV infection. Either of these conclusions would produce an emotional reaction to or avoidance of a sexual health assessment, and may potentially deter a Latina from obtaining results of her HIV test. Before providers offer an HIV or other STI test to a Latina, the procedure should be normalized for the patient, explaining that it is part of good sexual health care. Furthermore, making sexual health assessments part of every healthcare encounter was suggested by many of our participants. Two or three assessment questions could be integrated into the healthcare visit by the provider, in order to normalize the conversation. This is recommended not only for females, but also for Latino males, in order to further normalize the conversation. Providing more information about HIV is also recommended, so that women understand that HIV is not the death sentence that it once was.

RECOMMENDATION 4: Our data support previous researchers' identification of stigma as a barrier to sexual health assessments (Acevedo, 2008; Hargreaves et al., 2010). It is important to note that our participants reported feeling stigma not only from other individuals in the community, but also feeling stigma from their healthcare provider in their native country, as well as by healthcare providers and interpreters in the U.S. Participants suggested to us that healthcare providers should make sexual health assessments a regular part of every visit in order to normalize the conversation for Latinas, and thus reduce stigma associated with the assessment. Participants also recommended making HIV education available to groups of Latina women, such as providing education and information about testing at health fairs, rather than singling them out individually.

RECOMMENDATION 5: The concept of familismo was highlighted as an important concept by participants, which aligns with previous research (Hargreaves et al., 2010). Latinas will put the needs of their children before their own needs. The women in our study suggested that emphasizing the importance for HIV screenings to Latinas for the sake of their children's health could be an effective approach to increasing the chances that Latinas will get tested for HIV and STIs. We suggest this could come in conjunction with recommendations for integrating personalism. For example, when a provider takes initial moments in the encounter to ask about her family, he can also applaud her for taking responsibility and initiative to care for herself.

RECOMMENDATION 6: Though we did not ask our participants if they perceived themselves to be at risk for HIV or other STIs, respondents echoed previous research claims that Latinas tend not to see themselves at risk for HIV or other STIs. Because HIV is so stigmatized, it is not discussed, and therefore women do not have appropriate information to fully understand the risk factors and the need to protect themselves. Participants in our study called for more information regarding HIV and STIs in order to improve Latinas' knowledge of risk factors that might be applied to them. Information should be provided in Spanish in manageable forms (i.e., the information should be basic and not overwhelming), and should be located in waiting areas of community healthcare centers as well as public health centers. Latinas associate HIV and other STDs with issues of female morality. Information should put HIV in a context that emphasizes a responsible spouse or parent getting tested, and getting tested as a couple, not singling the women out.

Implications

Addressing racial and ethnic inequities in relation to health and health care means attending to the discrimination and stigma associated with infectious diseases such as HIV/AIDS (Earnshaw, Bogart, Dovidio &Williams, 2013), and improving the way in which patients are cared for within healthcare contexts, as well as the way in which messages about care and health are carried back to patients' communities. Using critical theory as our guide, we employed a collaborative and participatory research approach as a culturally sensitive way to explore the sexual healthcare experiences of Latina immigrants with providers on both sides of the U.S.-Mexico border. Critical theorists seek to explain phenomenon and transform circumstances, thus liberating individuals from otherwise constricting conditions. In the spirit of critical theory, we encourage policy makers to standardize and professionalize medical interpretation services in order to address potential barriers to sexual health care. Furthermore, professionalizing interpretation services may potentially reduce the unresolved healthcare issues Latinas experience.

Further research should be conducted to explore use of medical interpreters during a sexual health assessment with Latina immigrants in various healthcare settings. Our participants lived in a primarily rural geographic setting in eNC. Researchers should also conduct binational studies in order to get a more systemic view of how immigration affects Latinas' health. Furthermore, researchers conducting collaborative and participatory research must be prepared to invest an extensive amount of time for development and maintenance of relationships between the university researchers and members of the community. The PI stayed involved with the community members throughout the research study, and continues to stay involved with the organization. It is the opinion of the PI that the richness of the interview data that was collected in this study was due to the comfort level the participants had with the PI and the interpreter, thus the time invested in the relationships.

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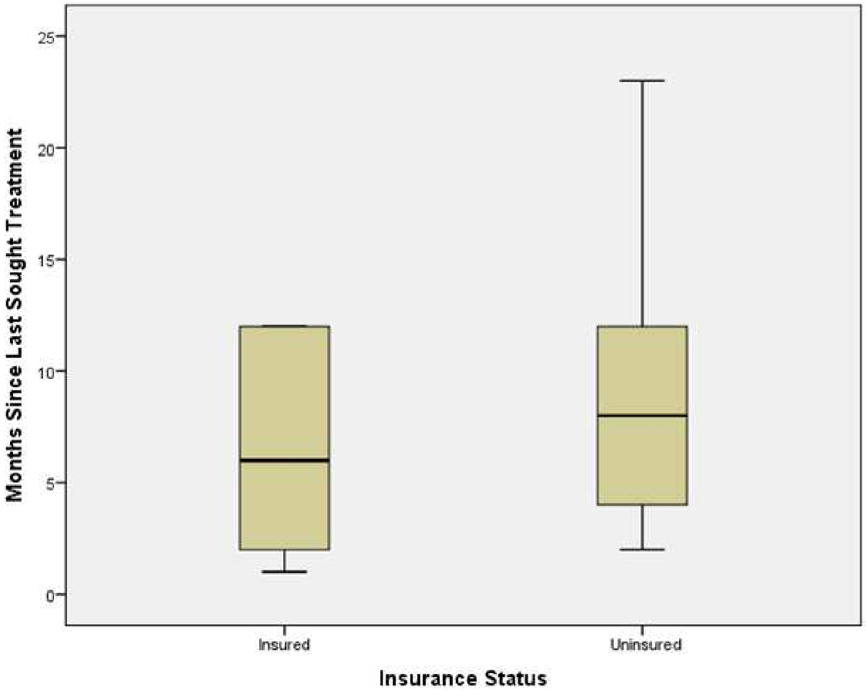
Table 1: Definitions and Frequencies of Themes

	Theme	Count	N
1	Communication Style *Cultural concepts such as personalismo (e.g., importance of establishing relationship with healthcare provider) and directive vs. nondirective communication*	56	10
2	Capacity of HCS *Capacity of healthcare system to assess for sexual health, and to resolve healthcare concerns*	55	10
3	Access to Care *Barriers to care such as distance to health care, language (including use of interpreters), cost or insurance status*	49	11
4	Time Orientation *Present time orientation (e.g., accessing health care only when there is a problem or symptoms) vs. future time orientation (e.g., accessing health care for preventive care)*	40	10
5	Stigma *Community's perception of HIV / STIs as taboo, not normal to discuss*	35	10
6	Familismo *Latinos place needs of family before those of the individual; and seek advice of family for healthcare concerns*	18	8
7	Perception of Risk *Recognizing (or not recognizing) factors associated with HIV that could be applicable to oneself*	13	9

N= 11; n = number of participants who responded to this theme

Figure 1: Frequency of Seeking Medical Care vs Insurance Status



CHAPTER 6: CORE COMPETENCIES AND CODE OF ETHICS: A CALL TO ACTION

Background

Historically considered to be a country of immigrants (Agnew, 2013), the United States (U.S.) has 45.7 million foreign born residents that, in 2013, was more such residents than any other country (United Nations, 2013). According to the 2007 American Community Survey, approximately 20% of U.S. residents who were five years of age or older spoke a language other than English in their home (Shin & Kominski, 2010). Furthermore, of those who spoke a language other than English, approximately 35% of these individuals were considered to have limited English proficiency (LEP). LEP has been defined by Alborn and McKinney (2014) as “individuals who do not speak English as their primary language and who have a limited ability to read, write, speak, or understand English” (p. 1044). Nearly 40% of individuals with LEP report Spanish as their primary language, compared to less than 3% for any other language group (Gonzalez-Barrer & Lopez, 2013). These percentages are not surprising, given that Latinos now represent the largest minority group in the U.S. (18%), with a projected 24% of the population by the year 2065 (Gonzalez- Barrer & Lopez, 2013). As the Latino immigrant population expanded into communities across the nation, and particularly into regions that have been caught unprepared by the exponential growth in the Latino population (Bellamy et al., 2015a), it is essential that healthcare professionals at all levels have the necessary skill sets for and can adapt to the needs of an evolving, increasingly diverse community.

Though the interpreting profession is well established globally across fieds of diplomacy and international conferencing, it has only recently been highlighted in the U.S. and healthcare arenas (National Council on Interpreting in Health Care [NCIHC], 2001). Early encounters in healthcare settings requiring language interpreters involved family members, non-medical staff, and sometimes other patients (NCIHC, 2001). But over time this avenue has not shown to be consistently effective (Flores, 2005; Jacobs et al., 2001). For example, even though bilingual staff may have the advantage of familiarity with the healthcare clinic, they may not have the language skills needed to provide the level of interpreting services required for medical interpreting (i.e., they may not be familiar with medical terminology) (Morero, Otero-Sabogal, & Newman, 2007). It has also been shown that using family members' results in excluding up to half of all questions asked to a patient by their healthcare provider, and increases the likelihood of errors with clinical consequences (Flores, 2005). Some researchers have highlighted concerns regarding access to health care when language barriers were a concern. For example, Woloshin, Schwartz, Katz, & Welch (1997) demonstrated that women (whose main spoken language was not English) accessed screenings for breast and reproductive health at lower rates than those who spoke English. Other researchers have found that among Latino patients, those who were primarily Spanish-speaking were not as likely to report having a primary care provider (Hu & Covell, 1986) as Latinos who spoke English. The usefulness of having adequate, professionally trained healthcare interpreters available to LEPs is essential to quality care. As such, additional attention should be toward providing healthcare interpreters with appropriate standards for their profession.

Most healthcare professionals (medical and mental health providers alike) are required to complete coursework pertaining to ethics as well as diversity awareness. However, such expectations and standards are not well layed out for healthcare interpreters. For example, healthcare professionals across various clinical disciplines have specified core competencies (or defined roles and skills) and codes of ethics as a guide to their clinical practice and decision making (American Medical Association (AMA), 2001; American Psychological Association

(APA), 2010; American Association of Marriage and Family Therapy (AAMFT), 2015; National Association of Social Workers (NASW), 2008; American Nurses Association (ANA), 2015), yet nothing is in place for healthcare interpreters. Furthermore, formal training for healthcare interpreters has varied considerably across the U.S., and has resulted in efforts to standardize the profession (NCIHC, 2011). The NCIHC identified a need to raise the quality of interpreting services available in healthcare settings (2004), and subsequently introduced efforts to develop national standards of practice and code of ethics (2004, 2005). Standards of practice and core competencies established by professional guilds help to outline baseline knowledge and skills for its members (AMA, 2001; APA, 2010; AAMFT, 2015; NASW, 2008; ANA, 2015).

Core competencies of a professional guild are the core knowledge and skills set that are deemed instrumental to succeed in a given profession (AMA, 2001; APA, 2010; AAMFT, 2015; NASW, 2008; ANA, 2015). In a concerted effort to build a "safe and better, patient-centered and community/population oriented healthcare system," various national healthcare professional associations called for the development of core competencies for interprofessional collaborative practice (Schmitt, Blue, Aschenbrener, & Viggiano, 2011, p. 1351). Yet healthcare interpreters were not among those to be a part of this effort.

The roles assumed by Latino language interpreters who work in healthcare settings are hardly those of neutral contributors, but rather they influence the patient-provider interaction process (Hsieh, 2007). Interpreters are the only ones between patient and provider who understand both languages, thus giving them tremendous power to influence the communication process (Hsieh, 2006). As such, core competencies and a code of ethics are vital to the profession of healthcare interpreter, particularly for those who have a role in the treatment of immigrant patients. Unfortunately, there is no system in place for ensuring or evaluating the quality or accuracy of ethical care provided by interpreters (Hseih, 2007).

Thus, the focus of this call to action is to bring attention to the need for proper culturally-based resources (i.e., translating and interpreting services) and oversight (i.e., quality assurance and ethical guidelines) of those who translate or interpret for immigrant and non-English speaking populations (Bellamy et al., 2015b; Dysart-Gale, 2007). Given that the majority of non-English speaking patients across the nation are Hispanic (Gonzalez-Barrer & Lopez, 2013; Rosenthal et al., 1998), attention is directed toward a specific group of interpreters, known as *Promotores de Salud (PdS)* (promoters of health), who primarily help bridge the communication between Latinos and their healthcare providers (Bellamy et al., 2015b). The following call to action is based on the culmination of a series of articles that were developed and written over the course of two years that capture the complexities and concerns pertaining to health care for Latino patients and included services with PdS (Bellamy et al., 2015a; 2015b; 2015c). See Appendix H for a summary of the Bellamy et al. (2015a; 2015b; 2015c) initiatives. The sections in this call to action provide: (a) a background on the origins of promotoras de salud, (b) previous attempts at establishing standards of practice for interpreters, (c) current healthcare policies that promote the need for promotores in health care, and (d) recommended core competencies and a code of ethics for promotores.

Origins of Promotoras de Salud (PdS)

Health literature generally refers to PdS as health educators who are local to the communities that they serve and assist with populations that are typically underserved or marginalized (Mayfield-Johnson, 2011; Pérez & Martinez, 2008; Rosenthal et al., 2010; Witmer, Seifer, Finocchio, Leslie, & O'Neil, 2011). The Center for Disease Control and Prevention

(CDC) refers to PdS as the Spanish alternative term for *community health workers* (2015). Other titles used to describe PdS include community health advisors, outreach workers, patient navigators, and lay health advocates (Goodwin & Tobler, 2008; Rosenthal et al., 2010; Rosenthal et al., 1998; WestRasmus, Pineda-Reyes, Tamez, & Westfall, 2012), as well as PdS who additionally provide interpreting and translating services (Goodwin & Tobler, 2008).

The origination of PdS began in the early 17th century and developed out of need to get basic medical care to military personnel in Russia when there was a shortage of doctors (Kenyon, 1985). Community health workers (i.e., PdS) later became known for providing primary care to remote and rural areas in China, when there were no doctors available (La Familia Sana Programs, 1992). More recently, PdS have gained recognition for distributing health resources to underserved populations (Perez & Martinez, 2008). For more than sixty years, PdS have served as community health workers in the U.S. (Balcazar et al., 2011) within the Latino community (Mayfield-Johnson, 2011), bringing health education and interpretation services to the community that they are traditionally members of (Bellamy et al., 2015b; Goodwin & Tobler, 2008; Mayfield-Johnson, 2011) in an effort to provide more culturally appropriate care (Bellamy et al., 2015b).

The objective of culturally and linguistically competent health care is the assurance of equality of care between ethnic and racial groups (Kosoko-Laski, Cook, & O'Brian, 2009). Federal mandates and other governmental policies that require implementation of interpreting services to LEP patients are seen as a step in the right direction, yet offer no final resolutions. For example, the Civil Rights Act of 1964, sections 601 and 602, is often cited when arguing that federally funded healthcare facilities are required to provide linguistically appropriate healthcare services for patients with LEP (McDowell, Messias, & Estrada, 2011). However, these policies do not come with funding (Juckett, 2014), so healthcare providers are often left to manage complex patient needs in an increasingly challenging economic environment. One approach that many community health centers take is an “in-house” strategy, hiring a bilingual staff person (Riddick, 1998), of which PdS are included (Goodwin & Tobler, 2008) to help meet Spanish speaking patients’ needs. In a report issued by the NCIHC, the promotores’ model was noted as a successful way to connect Latinos to culturally and linguistically appropriate health care (2004).

National standards for interpreters in healthcare settings are offered by the NCIHC (2011); however, these standards are not specific to healthcare interperters who might also serve as community health educators (as is the case for PdS) (Rosenthal et al., 2010). PdS are specialized in that they “develop peer-to-peer relationships of trust with patients, rather than provider-client relationships” (Rosenthal et al., 2010, p. 1339), and thus need standards of practice in line with their specialized roles to further strengthen the work that they already provide to the community.

In an effort to provide this comprehensive support system, and to be in line with the standards of practice recommended by the NCIHC, core competencies and a code of ethics are recommended to address specifically the position of the PdS. Below is a description of (a) the previous attempts at establishing practice standards, (b) the most recent policies that punctuate the importance and role of PdS in health care, and (c) a call to action to construct a code of ethics and set of professional standards, in order to ensure that PdS across the nation are recognized as having commonalities through professional standards and a code of ethics that aligns best with the complexities associated with their practice and roles.

Previous Attempts at Establishing Standards

In 1998, the NCIHC was founded with the primary goal of establishing a framework that promotes culturally competent healthcare interpreting, including standards for the provision of interpreter services in healthcare settings (i.e., core competencies) and a code of ethics for interpreters in health care (NCIHC, 2004). In 2000, Executive Order No. 13116 (1999) was implemented by President Clinton for the establishment of medical interpreting degrees and certification programs. One year later, the National Standards for Culturally and Linguistically Appropriate Health Care Services (CLAS) were published by the U.S. Department of Health and Human Services (USDHHS) Office of Minority Health (2001). This was a notable move for professionalizing the field of medical interpreting on multiple fronts. But, the field remains fragmented, with varying interpretations of language services provided, and unstandardized expectations from the field (McDowell et al., 2011), creating challenges for interpreters, as well as healthcare providers. For example, (a) most bilingual staff have not been assessed/evaluated for their level of language and culture competency (Morero et al., 2007; Riddick, 1998), (b) their ability to translate medical terminology into the target language may not be sufficient (Morero et al., 2007; Riddick, 1998), and (c) while they must comply with the Health Insurance Portability and Accountability Act (HIPAA) (USDHHS, 2006) they do not function under the jurisdiction of or have standard training in a code of ethics (NCIHC, 2004), which may ultimately mean that confidential information is shared with others that should be kept between patient and provider.

To further complicate matters, a recent national survey found that only about half of resident physicians had any training in working with interpreters in the healthcare setting (Hsieh, 2010). Subsequently, job conflicts between physicians and interpreters emerge due to a lack of clearly defined roles (Riddick, 1998; Rosenthal et al., 1998) and expectations of the training associated with the PdS role. In a recent qualitative study, McDowell and colleagues (2011) reported that "constant multitasking and negotiating of blurred role boundaries and competing, often conflicting, expectations frequently resulted in mental, physical, and emotional exhaustion" for individuals functioning as a promotora (p. 139). These researchers described the conflicting role expectations encountered by PdS to include conflicts in values or issues of ethics stemming from dual role expectations (McDowell et al., 2011). In an example offered by the researchers, an interpreter described the challenge: "it's a big challenge to keep everyone happy….It's like keeping the protocol for the interpreter, keeping this informed doctor satisfied with your work, and trying to explain to the patient at the same time what your arelimitations as an interpreter" (McDowell et al., 2011, p. 141).

Addiitonally, there is a concern pertaining to high staff turnover. In a recent health outreach study facilitated by PdS, researchers noted a significant number of PdS quit throughout the outreach program (Trejo, Arcury, Grzywacz, Tapia, & Quandt; 2013). Those who quit mentioned lack of support from family, partner agency, employer and staff as reasons for dropping out (Trejo et al., 2013). The researchers concluded that "open communication and a comprehensive support system within the program are imperative to maintaining success and reducing failure when Lay Health Workers [i.e., promotoras/es] are faced with difficult tasks or obstacles when performing their jobs" (Trejo et al., 2013, p. 83). Unfortunately, there are no current federal laws in place to mandate that medical interpreters (including PdS) receive appropriate training and supervision, and thus no formal support to guide them in their work (Searight & Searight, 2009).

While PdS offer many strengths to the communities they serve, without core competencies and a code of ethics, multiple ethical challenges may emerge. Currently, more than 120,000 PdS are estimated to be working in locations across the nation, such as in local neighborhoods, homes, schools, health departments, clinics and hospitals (Rosenthal et al., 2010). Given the growing number of PdS, policy recommendations have been made that call for occupational regulation with trainings and certifications (Rosenthal et al., 2010). Though this is a step in the right direction, there remains a lack of standard role definition, already noted to be a defining barrier to professionalizing the area of service (Rosenthal et al., 1998). Therefore, a standardized set of core responsibilities for PdS, would unify the profession and ensure the integrity and rigor necessary for the continued success of PdS in health care, particularly as new policies have emerged that punctuate the importance of PdS.

Current Health Care Policies Involving Promotores

Recognition of the benefits that PdS bring to healthcare systems is growing in acknowledgment by policy makers (Rosenthal et al., 1998; WestRasmus et al., 2012). PdS are becoming more imbedded as integral members of primary healthcare teams (Rosenthal et al., 2010). This is perhaps most evident in such recent policies as The Patient Protection and Affordable Care Act (2010) that offer advancement for PdS to provide the healthcare enrollment assistance that is needed for Spanish speaking individuals (WestRasmus et al., 2012), as well as the PdS initiative of the United States Department of Health and Human Services, Office of Minority Health (2011), that supports a collaborative effort between PdS and Health and Human Services agencies (WestRasmus et al., 2012).

In May of 2011, the U.S. Department of Health and Human Services' (HHS) Office of Minority Health initiated a program to fund Community Health Workers (CHWs) and PdS in their outreach efforts to the Latino community (WestRasmus et al., 2012). Fifteen promotores were selected to oversee PdS and CHW work throughout the country, and provide information back to the Federal Work Group about the functions and roles of these workers (2012). With such visible support from federal government for PdS to bridge healthcare information and services to a growing Spanish speaking population (Gonzalez- Barrer & Lopez, 2013), now is the time to call for professional standards that will help guide PdS in their professional responsibilities and duties.

The Call to Action: Recommended Practice Standards and a Code of Ethics

Based on recent literature (Flores, 2005; Hsieh, 2006, 2007; Morero, 2007) and recent findings from a study by Bellamy and colleagues (2015c), it became clear that core competencies and a code of ethics were essential for PdS in order to ensure a standard of practice that upholds integrity and rigor. Recommendations for the adoption of standards for practice (i.e., a set of core competencies) and a code of ethics that are tailored specifically for PdS, and the authorities that hire them, are provided below.

According to the NCICH (2004), standards of practice can be used as a reference by interpreters (in this case, PdS), to guide them in practice, as well as by those who hire them, train them, and work with them. When hiring, authorities can refer to these standards during the interview process and again during performance evaluations. Furthermore, supervisors can incorporate these essential core competencies and ethical principles into their training programs for PdS. Below is a call to action for researchers and policy makers to establish core competencies with consideration for four working domains: (a) Ethics, (b) Diversity Awareness, (c) Professional Competence, and (d) Collaboration and Systems of Care. Following the description of core competencies, is the call for a specific code of ethics for PdS.

Core competencies

The competencies described below offer a description of key skills and knowledge required of PdS to perform as healthcare educators and interpreters within a healthcare setting or environment (Bellamy et al., 2015; NCIHC, 2004). These competencies are grounded in research and were established out of findings from feedback from individuals who have received health care that included a PdS as part of their visit (Bellamy et. al., 2015b; 2015c). A complete list of core competencies are provided in Table 1

Domain 1: Ethics. Core competencies should include (1.1.) responsibility to patients by offering patient centered care that is central to their well-being, (1.2) confidentiality for the exchange of patient information, and professional integrity in relation to respect for patient autonomy (1.3). Interpreters are in a unique position of bridging the patient with his or healthcare provider. In a study by Bellamy and colleagues (2015), participants indicated that they needed to feel a connection to their healthcare provider before treatment began in order to feel they could ask and answer questions relevant to their health. This approach to patient centered care is known as personalismo and helps to ensure that care is ethical and personalized.

Beyond having person-centered care, Latina patients have expressed concerns over confidentiality when needing to use a medical interpreter during health assessments (Bellamy et al., 2015c). In fact, some of the women in the Bellamy et al. (2015) study expressed concerns about health information leaking out to others in the community. As such, PdS should treat all information exchanged between patient and provider as confidential and respect the vulnerability of patients in healthcare systems.

Domain 2-Diversity Awareness. Core competencies should include an understanding of the medical culture in the U.S. and how this may differ from healthcare systems in other cultures/countries (e.g., preventive care vs disease care) (2.1). For example, Bellamy et al. (2015c) demonstrated that Latina immigrants experienced health assessments by U.S. providers as judgments on their moral character. This emerged as the result of differences in healthcare models between the U.S. (practicing preventive care) and Mexican (practicing disease care) healthcare systems. The women were less familiar with preventive care, and thus felt their moral character was being judged by their providers. PdS should be aware of these cultural differences and inform providers of the differences between the medical systems when it is appropriate to do so.

Core competencies should also include (2.2) cultural competency by demonstrating knowledge of one's own cultural background and how this effects one's thinking and behavior. For example, researchers found that sexual health issues such as HIV are highly stigmatized in the Latino culture (Infante et al., 2006). PdS may react to sexual health assessments and conversations in their professional environment in ways that are biased and not conducive to positive outcomes for patients' health and wellbeing. Being aware of one's own cultural biases is imperative to the profession of PdS in a healthcare environment. Awareness may be possible through journaling difficult situations or populations and then reviewing these scenarios with a supervisor.

PdS should also demonstrate cultural competency across social locations (e.g., differences within and between gender, age, ability, ethnicity, religion, sexual identity). PdS should respond to diverse patients using cultural humility and by ensuring that health education and interpreting reflects the needs, strengths, and concerns of diverse social locations.

Domain 3-Professional Competence. Core competencies should include knowledge of medical terms (3.1a) and accuracy in medical linguistics (3.1b), as well as recognizing medical terminology in written and oral forms. Some of the participants in the Bellamy et al. (2015c) study indicated that they were unable to discuss health issues with their provider, due simply to not knowing the correct words to use. Furthermore, women in this study stated that they were given confusing messages about their diagnoses (Bellamy et al., 2015). PdS should be trained to follow up with patients to be sure they understand the provider's diagnosis and healthcare instructions (3.1.c).

Core competencies should include training in professionalism (3.4). PdS should demonstrate knowledge of how to position herself during a medical care encounter. A participant in the Bellamy et al. (2015c) study recalled having an interpreter in the room during a sexual health exam who was standing behind the provider at the time of the exam. The participant stated that if an interpreter is needed during a procedure or exam, she should have been trained to stand behind the patient instead of behind the provider. This would have made the patient feel more relaxed during the exam.

Domain 4-Collaboration and Systems of Care. Finally, core competencies for PdS should include training on how to function in a collaborative environment and across systems of care. Particularly, PdS should know how to serve as an advocate for patients, when appropriate. This training should take place across four different systems: (4.1) collaborating with providers within the healthcare system, (4.2) collaborating with family and community systems, (4.3) collaborating with community systems in a patient's country of origin, and (4.4) collaborating with a relevant national or international organizations.

As a country of immigrants (Agnew, 2013; United Nations, 2013) with a large and growing Spanish speaking immigrant population (Gonzalez- Barrer & Lopez, 2013), the need for healthcare systems to collaborate across borders will be inevitable. PdS are well prepared in many ways, since they are after all community members themselves. However, training PdS to operate professionally within systems and across systems will be imperative. A set of core competencies for PdS provides a consistency in the care delivered across the nation and ensures quality and rigor in the dissemination of services conducted. In addition, a code of ethics strengthens the integrity of the profession and safeguards against exploitation of vulnerable populations.

Code of Ethics

While all of the domains are essential to the practice of PdS, most professionals operate under a specific code of ethics and as such we have provided a call to action for a specific code of ethics for PdS. The ethical principles listed here are recognized as central to PdS in their role as healthcare educators and interpreters within a healthcare setting and are based on findings in research and current guidelines for interpreters (Bellamy et al., 2015c; NCIHC, 2004).

The purpose and value of a code of ethics is varied (Dahnke, 2014; Dysart-Gale, 2005; NCIHC, 2004). From a philosophical perspective, Dahnke (2014) offers that codes of ethics “can help to instill critical thinking and in-depth analysis of ethical issues and problems…” (p. 612). From an academic perspective, Dysart-Gale (2005) suggested that a code of ethics functions to “integrate interpreters into the clinical culture, coordinating their work with other practices within the clinic” (p. 93). And still further, an anonymous respondent (who commented in a survey from the National Council for Interpreters in Health Care (NCIHC) (2004)) stated, “The role of interpreter is a ‘tightrope’ balancing act: A code of ethics is a good guide for the ‘bar’ carried on such a walk on the tightrope. It offers balance, some security and especially is a comfortable way to face the unknown risks faced on the interpreter’s path” (p. 4). While codes of ethics benefit numerous clinicians across a wide array of healthcare professions, such as physicians (AMA, 2001), mental and behavioral health providers (APA, 2010; AAMFT, 2015; NASW, 2008), and nurses (ANA, 2015), to name just a few, more recent additions to healthcare teams (i.e., promotores de salud) could benefit as well.

Provided below are specific recommendations toward a code of ethics for PdS. The recommended code is arranged into five segments: (1) responsibility to clients, (2) confidentiality, (3) professional competence and integrity, (4) technology in professional services, and (5) financial arrangements.

Responsibility to clients (1.0). The PdS exhibits patient-centered care. PdS are to use relevant and culturally appropriate care with a patient to aid in a quality and trustworthy healthcare encounter. PdS integrate concepts of personalismo and familismo into the healthcare encounters, so as to help the patient feel comfortable with the provider and in the healthcare setting.

Confidentiality (2.0). The PdS extends confidentiality to all patients. PdS are knowledgeable about healthcare policies in the work context as well as relevant requirements regarding disclosure set forth in the Health Insurance Portability and Accountability Act (HIPAA). PdS are to keep private and personal healthcare interactions and information confidential and maintain trust among all parties. PdS only disclose patient information through a formal release of information and in protected contexts (e.g., not in hallways and not with anyone who is not part of the patient's healthcare team).

Professional competence and integrity (3.0). PdS act with integrity and honesty in all professional roles and responsibilities. PdS promote the community's trust by upholding the professional responsibilities and duties of a PdS. A PdS should not coerce patients against their will, should not respond with inappropriate or uniformed information on behalf of a patient, or influence patient decision making in order to personally benefit from said outcome. PdS should interpret, with accuracy, what is said in the medical encounter, even if it is embarrassing or difficult to say. PdS will disclose any limitations of his/her skills or knowledge with respect to a particular assignment; showing respect for other professionals within the workplace setting and honoring each contributors scope of practice.

Diversity awareness in medical care systems (3.1). The PdS provides information in an ethical manner, when appropriate to patient and/or provider, about culturally relevant issues regarding cultural differences in medical settings. PdS provide patients with a culturally appropriate healthcare encounter. PdS help patients understand that healthcare assessments are routine in the U.S. healthcare system, and questions in the assessment are not meant to be judgmental, but rather to improve overall health and wellbeing.

Diversity awareness across social locations (3.2). The PdS practices cultural humility across social locations (gender, age, ability, ethnicity, religion, sexual identify). PdS are aware of and monitor their own biases in these areas, seeking supervision when it is necessary to ensure unbiased interactions with patients.

Medical linguistics (3.3). PdS exchange patient and provider messages accurately; conveying the content as close to the original message as possible, taking into consideration its cultural context. PdS will capture what is said, even if the content seems redundant, unnecessary, or embarrassing.

Cultural language proficiency (3.4). The PdS recognizes and works to eliminate stigmatizing language during a healthcare visit. PdS work to reduce stigma that could otherwise serve as a barrier to care.

Financial accountability (3.5). The PdS clarifies his or her scope and limits of the role as interpreter or health educator regarding how services are paid for, in order to avoid conflicts in role or duties. A PdS who also serves in a dual role (i.e., a healthcare educator) will recognize the dual roles, and understand the boundaries associated with the two roles and will also make sure any financial agreements are clearly distinguished by role.

Multiple relationships and role boundaries (3.6). A PdS will make every effort to recognize multiple relationships that could risk impairing professional services or risk exploitation of patient due to such multiple relationships and roles. The PdS maintains the boundaries of the professional role as the interpreter, or as the health educator. The PdS clarifies his or her scope and limitatations of the role in order to avoid conflicts in role or duties. A PdS who also serves in a dual role (i.e., a healthcare educator) will recognize the dual roles, and understand the boundaries associated with each role.

Technology in professional services (4.0). The PdS engages in use of technology that promotes and facilitates communication between patient and provider in the healthcare setting, and is aware of ethical protections via all uses of technology. PdS seek out training for best practices in the use of technology in order to improve efficiency and reduce miscommunication between patient and provider.

Summary

Latinos represent an increasingly large segment of the U.S. population (Gonzalez-Barrer & Lopez, 2013), many whom identify as LEP (Gonzalez-Barrer & Lopez, 2013). Healthcare professionals are striving to meet the healthcare needs of this population in an increasingly difficult financial environment (NCIHC, 2004; Riddick, 1998). PdS have been identified as a culturally appropriate and integral addition to the healthcare setting, providing linguistic and other forms of support to Spanish speaking clients (NCIHC, 2004).

As such, we have constructed a set of research informed domains that serve as the foundation for a series of core competencies as well as recommended principals toward the establishment of a code of ethics for PdS. Based on our recommendations, we call on policy makers to require the subsequent implementation of these core standards and ethics for all federally funded as well as locally funded healthcare centers and public health departments that employ PdS as interpreters and/or health educators. Hiring authorities are called to use these standards as a guide for hiring, training, and evaluating PdS, so that PdS will finally have a framework for responsibilities and skills of a PdS and a guide for ethical decision making in their daily encounters with patients and healthcare team members.

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Table 1. Core Competencies for Promotores de Salud (PdS)
Domain 1: Ethics

NUMBER	STANDARDS OF PRACTICE	COMPETENCE
1.1	Responsibility to Clients	Exhibit person-centered care (personalismo)
1.2	Confidentiality	Confidentiality is upheld with all information learned from discussions and appointments that include patients (unless granted a formal release of information)
1.3a	Professional Integrity	Respecting patient autonomy in decision making Declining assignments that go beyond training
1.3b		Make appropriate referral for patient's circumstances that go beyond scope/training
1.3c		Uphold financial integrity (i.e., do not accept gifts or accept direct payment for services provided)

Domain 2: Diversity Awareness

NUMBER	STANDARDS OF PRACTICE	COMPETENCE
2.1	Diversity in medical care systems	Know and understand hierarchy of healthcare systems -Non-directive (patient-centered) vs Directive communication -Time orientations (preventive care vs disease centered)
2.2a	Diversity of culture	Demonstrate of knowledge of one's own cultural background and how this effects one's thinking and behavior
2.2b		Honor and extend cultural humility across social locations (gender, age, ability, ethnicity, religion, sexual identity)
2.2c		Recognize different dialects and make appropriate referral if unable to accurately interpret on behalf of the patient

Domain 3: Professional Competence

NUMBER	STANDARDS OF PRACTICE	COMPETENCE
3.1a	Medical linguistics	Recognize medical terminology (both written and orally)
3.1b		Interpret all that is communicated between provider and patient with accuracy
3.1c		Follow-up with patient in appointment to be sure they understand provider's diagnosis and advice for care
3.2	Cultural language proficiency	Identify stigmatizing language and behaviors and move to reduce such stigma
3.3	Technology	Demonstrate familiarity with forms, strengths, and limitations of technology that can aid interpreters working in healthcare settings
3.4	Professional Conduct	Know how to appropriately position oneself for interpreting services during a medical care encounter
3.5	Role boundaries	Recognize dual roles and understand the challenges of assuming dual roles (e.g., working as an interpreter and also a health educator)

Domain 4: Collaboration & Systems of Care

NUMBER	STANDARDS OF PRACTICE	COMPETENCE
4.1	Collaborations with providers in healthcare system	Demonstrate ability to serve as patient advocate: Follow up with patients to be sure all concerns are appropriately addressed
4.2	Collaborations with community systems	Demonstrate ability serve as patient advocate: as a bridge between patient's family and community systems, and medical care system when appropriate to do so
4.3	Collaborations with systems in country of origin	Demonstrate ability serve as patient advocate: as a bridge between patient's healthcare system in U.S. and patient's healthcare systems in country of origin
4.4	Collaborations with embassy or other immigration agencies	Demonstrate ability serve as patient advocate: Be familiar with embassy representatives who are relevant to patients who are served in healthcare settings

APPENDIX A: LETTER OF IRB APPROVAL

EAST CAROLINA UNIVERSITY
University & Medical Center Institutional Review Board Office
4N-70 Brody Medical Sciences Building· Mail Stop 682
600 Moye Boulevard · Greenville, N.C. 27834
Office 252-744-2914 · Fax 252-744-2284 · www.ecu.edu/irb

Notification of Initial Approval: Expedited

From: Social/Behavioral IRB
To: Roberta Bellamy
CC: Angela Lamson
Date: 12/4/2014
Re: UMCIRB 14-001348
Latina Immigrants, HIV, and their Experiences with Health Care Providers in the U.S. and in their Home Country

I am pleased to inform you that your Expedited Application was approved. Approval of the study and any consent form(s) is for the period of 12/3/2014 to 12/2/2015. The research study is eligible for review under expedited category #6, 7. The Chairperson (or designee) deemed this study no more than minimal risk.

Changes to this approved research may not be initiated without UMCIRB review except when necessary to eliminate an apparent immediate hazard to the participant. All unanticipated problems involving risks to participants and others must be promptly reported to the UMCIRB. The investigator must submit a continuing review/closure application to the UMCIRB prior to the date of study expiration. The Investigator must adhere to all reporting requirements for this study.

Approved consent documents with the IRB approval date stamped on the document should be used to consent participants (consent documents with the IRB approval date stamp are found under the Documents tab in the study workspace).

The approval includes the following items:

Name	Description
APPENDIX A Role of CBPR Researchers.docx	Additional Items
APPENDIX C.Flyer.English.doc	Recruitment Documents/Scripts
APPENDIX C.Flyer.Spanish.doc	Recruitment Documents/Scripts
APPENDIX D.Phone Script.English.docx	Recruitment Documents/Scripts
APPENDIX D.Phone Script.Spanish.docx	Recruitment Documents/Scripts
APPENDIX E.Interview Guide.English.docx	Interview/Focus Group Scripts/Questions
APPENDIX E.Interview Guide.Spanish.docx	Interview/Focus Group Scripts/Questions
APPENDIX F.Demographic Questionnaire.English.docx	Surveys and Questionnaires
APPENDIX F.Demographic Questionnaire.English.docx	Data Collection Sheet
APPENDIX F.Demographic Questionnaire.Spanish.docx	Data Collection Sheet
APPENDIX F.Demographic Questionnaire.Spanish.docx	Surveys and Questionnaires
Chapter 4 Method 11_13.docx	Study Protocol or Grant Application
IRB informed consent form.English.doc	Consent Forms
IRB informed consent form.English.doc	Translated Consent Document

The Chairperson (or designee) does not have a potential for conflict of interest on this study.

IRB00000705 East Carolina U IRB #1 (Biomedical) IORG0000418
IRB00003781 East Carolina U IRB #2 (Behavioral/SS) IORG0000418

APPENDIX B: FLYER (ENG/SPAN)

Association of Mexicans in North Carolina, Inc.

" Fostering the appreciation, understanding and prosperity of the Mexican and Latino Community through culture, leadership, health, advocacy, and education"

VOLUNTEERS NEEDED

For a research study

"Latina Immigrants and Experiences with Healthcare Providers in U.S. and Country of Origin"

The purpose of this study is to learn about Latina immigrants' experiences with health care providers in their home country, as well as in the U.S., in an effort to understand how Latina immigrants experience health care and potentially improve the experience of care.

Participant will be asked to talk to a researcher about her experiences with healthcare providers. All interviews and personal information will be kept confidential.

Time commitment: One visit that lasts approximately 1 ½ to 2 hours, and will take place either in the participant's home, the AMEXCAN office, or another location of the participant's choosing.

You will be reimbursed for your time.

This study is being conducted through a collaborative effort between AMEXCAN (Association of Mexicans in North Carolina) and East Carolina University Medical Family Therapy doctoral program.

If interested, you may contact:

Ana Nava, 5:00pm to 7:00pm, Monday – Friday,
at 252-757-3916
or Juvencio Rocha Peralta, 9:00am to 5:00pm, Monday – Friday,
at 252-757-3916

Juvencio Rocha-Peralta	Roberta Woodlief Bellamy (252-737-1415)
Executive Director	Medical Family Therapy
AMEXCAN	East Carolina University
Belvor Hwy 261 Greenville, N.C. 27834	612 E 10th St, Greenville, N.C. 27858

Association of Mexicans in North Carolina, Inc.

"Fostering the appreciation, understanding and prosperity of the Mexican and Latino Community through culture, leadership, health, advocacy, and education"

SE NECESITAN VOLUNTARIOS

Para un estudio de investigación

"Los inmigrantes latinas y experiencias con los proveedores de atención médica en los Estados Unidos y el país de origen"

El propósito de este estudio es conocer las experiencias de los inmigrantes latinas con los proveedores de atención de salud en su país de origen, así como en los EE.UU., en un esfuerzo por comprender la experiencia inmigrantes médico cómo Latina y potencialmente mejorar la experiencia de la atención.

Se pedirá a los participantes a hablar con un investigador acerca de sus experiencias con los profesionales de la salud. Todas las entrevistas y la información personal se mantendrán confidencial.

Compromiso de tiempo: Una visita que dura aproximadamente 1 ½ a 2 horas, y se llevará a cabo ya sea en el domicilio del participante, la oficina AMEXCAN, o en otro lugar elegido por el participante.

Se le reembolsará por su tiempo.

Este estudio se lleva a cabo a través de un esfuerzo de colaboración entre AMEXCAN (Asociación de Mexicanos en Carolina del Norte) y la Universidad de Carolina del Este Terapia Familiar Médica programa de doctorado.

Si está interesado, puede comunicarse con:

Ana Nava, 5:00 pm a 7:00 pm Lunes - Viernes,

al 252-757-3916

o Juvencio Rocha Peralta, de 9:00 am a 5:00 pm, de lunes - viernes,

al 252-757-3916

Juvencio Rocha-Peralta
Executive Director
AMEXCAN
Belvoir Hwy 261 Greenville, N.C. 27834

Roberta Woodlief Bellamy
Marriage & Family Therapist
East Carolina University
612 E 10th St, Greenville, N.C. 27858

APPENDIX C: PHONE SCRIPT (ENG/SPAN)

Amexcan is working with researchers from East Carolina University on a research project. The purpose of the study is to learn about Latina immigrants' experiences with health care providers in their home country, as well as in the U.S., in an effort to understand how Latina immigrants experience health care and potentially improve the experience of care. So we are looking for volunteers who meet the criteria of the study and would be interested in being interviewed about their health care experiences. Participants' identities and all information shared during the interview will be kept confidential. If you are interested, we can discuss the criteria and see if you meet these qualifications.

INCLUSION CRITERIA:

- Is at least 18 years of age
- Identifies as a 1st generation Latina immigrant
- Has had an experience with a health care provider (i.e., has been seen by a medical provider in the U.S. and their home country
- Has been asked to answer questions about her sexual history

EXCLUSION CRITERIA:

- Participant is pregnant
- Has never received health care (i.e., has never been seen by a medical provider) and has never been asked questions about her sexual history

IF PARTICIPANT MEETS CRITERIA, AND WOULD LIKE TO VOLUNTEER:

- The researchers can meet with you here at the AMEXCAN office, or they can meet with you in your home, whichever is more comfortable for you.

- Will you need childcare?
    - If so, AMEXCAN can provide this
- The interview will last approximately 1 ½ to 2 hours
- This study will help us better understand how Latinas are asked about their sexual health, including how they are assessed for sexually transmitted infections and HIV/AIDS within the Latina community in the country. You will not be asked if you have or have had a sexually transmitted infection, HIV, or AIDS. Through the work of other researchers, we know that it is very important for individuals to be screened for infectious diseases such as sexually transmitted diseases and HIV. We also know that Latina immigrants face many barriers to accessing appropriate screenings. Researchers of this study want to better understand the experiences Latina immigrants have when visiting their health care provider or doctor.
- If you wish to change your mind at any point and not participate or finish with your interview, that is perfectly ok. At no time are you obligated to continue.
- You will receive a $25 gift card to reimburse you for your time

If you are interested in volunteering, please give us a phone number that one of the researchers can call you at to set up an interview appointment; and please offer some times that would be good for us to call. We will not leave a message if you are not available when we call.

We thank you for your call and interest in this study, and will be contacting you soon.

AMEXCAN está trabajando con investigadores de la Universidad de Carolina del Este en un proyecto de investigación. El propósito del estudio es conocer las experiencias de los inmigrantes latinas con los proveedores de atención de salud en su país de origen, así como en los EE.UU. , en un esfuerzo por comprender la experiencia inmigrantes cuidado de la salud cómo Latina y potencialmente mejorar la experiencia de la atención. Así que estamos buscando voluntarios que cumplan con los criterios del estudio y estarían interesados en ser entrevistado acerca de sus experiencias de cuidado de la salud. Las identidades de los participantes y toda la información compartida durante la entrevista se mantendrán confidenciales. Si usted está interesado, podemos discutir los criterios y ver si cumple con estos requisitos.

CRITERIOS DE INCLUSIÓN:

- ¿Está al menos 18 años de edad
- Identifica como una inmigrante latina primera generación
- ¿Ha tenido una experiencia con un proveedor de atención de salud (es decir, ha sido visto por un proveedor de servicios médicos en los EE.UU. y su país de origen
- Se ha pedido que responder a preguntas sobre su historia sexual

Criterios de exclusión:

- El participante está embarazada
- Nunca ha recibido la atención de salud (es decir, nunca ha sido visto por un proveedor de servicios médicos) y nunca se ha hecho preguntas sobre su historia sexual

SI EL PARTICIPANTE CUMPLE CRITERIOS, Y le gustaría ser voluntario:

- Los investigadores pueden reunirse con usted aquí en la oficina AMEXCAN, o pueden reunirse con usted en su casa, lo que sea más cómodo para usted.
- ¿Va a necesitar cuidado de los niños?

Si es así, puede proporcionar esta AMEXCAN

- La entrevista tendrá una duración de aproximadamente 1 ½ a 2 horas
- Este estudio nos ayudará a entender mejor cómo las latinas se les preguntó acerca de su salud sexual , incluyendo la forma en que se evalúan, para las infecciones de transmisión sexual y el VIH / SIDA dentro de la comunidad latina en el país . No se le preguntó si tiene o ha tenido una infección de transmisión sexual, el VIH o el SIDA. A través del trabajo de otros investigadores, sabemos que es muy importante para las personas que se proyectarán a las enfermedades infecciosas como las enfermedades de transmisión sexual y el VIH. También sabemos que los inmigrantes latinas se enfrentan a muchas barreras para acceder a pruebas de detección adecuados. Los investigadores de este estudio quieren entender mejor las experiencias de los inmigrantes latinas tienen cuando visite a su proveedor de atención de la salud o médico.
- Si desea cambiar de opinión en cualquier momento y no participar o terminar con la entrevista, que es perfectamente aceptable. En ningún momento se le obligado a continuar.
- Usted recibirá una tarjeta de regalo de $ 25 que le reembolse por su tiempo

Si usted está interesado en ser voluntario, por favor nos da un número de teléfono que uno de los investigadores puede llamar a usted en la creación de una cita para la entrevista; y por favor, ofrecer algunas veces que sería bueno para nosotros llamamos. No vamos a dejar un mensaje si usted no está disponible cuando llamamos.

Le damos las gracias por su llamada y el interés en este estudio, y pondremos en contacto con usted en breve.

APPENDIX D: ROLE OF THE CBPR TEAM MEMBER

Primary Investigator- Roberta W. Bellamy

As the primary investigator for a qualitative community-based participatory research study, my role in this study is significant. Husserl suggests that it is possible for the researcher to suspend judgment and biases (Husserl, 1960); however, it is important for the researcher to first acknowledge her biases, otherwise these may influence the researcher during the course of the study (Hennink, Hutter, & Bailey, 2011). To address this, it is important that I and all other CBPR team members engage in the process of reflection (Hennink et al., 2011), and provide a "role of the CBPR team member" bias statement in order to share the biases, assumptions, beliefs and values that we each are aware of in ourselves prior to our engagement in this study.

I have grown up in eastern North Carolina, and have lived here in various eastern counties for all of my life. I grew up primarily in the rural poverty of Vance County, and have seen many people suffer from health disparities due to a lack of resources, or barriers to resources. My father was diagnosed with paranoid schizophrenia when I was 15 years old, but symptoms had begun to show five years earlier. Few people were aware of this type of mental illness in my community, and resources for screening and treatment were scarce. My father displayed paranoia as well as symptoms of dissociating. Extended family members and others in our small community were unable to believe me or my mother and sister when we would explain our father's violent behavior toward us, as this was not his typical personality. When he would dissociate and become paranoid, and his thoughts become disordered, he would act as though he were a different person. There were a few episodes where guns were involved. We feared for our lives for a duration of about two years while no one believed us. We were essentially ostracized from family and others in the community; no one could accept our explanations of a mental illness. Eventually, others began to see his mental illness themselves, and we were given some limited support in getting him help. However, the scars of the prejudices and essential abandonment stayed with me.

I have moved through life with determination, and I feel these early years of edification have produced in me a strong, and yet gentle, character. I feel a deep sense of empathy for those people around me who are ostracized by a community; and I appreciate the determination that it takes a person to overcome unusual hardships in order to make their life as well as their relationships with family better. Many of the Latinos that I have grown to know share with me their own stories of danger in their home communities, and discuss with me their determination to move past this and provide a safe and nurturing place for their children. While I am not Latino and have not directly experienced many of the challenges that they have shared with me, I understand the feelings associated with fear, a lack of safety, a need for a caring community, and a desire for a sense of belonging.

I have seen poverty, I have experienced fear for my own safety and the safety of my family, I have experienced a great sadness watching my father become more lost in the depths of his mental illness due to barriers to health care that exist in the rural community we lived in; and I understand from personal experience the feelings of isolation and pain that is encountered when a community essentially discards you. Furthermore, and perhaps more importantly, I recognize the strength of spirit and the edification of character that comes with such adversity. I appreciate these things that I see in the Latino immigrant population that I have encountered.

It has been my own personal experiences that have given me the drive and determination to seek education, first in marriage and family therapy, and now in the field of Medical Family Therapy. I believe that we all have a right to health care, and that good health is the product of the integration of biological, psychological, sociological, and spiritual wellbeing. My interest in working with the Latino population is primarily from admiration for people who are willing to suffer such hardship in order to make a better life for themselves and their family. I find the culture one that is rich and worthy of attention. It is all of these things that add to my desire to conduct research, write grants, promote clinical services, and offer international collaborations with this group in addressing health care needs.

Roberta Woodlief Bellamy, MS, LMFTA
Medical Family Therapy doctoral student
Primary Investigator

CBPR Collaborator- Juvencio Rocha-Peralta

As a member of the CBPR team, and the gatekeeper of a vulnerable community, I feel an obligation to acknowledge the biases that I come into the study with. First, I am an immigrant to the United States, and to North Carolina. I have experienced firsthand the very difficult and treacherous process of leaving the familiarity of my homeland and support systems, to begin a new life in an unknown environment that is sometimes unwelcoming to immigrants. I feel a sense of responsibility to the community that I serve, and a desire to protect this population. I have a strong aversion to injustice, and have fought most of my life as an advocate for social justice and rights of Latinos, as well as other underprivileged groups. This is the bias that I bring with me to this CBPR study.

Juvencio Rocha-Peralta, Executive Director
AMEXCAN

CBPR Collaborator- Francisco J. Limon

I am a 48 year old Hispanic immigrant who moved to the U.S. at the age of 17 without the proper immigration inspection. I grew up in a large, poor family without a father. I was still in elementary school when I became keenly aware of social inequality and lack of opportunities for people like myself. I also noticed how religious teachings conditioned us to accept our position of under-privilege. This new view of religion resulted in me decoupling the church as a human organization and my beliefs in the divine. Thus, my world-view was shaped by my experience with poverty and my questioning of religious teachings.

Having migrated to the U.S. without authorization placed me in a position of under-privilege on many fronts. First by being an ethnic minority; second by not having legal authorization to work, travel, and the many other rights that U.S. citizens enjoy; third by not being able to speak the language, and fourth by earning low wages and being unable to adequately meet my family's most basic needs. The immigrant experience further impacted my views on social class and as I became an adult a deep motivation for community activism to pursue social justice developed.

I became interested in the workings of the human mind when I was a pre-teen and as an adult I pursued a career in mental health. My work in mental health has always been informed by my passion for social justice and I have always worked with vulnerable populations as a mental health professional. As a researcher, I continue to work from my social justice lens by working on behalf of marginalized populations and ensuring that the research primarily benefits the population of interest in the research project. Finally, one of my most important goals as a researcher is to engage research participants on their own terms to prevent dominant cultural narratives from objectifying and further disempowering them.

Francisco J. Limón, MS, LMFTA
Medical Family Therapy doctoral student

CBPR Collaborator- Ashely Maag

In any qualitative study, it is important that researchers acknowledge potential biases that may influence the results and interpretation of qualitative data. As such, I would like to acknowledge some of my own experiences and biases that may impact my work with this underprivileged Latino community. Growing up in a predominately Caucasian, religious, and wealthy neighborhood in Utah, I have not experienced firsthand the social injustices that comes with being Latino or underprivileged. More specifically, I have not personally experienced injustices in health care and small communities that many minorities face on a daily basis. However, I have spent several years living among, interviewing, and empathizing with Latinos about their own experiences of social injustice. These experiences include serving the Latino communities in the ghettos of New York City, Utah, North Carolina, and in Bolivia in various capacities, including as a friend, missionary, self-employment specialist, family therapist, and as a medical family therapy intern. While serving in these capacities, I have observed and empathized with the plight of the Latino community both in and outside of the United States in regards to health care, economic status, community safety, and difficult family situations. Because of these experiences, I have developed a love for and a desire to protect vulnerable Latino populations, and particularly of Latino women.

Ashley Maag, MS
Medical Family Therapy doctoral student

APPENDIX E: INTERVIEW QUESTIONS (ENG/SPAN)

Grand Tour Question: Describe any experiences that you have had with your doctor, or other health care provider, in your home country and the United States who have asked to complete a sexual history, screening, and/or assessment regarding sexually transmitted infections or diseases.

- Without disclosing any names, can you tell me about your thoughts or feelings about the last provider that you went to for care?
    - How well did the provider assess for sexual health concerns? STIs?
    - Did this appointment take place in the U.S. or in your home country?
- Without disclosing any names, tell me why you chose to go to this provider?
    - In what ways was the experience a good one for you?
    - What did you not like about the visit?
- What concerns you most about going to a health care provider like a doctor for some problems you have been experiencing/have experienced?
- What health problems would be most difficult to talk about with a doctor?
    - What makes these discussions most difficult to discuss?
- If there comes a time when you are concerned about a sexually transmitted infection, who would you be most likely to talk to about it?
    - How confident are you that this information would be accurate?
- If you ever had to talk to a doctor about a sexually transmitted infection, what do you think would make that discussion go the best way possible?
    - What do you think would make the discussion go as badly as possible?

- What concerns would you have, if any, about talking with your doctor about sexually transmitted infections?
- If you had concerns or questions about HIV who would you talk to about those concerns?
- What messages do people receive from the community about being tested for sexually transmitted infections?
- What messages do people receive from the community about being tested for HIV?
- What do you think would improve the chances that Latina immigrants would get screened for sexually transmitted infections or diseases, or HIV?
- What do you think would improve the chances that Latina immigrants would talk with a doctor or other health care provider about sexually transmitted infections or diseases, or HIV?
- What do you wish U.S. providers learned from providers in your home country about assessing for sexual health concerns, STIs, and HIV?
- What do you wish the providers in your home country learned from U.S. providers about assessing for sexual health concerns, STIs, and HIV?
- Describe your preferred provider for sexual health issues: age, gender, ethnicity, etc.

Interview Closing

- What have we not yet talked about that you think is important for me to know in relation to the purpose of this study?

Grand Tour Pregunta: Describa cualquier experiencia que usted ha tenido con su médico u otro proveedor de atención de la salud, en su país de origen y los Estados Unidos que han pedido para completar una historia sexual, detección y / o una evaluación en relación con las infecciones o enfermedades de transmisión sexual.

- Sin revelar ningún nombre, me puedes decir acerca de sus pensamientos o sentimientos sobre el último proveedor que usted fue a por el cuidado?
  - ¿Qué tan bien el proveedor para evaluar las preocupaciones de salud sexual ? Infecciones de transmisión sexual?
  - ¿ esta cita tenga lugar en los EE.UU. o en su país de origen ?
- Sin revelar ningún nombre, dime por qué eligió ir a este proveedor?
  - ¿De qué manera fue la experiencia sea buena para usted ?
  - ¿Qué no le gusta de la visita ?
- ¿Qué preocupaciones que más le va a un proveedor de atención de la salud como un médico para algunos problemas que han estado experimentando / has experimentado?
- ¿Qué problemas de salud sería más difícil hablar con un médico?
  - ¿Qué hace que estas discusiones más difíciles de discutir ?
- Si llega un momento en el que usted está preocupado por una infección de transmisión sexual, que estaría usted más probabilidades de hablar de él?
  - ¿Qué tan seguro está usted de que esta información sería exacto ?
- Si alguna vez tenía que hablar con un médico acerca de una infección de transmisión sexual, ¿qué crees que haría que el debate vaya de la mejor manera posible?
  - ¿Qué crees que haría que el debate vaya tan mal como sea posible ?
- ¿Qué preocupaciones le tienen, en su caso, de hablar con su médico acerca de las infecciones de transmisión sexual?

- Si usted tuviera inquietudes o preguntas sobre el VIH que usted hablar acerca de esas preocupaciones?
- ¿Qué mensajes reciben Por qué la gente de la comunidad sobre las pruebas para infecciones de transmisión sexual?
- ¿ Por qué las personas reciben mensajes de la comunidad acerca de la prueba del VIH?
- ¿Qué crees que podría mejorar las posibilidades de que los inmigrantes latinas serían examen de detección de infecciones o enfermedades de transmisión sexual o el VIH?
- ¿Qué crees que podría mejorar las posibilidades de que los inmigrantes latinas podrían hablar con un médico u otro proveedor de atención médica acerca de las infecciones o enfermedades de transmisión sexual o el VIH?
- ¿Qué es lo que desean los Estados Unidos aprendimos de los proveedores de los proveedores en su país de origen sobre la evaluación de los problemas de salud sexual, ITS y el VIH?
- ¿Qué es lo que desea los proveedores en su país de origen aprendidas de los proveedores de los Estados Unidos acerca de la evaluación de los problemas de salud sexual, ITS y el VIH?
- Describa su proveedor preferido para los problemas sexuales de la salud: la edad, el género, el origen étnico, etc.

Cierre Entrevista

- ¿Qué hemos aún no hemos hablado de que usted piensa que es importante para mí saber en relación con el propósito de este estudio?

APPENDIX F: DEMOGRAPHIC QUESTIONNAIRE (ENG/SPAN)

About You

1. What is the zip code of your current residence? (Put 5 digit zip code)

   ____

2. What county in the U.S. do you currently live in? _______________________________

3. What is your nationality? (Name of your country of birth- State or Region)

4. How long have you lived in the U.S.? __________________________________

5. How long have you lived in North Carolina? ___________________________

6. How old are you?

7. What is your current marital status?
   a. Single
   b. Married
   c. Gay/Lesbian-partnered and living together
   d. Gay/Lesbian-partnered and not living together
   e. Heterosexual-partnered and living together
   f. Heterosexual-partnered and not living together
   g. Separated
   h. Divorced
   i. Other

8. What is your gender: male ______ female ______

9. What is the highest level of education you have completed?

   a. No formal education
   b. Elementary school
   c. Junior high school
   d. High school/GED
   e. Some college (less than two years)
   f. 2-year college degree (Associate degree)
   g. 4-year college degree (Bachelor's degree)
   h. Master's degree
   i. Doctoral degree
   j. Professional degree (MD, JD)

10.a. When was the last time you saw a health provider in your home country?

_______months _______years

10.b. When was the last time you saw a health provider in the U.S.?

________months ________years

11. How often did you typically seek health care or treatment in your home country?

   a. Never
   b. Once a year
   c. About six times a year
   d. At least once a month
   e. At least twice a month

12. How often do you seek medical treatment in this country?

    a. Never
    b. Less than once a year
    c. About once a year
    d. About six times a year
    e. At least once a month
    f. At least twice a month
    g. More than twice a month

13. How often do you go back to your home country?

    a. Never
    b. Less than once a year
    c. Once a year
    d. Twice a year
    e. More than twice a year

14. How many states have you lived in while in the United States? _____________

15. Have you received healthcare during a pregnancy?

16. What other types of caregivers have you received care from other than a medical doctor in relation to your health?

17. What type of medical insurance do you have?

- a. Privately purchased insurance
- b. Job sponsored insurance
- c. Government assisted insurance, such as Medicare and Medicaid
- d. I do not have health insurance

18. Have you ever helped with or been a part of providing healthcare for Latinos other than those in your own family?

a. _______no

b. _______yes

If yes, in what way?

____

____

____

19. In the last year, how many times did you miss a scheduled medical visit?

20. In the last year, how many times did you schedule a medical visit for a sexual health concern?

21. What quality or characteristic is most important to you when following your doctor's advice?

Acerca de Ti:

1. ¿Cuál es el código postal de su residencia actual? (Ponga el código postal de 5 dígitos)

____

2. ¿En qué condado en los EE.UU. vive usted actualmente?

____

3. ¿Cuál es su nacionalidad? (Nombre de su país de Estado al nacer o región)

4. ¿Cuánto tiempo ha vivido en los EE.UU. ? _________________________________

5. ¿Cuánto tiempo ha vivido en Carolina del Norte? ___________________________

6. ¿Cuántos años tienes?

7. ¿Cuál es su estado civil actual?

a. Solo
b . Casado
c . Gay / Lesbiana - pareja and convivencia
d. Gay / Lésbico - pareja and no viven juntos
e. Heterosexual - pareja and convivencia
f . Heterosexual - pareja and no viven juntos
g . Apartado
h . Divorciado
yo . Otro

8. ¿Cuál es su género: masculino ______ ______ femenino

9. ¿Cuál es el nivel más alto de educación que ha completado?

a. Sin educación formal

b . Escuela primaria

c . Escuela secundaria

d. La escuela secundaria / GED

e. Un poco de universidad (menos de dos años)

f . Título universitario de 2 años (grado asociado)

g . Título universitario de 4 años (Licenciatura)

h . Maestría

yo . Doctorado

j . Título profesional (MD, JD)

10.a. ¿Cuándo fue la última vez que vio a un proveedor de salud en su país de origen ?

_______months _______years

10.b. ¿Cuándo fue la última vez que vio a un proveedor de salud en los EE.UU. ?

________Meses ________years

11. ¿Con qué frecuencia usted normalmente busca de atención médica o tratamiento en su país de origen?

a. nunca

b . Una vez al año

c . Cerca de seis veces al año

d. Al menos una vez al mes

e. Al menos dos veces al mes

12. ¿Con qué frecuencia usted busca tratamiento médico en este país?

a. nunca

b . Menos de una vez al año

c . Aproximadamente una vez al año

d. Cerca de seis veces al año

e. Al menos una vez al mes

f . Al menos dos veces al mes

g . Más de dos veces al mes

13. ¿Con qué frecuencia usted va de nuevo a su país de origen?

a. nunca

b . Menos de una vez al año

c . Una vez al año

d. Dos veces al año

e. Más de dos veces al año

14. ¿Cuántos estados tienen que viviste en mientras que en Estados Unidos? _____________

15. ¿Ha recibido atención médica durante el embarazo?

16. ¿Qué otros tipos de cuidadores has recibido atención de que no sea un médico en relación con su salud?

17. ¿Qué tipo de seguro médico tiene usted?

a. Seguros privada comprado

b . Seguro patrocinado Trabajo

c . Seguros Gobierno asistida, tales como Medicare y Medicaid

d. No tengo seguro de salud

18. ¿Alguna vez ha ayudado con o sido parte de la prestación de la asistencia sanitaria para los Latinos que no sean los de su propia familia?

a. _______No

b . _______Si

En caso afirmativo, ¿de qué manera?

____

____

____

19. En el último año, ¿cuántas veces te pierdas una visita médica programada?

20. En el último año, ¿cuántas veces se programa una visita médica para un problema de salud sexual?

21. ¿Qué cualidad o característica es más importante a la hora de seguir el consejo de su medico?

APPENDIX G: INFORMED CONSENT (ENG/SPAN)

Project 2014-2015

Informed Consent Form

You are being asked to participate in a project that includes a research study.

Ask as many questions as you like before you decide whether you want to be in this project. You are free to ask questions at any time while you are in this project.

No information about your participation in this study will be given out.

PURPOSE OF UNDERSTANDING PROVIDER ROLES

The Latina Immigrants and Health Care project is developed to understand the experiences that Latina immigrants have had with health care providers in their home country and the United States who have asked about sexual health, including how they asked about sexually transmitted infections. The purpose of this study is to explore Latina immigrants' experiences with health care providers in their own country of origin and in the United States.

PARTICIPATION REQUIREMENTS

*Participants must identify as Latina immigrant, 1st generation, who has had health care experiences that include sexual health care with a health care provider in their home country as well as in the U.S.

POSSIBLE RISKS

There is the possible risk of increased stress or embarrassment from sharing your personal thoughts and feelings through the short survey and research interview. During the research process, information that you share with the researchers may make you uncomfortable. You are welcome to stop at any time. If content from the interview includes information deemed to be of concern to the researcher, medical or behavioral health recommendations will be provided to you. The researchers are trained therapists and are available to help guide you toward appropriate services, if anything makes you uncomfortable. You may stop your participation in the research project at any time.

POSSIBLE BENEFITS

You may find the interview to be a positive experience because you will be able to express your personal experiences, thoughts, and concerns about the health care experiences that you have had in the U.S. and in your home country.

LENGTH OF PROJECT

This interview and short survey, in which you agree to participate should take no longer than 90 minutes more. You are able to stop at any time and may do so without penalty.

INFORMATION COLLECTED

You will be asked to share information including, but not limited to:

- Completion of a short survey that asks you about your gender, marital status, level of education, country of origin, number of times you have seen a medical provider in country of origin and the U.S.
- Participation in an open-ended interview during which you will be able to discuss the experiences you have had with doctors, or other health care providers, particularly concerning talking with them about sexual health, HIV/AIDS, and other sexually

transmitted infections. You will not be asked if you have or have had a sexually transmitted infection or HIV/AIDS.

DATA COLLECTION

During the interview, a researcher, accompanied by a research assistant, will ask you questions. Your answers to questions will be audio recorded. With your permission, the researcher will take handwritten notes during the interview. Please feel free to ask the researcher any questions about anything you do not understand or is not clear. All notes and audio recording will be stored in a double locked unit within the Redditt House: Medical Family Therapy Research Academy and will only be accessible by the IRB approved research team.

PRIVACY

No information that identifies you will be released to any one without your written consent. No privacy information will be connected to your results. Each interview will be coded with a fictitious name.

PARTICIPANT RIGHTS

For purposes of research, participants have the right to:

☐Ask about the methods of research.
☐Ask about the role of clinical researcher.
☐Expect confidentiality about discussions pertaining to the research.
☐Stop participating at any time with no penalty.

I have received a complete explanation of the study and I agree to participate.

Print/Type Full Name:

Last___________ First___________ Middle___________

Signature: ______________

Date:

Month___________ Day_______ Year_______

Information about the person signing for the above in cases which the participant cannot read and/or write

I have received permission from the participant to sign on their behalf

Print/Type Full Name:

Last___________ First___________ Middle___________

Signature: ______________

Date: Age:______

Month___________ Day_______ Year_______

Witness:

☐Investigator:

Date:

Month___________ Day_______ Year_______

If you have any questions regarding this project,
please direct them to one of the following individuals.

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Proyecto 2014-2015

Formulario de Consentimiento Informado

Se le pide participar en un proyecto que incluye un estudio de investigación .

Haga todas las preguntas que quieras antes de decidir si quieres estar en este proyecto . Usted es libre de hacer preguntas en cualquier momento durante su estadía en este proyecto .

No hay información acerca de su participación en este estudio se dará a cabo .

PROPÓSITO DE ROLES PROVEEDOR COMPRENSIÓN

Las inmigrantes latinas y el Proyecto de Salud se desarrolla para comprender las experiencias que los inmigrantes latinas han tenido con los proveedores de atención de salud en su país de origen y los Estados Unidos que han preguntado acerca de la salud sexual , incluyendo la forma en que preguntaron acerca de las infecciones de transmisión sexual . El propósito de este estudio es explorar las experiencias de los inmigrantes latinas con los proveedores de atención de la salud en su propio país de origen y en los Estados Unidos.

REQUISITOS DE PARTICIPACIÓN

* Los participantes deben identificar como inmigrante latina , primera generación , que ha tenido experiencias de cuidado de la salud que incluyen la atención de la salud sexual con un proveedor de atención de salud en su país de origen , así como en los EE.UU.

POSIBLES RIESGOS

No es el posible riesgo de un aumento del estrés o vergüenza de compartir sus pensamientos y sentimientos personales a través de la breve encuesta y entrevista de investigación . Durante el proceso de investigación, la información que usted comparte con los investigadores pueden hacer sentir incómodo. Le invitamos a parar en cualquier momento. Si el contenido de la entrevista incluye las informaciones que serían de interés para el investigador, se proporcionarán recomendaciones médicas o de salud del comportamiento para usted. Los investigadores están terapeutas entrenados y están disponibles para ayudar a guiarlo hacia los servicios adecuados, si algo te hace sentir incómodo. Usted puede detener su participación en el proyecto de investigación en cualquier momento.

BENEFICIOS POSIBLES

Usted puede encontrar la entrevista para ser una experiencia positiva, ya que será capaz de expresar sus experiencias personales, pensamientos y preocupaciones sobre las experiencias de cuidado de la salud que usted ha tenido en los EE.UU. y en su país de origen .

LONGITUD DE PROYECTO

Esta entrevista y la encuesta corta, en la que usted se compromete a participar ya no deberían de 90 minutos más tomar. Usted es capaz de detener en cualquier momento y puede hacerlo sin penalización.

INFORMACIÓN RECOGIDA

Se le pedirá para compartir información, incluyendo, pero no limitado a:

- Finalización de una breve encuesta que le pregunta acerca de su sexo, estado civil, nivel de estudios, país de origen, número de veces que han visto un proveedor de servicios médicos en el país de origen y los EE.UU.
- Participación en una entrevista abierta en la que usted será capaz de discutir las experiencias que ha tenido con los médicos u otros profesionales de la salud , en particular en relación con hablar con ellos acerca de la salud sexual , el VIH / SIDA y otras infecciones de transmisión sexual . No se le preguntó si tiene o ha tenido una infección de transmisión sexual o el VIH / SIDA.

RECOPILACIÓN DE DATOS

Durante la entrevista, el investigador, acompañado por un asistente de investigación, le hará preguntas. Sus respuestas a las preguntas serán de audio grabado. Con su permiso, el investigador va a tomar notas escritas a mano durante la entrevista. Por favor, siéntase libre de preguntar al investigador alguna pregunta sobre cualquier cosa que no entienda o no es clara. Todas las notas y la grabación de audio se almacenan en una unidad de doble llave dentro de la Casa Redditt: Family Medical Academia de Investigación de Terapia y sólo se podrá acceder por la IRB aprobó equipo de investigación.

PRIVACIDAD

No hay información que lo identifica a usted se dará a conocer a cualquiera sin su consentimiento escrito. No hay información de privacidad se conectará a sus resultados. Cada entrevista se codificará con un nombre ficticio.

DERECHOS DE LOS PARTICIPANTES

A los fines de la investigación, los participantes tienen derecho a:

Ask acerca de los métodos de investigación.

Ask sobre el papel de investigador clínico.

☐Expect confidencialidad sobre los debates relativos a la investigación.

☐Stop participar en cualquier momento sin penalización.

He recibido una explicación completa del estudio y estoy de acuerdo en participar.

Imprimir / Tipo Nombre Completo:

Apellido Nombre

Firma:

Fecha:

Mes___________ Fecha_______ Año_______

Información sobre la persona que firma para lo anterior en los casos en que el participante no puede leer y / o escribir

He recibido el permiso del participante para firmar en su nombre

Imprimir / Tipo Nombre Completo:

Apellido Nombre

Firma:

Fecha: Edad: ______

Mes___________ Fecha_______ Año_______

Testigo:

Investigator:

Fecha:

Mes___________ Fecha_______ Año______

APPENDIX H: HIGHLIGHTS OF OUR COMMUNITY-BASED PARTICIPATORY RESEARCH STUDY

This research study utilized a collaborative approach that involved key community individuals, working together to better understand the sexual health care experiences of Latina immigrants that contribute to human immunodeficiency virus (HIV) health disparities in this group. Specifically, researchers from East Carolina University partnered with a local grassroots, Latino-serving, community-based organization (the Association of Mexicans in North Carolina, Inc. [AMEXCAN]) to answer health care concerns from the Latino community. In the fall of 2012, the executive director of the AMEXCAN organization, Mr. Juvencio Rocha-Peralta, met with the PI, Roberta Woodlief Bellamy, for the purpose of exploring how this dissertation could be used as the venue for addressing concerns regarding HIV in the Latino population. This dissertation is the product of that conversation and subsequent partnerships. We present here the highlights from these chapters to showcase that journey, and lessons learned.

Latino immigration patterns have recently shifted to the southeastern region of the United States (U.S.), a segment of the country that has had little history of immigrant settlements by Latinos (Bankston, 2007). This shift began in the early 1990s, and happened suddenly (Bankston, 2007). Growth of the Latino immigrant population in southern states such as North Carolina (N.C.) has been such that health care infrastructures have struggled to meet the health care needs of this population (NCDHHS, 2013). The expansion of Latino growth and subsequent challenges to meet health care needs in N.C. are evident in concerns of public health issues such as (HIV) infection rates and access to care (NCDHHS, 2013).

The proportion of Hispanics/Latinos in N.C. with unmet needs (defined as diagnosed HIV positive, but not in treatment) has steadily increased over the last five years, representing a 43.7% relative increase over that timeframe (NCDHHS, 2013). A similar increase in unmet needs in the Hispanic/Latino population exists for people living with AIDS, at 44.7% relative increase over the last five years (NCDHHS, 2013). The literature is clear that Latinos experience many barriers to sexual health care, compared to other groups (Branch, Harvey, Zukoski, & Warren, 2010), and Latinas (females) are noted to be especially vulnerable for HIV infection (CDC, 2005; Peragallo et al., 2002). Clearly, this is a public health concern. However, connecting Latinos with health care and health care research has been historically difficult (McGill, 2013). Therefore, we investigated the literature for evidence of using CBPR as a way to effectively tackle HIV in the Latina population, with culturally appropriate and sensitive measures.

We conducted a systematic review in order to distinguish the value of utilizing CBPR with the Latino population to address HIV. This review resulted in evidence that working with Latino community-based organizations through an equitable partnership could be a productive venue for tackling HIV in the Latina population in N.C. Furthermore, we designed a CBPR phenomenological study to explore the sexual health care experiences of Latina immigrants with health care providers from the U.S. and country of origin. Among the results from this study emerged concerns about utilizing *promotoras de salud (PdS)* (i.e., promotors of health) as interpreters during a sexual health care encounter (Bellamy, Lamson, Hodgson, Knight, & Baugh, 2015). Because of the stigma in the Latino community related to HIV and other sexually transmitted infections (STIs), sexual health assessments warrant sensitive considerations when needing interpreting services (Bellamy et al., 2015). With this information emerging from the interviews, the research team (i.e., the PI, research faculty from ECU, and AMEXCAN) came together to agree on the need for a set of core competencies and code of ethics specifically for PdS working in the health care arena. CBPR emphasizes the importance of research that is valuable to the community and is disseminated in a way that strengthens the community of interest (Israel, Eng, Shultz, & Parker, 2013). Our research has resulted in not only a core set of competencies and code of ethics being established, but also increased the capacity for future research between university researchers and the AMEXCAN organization.

Israel and colleagues (2013) state that through the CBPR research process, peer mentorships are established; and these mentorships are reciprocated. Community members learn about research processes, and academic partners learn how to work with communities. In our research study, several individuals from the Latino community were involved in various ways throughout this process. The PI shared her research knowledge with community members, and has received knowledge and guidance from these community members that have improved the research process. Furthermore, since capacity building is also a goal of CBPR, our work through this project has extended to the development of a permanent research advisory team at the AMEXCAN organization. By framing this study within a CBPR approach, we respond to growing support for using CBPR to tackle health disparities within minority communities, and add to the health literature of collaborative research.

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