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UNDERSTANDING SOCIAL DETERMINANTS OF HEALTHCARE ACCESS FROM THE
PERSPECTIVE OF HISPANIC LATINO IMMIGRANTS IN LOUISVILLE, KY

By

Jean S. Edward

B.S.N. Bellarmine University, 2008

CHPE, University of Louisville, 2011

A Dissertation

Submitted to the Faculty of the

School of Nursing of the University of Louisville

in Partial Fulfillment of the Requirements

for the Degree of

Doctor of Philosophy

School of Nursing

University of Louisville

Louisville, Kentucky

May 2013

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A Dissertation Approved on

April 10th, 2013

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DEDICATION

This dissertation is dedicated to my parents, sister and family, who sacrificed me for ten years to see me achieve my dreams.

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First and foremost, I would like to thank my participants for inviting me into their lives and sharing their stories with me. I truly admire your courage and perseverance that will forever inspire me as an individual and researcher. I would not be at this stage of my doctoral studies without the continual support of Dr. Vicki Hines-Martin my mentor and chair, whose patience and wisdom has guided my development as a student and researcher. Thank you for always holding me to the highest standards and challenging me to be my best. I owe much gratitude to Dr. Robert Topp who has seen me through the highs and lows as a doctoral student, while always reminding me of the most important thing in life. I thank my dissertation committee members Drs. Celeste Shawler, Whitney Nash and Bradley Carpenter, for their continued support and enthusiasm for my research and development as a student. In addition to my committee I would like to thank all the School of Nursing faculty who have been my inspiration throughout the years; to Dr. Rosalie Mainous and Dr. Lynn Hall for seeing me through the doctoral program and providing support for my professional development in academia; to the School of Nursing staff who have reminded me not to overlook the details; to librarians John Chenault and Kevin Peers for providing their expertise on obtaining historical data; to Linda Taylor who took me under her wing and provided me with opportunities to grow as a research assistant; and, to all my colleagues, especially Maryam Alaradi and Jiyong Ling, who supported me throughout the doctoral program by empowering each other to be better learners, teachers and researchers. I couldn't have made it through the program without the encouragement of my peers and faculty. I am grateful for the continual support of Dr. Sue Davis and Jayne BecVar, who's gracious and loving spirits have helped me succeed in my nursing career. I would like to thank the Sigma Theta Tau International Honor Society of Nursing, Iota Zeta Chapter, the Commission on Diversity and Racial Equality at the University of Louisville, and the Kentucky Nurses Association for providing me with the funds to carry out my program of research.

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ABSTRACT

UNDERSTANDING SOCIAL DETERMINANTS OF HEALTHCARE ACCESS FROM THE PERSPECTIVE OF HISPANIC LATINO IMMIGRANTS IN LOUISVILLE, KY

Jean S. Edward

April 10th, 2013

In the last decade, the total foreign-born population in the U.S. has grown exponentially, with the Hispanic Latino immigrants (HLI) experiencing the greatest growth. The literature clearly identifies that HLI experience significant health disparities as a result of the negative impact of influential social determinants of health, such as access to healthcare services. Barriers to healthcare access among HLI are related to the access dimensions of accessibility, availability, affordability, and acceptability. Despite research on the barriers to healthcare for this population, issues of access from the perspective of immigrant community members are poorly understood. There is an increased need to understand barriers and facilitators to healthcare access as perceived by HLI themselves to develop culturally appropriate strategies aimed at eliminating healthcare access inequities and health disparities.

The purpose of this dissertation was to critically explore the perceived barriers and facilitators to primary healthcare access among HLI residing in highly concentrated communities of the southern metropolitan city of Louisville, KY. Critical ethnographic methods and postcolonial theory were used to investigate access to healthcare in this community within historical, sociocultural, economic and political contexts. Twenty participants were interviewed for this study using a semi-structured interview guide and descriptive survey form. Participant observations, document reviews and geospatial analysis assisted in providing in-depth understanding of findings within various contexts.

Research findings revealed that significant barriers and facilitators to healthcare access were closely related to historical, sociocultural, political and economic contexts that shaped HLI health experiences in Louisville. These social determinants of healthcare access were influenced by the underlying social structures of race, ethnicity, power and oppression embedded in the colonial histories of the

Americas. Additionally, findings indicated that although providers and HLI recipients shared similar perspectives on healthcare access, discrepancies between the provision and utilization of healthcare services were perpetuated by the social determinants of healthcare access. Findings from this study provide several implications and recommendations for healthcare systems, community programs, nursing, policy reform and future programs of research focused on enhanced culturally appropriate interventions and programs addressing the perceived needs of HLI in the Louisville community.

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CHAPTER I

INTRODUCTION AND SIGNIFICANCE

Statement of the Problem

In 2010, it was estimated that a total of 50.5 million Hispanic Latino Immigrants (HLI)¹ reside in the United States, representing a 43% population increase since the year 2000 (U.S. Census Bureau, 2011). As one of the largest and fastest growing immigrant populations in the U.S., HLI continue to experience disproportionately higher rates of health disparities. Although prior research at one time identified that HLI had better health outcomes in respect to infant mortality, low birth weight, and mortality when compared to their U.S.-born counterparts (Acevedo-Garcia, Soobader, & Berkman, 2005; Frisbie & Song, 2003; Hummer, Rogers, Amir, Forbes, & Frisbie, 2000; Singh & Siahpush, 2001), more recent research indicates worsening health outcomes for HLI with greater length of residence in the U.S. (Cacari Stone, Acevedo-Garcia, & Virruell-Fuentes, 2007).

In the National Health Disparities Report (NHDR) the Agency for Healthcare Research and Quality (AHRQ, 2008) reported that that Hispanics were less likely than non-Hispanic Whites to have health insurance (66.7% compared with 87.5%) or have a usual primary care provider (64.7% compared with 80.1%). Additionally, it was found that the percentage of people with a specific source of ongoing care was significantly lower for Hispanics (77.1%) than for either Blacks (84.7%) or non-Hispanic Whites (88.6%). Language also plays a central role in healthcare access, as the NHDR (AHRQ, 2010) indicates that people who spoke a language other than English at home were less likely to have a primary care provider than people who spoke English at home (62.3% compared with 78.4%). These data provide evidence for the relationship between socioeconomic status, race and ethnicity, and culture and language, on healthcare access and overall health outcomes. Disparities in healthcare access have been shown to be associated with negative health outcomes and increased health disparities within the HLI community

¹ Operational definition of terms can be found in Appendix D.

(Durden & Hummer, 2006; Escarce & Kapur, 2006; Passel, 2006). Underlying reasons for these disparities have been attributed to the social determinants of health (SDH) that impact healthcare access for the Hispanic Latino population in the U.S. (AHRQ, 2010; Cacari Stone & Balderrama, 2008).

The Social Determinants of Health

According to the World Health Organization (WHO, 2012), SDH are “the conditions in which people are born, grow, live, work and age, including the health system.” Social determinants of health are represented by conditions of daily living and structural determinants that are influenced by the distribution of money, power, and resources. According to the Commission on Social Determinants of Health (2008), the inequities faced in society are “systematic, produced by social norms, policies and practices that tolerate or actually promote unfair distribution of and access to power, wealth, and other necessary social resources” (p.10). The relationship between factors that determine the social determinants of health and health inequities are illustrated in the WHO’s SDH Conceptual Framework (Figure 1).

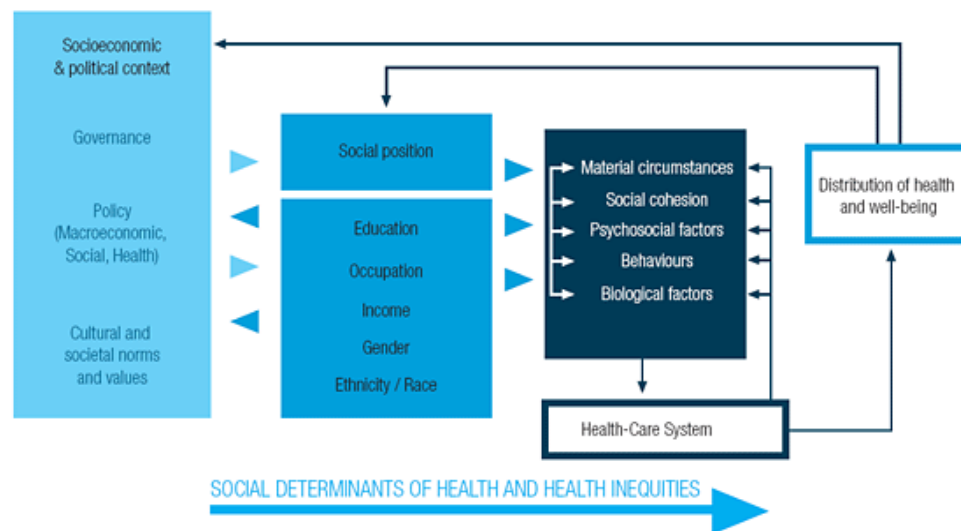


Figure 1. WHO’s Social Determinants of Health Conceptual Framework (Solar & Irwin, 2007).

The structural determinants that constitute the social determinants of health inequities are represented by an individual’s socioeconomic position that is influenced by various historical, sociocultural, economic and political factors (CSDH, 2008). However, the social determinants that serve as barriers to accessing healthcare services have been identified as a leading source of health disparities in the U.S. affecting a broad spectrum of minorities including HLI (Coffman, Shobe, Dmochowski, Fox, 2007; Durden & Hummer, 2006; Stone & Balderrama, 2008; Bustamante, Fang, Rizzo, Ortega, 2009). The Health Disparities and Inequalities Report (Centers for Disease Control [CDC], 2011), identifies a strong

correlation between negative health outcomes and determinants of health such as socioeconomic status, environmental impact, geographic location, gender, race and ethnicity. This report found that although quality of healthcare was improving, access and disparities were not, especially regarding preventive services, cancer screening and diabetes management. Healthcare quality and access were especially suboptimal for minority and low-income groups, including HLI. Health disparities often occur in relation to healthcare inequities, which primarily address access to and quality of healthcare services (AHRQ, 2011; USDHHS, 2000; Institute of Medicine [IOM], 2003). Therefore, understanding access is central to identifying the influence of SDH on health outcomes and healthcare access.

Access to Healthcare

Identified as a vital SDH, both influenced by and influencing the effects of other SDH, access to healthcare is broadly defined as the timely and appropriate utilization of health services to achieve optimal health outcomes (CDC, 2011; IOM, 1993). Studies have indicated that limitations or barriers to healthcare access among immigrants in general can be categorized under the dimensions of availability, accessibility, affordability, and acceptability (Jacobs, Ir, Bigdeli, Annear, Van Damme, 2011; Perez-Escamilla, Garcia, Song, 2010). These dimensions of access are influenced by various SDH that are specific to different contexts and racial and ethnic groups. Hispanic Latino immigrants are subjected to distinctive social determinants of healthcare access that arise from their experiences as an immigrant and a minority in the U.S. The lower socioeconomic positions of many HLI, in relation to their unique historical, sociocultural, and political experiences, make them vulnerable to increased healthcare access inequities as a result of the negative impact of SDH (Freeman & Lethbridge-Cejku, 2006; Durden & Hummer, 2006; Urrutia-Rojas et al., 2006). Understanding the social determinants of healthcare access among HLI begins with an examination of these contextual factors that shape the barriers and facilitators to access.

Defining the Population and Setting

In the U.S., the HLI population continues to grow at a higher rate in comparison to other immigrant groups (U.S. Bureau of the Census, 2011; Passell & Cohn, 2012; USDDHS, 2011, 2012). According to the Pew Hispanic Center (2012), in 2009 the largest foreign-born population in the U.S. consisted of immigrants from Mexico representing roughly 11.5 million of the total immigrant population. Immigrants from regions of South and Central America, and the Caribbean followed closely behind,

representing an estimated total of 9 million. Therefore, HLI represent roughly 53% of the total foreign-born population residing in the U.S. Another significant subgroup of HLI are undocumented immigrants, who attain this status as a result of entering the U.S. illegally (i.e. crossing the border) or by overstaying their visas and falling out of legal immigration status. The number of undocumented immigrants continues to rise with an estimated 11.5 million undocumented immigrants residing in the U.S. in January 2011 (Hoefer, Rytina, & Baker, 2011). Immigrants from Mexico, represented 59% (6.8 million) of the total undocumented population, followed by immigrants from El Salvador (660, 000), Guatemala (520,000), and China (280,000). In 2011, Hispanic immigrants represented over 8 million of the total undocumented immigrant population in the U.S.

Although a higher number of foreign-born people reside in coastal and border states, in recent years, an increasing number of immigrant groups have migrated inland, to states like Kentucky in search of new opportunities (Fennelly, 2006). According to the Migration Policy Institute (2007), Kentucky is one of the top ten states with the fastest growing foreign-born population. Roughly 50,000 immigrants represent countries from Latin America (38.9%), Asia (32.4%), Africa, (15%), and Europe (16.5%). Additionally, over 10,800 refugees from Cuba, Burma and Somalia relocated to Louisville, the largest metropolitan city in Kentucky, between 1994 and 2004 through federal resettlement programs. Hispanics and Latinos are also one of the fastest-growing immigrant populations in Louisville representing 4% percent of the total population (Office of Policy Planning and Evaluation, 2012; White, 2011). The Hispanic population in Louisville has almost doubled in size since 2000 from an estimated 12,370 to 23,715 in 2010 (U.S. Census Bureau, 2010). However, statistics on local HLI are inaccurate and underrepresented because they do not account for undocumented immigrants. Difficulties in obtaining accurate estimates on HLI and undocumented immigrants have become a local as well as national issue (Legislative Research Commission, 2002; White, 2011). According to the latest estimates by the Urban Institute, in 2000 18% of the Louisville immigrant community was undocumented, with the vast majority representing Mexico and other Latin American countries. Despite immigration reform and stricter border enforcement policies, this number has continued to rise (Capps et al., 2006).

Hispanic Latino immigrant populations are found to be predominantly concentrated in neighborhoods located in the southern region of Louisville, within zipcodes 40208, 40214, and 40215

(Urban Mapping, 2011; See Figure 2). Southern Louisville is further broken down into distinct neighborhoods such as South Louisville (area codes 40208, 40214, and 40215), Southside Louisville (area code 40214), and Iroquois (area code 40214). There are total of 8660 HLI living in these three zipcodes representing roughly 33 percent of the total HLI population in Louisville (Urban Mapping, 2011). The HLI population in Louisville has more than doubled over the last decade and groups have expanded in various other south central (zipcode 40219), southeastern (40220) and northeastern (40223) regions of the city.

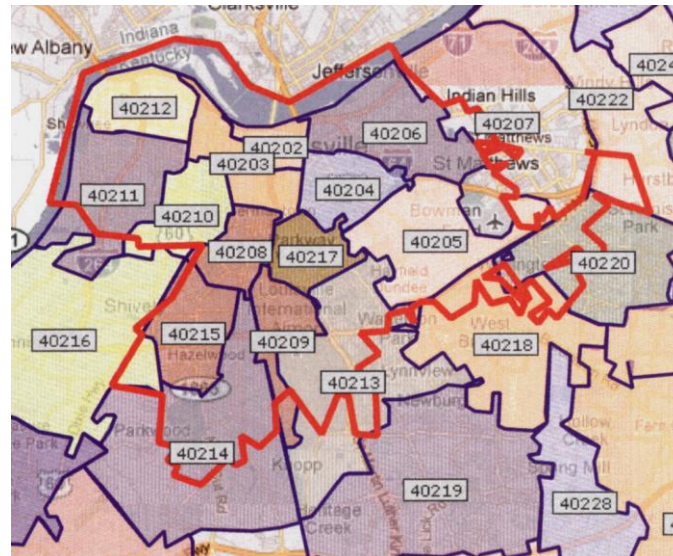


Figure 2. Map of Louisville zipcodes.

With rapid growth in the U.S. immigrant population, states like Kentucky lack sufficient resources and facilities to support the unique needs of these groups, especially HLI (Capps et al., 2006). Despite the establishment of federally funded refugee resettlement programs, and other health and social services in Louisville, HLI continue to experience difficulties in accessing appropriate services (Capps et al., 2006; White, 2011). Reasons for these inequities are attributable to the social determinants of healthcare access, which are shaped by the historical, sociocultural, economic and political contextual factors that influence healthcare access for the HLI population.

Framing the Historical, Sociocultural, Economic and Political Contexts

Historical contexts shape current structure of healthcare access for HLI and other racial and ethnic minorities (IOM, 2003). Historically, the colonial histories of the Americas from Spanish to British colonial rule have placed Hispanic Latino groups in segregated positions, making them vulnerable to social inequities and injustices (Delgado, 2007; Delgado & Stefancic, 2008; Hulme, 1995). As a result of

colonization, Hispanics have become a diasporic community subjected to both physical marginalization and social segregation (McLeod, 2000). This segregated position, which is predominantly defined by race and ethnicity, is manifested through various societal, cultural, economic and political structures, including healthcare (Harari et al., 2008; Khan, Velasquez, O'Connor, Simon, & De Groot, 2011). Experiences of social injustice and inequities result in perceptions of isolation and exclusion among HLI from mainstream U.S. society (Derose, Escarce, & Lurie, 2007; Nandi et al., 2008).

Sociocultural contexts are significantly shaped by geographic location, especially in states like Kentucky, where conservative political views stemming from the states historical events continues to influence its contemporary sociocultural and economic structures (Cabell, 2007; Zuniga & Hernandez, 2005). Sociocultural contexts significantly influence the acculturation process of HLI, which is defined as the process of change that individuals and groups undergo when interacting with another culture (Redfield, Linton, & Herskovits, 1936; Berry, Kim, Minde, & Mok 1987). In the immigrant population, this process involves migrating and adapting to a host country or culture different from their own. Stresses associated with the acculturation process, or acculturative stress, has been shown to have a significant, negative impact on health outcomes of HLI, increasing their vulnerability to disparate health outcomes (Torres, 2010; Crockett et al., 2007; Smart & Smart, 1994). Further impacting the acculturation process for HLI are other sociocultural factors, such as race, ethnicity and language that influence healthcare access.

As a result of growing foreign-born populations, language demographics of Louisville have changed drastically, with over 7.5% of the city's population speaking a language other than English in the home (Office of Policy Planning and Evaluation, 2012). Consequently, the number of English-as-a-second-language students in the school system grew by 122% between 2000 and 2005 with over 95 different languages spoken. Roughly 50% of Louisville's immigrants have limited English proficiency (LEP), with Latin American (58%) and Asian (50%) immigrants being the highest. Spanish is the most commonly spoken language at home other than English, with over 23, 000 Louisville residents speaking Spanish or Spanish Creole as their primary language (Office of Policy Planning and Evaluation, 2012). Therefore, HLI in Louisville represent diverse characteristics based on language and education, but also in relation to race, country of origin and immigration status. This demographic diversification can lead to issues of

discrimination and marginalization, which discourage health-seeking behaviors among HLI due to concerns of unequal treatment or deportation (Lauderdale, Wen, Jacobs, & Kandula, 2003).

Economic contexts are significantly shaped by levels of education, type of employment, income and LEP of HLI. According to the Kaiser Commission on Medicaid and the Uninsured (2003), immigrants are more likely to be poor and work for small businesses, agricultural, labor, repair industry, and other service occupation sectors due to their lack of education and LEP in the U.S. Capps et al. (2006) found that over half of the immigrant population in Louisville was poor and/or low-income, falling below 200% of the federal poverty level. Hispanic Latino immigrants, who represent the largest proportion of Louisville's foreign-born, had the highest poverty (30%) and low-income (65%) rates, with African immigrants (18%) following closely behind. The lower socioeconomic status of HLI has shown to be related to their educational levels and LEP, which consequently impacts employment status and job characteristics (Capps et al., 2006).

According to the Office of Policy Planning and Evaluation (2012), 26% of the Hispanic population in Louisville had no high school diploma, and over twice as many whites had bachelor's degrees compared to blacks and Hispanics. Lower levels of education impact the type of employment opportunities that are available to HLI and their levels of income. Representing the largest proportion of immigrants in Louisville's low-wage workforce, employed in manufacturing, retail trade, accommodation, and food industries, HLI face numerous barriers to equitable healthcare access as a result of their lower socioeconomic positions (Coffman et al., 2007; Passel, 2006). For example, working in low-wage jobs that do not provide any health insurance coverage or adequate salaries for individuals to buy health insurance impacted their ability to access healthcare services. In 2008 it was estimated that only 25.3% of HLI in Kentucky had health insurance coverage through their employers, leaving 46.7% percent of the HLI population without health insurance (Leon, 2012). In 2010, 38% of all Hispanics in the state of Kentucky were uninsured compared to 63% of HLI (foreign-born) who were uninsured (Pew Research Hispanic Center, 2010).

Political exclusion through the recent implementation of state enforced immigration, welfare and health policies and laws further restrict HLI from accessing public health and social services (California Immigration Policy Center, 2006). The recent healthcare reform act has introduced new policy-related

barriers to healthcare access based on immigration status and documentation eligibility (Quesada et al., 2011; Gradstein & Schiff, 2006; Canales, 2007). Representing the largest proportion of undocumented immigrants in Louisville and nationally, HLI have largely been affected by these policies, making them a central topic of recent political debates (Hoefler et al., 2011; Legislative Research Commission, 2002; Urrutia-Rojas et al., 2006). These restrictive policies and laws provide evidence for the underlying structure of power that influence the social positioning of HLI and subject them healthcare access inequities. Therefore, the influence of these historical, sociocultural, economic and political factors indicate the need to further understand the impact of the social determinants of healthcare access on HLI in order to reduce health disparities and improve overall health outcomes.

The influence of SDH on health outcomes has warranted global attention as healthcare systems strive to identify ways to tackle this threat to public health. The CSDH (2008) called for an enhanced focus on SDH in public health research in order to aptly address ways to reduce disparities in healthcare access and health outcomes. Despite growing research in the area of SDH, limited literature is available regarding the mechanisms through which these determinants serve as barriers or facilitators to healthcare access (McGibbon, Etowa, & McPherson, 2008). Furthermore, the majority of studies in the U.S. that examine barriers and facilitators to health services rely on cross-sectional national health survey data (such as the National Health Interview Survey) and quantitative techniques (Bustamante et al., 2009; Durden & Hummer, 2006). Although these studies indicate that accessibility issues do exist, key barriers to access as perceived by immigrants themselves are not adequately explored within historical, sociocultural, economic and political contexts (Asanin & Wilson, 2008). This can only be garnered through qualitative research that is enhanced by critical perspectives providing insight into social inequities and injustices that serve as the basis for the social determinants of healthcare access.

Purpose Statement

Examining access to healthcare among HLI is an important and timely research issue because of the growing immigrant population and the difficulties related to addressing their needs within U.S. society, especially in regions with newer immigrant groups. Access to healthcare, as one SDH, has been identified to be significantly influenced by historical, sociocultural, economic, and political contexts (CSDH, 2008; WHO, 2012). Further research is warranted to explore the impact of these factors on health behaviors and

health outcomes from the perspective of those who experience these influences using a qualitative, critical ethnographic approach. **Therefore, the purpose of this dissertation was to critically explore the perceived barriers and facilitators to primary healthcare access among HLI residing in highly concentrated communities of the southern metropolitan city of Louisville, KY.** Furthermore, by examining barriers and facilitators to healthcare access within a contextually based framework, this dissertation aimed to provide critical interpretations of the social determinants of healthcare access for this population.

Research Questions

The following research questions were used to understand perceptions of health and to contextually examine barriers and facilitators that influenced the social determinants of healthcare access for HLI in Louisville.

1. What are the perceptions of HLI on health, healthcare, and healthcare access?
2. What are the identified barriers to accessing healthcare services for HLI?
3. What are the identified facilitators to accessing healthcare services for HLI?
4. What are the historical, sociocultural, economic, and political contexts that shape the social determinants of healthcare access within this population?

Study Significance and Impact

In order to improve current healthcare systems, programs, and policies to meet the needs of diverse HLI groups, understanding barriers and facilitators to healthcare access is imperative (Keating et al. 2009). Although social determinants that impact healthcare access are identified in the literature, the association between the concept of access and SDH is not fully explicated (CSDH, 2008; McGibbon et al., 2008). Understanding access to healthcare as a social determinant of health further enhances knowledge of barriers and facilitators in larger historical, sociocultural, economic and political contexts. Furthermore, examining access to healthcare among HLI is an important and timely issue as a result of the growing health disparities related to access in this increasing and diverse immigrant population. This dissertation addresses these areas by providing a contextually based understanding on health disparities in relation to the social determinants of healthcare access experienced by HLI in Louisville, KY. Findings from this study may help inform health service providers, recipients and policymakers by identifying the subjective

and socially constructed barriers to healthcare access, adding to nursing science and promoting development of ways to reduce health disparities by improving access to healthcare for HLI.

Over the decades, eliminating healthcare access disparities among racial and ethnic minority populations has been and continues to be an important healthcare priority for the U.S. (IOM, 2003; USDHHS, 2005, 2010). The concept of access, however, is poorly defined, necessitating the need for continued research to clarify its operational definition by identifying adequate methods of measuring the phenomena (McGibbon et al., 2008). This study aimed to effectively measure the multifaceted phenomena of access by implementing a comprehensive conceptual, theoretical, and methodological approach that measures access within historical, sociocultural, economic, and political contexts (Peters et al., 2008).

According to the CSDH (2008), “understanding the impact that context has on health inequities and the effectiveness of interventions requires a rich evidence base that includes both qualitative and quantitative data” (p. 179). Health inequities, especially in relation to access, reflect a wide range of SDH factors, including culture and history, political environment and societal characteristics. Considering these influences, this study provides a contextually based understanding of the social determinants of healthcare access through the use of 1) qualitative, critical ethnography (CE) methods; 2) postcolonial theoretical perspectives; and, 3) the *Conceptual Framework for Assessing Access to Health Services* (CFAAHS; Peters et al., 2008). The purpose of this study contributes to the CSDH’s (2008) recommendations by enhancing research on the SDH using a contextually based approach. As this study focused on one specific population and setting (HLI in Louisville), it allows for an in-depth, holistic and contextually-based examination of access to healthcare for this population.

Further understanding of context was achieved through the use of a multiple approaches or a multidimensional approach to research based on critical perspectives. Critical perspectives such as postcolonialism and CE illuminate the influence of historical, sociocultural, economic, and political contexts on current health and social experiences of HLI. However, there is limited use of critical perspectives in theoretical and methodological underpinnings of healthcare studies (Mohammed, 2006; Cheek & Gibson, 1997; Ogilvie, Burgess-Pinto, Caufield, 2008). Although nursing research in the U.S. has begun to embrace theoretical perspectives and methodological approaches from critical traditions, application of postcolonial theories to immigrant health research, especially with HLI is rarely seen

(Mohammed, 2006; Cheek & Gibson, 1997; Ogilvie et al., 2008). With an overarching political stance, this study aimed to further critical scholarship in nursing and healthcare access research by introducing a method of inquiry based on postcolonial discourses and CE as described by Kirkham and Anderson (2002). Enhancing critical perspectives demonstrates to nurse practitioners and researchers that alternative ways of knowing as experienced by HLI must be understood in order to provide culturally appropriate interventions and programs to enhance access to healthcare within the HLI population. Providing culturally appropriate care enhances communication and trust in patient-provider relationships, motivating HLI to seek health services in an appropriate and timely manner.

Limited literature on healthcare access among HLI, especially in Southern states like Kentucky where the increasing demands of growing immigrant populations continue to overwhelm current health and social service infrastructures, warrants further research (Fennelly, 2006; City-Data, 2011; White, 2011; Capps et al., 2006). Geographic location serves as a factor for healthcare disparities as populations residing in central states, inner-cities, and rural areas have the highest need for improved quality and access to healthcare services (AHRQ, 2011). The NHDR reported that populations residing in inner-city and rural areas of central states like Kentucky are at increased risk for receiving poorer quality of, and access to, healthcare (AHRQ, 2011). As an inner-city area in the predominantly rural state of Kentucky, this study's setting of South Louisville served as a prime location to assess health and healthcare access disparities among HLI. Although it has been identified that immigrants experience difficulties in accessing services in these regions, there is limited demographic and health-related data on foreign-born populations, specifically on HLI, which further impedes the development of strategies to overcome barriers to access. Therefore, to identify and address the healthcare needs of growing HLI in Louisville, a more detailed, contextually based understanding of their experiences and perceptions of access to healthcare services is imperative. This study addresses this need by enhancing by informing nurses and other healthcare providers about the complexity of these issues and helping them identify ways to best address healthcare access inequities resulting from the SDH.

Nurses, who are in the forefront of providing primary healthcare services, especially to underserved populations, play a significant role in addressing the social determinants of healthcare access for HLI (International Council of Nurses, 2011; Reutter & Kushner, 2010). Additionally, nurses have taken

on expanding roles in health practice, research and policy, giving them a unique opportunity to influence changes in healthcare access for immigrants. However, insufficient nursing literature and research on SDH and access is available to guide nurses to develop culturally competent interventions and programs targeted at improving healthcare access for HLI. Eliminating barriers to healthcare access through enhanced provision of healthcare services, educational materials, and community outreach programs for HLI can be accomplished using a culturally competent and contextually-based approach. Based on this need, knowledge gleaned from this study contributes to increased understanding of these concepts in relation to health outcomes. As suggested by the CSDH (2008), this evidence will assist in the “training of policy-makers and advisors, medical and health practitioners, and other practitioners (such as urban planners) and in increasing public understanding of SDH” (p.179). This study supports the need for provision of culturally and linguistically competent preventive care and community programs to encourage healthy behaviors and improve healthcare access for HLI in Louisville. Additionally, nurses in community and public health can use this information to help create proactive approaches to transform notions of health in the HLI population by promoting prevention and enhancing timely health-seeking behaviors.

Conclusion

Examining access to healthcare among HLI is an important and timely issue as a result of the growing healthcare access disparities in this increasingly diverse immigrant population. The purpose of the study was to critically explore the social determinants of healthcare access among HLI in Louisville, KY. The study provides significant contributions to existing knowledge on the health and health behaviors of HLI, the SDH that impact healthcare access, and methods of inquiry based on critical scholarship. Limited literature on healthcare access among HLI, especially in Southern states like Kentucky where the increasing demands of new immigrant populations overwhelm current health and social service infrastructures warrants further research. This study aims to address these gaps by furthering understanding of the experiences of HLI with healthcare access that can serve as a foundation for identifying and minimizing the social determinants that serve as barriers to healthcare access in this population. The purpose of the study meets the CSDH’s recommendations by generating research on the SDH using a contextually based approach guided by critical perspectives, which are further explicated in the following chapters of this dissertation.

CHAPTER II

PART I: REVIEW OF LITERATURE

Introduction

Access to healthcare is defined as the measure of congruency between quantity and quality of healthcare services, and utilization of services, influenced by contextual (historical, sociocultural, economic, and political) factors, which are represented under the four dimensions of availability, accessibility, affordability, and acceptability (Aday & Andersen, 1975; IOM, 1993; Pechansky & Thomas, 1981; Peters et al., 2008; WHO, 1978). The literature indicates distinctive barriers and facilitators to healthcare access among HLI under these four dimensions that are related to individual, societal, organizational, structural, and/or healthcare provider factors (Cristancho, Garces, Peters, & Mueller, 2008). The following section of this dissertation will present studies that have explored barriers and facilitators to primary healthcare access in association with (1) availability; (2) accessibility; (3) affordability; and, (4) acceptability dimensions of access.

Barriers and Facilitators to Healthcare Access for HLI

Availability

Availability refers to accessing appropriate types of healthcare services, providers and materials (Peters et al., 2008). Availability barriers and facilitators to healthcare access pertain to the quantity and quality of both healthcare services and providers and were most frequently cited in the literature as essential determinants of access for HLI (Pechansky & Thomas, 1981; Peters et al., 2008; Ricketts & Goldsmith, 2005). Factors pertaining to availability include characteristics of the healthcare system or organization, healthcare professionals and the process of providing care, and patient characteristics (Betancourt, 2006). Although these factors have direct relationships with access to healthcare, they are also highly interconnected, and therefore must be understood relative to one another.

Healthcare system. At the system level, real availability barriers experienced by HLI include limited office hours that do not meet the needs of patient work schedules, and limited availability of appointments, leading to longer waiting times and delayed treatment (Betancourt, 2006; Escarce & Kapur, 2006; Peters et al., 2008). On average, primary care facilities maintain office hours, which do not conveniently meet work schedules of patients in general. Working predominantly in service, agricultural, and manufacturing jobs, with longer, nontraditional work days and hours, HLI are further impeded from accessing services during regular office hours (Passel, 2006). As a result, a higher percentage of HLI seek healthcare services at emergency rooms and other community clinics that have expanded weekday and weekend hours to match work schedules of immigrants (Derose et al., 2007; Chavez, 2012). Community centers and clinics geared towards providing affordable and convenient healthcare services for immigrants facilitate availability of healthcare for HLI.

Culture and language. Cultural and linguistic competency of healthcare professionals serve as important determinants of healthcare access. The use of culturally and linguistically trained interpreters, and bilingual healthcare providers has been shown to positively affect patient satisfaction, quality of care, and health outcomes of LEP immigrants (Cacari-Stone & Balderrama, 2008; Gurman & Becker, 2008; Pares-Avila et al., 2011). Additionally, increasing workforce diversity through the representation of racially, ethnically, and linguistically diverse healthcare professionals has been shown to facilitate access and encourage utilization of services, especially among Latino communities (Rivers & Patino, 2006). Use of interpreter services (face-to-face or phone) facilitates and enhances patient-provider communication and patient satisfaction, which are indicative of a higher quality of healthcare. Title VI of the 1964 Civil Rights Act legally mandates equivalent access to services by all federal agencies for non-English speaking individuals (National Archives and Records Administration, 2004). The enforcement of Title VI by local and federal government agencies helps establish the use of interpreter services in healthcare organizations, especially those serving LEP immigrants (Derose et al., 2007). Increased communication has been shown to enhance the patient-provider relationship and promote health-seeking behaviors among immigrants.

Although the above-mentioned factors have been identified as important approaches to address cultural and linguistic barriers, they have also identified that there is still much work to be done. Studies have identified lack of cultural competency among healthcare providers and delivery of services as a

significant barrier to healthcare access among HLI (Asanin & Wilson, 2008; Castaneda, Ruelas, Felt, Schenker, 2011; Rivers & Patino, 2006). In a study testing the psychometric properties of the Hispanic Immigrant Barriers to Health Care Scale, Keatings et al., (2009), identified cultural identification, economic resources, convenience, and provider characteristics to explain the highest amount of variance among scale items. Cultural identification, which refers to the level of social connectedness between the healthcare provider and patient, was strongly associated with health-seeking behaviors of HLI, indicating that patients prefer to access services from providers with whom they can relate based on similarities in culture and language background.

Language has been identified as significant barrier to healthcare access among HLI (Derose et al., 2007; Cristancho et al., 2008; Gurman & Becker, 2008; Harari et al., 2008; Perez-Escamilla et al., 2010). Influenced by patient characteristics (LEP) and the healthcare system (provision of certified Spanish interpreters), language barriers continue to threaten access for the growing, predominantly Spanish-speaking, HLI population. According to the IOM (2003), over 14 million Americans, and one in five Spanish speaking Latino's have LEP, which serves as a major impediment to health seeking behaviors. HLI with LEP, experience compromised quality of care and increased risk of adverse health outcomes, which leads to growing health disparities within this population (DuBard & Gizlice, 2008; Flores, 2005; Perez-Stable, 2007). Studies (Asanin & Wilson, 2008; Harari et al., 2008) exploring perceived language barriers among immigrants revealed that patients expressed apprehension and concern regarding their ability to effectively communicate with providers regarding their health concerns, leading to delay in seeking care and lack of confidence and confusion when care is sought. Additionally, in a qualitative study by Cristancho et al., (2008), language and communication were the primary perceived barriers to access among rural HLI. Limited English Proficiency levels of HLI influenced their ability to understand health needs and consequently their health seeking behaviors. Language barriers are further exacerbated due to the limited availability of qualified Spanish interpreters, leading to the use of ad hoc interpreters (such as family members, and non-health related staff).

Despite the establishment of Title VI, Spanish-speaking HLI continue to face barriers in accessing certified interpreters and bilingual staff at healthcare agencies (Chen, Youdelman, Brooks, 2007; Pares-Avila, Sobralske, Katz, 2011). Barriers to the availability and utilization of interpreter services include

costs associated with employment and training, and lack of familiarity with care-seeking processes among those interpreters. The use of interpreters is further limited in midwestern and southern regions of the U.S. with relatively newer HLI populations and limited availability of services (Alcalde, 2005; Capps et al., 2006; Coffman et al., 2007; Harari, et al., 2008). Despite the availability and utilization of interpreters during healthcare visits, HLI report negative experiences with poorly trained interpreters with lack of Spanish proficiency (Gurman & Becker, 2008). These factors further discourage HLI from accessing healthcare services due to the fear of not being able to effectively communicate with providers.

The use of culturally and linguistically trained interpreters, and bilingual healthcare providers has been shown to positively affect patient satisfaction, quality of care, and health outcomes of LEP immigrants (Cacari-Stone & Balderrama, 2008; Gurman & Becker, 2008; Pares-Avila et al., 2011). Additionally, increasing workforce diversity through the representation of racially, ethnically, and linguistically diverse healthcare professionals has been shown to facilitate access and encourage utilization of services, especially among Latino communities (Rivers & Patino, 2006). Use of interpreter services (face-to-face or phone) facilitates and enhances patient-provider communication and patient satisfaction, which are indicative of a higher quality of healthcare. The enforcement of Title VI by local and federal government agencies helps establish the use of interpreter services in healthcare organizations, especially those serving LEP immigrants. In order to reduce language barriers, federal funding should be allocated to provide interpreter services in primary care centers and develop educational programs for bilingual proficiency (Derose et al., 2007). Increased communication has been shown to enhance the patient-provider relationship and promote health-seeking behaviors among immigrants.

Accessibility

Accessibility refers to geospatial factors, such as location, physical distance, and travel time from point of service delivery to the recipient (Peters et al., 2008). However, accessibility is also influenced by eligibility for public health programs based on immigration status (citizen, non-citizen, undocumented) as evidenced by federal, state, and institutional policies and eligibility criteria. Factors influencing barriers to accessibility frequently identified in the literature focus on both geospatial factors and immigration status factors affecting the eligibility of immigrants to access public health services. Accessibility related to geospatial factors influence the relationship between the healthcare provider and the recipient, measuring

geographic location, physical distance, and transportation as determinants of access (Asanin & Wilson, 2008; Khan & Bhardwaj, 1994; Peters et al., 2008). This section explicates accessibility in relation to both geospatial factors and immigration status.

Geographic and spatial accessibility. Access to healthcare among HLI has been shown to vary across the U.S., depending on the geographic location and physical characteristics of the residential environment (Derose et al., 2007; Gresenz, Rogowski, & Escarce 2009). Variations in access have been identified in several midwestern and southern regions of the U.S., where local agencies are unable to adequately meet the healthcare needs of growing HLI populations (Abraido-Lanza, Cespedes, Daya, Florez, & White 2011; Alcalde, 2005; Capps et al., 2006; Coffman et al., 2007; Harari, et al., 2008). Differences in availability and access to healthcare services have also been related to rural areas experiencing growing HLI populations, where further limitations in access relative to geospatial factors exist (Cristancho et al., 2008; Berdahl, Kirby, & Torres-Stone, 2007). These findings provide evidence of physical segregation of HLI groups, which leads to social isolation from mainstream community and resources (Khan et al., 2011). Harari, et al. (2008) explored healthcare experiences of recent Latino immigrants in Midwest communities in which 48% of HLI reported feeling social isolation, and lack of strong social and information networks. Additionally, it was found that segregated HLI communities located in the outskirts, bordering metropolitan areas usually have limited access to and knowledge of healthcare services. Living in isolated communities increases travel time to access services and demands the need for transportation, which serve as additional barriers to access.

Residential location and demographic characteristics that facilitate access to healthcare among HLI include integrated communities in more urban settings, with diverse racial and ethnic composition (Derose et al., 2007; Khan et al., 2011; Kirby, Taliaferro, Zuvekas, 2006). In a study exploring the effects of community demographic characteristics on healthcare access among Hispanics, Gresenz et al. (2009) found that both insured and uninsured Mexican immigrants had increased access to care when residing in areas with relatively more Hispanic immigrants and Spanish speakers. Additional facilitators to overcoming geospatial barriers to access include the establishment of healthcare service sites in underserved areas, and expansion of infrastructure through enhanced affordable and convenient public transportation (Keatings, et al., 2009).

Immigration status and eligibility accessibility. The literature identifies immigration status, especially being undocumented, to have significant influences on both access to healthcare and health outcomes of HLI (Durden & Hummer, 2006; Khan et al., 2011; Quesada et al., 2011). Increasingly, immigration and related health policies such as the Support Our Law Enforcement and Safe Neighborhoods Act (Senate Bill 1070, 2010) and the Personal Responsibility and Work Opportunity Reconciliation Act (Pub. Law No. 104-193, 1996) have focused on curbing rates of undocumented immigrants and restricting them from accessing vital services such as healthcare (Derose, et al., 2007; Okie, 2007; Sonfield, 2007). The recent Patient Protection and Affordable Care Act (PPACA, Pub. Law No. 111-148, 2010), which mandates health insurance coverage for all citizens and legal immigrants, further emphasizes restrictions on access to healthcare for undocumented immigrants, requiring proof of citizenship as eligibility criteria to participate in health insurance programs. With the establishment of these new laws, undocumented immigrants are further discouraged from seeking healthcare due to the lack of understanding of eligibility criteria and fears of deportation related to undocumented status (California Immigrant Policy Center, 2006).

Hispanic Latino immigrants represent the largest percentage of the undocumented population in the U.S., making them highly susceptible to experiencing health and healthcare access disparities (Urrutia-Rojas et al., 2006). Being undocumented has been shown to have direct effects on healthcare access and utilization (Ortega et al., 2007; Nandi et al., 2008; Dang, Giordano, Kim, 2012). Studies have indicated that undocumented Latino immigrants have lower education, income and health literacy rates, and are less likely to have health insurance or access to healthcare compared to their U.S.-born counterparts (Passel & Cohn, 2009; Gossey & Volk, 2008; Bustamante et al., 2012; Rodriguez, Bustamantes & Ang, 2009). The inability of undocumented immigrants to legally receive healthcare and other federally funded, public welfare programs poses a severe threat to the health of immigrants and the nation as a whole. Perceived barriers associated with undocumented status include fear of deportation and feelings of inferior treatment evidenced by poorer quality of care. Findings from a recent study by Chavez (2012) on undocumented HLI indicate increased stressors related to immigration status led to underutilization of medical services and health insurance. Rodriguez et al., (2009) in a national study found that undocumented HLI were less likely to report having received excellent or good quality of care, and more likely to receive no health or healthcare information from providers when compared to the U.S.-born. These findings indicate the

influence of immigration status on perceived availability and quality of care, which consequently affects health seeking behaviors.

Over the years, the establishment of free community clinics has increasingly met healthcare needs of HLI, especially those ineligible for federal health services and insurance coverage. Although limited in funding and other resources, clinics which are centrally located in areas of high HLI concentrations are able to better understand and meet the needs of their community (Derosé et al., 2007). Studies show that HLI are more likely to access services from community clinics that are geographically easier to access, and do not require proof of citizenship or legal immigration paperwork (Durdén & Hummer, 2006; Chavez, 2012). Additionally, the use of community health workers (CHW) or *promotoras* further enhances patient-provider communication, reduces cultural and language barriers, and encourages healthcare access and utilization among HLI (Pacheco, Ramirez, & Capitman, 2012). Policies and organizations that improve accessibility to health services and insurance, lead to affordable healthcare access and decreased healthcare expenditures.

Affordability

Affordability refers to the relationship between the price or cost of services and the willingness and ability of recipients to pay for those services while being protected from the negative economic consequences of health costs (Pechansky & Thomas, 1981; Peters et al., 2008). The financial ability of HLI to pay for healthcare services is influenced by socioeconomic factors, such as low levels of education, employment, and income. These factors directly influence rates of health insurance coverage. In 2007, the Center for Immigration Studies estimated that roughly 34% of all immigrants (legal and undocumented) in the US lack health insurance coverage, accounting for 27% of the total uninsured population (Camarota, 2009). Additionally, factors such as immigration status have such extensive effects on acquiring health insurance coverage that discrepancies in access continue to exist despite rises in income levels (Siddiqi, Zuberi, & Nguyen, 2009).

Education, employment, and income. The ability to afford healthcare services and insurance coverage for HLI is greatly affected by higher rates of those with lower levels of education leading to employment in low-wage, service industries (such as agriculture, construction, domestic and food services) which results in limited income (Escarce & Kapur, 2006; Passel, 2006). Low levels of income and

educational attainment impairs the ability of HLI to navigate the complex healthcare delivery system in the U.S., effectively communicate with providers and impedes their ability to receive timely and appropriate care. In a study of health access and utilization, Coffman et al., (2007), found that healthcare service use among HLI was significantly associated with health literacy, education levels, and income. Racial and ethnic variations among HLI in socioeconomic and immigration status have been shown to impact affordability, access, and utilization of healthcare services (Durden & Hummer, 2006; Bustamante et al., 2009). Despite being the largest subgroup of HLI in the U.S., Mexican immigrants are more disadvantaged relative to education, income, and legal residency status.

Compared to other HLI, Mexican immigrants are highly vulnerable to experiencing healthcare access inequities as a result of poverty, lack of insurance, undocumented status, and cultural and linguistic barriers (Castaneda, et al., 2011; Rivers & Patino, 2006; Wallace, Gutierrez, Castaneda, 2008). In a study comparing disparities to access among documented and undocumented Mexican immigrants in north Texas, Urrutia-Rojas, et al. (2006) found the undocumented to be younger and less educated, and have LEP and lower income. As a result, Mexican immigrants are less to have a regular source of healthcare, leaving them susceptible to negative health outcomes (Berdahl et al., 2007; Freeman & Lethbridge-Cejku, 2006). Levels of education, employment and income also affect the ability of Mexican immigrants and other HLI to afford health insurance coverage.

Health insurance coverage. Health insurance is a significant social determinant of healthcare access, and has been directly associated with chronic illnesses and mortality (Khan et al., 2011; Wilper et al., 2009a; Wilper et al., 2009b). According to the Pew Hispanic Center, HLI work in low-level service industries, which do not provide adequate compensation for healthcare insurance coverage (Passel, 2006). Low-wage employment impacts their ability to buy private insurance, and restricts participation in state-wide health insurance exchanges, which was established by the PPACA (Pub. Law No. 111-148, 2010). With the implementation of healthcare reform, health insurance becomes mandatory for all legal citizens and immigrants, but will continue to remain as a barrier to healthcare access for undocumented HLI.

Universal healthcare coverage established in other developed nations (e.g. Canada), has been identified as the primary mechanism to successfully overcome barriers to healthcare access for immigrants. Prus, Tfaily, & Lin (2010) identified this effect which resulted in reduced health disparities and improved

overall community wellbeing. Although the U.S. spends more on healthcare (15.3% of GDP) than Canada (9.8% of GDP), it continues to experience more negative health outcomes than other developed nations. Both foreign-born and minority populations in the U.S. have poorer health outcomes related to unmet healthcare needs, and are less likely to have a regular doctor when compared to Canadian immigrants (Lasser, Himmelstein & Woolhandler, 2006). Prus et al. (2010) identify that although both nations have diverse immigrant populations, they markedly differ in their ethnic and socioeconomic characteristics, history of racial segregation, and health and immigration policies, which impacts the social status and consequently health experiences of immigrants in each country. Canada's universal healthcare system eliminates significant barriers to access, especially those related to affordability factors, while the privatized U.S. healthcare system continues to limit access for HLI.

Acceptability

Acceptability measures both the attitudes and perceptions of recipients towards the healthcare system and vice versa (Pechansky & Thomas, 1981). Perceptions of healthcare and healthcare systems are highly applicable in understanding acceptability barriers and facilitators to access among recipients from multicultural backgrounds, such as HLI. Literature on acceptability factors influencing healthcare access among HLI can be categorized under external factors such as social isolation, segregation, and discrimination, and internal factors or individual characteristics related to stigma.

External factors. Social isolation or exclusion of HLI populations is apparent through the physical segregation of communities, and policies that restrict immigrants in their integration into society at large. Socioeconomic, cultural, political and historical characteristics of the U.S., which result in social exclusion and marginalization of these groups, continue to keep immigrants in vulnerable positions, restricting their level of healthcare access (Derose, et al., 2007; Nandi et al., 2008). Political exclusion through immigration laws and other structural barriers restrict HLI, especially the undocumented, from accessing public services and basic human rights (Quesada et al., 2011; Gradstein and Schiff, 2006; Canales, 2007). Social exclusion disempowers immigrants from furthering education, employment, and improving overall socioeconomic status which create additional barriers to healthcare. Findings from Sanchez-Birkhead, Kennedy, Callister, Myamoto's (2011) descriptive qualitative study, exploring experiences of HLI women in navigating the healthcare system in Utah, reported that social isolation was

the leading sociocultural barrier to healthcare utilization. Social isolation resulted in lack of social support, lack of familiarity and trust with healthcare providers, and perceived discrimination from healthcare systems. Issues of perceived discrimination and marginalization significantly impede access to services, making immigrants reluctant to seek care due to concerns of unequal treatment or fears of deportation (Lauderdale et al., 2003; Perez, Fortuna, & Alegria, 2008).

The literature identifies numerous types of sociodemographic-based discrimination. These include language, health insurance, and racial and ethnic background which are most commonly experienced by HLI (Cristancho et al., 2008; Gurman & Becker, 2008). Despite Title VI of the Civil Rights Act (National Archives and Records Administration, 2004), HLI with LEP continue to face difficulties in accessing healthcare due to the lack of qualified interpreter services. Discrimination related to LEP, as viewed by HLI, results in emotional barriers that have strong influences on health-seeking behaviors (Sanchez-Birkhead et al., 2011). Similarly, perceived discrimination as it relates to the lack of health insurance especially for those who are undocumented, has been reported to be associated with feelings of inferiority, and unwelcome within the healthcare system. Perceived differential treatment results in hesitation in seeking care (Harari et al., 2008).

Racial and ethnic discrimination has direct and indirect effects on health outcomes through its influence on lower social class, segregation, and socioeconomic position of HLI. Perceptions and experiences of racial/ethnic discrimination in this population have been identified as a source of increased stress and other negative physiological and psychological consequences (Flores et al., 2008; Lauderdale et al., 2006; Prus et al., 2010). Lack of understanding, awareness, and acceptance within the healthcare system of immigrants from diverse backgrounds, reduces patient satisfaction with services, indicating lower quality of care.

As identified in the previous discussion, factors that support acceptability of healthcare and facilitate healthcare access among HLI includes increasing diversity in the healthcare workforce and provision of culturally and linguistically competent care through the use of certified interpreters and bilingual staff (Betancourt, 2006; Keating et al., 2009). The roles of Community Health Workers (CHWs), who share similar culture and language as the immigrants they serve, have been shown to effectively improve health behaviors and outcomes (Pacheco et al., 2012). Although, CHWs help HLI overcome

perceived acceptability barriers to healthcare access, they do not impact policies, which serve as the real barriers to determining access. Limited research literature (Betancourt, 2006; Keating et al., 2009; Pacheco et al., 2012) on the real and perceived facilitators to healthcare access among HLI indicates the need for future studies that aim to understand the effects of acceptability factors on access.

Internal factors. Stigma associated with illnesses and treatment seeking represents an influential individual factor that affects acceptability of healthcare access among HLI. Some studies have reported negative stigma associated with certain diseases such as HIV/AIDS, STI's, mental illnesses, and cancer as barriers to healthcare access in this population (Dang et al., 2012; Horwitz et al., 2008; Olshefsky et al., 2007). Stigmatizing illnesses serve as a cultural barrier that negatively influences immigrants' perceptions of the healthcare system access and utilization. Additionally, stigma has been found to negatively affect perceptions of social support. Analysis of data from the National Latino and Asian American Study (Mulvaney-Day, Alegria, & Sribney, 2007) revealed that strong social networks and social support serve as facilitators to overcoming illness-related stigma, healthcare avoidance and improved health outcomes. Perez-Escamilla et al. (2010) identify the existence of variations among HLI subgroups in illness-related stigma. The study indicated that there is a combined influence of cultural differences, levels of education, and acculturation on healthcare access.

Findings from the systematic review of literature within this dissertation on real and perceived barriers and facilitators to healthcare access among HLI, reveal that availability, accessibility, affordability, and acceptability dimensions of access play a significant role in framing the social determinants of healthcare access in this population. Under the four dimensions of access, barriers and facilitators to healthcare were related to numerous social, cultural, economic, and political contextual factors (Peters et al., 2008). Despite these findings, few studies aimed to contextualize barriers and facilitators to healthcare access based on specific HLI populations in varying geographic settings. Lack of culturally competent healthcare providers and interpreters, LEP and lower socioeconomic status of HLI, geospatial access, undocumented status, and discrimination were predominantly identified in the literature as significant barriers to access. However, few studies aimed to understand these barriers and ways to overcome them from the perspective of HLI. Limited extent literature on facilitators of healthcare access, especially those perceived by HLI, identify that the diversity of healthcare providers and communities facilitate availability

and accessibility of healthcare services. Additionally, expanded health insurance coverage and free community clinics serve as facilitators to access. These limited findings indicate gaps in the literature pertaining to facilitators to healthcare access for HLI that need to be explored further to establish programs and interventions to improve access. Despite the identification of patient satisfaction as a strong indicator of healthcare quality and a facilitator to access, limited studies explore these perceptions among HLI and immigrants in general (Abraido-Lanza, et al., 2011; Gurman & Becker, 2008). Among others, these limitations indicate the need for continued research to further understand the social determinants of healthcare access as perceived by HLI within historical, sociocultural, political, and economic contexts.

Pilot Study

As a foundation for this dissertation research and to provide rationale for the need to explore access to healthcare among HLI within the context of Louisville, KY, a two-phased pilot study was conducted. The first phase of the pilot study used qualitative ethnographic methods to explore the provider's perspective of the availability of health and social services for immigrants and refugees in Louisville. Health and social service providers focused on immigrants and refugees (n=10) were recruited using purposive and snowball sampling methods. Data were collected using in-depth interviews, participant observations, document reviews, and a demographic survey over a period of 3 months until data saturation was achieved. Based on findings from this first phase, the second phase of this pilot used case study techniques to explore three (two federally qualified and one private) non-profit, health service organizations, who served a significant number of HLI in Louisville. The pilot study's aim was to identify how these organizations determined their consumers' needs and adapted to provide them culturally and linguistically appropriate health services.

Findings from this pilot study were consistent with the literature identifying barriers and facilitators to healthcare access among general immigrant and refugee populations in Louisville under the dimensions of availability, accessibility, affordability, and acceptability. However, findings revealed that as the largest immigrant subgroup, HLI experienced the greatest disparities in health outcomes and healthcare needs; therefore serving as the target population for this study. Areas of the city with the highest concentration of HLI were identified in southern Louisville, including zipcodes 40214, and 40215, which serve as the primary settings for this study. Pilot study findings revealed significant availability barriers in

accessing primary healthcare services, especially in relation to culture and language, socioeconomic status, policies pertaining to immigration status and eligibility, and other societal factors. These findings were consistent with previous studies and frameworks measuring access to healthcare among HLI and other immigrant populations (Pechansky & Thomas, 1981; Peters et al., 2008). Pilot study findings are further discussed in chapter five of this dissertation to examine the congruence or incongruence between the actual healthcare needs of the recipients as indicated by participant narratives and the perceived healthcare needs as identified by health and social service providers

Despite pilot study findings, barriers and facilitators to healthcare access as perceived by HLI in this setting are not well understood, especially in light of historical, sociocultural, economic, and political factors that are unique to this setting (Asanin & Wilson, 2008). Additionally, although several barriers were identified, facilitators or methods used by HLI to overcome barriers within this setting are inadequately investigated, providing evidence for the need to explore this perspective as the next logical step to this program of research. Pilot study and literature review findings served as a foundation for this dissertation study. This study aims to enhance the understanding of healthcare access barriers and facilitators in this population to inform nurse practitioners and researchers to identify ways to best address healthcare access inequities related to the SDH. Pilot study findings support the use of critical perspectives that serve as the foundation for the theoretical and methodological frameworks of this dissertation. The influence of the pilot study on the selection of theory, study setting and sample, and data collection methods and tools, and will be further discussed in the following sections of this dissertation.

PART II: EXAMINING CONTEXT USING A MULTIDIMENSIONAL APPROACH

Introduction

Acquiring a contextually based understanding of the social determinants of healthcare access among HLI warrants a multidimensional approach, and was achieved in this study using the Conceptual Framework for Assessing Access to Health Services (CFAAHS; Peters et al., 2008), in addition to critical perspectives which will be discussed. At the conceptual level, the CFAAHS will serve as a framework for examining perceptions of access to healthcare services. Postcolonial theory and critical ethnography (CE) methodology will be used to guide the theoretical and methodological approaches. The application of this combined conceptual (access framework), theoretical (postcolonial theory), and methodological (critical ethnography) approach throughout the research process strengthens the multidimensional perspective that serves as the foundation for the research design. This framework also and enhances the understanding of access to healthcare for HLI within historical, sociocultural, economic, and political contexts.

Access: A Conceptual Framework

Access to healthcare is a complex concept, resulting in its inconsistent and unclear use in health research (McGibbon et al., 2008). Review of nursing and health literature over the years, reveals definitions of access that considers the fit among individual, sociocultural, economic and healthcare system-related factors and the ability of these factors to meet individual and community healthcare needs (Gulzar, 1999; Norris & Aiken, 2006). As there is no universally accepted definition of access to healthcare, for the purpose of this dissertation, a comprehensive description of access was used based on four existing seminal definitions: *Access is the measure of congruency between quantity and quality of healthcare services, and utilization of services influenced by contextual (historical, sociocultural, economic, and political) factors represented under the dimensions of availability, accessibility, affordability, and acceptability* (WHO, 1978; IOM, 1993; Pechansky and Thomas, 1981; Peters et al., 2008).

Due to the complex nature of access to healthcare and related concepts, numerous theoretical frameworks have been developed in health service research, each with its own unique angle of measurement (Ricketts and Goldsmith, 2005). Two major frameworks, most cited in literature, distinctly differ in their approach to define and measure access based on utilization (Aday & Andersen, 1974) and the degree of fit (Pechansky & Thomas, 1981). Aday and Andersen's (1974) Behavioral Model of Health

Services Use, primarily developed to inform health policy, explores the relationship between process and outcome indicators, and the factors affecting the health system (Gulzar, 1999). Despite the wide application of this model, the emphasis on utilization limits the definition and scope of access by focusing more on health-seeking behaviors and individual factors, whereas access has shown to be influenced by numerous other factors (Ricketts & Goldsmith, 2005; Pechansky & Thomas, 1981; WHO, 1978).

As an alternative approach, Pechansky and Thomas's (1981) model of access focuses on the degree of fit between needs of health service recipients, and the ability of the healthcare system to meet those needs (Pechansky & Thomas, 1981). This approach allows the framework to examine both real and perceived factors affecting healthcare access. However, applicability and use of this framework is limited, especially in addressing SDH affecting increasingly diverse and disparate communities in current social contexts. Therefore, although examining access based on these existing frameworks are relevant to health services research today as it was three decades ago, recent demographic and societal changes warrant the use of renewed and adaptable versions of the framework. To examine issues of access in an increasingly globalized society, recent adaptations of Pechansky and Thomas's (1981) model of access has resulted in the development of contextually based frameworks for measuring access (Ensor & Cooper, 2004; O'Donnell, 2007; Peters et al., 2008). Utilization of these frameworks have indicated significant overlap or interactions between various dimensions of access, indicating that barriers to healthcare have the ability to influence each other and are not mutually exclusive (Jacobs et al., 2011).

The CFAAHS (Peters et al., 2008) provides an innovative, adaptable, and contextually based method of examining the four dimensions of healthcare access (availability, accessibility, affordability, and acceptability), focusing both on the supply of and demand for healthcare services. As one of only two existing frameworks that focus on measuring barriers to healthcare access, the CFAAHS was initially developed to assess access to healthcare services in relation to poverty and other socioeconomic factors in developing countries (Peters et al., 2008; Ensor & Cooper, 2004). It has been used in international health research to explore the social determinants that serve as barriers to accessing primary healthcare in low and middle-income countries (Al-Taiar, Clark, Longenecker, Whitty, 2010; Jacobs et al., 2011; Ray & Ebener, 2008). Based on longstanding conceptual definitions of access to healthcare, including those central to guiding this dissertation, the CFAAHS purports that the four dimensions of access (availability, geographic

accessibility, financial accessibility or affordability, and acceptability) with both demand and supply side elements, significantly influence and are influenced by the SDH and health outcomes (Aday & Andersen, 1978; Pechansky & Thomas, 1981; Peters et al., 2008; WHO, 1978; Figure 3).

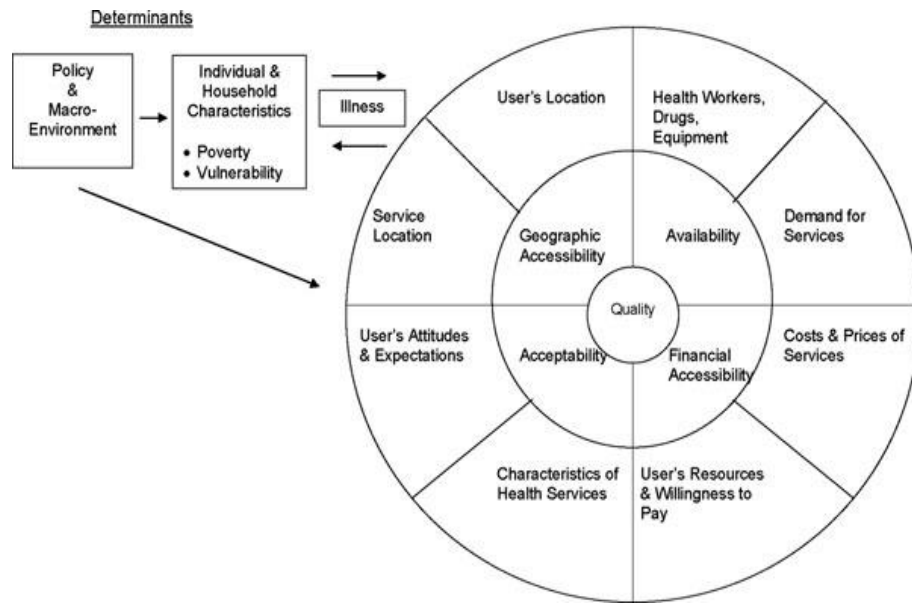


Figure 3. Conceptual Framework for Assessing Access to Health Services (Peters et al. 2008).

The dimension of availability refers to accessing appropriate types of healthcare services, providers and materials (Peters et al., 2008). Location, physical distance, and travel time from point of service delivery to the recipient constitute the dimension of geographic accessibility. Financial accessibility or affordability refers to the costs of acquiring healthcare services and the ability and willingness of recipients to pay for services, while simultaneously being protected from the economic consequences of healthcare costs (Jacobs et al., 2011). Acceptability measures the congruency between responsiveness of healthcare providers to sociocultural needs of individuals and communities. Central to these four dimensions is quality of care, which is indicative of the ability of healthcare services to directly affect health outcomes. Factors that affect access at the policy, macroenvironmental, individual, and household levels are identified as distal determinants, but may equally influence access to healthcare. The cyclical nature of the framework emphasizes the significant overlap or interactions between various dimensions of access, indicating that barriers to healthcare are not mutually exclusive and have the ability to influence each other (Jacobs et al., 2011). The comprehensiveness of this model provides a systematic method to

assess the SDH that affect the four dimensions of healthcare access within historical, sociocultural, economic, and political contexts.

This study addressed all four dimensions of access reflected in the CFAAHS, but expanded on the dimensions of geographic accessibility and financial accessibility, by focusing on broader definitions of accessibility and affordability (Peters et al., 2008). Based on the review of literature, the dimension of accessibility was expanded to be more appropriate to HLI by including eligibility to accessing healthcare services based on immigrant status and documentation (Jacobs et al., 2011). Affordability included factors that influence financial ability to pay for services, including educational level, employment, income, and health insurance coverage. All four dimensions served as the basis for data collection methods used in this study. The applicability of the CFAAHS in guiding this study is founded on: 1) its relevancy to the purpose; 2) its ability to promote further understanding of the concept of access; 3) its contribution to gaps in literature pertaining to access in HLI; and, 4) its ability to enhance the understanding of SDH.

The ability of the CFAAHS to measure both supply and demand side factors influencing barriers to healthcare access among underserved groups supported the purpose of this study (Peters et al., 2008). This study aimed to utilize and measure access as a comprehensive concept that measures the actual use of health services, as well as the degree of fit between needs of health service recipients, and the ability of the healthcare system to meet those needs. Therefore, both demand and supply side factors influencing access were viewed from the perspective of HLI. Additionally, the initial development and use of the framework to explore socioeconomic barriers to healthcare access in developing countries, serves as evidence for its applicability to underserved, marginalized HLI in the U.S. The growing HLI community continues to suffer from social and health inequities as a result of maldistribution of power, money, and resources, making it imperative to explore how social determinants deter access to healthcare services in this population (Prus et al., 2010; Quesada et al., 2011).

Few studies that have used the CFAAHS focused predominantly on the dimension of geographic accessibility of healthcare services in developing countries (Jacobs et al., 2011; Pechansky & Thomas, 1981; Peters et al., 2008). In a study investigating the influence of physical accessibility on the utilization of health services in Yemen, Al-Taiar, Clark, Longenecker, & Whitty (2010) found a strong association between distance (driving distance and driving time) to acquiring preventive health services and the

vaccination of children. By focusing on geographic accessibility, the use of the framework in this study highlights the influence of geospatial and socioeconomic SDH on healthcare access and health outcomes. Similarly, Munoz & Kallestal (2012) focused on the geospatial aspects of the CFAAHS by measuring geographic accessibility of the primary healthcare facility network in the Western Province of Rwanda. Findings from this study indicated that the majority of the population in this underserved Western Province has significantly restricted access to the primary healthcare network. Barriers to accessing healthcare services were attributable to the financial capacity of the healthcare system, existing federal policies and regulations, roadway infrastructure, and the ability of underserved populations to afford transportation to access services. The CFAAHS was used in this study to provide an understanding of geographic accessibility within a sociocultural, economic and political context. Although these studies focus solely on geographic accessibility, findings demonstrate the ability of the CFAAHS to elucidate a contextually based understanding of other social determinants of healthcare access.

Gaps in literature on the use of the CFAAHS indicate the need for continued research aimed towards clarifying the concept of access, which is poorly defined and understood by health service providers, recipients, and policymakers alike (McGibbon et al., 2008). Applying the CFAAHS to this study helped identify the central areas where barriers pertinent to determining access to healthcare must be measured (Peters et al., 2008). The application of the CFAAHS in understanding the social determinants of healthcare access contributes to the CSDH's (2008) recommendation that calls for enhanced research using multi-method approaches to provide in-depth, contextually based understandings of SDH. Aligned with the WHO's definition of access, the CFAAHS provides an understanding of access in relation to SDH, which incorporates historical, sociocultural, economic, and political factors. The emphasis on historical contexts, which shape current sociocultural, economic, and political structures, is the hallmark of postcolonial scholarship, which will be used to guide the theoretical underpinnings of this study.

Postcolonialism: A Theoretical Framework

In general, postcolonialism refers to theoretical and empirical works that focus on the issues of colonialism and their aftermath (Ashcroft, Griffiths, & Tiffin, 2006; McLeod, 2000). The prefix 'post' does not refer to a chronological succession alone, but also to the opposition of dominant references of knowledge established by the colonizer (Loomba, 2005). Postcolonialism purports that subjectivities or the

identities of the colonized are determined through the discourses of colonial power, which situate the colonized in inferior positions and frames them as the ‘Other’² in order to set them apart from the colonizer (Slemon, 1995; Smith, 1999). Although, the unique theoretical strands of postcolonialism cannot be defined as being of one unified field, there are several fundamental themes that can be found in most postcolonial studies, including race and ethnicity, Other and the subaltern, and identity and hybridity.³ Postcolonial critical inquiry has slowly emerged in healthcare research to further understand health experiences of marginalized groups, in an attempt to bring subjugated knowledges⁴, or other ways of knowing into the current context of health (Anderson, 2000a; Foucault, 1972; Kirkham & Anderson, 2002, 2010). This critical theoretical lens enhances knowledge of the everyday experiences of marginalization through the mechanisms of race, culture, power, and oppression, and the intersectionality of these mechanisms in relation to health and illness (Kirkham & Anderson, 2002; Mohammed, 2006).

Colonialism and Postcolonialism as the Foundation of Theory

Historically, colonialism occurred with the expansion of European empires as a commercial operation, with the desire to create and control markets for Western goods through the exploitation of other non-Western nations (Judd, 1996; McLeod, 2000). Boehmer (1995) defines colonialism as “the settlement of territory, the exploitation or development of resources, and the attempt to govern the indigenous inhabitants of occupied lands” (p.2). This definition emphasizes settlement, economic impact, and unequal power relations as a result of colonialism. The colonial histories of the Americas, especially in relation to Hispanic Latino communities in the U.S. are often underrepresented or misrepresented throughout history (Perea et al., 2007; Telles & Ortiz, 2008). Historical accounts of colonialism are focused predominantly on Eastern colonization by Western empires, disregarding the oppression and domination of other regions of Latin America and the Caribbean (Turner & Guerrero, 2003). However, the colonality of these groups is central to understanding current social injustices experienced by HLI in the U.S. (Delgado, 2007; Delgado & Stefancic, 2007).

The independence of the U.S. and Mexico from British and Spanish colonial rule respectively, marked the end of colonality in the Americas and the beginning of neocoloniality and imperialism (Sage,

² Conceptual definition of terms can be found in Appendix D.

³ *Ibid.*

⁴ *Ibid.*

2010). Early in this period, years of war and conflict resulted in the Mexican cession, where large portions of land that once belonged to Mexico, including present-day states of California, Nevada, Utah, New Mexico, most of Colorado, and parts of Texas, Oklahoma, Kansas, and Wyoming, were ceded to the U.S. (Mills, 2003). As the U.S. used its military prowess and resources to seize and control these Mexican territories, it radically changed from being a once-colonized nation to being the colonizer (Boehmer, 1995; Childs & Williams, 1997).

Although not commonly portrayed as a colonizing nation in popular history, the use of imperialistic tactics by the U.S. to overthrow Mexican governance over the Northwestern territories of America resembles colonial approaches to conquest. Exertion of this imperial power is not easily identified in history, often times masked by several treaties and compromises that occurred amidst relentless conflict and bloodshed (Delgado, 2007; Delgado & Stefancic, 2008; Haynes, 2001). These treaties deprived original settlers of their ancestral lands, who both voluntarily and involuntarily fled their homes seeking opportunities further south. Others were forced to find employment as farm workers, tending to the fields of Anglo farmers that once belonged to them. Following the Mexican-American war in 1848, the U.S. continued to expand its ownership of territories such as Puerto Rico and other islands formerly under Spanish rule, establishing itself as a leading imperial force (Malavet, 2004; Perea et al., 2007).

The history of the U.S. from being a colonized entity to becoming a Western imperial powerhouse sheds light on the influences of colonial discourses of power on the subjugation and oppression of the colonized, especially Native Americans and Hispanic Latino groups (Perea et al., 2007). As colonialism around the world has indicated, both physical occupation of land as well as the colonizing of the mind can have serious and lasting psychological repercussions on the colonized (McLeod, 2000). Colonizing of the mind is a method of internalization that occurs when the colonized accept and perpetuate their inferior social positions and redefined colonial identities as a reality. Therefore, the subjectivities or the identities of the colonized are determined through the discourses of colonial power, which situate them in inferior positions and frames them as the Other in order to set them apart from the colonizer (Slemon 1995, Smith 1999). These constructs of subjectivity, identity, power, and the Other, represent the foundations of postcolonial theory.⁵

⁵ Conceptual definition of terms can be found in Appendix D.

Postcolonial Theory

The emergence of postcolonial theories is rooted in literary studies focused on the representation of colonial discourses through language and texts. Similar to other critical perspectives such as postmodernism, poststructuralism, and Marxist-feminism, postcolonialism encompasses a broad and diverse range of theoretical orientations that are historically situated (Chrisman & Williams, 1994). Over the years, postcolonial critics and theorists in various other disciplines have explored numerous representations of postcolonialism in an attempt to develop theories that can be methodologically applied to research. Following the fall of Western colonial empires, anti-colonial movements that began in the 1950s sparked the publication of many works that serve as the cornerstone for postcolonial theory and writing (Loomba, 2005; Ashcroft, Griffiths, Tiffin, 2006). These include works by anti-colonial writers, such as Frantz Fanon's *Black Skin, White Masks* (1952), Aime Cesaire's *Discourse on Colonialism* (1950), and Albert Memmi's *The Colonizer and the Colonized* (1965). As anti-colonial writings and theories continued to develop, the concept of postcolonialism emerged through the works of several influential writers including Edward Said, Homi Bhabha, and Gayatri Chakrovorty Spivak. Referred to as the "Holy Trinity" of postcolonial writers (Young, 1995, p.165), Said, Bhabha, and Spivak, provide profound understandings of postcolonial theory in different settings around the world. Represented through various discourses, these global perspectives highlight the complexity and unique ability of postcolonial theory to express subjugated knowledges, freed from the dominance and oppression of colonization (Spivak, 1994).

Although, the unique theoretical strands of postcolonialism cannot be defined as being of one unified field, there are several fundamental themes that can be found in most postcolonial studies, including race and ethnicity, Other and the subaltern, and identity and hybridity.⁶ Supported by the works of influential critics and theorists, these central themes are represented under the postcolonial considerations of global, local, and modern (Dirlik, 2006). Postcolonial considerations of global and local are often referred to in conjunction with each other, as the structure of global power relations and influence of this domination on local communities explicates current understandings of globalization and glocalization (Dirlik, 1994; Gikandi, 2006; Robertson, 2006). The current notions of globalization based on postcolonial theory are concerned with "new forms of social and cultural organization whose ambition is to transcend

⁶ Conceptual definition of terms can be found in Appendix D.

the boundaries of the nation-state” (Gikandi, 2006, p.627). By bringing together the global and the local, new venues for understanding globalization and cultural heterogeneity based on a de-centered framework are established. Glocalization represents such a framework, which emphasizes the interconnectedness of global and local cultures, and decenters dominant colonial discourses to expose subjugated voices. These perspectives are represented through postcolonial understandings of Other (ness), hybridity, and unhomeliness.

Otherness and the Other. The earliest impact of postcolonialism was seen in the academic world with Said’s (1978) *Orientalism*, which serves as a seminal piece for challenging dominant colonial discourses in literary studies (Loomba, 2005; McLeod, 2000). A shift in the paradigm of postcolonialism was prompted by Said’s use of French high theory and Marxist ideology as a method of deconstructing and historically examining the roots of the concept of *Orientalism* (Ghandi, 1998; Moore-Gilbert, 1997). *Orientalism* utilizes the method of discourse analysis to explore how the study of the ‘Orient’ (referring to what is now the Middle East and Far East regions) and related texts were influenced by dominant, colonial ideologies (Said, 1978). Therefore, subjugated knowledges of the colonized were considered to be muted or made obsolete relative to the knowledge created by colonial powers. The marginalization of the indigenous centered the colonizer and created a sense of ‘otherness’, where the colonized were considered to be inferior or less than human (Said, 1994).

Postcolonial perspectives of glocalization focus on decentering the colonizer and other dominant ideologies to reveal the complex, overlapping nature of culture (Gikandi, 2006). According to Appadurai (1996), globalization constitutes “a complex overlapping, disjunctive order that cannot any longer be understood in terms of existing center-periphery models” (p.32). The global culture produces new perspectives of knowledge related to its heterogeneity of race, ethnicity, culture, identity, and subjectivities, also referred to as hybridity.

Hybridity and unhomeliness. Similar to Said, postcolonial theorist Homi Bhabha focuses on the experiences of the colonized, emphasizing issues of conflicting cultural identity (Loomba, 2005). Primarily based on aspects of psychoanalysis, Bhabha’s approach to postcolonial theory is represented through abstract and complex venues (McLeod, 2000). One of Bhabha’s most influential contributions to postcolonial studies is the concept of hybridity. Bhabha considers hybridity to be a “discursive,

enunciatory, cultural, subjective process having to do with the struggle around authority, authorization, deauthorization, and the revision of authority” (Olson & Worsham, 1999). Therefore, Bhabha views hybridity not as a diverse representation of cultures, but as a social process. Hybridity refers to the ambivalence associated with colonial identities that creates a sense of ‘unhomeliness’, or the feeling of being caught or trapped between two cultures (Bhabha, 1994). The sense of being unhomed, or not feeling at home even in one’s own home, is resonant of a cultural identity crisis that serves as both a physiological and psychological sense of entrapment (Tyson, 2006). An important aspect of Bhabha’s view on postcolonialism and hybridity is his definition of colonial identities, which are unstable, agonized, and in constant flux, underlining that neither the colonized nor the colonizer are independent of each other (Loomba, 2005, p.149).

In terms of postcolonial globalization, hybridity helps harmonize the global and the local, or the universal and the specific in understanding the multiplicities of cultural knowledge and relationships (Gikandi, 2006; Bhabha, 1994). According to Pieterse (1998), it is through postcolonial hybridity that globalization is able to defy homogeneity, imperialism, westernization, and Americanization. The ideologies of home and homelessness with respect to globalization resonate with the postcolonial concept of unhomeliness, which influences the subjectivities or identities of individuals and cultures. Therefore, glocalization, which considers both global and local, helps understand the concept of hybridity in relation to cultural diffusion and heterogeneity (Robertson, 2006). Understanding cultural heterogeneity as a result of glocalization is especially significant to the experiences of diaspora communities, such as HLI.

Neocolonialism and Imperialism

Neocolonialism refers to the idea of being economically and/or culturally dependent on colonial rule, which primarily occurs through modern colonial manifestations of imperialism (Loomba, 2005; McLeod, 2000). Resembling a contemporary form of colonialism, neocolonialism alludes to any form of control over once colonized regions or populations that continue to suffer under conditions of internal colonialism. In postcolonial discourses, however, neocolonialism is more insidious and difficult to detect and challenge than overt manifestations of colonialism (Browne, Smye, & Varcoe, 2005). Therefore, the voices of the oppressed and disenfranchised in once-colonized communities continue to be subjected to

neocolonialism through imperialist forces. Postcolonialism aims to rediscover and give voice to these subjugated knowledges, known in postcolonial theory as the 'subaltern'.

Subaltern. Based on the works of early twentieth-century Italian Marxist thinker Antonio Gramsci, subaltern is defined as "the general attribute of subordination..., whether this is expressed in terms of class, caste, age, gender and office or in any other way" (Guha, 1988, p.35). While Bhabha constitutes that the voices of the subaltern, though ambivalent, are represented in colonial text, Spivak argues that these voices are suppressed or altogether muted (Gandhi, 1998; McLeod, 2000; Parry, 2004; Spivak, 1994). Spivak (1994) purports that subaltern voices are muted, or lost in the transaction between the speakers and the listeners. So it is not that the subaltern cannot speak, but rather that the listeners do not know how to listen or contextually interpret subaltern voices (McLeod, 2000). Unlike Said and Bhabha, Spivak brings a unique positionality to postcolonialism based on feminist, Marxist, and deconstructionist theories. Postcolonial theorists understand that they cannot speak for the subaltern, but rather must allow the subaltern to express narratives and interpretations based on their own experiences. In modern considerations of postcolonial theory, subaltern voices subject to neocolonial and imperial domination, are not adequately heard and represented, especially in cultural studies such as ethnography. Giving voice to the subaltern is particularly significant in cultural studies of HLI in the U.S., because of their marginalized positions based on race and ethnicity, socioeconomic status, and levels of educational and English proficiency.

American postcoloniality and contemporary neocolonialism. Though colonial rule has become obsolete in the contemporary world, imperialism continues as the Western world attempts to secure wealth and power through economic exploitation of other less-developed nations (Boehmer, 1995; Judd, 1996; McLeod, 2000;). The imperialism of the U.S. is an example of the ability of nations to globally wield economic and military power without exercising direct political control, allowing it to function without formal colonies (Lomba, 2005). American imperialism has had and continues to have a significant impact on the current conditions and experiences of HLI in the U.S. Furthermore, postcolonialism and contemporary neocolonialism help shed light on the current social conditions and inequities affecting HLI (Delgado & Stefancic, 2008).

Despite close physical proximity and what is conceived to be fairly strong international or foreign policy relations with the U.S., Latin American and Caribbean nations continue to struggle with the aftereffects of historical colonial domination, and current effects of neocolonialism (Loomba, 2005). Similarly, HLI communities situated in the U.S. remain marginalized from society as a result of laws, policies, and racial discrimination affecting their ability to obtain access to equitable public services and resources (Delgado & Stefancic, 2008). A popular neocolonial perspective shared by critics is the idea that HLI communities within the U.S. represent an internal colony, marginalized from mainstream society and subjected to oppression and domination similar to colonial rule (Acuna, 2005; Delgado, 2007; Delgado & Stefancic, 2008). This notion disassociates postcolonialism from formal decolonization, suggesting that colonial oppression affects people living in both once-colonized and once-colonizing countries (Klor de Alva, 1992).

It is evident that American coloniality, postcoloniality, and neocoloniality play a significant role in understanding the current sociocultural, economic, and political structures affecting HLI in the U.S.. The cultural and racial identities of Hispanics and Latino's continue to be defined from dominant, Western ideologies influenced by colonialism that continues to place them in marginalized positions. Through the postcolonial considerations of the global, local, and modern, several key constructs such as the Other, hybridity, unhomeliness, and the subaltern, have been shown to be relevant to HLI. Therefore, inclusion of American colonialism in understanding contemporary issues affecting increasingly globalized and diverse U.S. societies is further recommended in the field of postcolonial studies (Anderson, 2000a; Hulme, 1995; Klor De Alva, 1992).

Applying Postcolonial Theory to Research

Over the years, a limited number of nurse researchers and theorists have adopted postcolonialism to provide basis for understanding the health experiences of marginalized indigenous populations (Kirkham & Anderson, 2002, 2010). Although these researchers and theorists relate postcolonial theory to health research (Anderson, 2000b, 2004; Anderson & McCann, 2002; Blackford, 2003; Racine, 2003), only one study successfully operationalizes the theory by applying the postcolonial framework at various stages of the research process (Mohammed, 2006). Mohammed (2004) used CE to explore how contextual factors and colonial discourses shaped the way urban American Indians interpreted their life and experiences with

diabetes. Findings revealed that participants viewed diabetes as a physiological disease, but associated diabetes with their colonial histories and its influence on current interactions with dominant, white society. By using postcolonial theory, Mohammed (2004) was able to describe how historical, sociocultural, economic, and political factors affect an individual's health and overall lifestyle.

No studies could be found that operationalized postcolonial theory to examine the health experiences of HLI. The lack of research in this area is primarily due to the limited understanding of the colonial history of the Americas and the influence of colonization and migration of diasporic Hispanic groups on current social structures (McLeod, 2000). The impact of colonialism on the increased rates of migration and resettlement illuminates the centrality of diasporas on postcolonial studies and is especially important in illuminating the social position of HLI in current U.S. society (Ashcroft et al., 2006; Clifford, 2006). Among numerous other historical diasporas, including slavery, the diasporas of Hispanic Latino populations in the U.S. have significant social, cultural, economic, and political implications. The majority of Hispanics and Latinos became a part of the U.S. by conquest or arrived here by immigration (Delgado & Stefancic, 2008; Perea et al., 2007). The 19th century Mexican diaspora into the U.S. occurred as a result of ongoing labor shortages within the nation, prompting the heavy recruitment of Mexican laborers for railroad, mining, and farming industries (Latapi & Janssen, 2006). Throughout the years, Mexican migration in and out of the country continues to be greatly influenced by labor markets, and political and economic forces. Rinderle (2005) purports that individuals residing in the U.S., identified under the ethnic and racial categories of Mexicano/a, Mexican American, Chicano/a, Hispanic, and Latin have all resulted from the Mexican diaspora, making them subjects of both diasporic and colonial discourses.

As a diaspora community subjected to both physical marginalization and social segregation, HLI are isolated and often feel excluded from the mainstream U.S. culture (McLeod, 2000; Delgado & Stefancic, 2008). As in other developed, Western nations, immigrants in the U.S. are frequently not recognized as being a part of the larger society, situating them (migrants) in a displaced position. This segregated positionality, defined by the dominant discourses of race and ethnicity, and influenced by historical, sociocultural, economic, and political societal structures, is manifested through various institutions. Immigrant experiences, however, challenge and redefine these dominant colonial discourses. Postcolonial theory and the concepts of race, ethnicity, culture, and identity illuminate the influence of

colonial discourses on the positioning of HLI in the hierarchical social structure of the U.S. Hierarchical social positioning is a manifestation of imperialism, which can be further understood through the postcolonial derivative of neocolonialism.

The ancestral roots of HLI groups has been minimized or erased as a result of colonization and colonial diasporas, consequently leading to minimal recognition of these effects on current social structures. Despite these limitations, it is essential to understand the historical, sociocultural, economic, and political contexts that influence the current experiences of HLI, especially in terms of social justice and equity to healthcare access. By using postcolonial theoretical perspectives to represent subjugated knowledges of health and healthcare access among HLI in the U.S., the existence of alternative ways of knowing are represented (Kirkham & Anderson, 2002, 2010; Mohammad, 2006; Foucault, 1972).

This study represents subjugated knowledges⁷ by exploring the SDH that serve as barriers and facilitators to healthcare access as perceived by HLI in Louisville, KY (Dirlik, 1994; Slemon, 1990). In particular this study examined how knowledge, belief, and value systems of health and healthcare access for HLI are indirectly influenced by postcoloniality. This approach to postcolonial theory provided a mechanism to explore the multiplicities of knowledge through the constructs of colonial discourses in relation to ethnicity, race and racialization,⁸ within the context of HLI experiences (Bhabha, 1994, Said, 1978; Spivak, 1993, 1994). As the overarching theoretical stance of this study, postcolonial theory was used to guide various aspects of the research process, including critical ethnographic methodologies, selection of study settings and participants, and data collection methods. This study used five distinctive features to effectively incorporate postcolonial theory in the research methods.

First, this study was framed from a political stance built on the postcolonial concepts of ethnicity, race and racialization, and power relations as a result of colonization, allowing for a presentation on “how domination and resistance mark intercultural healthcare encounters at individual, institutional, and societal levels” (Kirkham & Anderson, 2002, p.10). Second, by utilizing a reflexive research process, the socially constructed nature of the meanings of health and practices of healthcare derived from experiences of the participants were positioned in larger historical, sociocultural, economic, and political contexts. Explicating experiences utilizing such a reflexive process allows us to see how they are shaped by dominant discourses

⁷ Conceptual definition of terms can be found in Appendix D.

⁸ *Ibid.*

of power and oppression (Campbell & Manicon, 1995). The use of critical ethnographic methods in this study provided an ideal mechanism from which to understand the socially constructed experiences of everyday life by “giving voice” to participants within different contexts (Stevens, 1989). Third, by incorporating the perspectives and experiences of marginalized HLI, this study deliberately decenters dominant ideologies and culture that consequently gives voice to subjugated knowledges of the subaltern or the oppressed (Freire, 1970; Spivak, 1994). Fourth, by acknowledging the dominant postcolonial theme of race with equally significant themes of class, gender and nationality, this study accounted for the intersectionality of the analyses of oppression of HLI within the context of historical colonialism (Kirkham & Anderson, 2002). Fifth, this study aimed to be praxis-oriented, challenge the status quo, illuminate inequities in the distribution of power and resources, and function as a foundation for building a just society through social change (Freire, 1970; Creswell, 2007).

According to Kirkham and Anderson (2002), the role of nursing scholarship within an emancipatory research paradigm requires a commitment to critical inquiry that moves beyond describing what “is” to what “ought” to be (p.13). By exploring the social determinants of healthcare access among HLI, the emancipatory goal of this study is to illuminate the structural barriers to healthcare access stemming from colonial and imperial hegemony, which may serve to empower HLI to understand their rights to accessing healthcare with the goal of promoting social justice and reducing health inequities. This necessitates the use and application of postcolonial perspectives through various stages of the research process and can best be achieved through the use of critical ethnographic methods.

The Dialectic Between Postcolonial Theory and CE Methodology

A central feature of postcolonial scholarship is a strong research-theory dialectic that provides an interpretive, critical lens to research by recognizing historical influences that shape everyday experiences (Kirkham & Anderson, 2002). This study addressed this vital characteristic through the partnering of postcolonial theory and CE. Critical ethnography, guided by critical theory, is an ethnographic method of research with the purpose of uncovering social injustices and inequities afflicting the oppressed (Bransford, 2006; Carspecken, 1996; Madison, 2005; Thomas, 1993). It goes beyond conventional ethnography by focusing on changing cultures through the uncovering of hidden agendas and assumptions governed by dominant discourses, and raising awareness of historical, sociocultural, economic and political influences

of power on contemporary social structures (Bransford, 2006; Carspecken, 1996; Madison 2005; Thomas, 1993).

Guided by critical theory, an essential ontological assumption of CE purports that the social structures and content of culture create debilitating and unequal social conditions for oppressed groups (Thomas, 1993). According to Thomas (1993), “cultural forces may shape both the condition and social responses that disadvantage some groups more than others” (p.33). Therefore, CE serves as an ideal methodological framework from which to explore the oppressive mechanisms integral to culture and societal contexts. Another assumption of CE is that historical interactions significantly influence dynamic cultural, political and economic social structures (Stevens, 1989). Discourses of cultural knowledge are a product of these social processes, often influenced by dominant ideologies and knowledges (Anderson, 1989). Therefore, the ontological perspectives of CE are closely related to epistemological constructs, where critical ethnographers aim to reveal the patterns of social domination and privilege that lie beneath the surface of dominant ideologies and reveal the oppressive side of social life. Critical ethnographers move beyond merely describing ‘what is’ to ‘what ought to be’ by revealing injustices that constrain the oppressed from social equality and pursuing knowledges that challenge the status quo.

Rooted in critical pedagogy, postcolonial theory and CE share similar theoretical tenets and features, yielding a comprehensive method for examining healthcare access inequities (Freire, 1970; Kirkham & Anderson, 2002). The methodological approach of CE was selected for this study because of its emphasis is on illuminating the injustices and inequities in current societal structure that HLI face as a result of their colonial histories (Thomas, 1993). Historical interactions and current sociocultural, political and economic structures provided a basis for understanding the marginalized and undeserved positionality of HLI (Stevens, 1989). Similarly, postcolonialism provides a framework to analyze the effects of race and racialization, structures of power, and situations of dominance and oppression as a result of historical colonialism (Bhabha, 1994, Said, 1978; Spivak, 1993, 1994). Therefore, the emphasis on historical contexts was manifested through the use of postcolonial theory and CE in this study.

Critical ethnography focuses on the exploration of social injustices experienced by the oppressed by raising awareness and empowering individuals to speak against social inequalities (Hammersley & Atkinson, 1995; Thomas, 1993). Postcolonial theories, also aim to give voice to the Other, subaltern, or

oppressed, illuminating subjugated knowledges suppressed by historical colonialism and contemporary neocolonialism (Ashcroft, Griffiths, & Tiffin, 2006; Said, 1978; Spivak, 1993). Conventional ethnographers often have a distant approach to acquiring knowledge, whereas critical approaches have a “fundamental interest in emancipation and empowerment to engage (the participant) in autonomous action arising out of authentic, critical insights (facilitated by the researcher) in the social construction of human society” (Grundy, 1987, p.19). The critical ethnographer often works in the capacity of an emancipatory role, by raising social consciousness and promoting change (Agar, 1996; Thomas, 1993). Unlike traditional realist ethnography, which represses the role of the investigator as being an independent and objective observer, CE explicitly defines the role of the investigator as being an integral part of the culture being studied (Hammersley & Atkinson, 1995). By critiquing existing cultural and social systems, they encourage dialogue to potentiate changes in the oppressive conditions of individuals and groups (Stevens, 1989). This gives CE the ability to create awareness among members of an oppressed group, regarding their current conditions in light of historical, sociocultural, and political contexts. Additionally, CE raises consciousness of members belonging to dominant groups in society concerning the effects of their privileged positions.

The ability of both postcolonialism and CE to bring multiple realities and narratives to the forefront of discourse is indicative of their capacity to assist in illuminating social injustices, and bring changes to current societal structures when applied as a unified method of inquiry (Kirkham & Anderson, 2002). The strong association between postcolonial theory and CE provide a resilient, critically informed approach to the study purpose, research questions, and overall study design. As a combined critically informed theoretical and methodological approach, this framework was central in guiding the research design of this study, including study settings, participants, and data collection techniques.

Conclusion

As HLI continue to grow in the U.S., it is imperative to examine the social determinants of healthcare access that contribute to growing health disparities in this population. However, review of literature reveals limited empirical evidence on SDH impacting access to health services within this population. In order to further understand barriers to healthcare access, continued research utilizing contextually based conceptual frameworks of access is warranted. The CFAAHS provided an ideal framework to explore the SDH that serve as barriers to healthcare access for HLI (Peters et al., 2008).

Through the application of this framework, this research study further enhances understanding of the concept of access in relation to SDH, by identify the perceived barriers and facilitators to healthcare access. The frameworks ability to explore the effect of historical, sociocultural, economic, and political contexts on healthcare access, complemented the theoretical perspectives of postcolonialism. With the goal of destabilizing Western hegemonic ideologies and producing alternative knowledges to dominant colonial discourses, postcolonial theories can irreproachably bring light to the oppressed voices of HLI (Latin American Subaltern Study Group, 1993). The major tenets of postcolonial theory are also appropriately aligned with critical ethnographic methodologies. Informed by critical theory and pedagogy, critical ethnography (CE) is an ethnographic method of research with a political stance, aimed at emancipation of the subjugated and oppressed from social injustices and unfairness (Freire, 1970; Thomas, 1993). With the ethical responsibility of uncovering inequalities afflicting the oppressed, CE raises awareness of historical, sociocultural, economic, and political influences of power on current societal structures (Bransford, 2006; Madison, 2005). Therefore, CE serves as the ideal methodological framework to analyze social injustices and inequities that serve as barriers to healthcare access among underserved HLI in the U.S.

CHAPTER III

METHODOLOGY

Introduction

This study utilized CE to guide the research design and methods based on the theoretical underpinnings of the CFAAHS and postcolonial theory. Examining access to healthcare from the perspective of HLI in the light of various cultural contexts necessitates a qualitative, interpretive approach to research design. According to Denzin & Lincoln (2005), this approach allows for the study of the social world from the perspective of the individual, and is highly applicable to recognizing complexities represented by multiple personal narratives embedded within broader cultural discourses. Ethnography is particularly useful in viewing alternate narratives or realities, as it explores the social and cultural practices of specific cultural groups (Buch & Staller, 2007). However, critical perspectives that are not represented in conventional ethnographic research provide a more suitable method of critical interpretive inquiry of healthcare experiences of marginalized HLI in the U.S.

Although data collection methods in CE are similar to conventional ethnography, the process of collecting data itself is not a neutral process; therefore, the data sources can dramatically influence the critical potential of the study (Thomas, 1993). Initially, it is essential to identify data sources, including key informants and organizations, locations and events, and artifacts (documents, policies, websites, etc.) that can provide the most relevant information. This study fulfilled this need by: 1) selecting geographically identified regions of Louisville with the highest concentration of HLI as the broader setting for the study; 2) identifying particular community organizations that provided health and social services utilized most frequently by HLI; 3) recruiting individual key informants and groups who can provide rich data; 4) collecting relevant documents and artifacts pertaining to healthcare access; and 5) the investigator's immersion into the field of study viewing everything as potential sources of data on which critical analysis is based.

Setting

The setting for the study was the southern region of Louisville, KY, which has a large concentration of HLI predominantly residing in zipcodes 40208, 40214 and 40215 (Urban Mapping, 2011; See Figure 4). Southern Louisville is further broken down into distinct neighborhood areas such as South Central Louisville and South Louisville, which also represent zipcodes 40208, 40214 and 40215 (Center for Health Equity, 2011). It was estimated that a total of 8660 HLI living in these three zipcodes representing roughly 33 % of the total Hispanic Latino population in Louisville (Urban Mapping, 2011). These regions are also subdivided into census tracts 37, 38, 44, 45, 46, 56, and 90, with census tracts 56 and 90 predominantly representing zipcodes 40208, 40214, and 40215 (Figure 4). Census tracts data provide the most accurate estimates of Hispanic Latino populations in southern Louisville. According to the U.S. Census Bureau (2010), census tracts 56 and 90 have the highest concentration of Hispanics and Latinos. Census tract 56 which is bordered by Watterson Expressway, Southside Drive, Southland Boulevard, and Strawberry Lane, has 895 Hispanic Latino residents and census tract 90 has 748 residents.

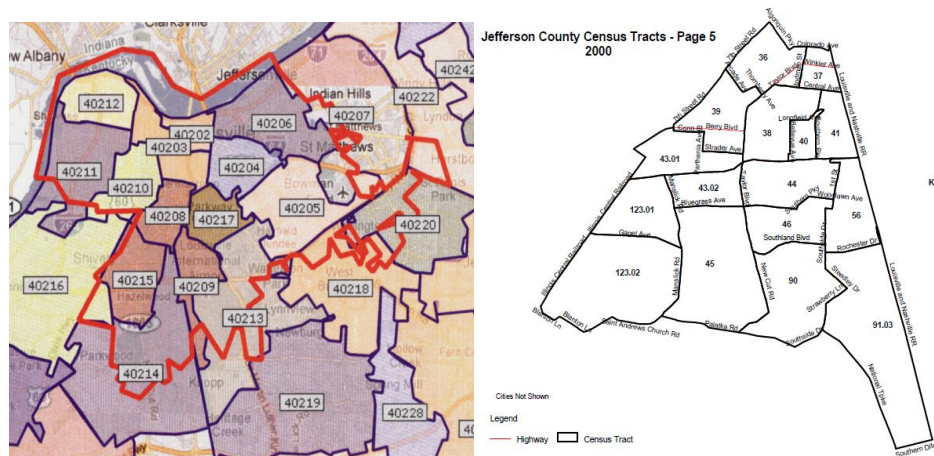


Figure 4. Southern Louisville zipcode and census tracts maps. (City-Data, 2012; Kentucky State Data Center, 2000).

Southern Louisville is home to several community organizations that provide health and social services targeting immigrant and refugee populations who predominantly reside in these neighborhoods. Participant recruitment and data collection occurred in three community and health centers located in this region, including a local community center that provided social services to immigrants and refugees, an infectious disease clinic that served individuals who were HIV positive, and a primary healthcare clinic that

served migrant workers in the horse racing industries. Through pilot work, the community center and the primary healthcare clinic were identified as locations with a significant number of HLI utilizing health and social services provided at these sites. Pilot work at these sites also helped the investigator develop formal relationships with gatekeepers that allowed for amenable recruitment for this study. Through fieldwork and informal interviews, the investigator identified the infectious disease clinic as an important site to recruit participants, especially as a result of the underrepresentation of the growing problem of HIV among HLI in Louisville. Recruitment from this site was made possible through the investigator's partnership with the infectious disease clinic and its medical case manager, who also served as the interpreter for this study.

Sample

Purposeful sampling methods were used to recruit 20 participants from the HLI community for individual interviews (Patton, 2002). Although Denzin and Lincoln (2005) state that a sample size of 30 to 50 interviews is deemed appropriate for ethnographies, Sandelowski (1995) emphasizes on the quality of the sources stating that an adequate sample size needs to be small enough to provide an in-depth, case-oriented analysis, and large enough to provide a varied understanding of experiences. Based on these recommendations, purposeful sampling methods were used to enroll information-rich cases until theoretical saturation of data occurred. Eight participants who were recruited from the community center site participated in this study: 2 mothers who were enrolled in the family education program; 3 employees; and, 3 community members who accessed social services at the center. Four female participants who were recruited from the primary healthcare clinic and 8 individuals (1 female and 7 males) who were HIV positive and accessed services at the infectious disease clinic participated in this study.

Inclusion Criteria. Inclusion criteria were: 1) self-identification as a Hispanic and/or Latino; 2) immigrant status (born outside of the U.S.) through self-report; 3) documented or undocumented; 4) spoke English and/or Spanish languages; and, 5) older than 18 years of age. The intent of participant enrollment in this study was to provide a broad range of experiences and narratives of HLI and their barriers to healthcare access. There were no limitations on the number of years of residence in the U.S. and on the level of English proficiency. These criteria were established because the investigator aimed to represent a variation in demographic characteristics to see if there are differences in experiences of healthcare access. Limited English Proficiency among HLI and immigrants in general has been identified as a significant

barrier to accessing healthcare; therefore, providing these perspectives strengthened the findings of this study (Asanin & Wilson, 2008; Rivers & Patino, 2006; Derose et al., 2007, Harari et al., 2008; Cristancho et al., 2008).

Exclusion Criteria. Only those HLI residents who 1) did not comprehend the informed consent provided verbally and in written format in the language they felt most comfortable using; or, 2) did not consent to having their interviews recorded were excluded from the study.

Procedures

IRB approval (12.0530) was obtained from the University of Louisville prior to initiation of the study. The investigator contacted the different study sites and obtained permission to recruit participants and conduct research. At this time, a certified Spanish to English interpreter was formally recruited and trained to assist with translation of recruitment materials, participant recruitment and data collection. All recruitment materials, informed consents, and data collection tools were translated from English to Spanish, and back-translated from Spanish to English to establish accuracy of content and meaning.

Informational sessions were held at the study sites and flyers were distributed and displayed at the study sites with information regarding the study. Participants were recruited on-site by the investigator and through word-of-mouth with the help of the organizations at the three identified study sites. Detailed description of these sites are provided in part one of research findings to provide a comprehensive understanding of the setting and population. Previous pilot studies with service providers at these various sites allowed the investigator to develop professional relationships with gatekeepers, organizational leaders, and other key individuals, and increased the chances for successfully accessing and recruiting this population. Additionally, the investigator attended various community events such as health fairs, conferences, and meetings that pertained to different areas of research including health disparities, cultural competence, health literacy, immigrant health, Hispanic Latino culture and health, and community outreach. This assisted in networking with key informants and gatekeepers, as well as recruitment. Over the years and throughout the course of this study, the investigator volunteered at various local organizations both in and out of her capacity as a healthcare professional, which allowed for immersion in the field, gaining the trust of local communities, and building networks.

Eligibility criteria for participants were determined for those who expressed interest. English proficiency needs were assessed through initial non-formal communication with participants, who were also asked if they would prefer to have an interpreter available at the interview sessions. For individuals with LEP, an interpreter was present at the interview. The investigator utilized the assistance of a certified Spanish interpreter who has worked with local Hispanic Latino organizations in health and social service sectors. This interpreter assisted in recruiting and conducting interviews with Spanish speaking or LEP participants. The use of interpreter services was utilized throughout the course of this study, because qualified interpreters are essential to assisting investigators in the interview and data collection process, as well as establishing and maintaining relationships with LEP participants (Maltby, 1999; Murray & Wynne, 2001). Although many investigators shy away from including LEP or non-English speaking participants in their studies due to translation problems, it is essential to represent the voice of these individuals through the use of interpreters (Raval & Smith, 2003; Temple, & Young, 2004). As this critical ethnography based on postcolonial theory is built on critical pedagogy, it aimed to include the voice of LEP participants so that multiple perspectives of HLI could be understood (Kirkham, 2000). Therefore, the use of an interpreter was essential in facilitating communication and maintaining the critical stance of this study.

Individual appointments were scheduled at the different recruitment sites with 20 participants. At the initiation of the interview appointment the investigator read through the informed consent, answered questions, discussed study details and verified the participant's understanding before obtaining written informed consent from the individual (see Appendix A for Informed Consent Forms in English and Spanish). During this meeting, interviews were conducted using a descriptive survey form and a semi-structured interview guide developed for this study, and interviews lasted approximately 60 minutes (see Appendix B). Interviews were conducted with 20 participants and all interviews were audio taped to assure accuracy in analysis of data. Compensation for participation in the study was a \$10 gift card to a local grocery store. Data collection lasted approximately 3 months.

Instruments. Instruments developed for and used in this study included a descriptive survey form and a semi-structured interview guide (see Appendix B). The descriptive survey form collected quantitative data on demographic and geospatial healthcare access related information. The descriptive survey addressed research questions 1 to 4 and provided further understanding of sociocultural and economic

contexts, by asking questions related to participant demographics including income, educational level and health insurance coverage. The semi-structured interview guide was developed based on previous pilot study findings and a review of literature, and was tested for reading level and comprehensibility prior to data collection. Mock interviews with two HLI and one immigrant (from another country) were conducted using the interview guide prior to data collection. A standard set of questions regarding the comprehensibility and language/reading level of the guide was asked of the participants once interviews were complete. Participant recommendations were incorporated in the final version of the interview guide used in this study. The semi-structured interview guide also addressed research questions 1 to 4 and provided data regarding individual, historical, sociocultural, economic, and political contexts. Both instruments were translated to Spanish for non-English speaking and LEP participants.

Data Collection. Consistent with CE methods, this study utilized interviews, participant observations, and document reviews as the primary method of data collection (Roper & Shapira, 2000; Wolcott, 1999). Individual, in-depth interviews with study participants were conducted using a descriptive survey form and a semi-structured interview guide (Appendix B). In-depth interviewing has been identified as an effective tool for gathering data that preserves the multifaceted and complex nature of the lived experience (Miller & Crabtree, 2004). As with other types of ethnographic research, CE requires the investigator to be aware of participant responses and constantly compare answers to identify contradictory information and gaps (Thomas, 1993). Critical ethnography requires the investigator to explore meanings that lie below the surface; therefore, several methods can be used to expand the data collection process and enrich the data. Essential to the data-gathering process is the ability of the investigator to be flexible and adaptable to the research process, by making appropriate changes to data collection tools as needed. This was accomplished in this study through the use of a semi-structured interview guide (Appendix B). Interviews using the descriptive survey form and semi-structured interview guide addressed research questions 1 to 4.

Participant observations were a central method in the data collection process of this study. Participant observation allows for the systematic attention to and analysis of practices of everyday life and the immersion of the investigator in the life of research participants (Wolcott, 1999). Immersion of the investigator in the field of study is a key characteristic of CE and allows for prolonged engagement and the

maintenance of detailed observations through extensive field notes, memos, and journals (Spradley, 1980). This method of data collection is also highly useful in the postcolonial approach, as it has the ability to provide a greater understanding of the contexts of everyday lives of HLI. In this study, participant observations were conducted in several ways. Initially, the investigator utilized prolonged engagement with community members at the three different study sites, health fairs, meetings, and other community events to address sociocultural and economic contexts. Informal interviews or discussions were conducted as part of participant observations to gain a deeper, contextual understanding of experiences of HLI. Informal conversations are an essential tool for collecting in-depth information and the opportunity to clarify new ideas and themes as they emerge during the participant observation process (Silverman, 2003). These informal interviews allowed the investigator to enhance participant observations and helped formulate new areas of inquiry in subsequent interviews (Merriam, 1998). To address political and historical contexts informal interviews were conducted with immigration attorneys and legislators, healthcare policy makers, hospitals and other health center representatives, health and social service providers (from private and public institutions) and community liaisons and activists. Participant observation also took place during interviews with participants. Participant observations, which lasted approximately 92 hours, addressed research question 4 and provided insight into all four contextual areas.

Document reviews helped further contextualize research findings on barriers and facilitators to healthcare access. In qualitative research, documents refer to a wide range of written, visual and physical material that helps “uncover meaning, developing understanding and discover insights relevant to the research” (Merriam, 1998, p.133). Documents reviewed in this study included Spanish newspapers and publications (*Al Día en América, El Kentubano, El Shopper Latino, La Prensa, and Kentucky Latinos*); federal, state, local and institutional level protocols, policies and laws pertaining to HLI; informational brochures; and, websites, which included information pertaining to contextual factors that shape the HLI healthcare access experience. Large-scale local studies, reports and documentaries pertaining to HLI, SDH and healthcare access in Louisville were included such as the *Louisville Metro Health Equity Report* (Center for Health Equity, 2011); the *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012); *Latino Immigrants Photo Ethnography* (Mujica, 2011); and, *Unnatural causes: Is inequality making us sick?*(California Newsreel, 2008). These documents helped examine sociocultural,

political and economic contexts. Annual reports from local advocacy and outreach organizations such as the Kentucky Commission on Human Rights (KYCHR) were collected to examine sociocultural and political contexts. Archival records of migratory patterns, immigration policies, changes in demographic profiles, were collected from local government organizations, resource centers (such as libraries) and websites to assist in understanding historical contexts.

Sample selection for content analysis of websites involved identification of organizations and institutions pertaining to immigration, HLI, advocacy, healthcare, social, legal and government services, and other relevant resources. Web pages were imported into qualitative data management software NVivo (QSR International, 2012) using the *NCapture*⁹ function for further analysis and stored for documentation purposes to preserve the integrity of the documents. Laws, bills, policies and other documents were analyzed in a similar manner. Initially, documents were chosen based on the literature review, which indicated there were several fundamental national, local and institutional immigration, welfare, health and social policies pertaining to the HLI experience. These documents were collected from The Library of Congress website and other internet-based resources. Political contexts were established through analysis of different immigration, welfare and healthcare-related policies. Institutional policies regarding provision of culturally competent care and interpreter services in healthcare facilities (local hospitals and health clinics) frequented by the target population, as well as national policies including Title VI (National Archives and Records Administration, 2004) and the PPACA (Pub. Law No. 111-148., 2010) were analyzed to understand political contexts. Hospital and other institutional policies pertaining to diversity, cultural competence, language services and other immigrant-related services were also collected during interviews with administrative staff at these various locations. Document reviews addressed research questions 2 to 4 and predominantly focused on revealing historical and political contexts. Ritchie and Lewis (2003) identify document review and analysis as particularly useful in understanding phenomena that have historical relevance and therefore serves as essential source of data for this dissertation, which is guided by postcolonial theory. Using these documents also helped verify and contextualize the data that was collected during interviews and participant observations (Mason, 2002). Ethical issues were taken into consideration when retrieving documents by obtaining permission from authorized parties.

⁹ See Appendix C for definition of Nvivo functions.

Geospatial accessibility to healthcare access was examined through the collection of geographic data in this study using the descriptive survey form and from existing community maps and records. Geospatial data provided information on the demographics of the HLI population in Louisville; number of primary healthcare providers and facilities within the study setting; distance to acquire health services; and transportation routes among other variables (LeCompte & Scheunsul, 1999). Geographic data assisted in community mapping, which was conducted by a Geographic Information Systems (GIS) Technology Specialist using ArcGIS® (ESRI, 2011).

In order to achieve greater understanding of interview narratives and contextualize all data and findings, detailed observations and descriptions were maintained in written field notes and memos of the physical setting, social interactions and relationships, meanings, beliefs, emotions, and other non-verbal methods of communication (LeCompte & Scheunsul, 1999; Spradley, 1980). Field notes and memos were maintained in field jottings, a diary and a log, and formal field notes including methodological notes, descriptive notes, and analytic notes (Bernhard, 2006). Field jottings were recorded on a notepad which was used to jot down key ideas that emerged during the data collection process, particularly during informal interviews. The investigator maintained personal thoughts and reflections in a diary that was kept separate from the field notes. This is especially significant in critical ethnographic methodologies which emphasize the reflexivity of the investigator and the influences of personal bias on data findings (Bernhard, 2006). The diary helped the investigator reflect upon own biases and perspectives to better understand how it may or may not have influenced the study. The log helped keep a daily account of how time and resources were spent by the investigator, allowing for a systematic collection of both qualitative and quantitative data and maintaining systematic fieldwork. Field jottings and logs were maintained in writing and electronically to help with management of data using NVivo (QSR International, 2012). Methodological, descriptive and analytic notes were maintained throughout the research process to help intellectualize and theorize what was being observed and critiqued by the investigator (Bernhard, 2006).

Data Analysis and Critical Interpretation

Data collection and analysis occurred concurrently and in several overlapping phases. Management and initial coding of qualitative data was facilitated through the use of NVivo data management software (QSR International, 2012). Audiotapes of in-depth interviews were transcribed by a

professional transcriptionist and verified by the investigator for accuracy. Thorough and systematized documentation of all field notes and memos were maintained electronically. All transcribed materials, documents, and fieldnotes and memos were imported into NVivo (QSR International, 2012), including websites and web documents using the *NCapture*¹⁰ function. This function preserves the integrity of the document being reviewed, representing texts and pictorial data used during analysis.

Interviews, participant observations, document reviews, field notes and memos. Descriptive coding was done in order to organize, categorize and contextualize interview and participant observation data, document reviews and field notes and memos using content analysis techniques (Richards & Morse, 2007). Content analysis is a research method that analyzes the presence, definitions and relationships between concepts that allows the investigator to make inferences about the individual or group being studied (Carley, 1990; Krippendorf, 1980; Webber, 1990). As content analysis requires the use of a predetermined set of categories, this study used concepts and categories that were developed based on the CFAAHS and postcolonial theory (Carley, 1972; Duncan, 1989). In this study, content analysis was conducted using word-based coding techniques such as word repetitions and frequency counts, text searches for key words and key-word-in-context (KWIC) searches using NVivo *Word frequency* and *Text Search* functions to determine key concepts and their relationships (Ryan & Bernhard, 2003).¹¹ Word frequency counts provided an efficient way to look for themes in large amounts of textual data, and KWIC helped further understand the use of concepts within various contexts, which helped identify themes (Ryan & Bernhard, 2003). Content analyses results were visually represented using tables and through cluster analysis reports imported from NVivo.¹²

Analytic coding using line-by-line analysis was conducted to help identify emerging patterns, categories, concepts and themes (Richards & Morse, 2007). This involved the use of constant comparison analysis and open-coding methods used in grounded theory methods, which allowed the investigator to analyze the data by dissecting, comparing, and categorizing the data, which resulted in more in-depth emergent themes (Strauss & Corbin, 1990). Guided by a multidimensional theoretical framework, pre-defined categories under the CFAAHS and postcolonial theory were used to attribute codes to the various

¹⁰ See Appendix C for definition of Nvivo functions

¹¹ *Ibid.*

¹² *Ibid.*

theoretical constructs. In order to facilitate group coding, transcribed participant interview texts, participant observation field notes and memos, and document reviews were analyzed into three major overarching categories, with themes and subthemes. For example, barriers to healthcare access pertaining to availability collected during participant interviews were categorized under the *PBAvailability* (Participant-Barriers-Availability) and corresponding themes such as *Healthcare Personnel Characteristics* and subthemes such as *Interpreter Availability and Training*. A detailed description of this analytic process is provided in the following section.

Interview data. The use of text queries assisted in the examination and representation of data from a theoretical perspective to help generate significant cultural and social themes (Bernhard, 2006; Ryan & Bernhard, 2003). By querying the text, the investigator was able to contextualize participant perspectives about their environment, community, relationships with healthcare providers, healthcare system, and political views among other areas (Bogdan & Bilken, 1982). According to Charmaz (1990), “Moving across substantive areas fosters developing conceptual power, depth, and comprehensiveness” (p.1163). To add depth to data analysis, the investigator also searched for missing information and themes, to identify if areas that were not discussed were significant to the study. The underlying political undercurrent of this study necessitated the investigator to be aware of use of silence, absence of topics discussed, signs of sensitivity, and other non-verbal cues that were at times more revealing than what was being said by the participants (Ryan & Bernhard, 2003).

Each step of the analysis process was conducted systematically using line-by-line coding, content analysis and constant comparative techniques. Major themes and subthemes were derived from coded data using NVivo cluster analysis results under each access dimension (QSR International, 2012).¹³ The use of cluster analysis provided theoretical insights and patterns that helped the investigator derive causal linkages or relationships between concepts (QSR International, 2012). Initially, line-by-line coding identified several recurrent themes in participant interviews that were further categorized into larger themes based on cluster analysis results. After data were sorted and categorized, it was then reconstructed and represented in meaningful and comprehensible ways for the reader to understand through tables (Jorgensen, 1989). Tables represent themes, subthemes, number of references and sources. Central themes and corresponding codes

¹³ Detailed descriptions on how to interpret cluster analysis and definitions of other NVivo functions are provided in Appendix C.

were discussed in further detail under study findings to give voice to participant experiences and perspectives. This analytic cycle was followed for availability, accessibility, affordability and acceptability dimensions of access under barriers and facilitators.

The derivation of themes from analysis of availability barriers was a complex process due to the depth and breadth of coded items under each theme and subtheme. Continual re-reading, coding and the use of cluster analysis results (Figure 5) assisted in the categorization of subthemes into larger themes displayed in Table 1.

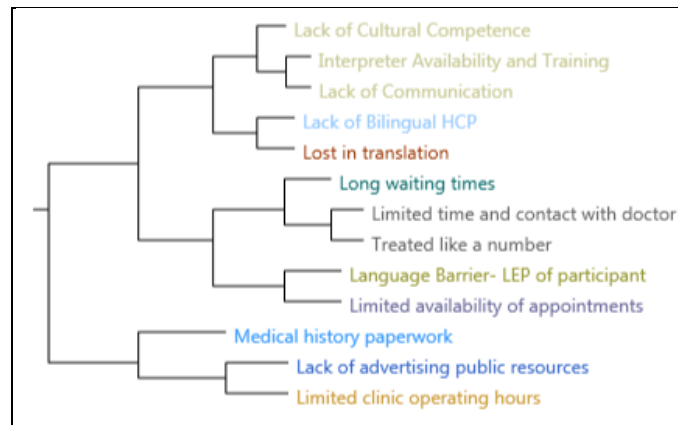


Figure 5. Cluster analysis results of availability barriers.

Table 1

Themes, Subthemes and Number of References and Sources of Availability Barriers

Themes	Subthemes (References, Sources)*
Time and Availability	Treated like a number (12, 6); Long waiting times (12,11); Limited time and contact with doctor (11, 6); Limited availability of appointments (8, 4); Limited clinic operating hours (1, 1)
Healthcare Personnel Characteristics	Interpreter availability and training (16, 9); Lack of cultural competence (11, 10); Lack of Bilingual Healthcare Personnel (8, 6)
Patient-Provider Communication	Lack of communication (25, 14); Lost in Translation (11, 9); Language Barrier-LEP of Participant (6, 9)
Navigating the Healthcare System	Medical history paperwork (5, 3); Lack of advertising public resources (5, 4)

Note: *See Appendix C for NVivo Functions

Coding for accessibility barriers was more direct than coding for availability barriers, indicating distinct themes as evidenced by cluster analysis results (Figure 6).

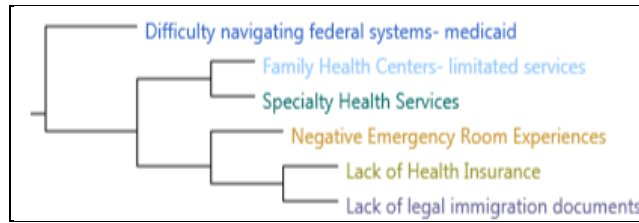


Figure 6. Cluster analysis results of accessibility barriers.

Cluster analysis results assisted in the categorization of barriers to accessibility subthemes into larger themes as displayed in Table 2.

Table 2

Themes, Subthemes and Number of References and Sources of Accessibility Barriers

Themes	Subthemes (References, Sources)*
Documentation	Lack of Health Insurance (21, 12); Lack of legal immigration documents (15, 10)
Emergency Room	Negative Emergency room experiences (13, 8)
Type of Healthcare Facility	Specialty Health Services (5, 4); Public health clinics (2, 2)

Note: *See Appendix C for NVivo Functions

Line-by-line coding identified several recurrent affordability barrier themes in participant interviews that were further categorized into larger themes based on cluster analysis results (See Figure 7).

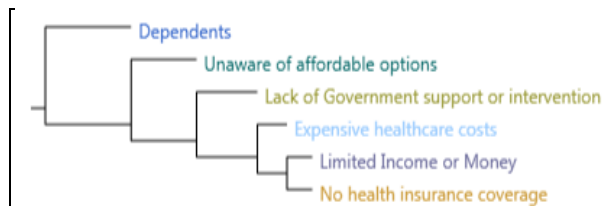


Figure 7. Cluster analysis results of affordability barriers.

Cluster analysis results assisted in the categorization of barriers to affordability subthemes into larger themes as displayed in Table 3.

Table 3

Themes, Subthemes and Number of References and Sources of Affordability Barriers

Themes	Subthemes (References, Sources)*
Financial Barriers	Expensive healthcare costs (33, 15); No health insurance coverage (27, 13); Limited income or financial resources (18, 9); Dependents (7, 5)
Knowledge and Awareness	Unaware of affordable options (4, 4)
Resources	Lack of Government support or intervention (3, 3)

Note: *See Appendix C for NVivo Functions

Similar to availability barriers, acceptability was another complex area to analyze as a result of the numerous codes and themes that emerged from the data. Line-by-line coding and cluster analysis results helped identify several recurrent themes (Figure 8).

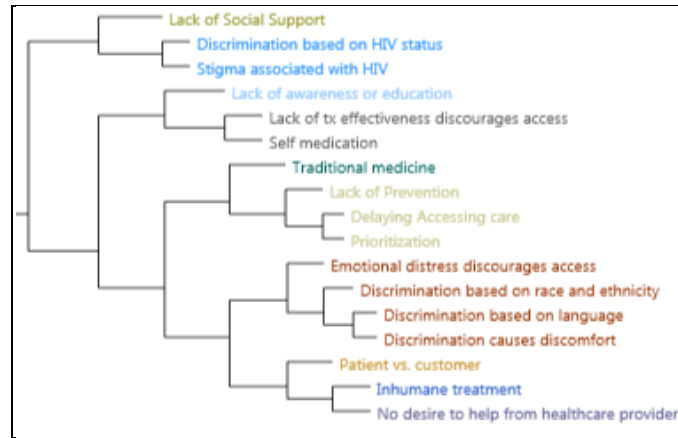


Figure 8. Cluster analysis results of acceptability barriers.

Cluster analysis results assisted in the categorization of barriers to acceptability subthemes into larger themes as displayed in Table 4.

Table 4

Themes, Subthemes and Number of References and Sources of Acceptability Barriers

Themes	Subthemes (References, Sources)*
Discrimination	Discrimination based on race and ethnicity (17, 12); Discrimination based on language (14, 11); Discrimination based on HIV status (8, 5)
Cultural Barriers	Stigma associated with HIV (11, 6); Self-medication (7, 5); Lack of treatment effectiveness discourages access (6, 5); Traditional medicine (4, 4)
Health-seeking Behaviors	Delaying accessing care (12, 8); Prioritization (8, 7); Lack of awareness or education (6, 5); Lack of prevention (4, 4)
Mental Health	Emotional distress discourages access (13, 6); Discrimination causes discomfort (9, 8)
Healthcare Business	No desire to help from healthcare provider (14, 8); Patient vs. Customer (11, 5); Inhumane treatment (8, 6); Lack of social support (3, 3)

Note: *See Appendix C for NVivo Functions

Line-by-line coding identified several recurrent availability facilitators to access themes in participant interviews that were further categorized into larger themes based on cluster analysis results (Figure 9).

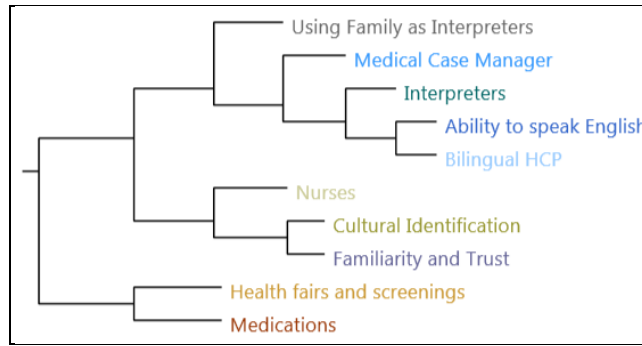


Figure 9. Cluster analysis results of availability facilitators.

Cluster analysis results assisted in the categorization of facilitators to availability subthemes into larger themes as displayed in Table 5.

Table 5

Themes, Subthemes and Number of References and Sources of Availability Facilitators

Themes	Subthemes (References, Sources)*
Healthcare Personnel	Bilingual healthcare personnel (23, 15) Interpreters (19, 15); Nurses (12, 8); Medical case manager (7, 5)
Patient-provider Communication	Familiarity and Trust (11, 6); Cultural Identification (9, 5); Ability to speak English (8, 7); Using family as interpreters (7, 6)
Resources	Medications (6, 6); Health fairs and screenings (4, 4)

Note: *See Appendix C for NVivo Functions

Line-by-line coding identified several recurrent themes under accessibility facilitators in participant interviews that were further categorized into larger themes based on cluster analysis results (Figure 10).



Figure 10. Cluster analysis results of accessibility facilitators.

Cluster analysis results assisted in the categorization of facilitators to accessibility subthemes into larger themes as displayed in Table 6.

Table 6

Themes, Subthemes and Number of References and Sources of Accessibility Facilitators

Themes	Subthemes (References, Sources)*
HIV	Infectious disease clinic (24, 9); HIV facilitates access (18, 8)
Type of Healthcare Facility	Emergency room (14, 9); Primary Healthcare Clinic (10, 4) Public health clinic (8, 5)
Documentation	Legal immigration paperwork (19, 11)
Quality of Care	Better quality of care (9, 8); Better access to healthier options (4, 4)

Note: *See Appendix C for NVivo Functions

Recurrent themes under affordability barriers were represented in the cluster analysis results

(Figure 11).

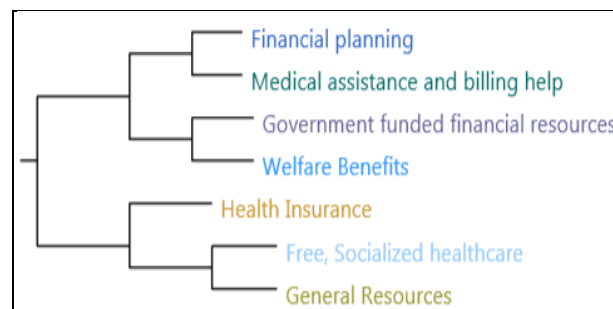


Figure 11. Cluster analysis results of affordability facilitators.

Cluster analysis results assisted in the categorization of facilitators to affordability subthemes into larger themes as displayed in Table 7.

Table 7

Themes, Subthemes and Number of References and Sources of Affordability Facilitators

Themes	Subthemes (References, Sources)*
Government Resources	Welfare benefits (15, 8); Government funded financial resources (7, 6)
Resources	Free Socialized Healthcare (13, 7); General resources (7, 5)
Financial Assistance	Financial planning (9, 5); Medical assistance and billing help (7, 5); Health insurance (4, 3)

Note: *See Appendix C for NVivo Functions

There were considerably fewer acceptability facilitators when compared to other facilitators of healthcare access. Line-by-line coding identified few recurrent themes in participant interviews that were further categorized into larger themes based on cluster analysis results (Figure 12).



Figure 12. Cluster analysis results of acceptability facilitators.

Cluster analysis results assisted in the categorization of facilitators to acceptability subthemes into larger themes as displayed in Table 8.

Table 8

Themes, Subthemes and Number of References and Sources of Affordability Facilitators

Themes	Subthemes (References, Sources)*
Knowledge and Awareness	Health-seeking behaviors (12, 8); Medication and treatment compliance (10, 7)
Social circumstances	Social and Family Support (4, 3); Understanding or accepting of discrimination (6, 6)

Note: *See Appendix C for NVivo Functions

This analytic process served as the basis for research findings on the availability, accessibility, affordability and acceptability barriers and facilitators to healthcare access, which are represented in chapter four of this dissertation. This systematic process allowed for maintaining rigor in data analysis techniques, which is an essential component in maintaining reliability and validity in qualitative methods (Lincoln & Guba, 1985). As indicated by Richards & Morse (2007), the investigator established methodological congruence and rigor in this study by maintaining the fit between method, data and data analysis techniques using content analysis, line-by-line coding and text querying analytic techniques.

Survey and geospatial data. Descriptive survey data were analyzed and represented using SPSS (IBM Corp, 2012). Quantitative spatial analysis was used to analyze geographic access data through the University of Louisville Center for Geographic Information Sciences (ULCGIS) using ArcGIS® (ESRI, 2011). Geographic Information Systems uses computer technology to collect, analyze and visualize geospatially referenced data (Gatrell, 2000). Community-mapping through geospatial analysis was central to this study as it helped visualize physical and social contexts of healthcare access for HLI in Louisville by examining the following factors: the demographic distribution and physical location of HLI, showing census tracts and zip codes in which reside; distribution of hospitals, pharmacies, and primary healthcare clinics; distance measure maps from HLI concentrated areas to healthcare facilities; and, access to bus

routes. Thematic maps were used to show aggregate data from the 2010 Census, indicating overall population of HLI by census tracts and zipcodes; poverty status by age; income; educational levels; and language skills. Point maps were used to show the distribution of hospitals, pharmacies, and other medical services (pediatricians, dentists, family health centers, family planning, family medicine, nurse practitioners, eye care providers, general practice clinics, OBGYN and internal medicine practices) by census tracts in relation to areas with high HLI concentrations. Drive time maps or distance maps were used to show the actual distances from HLI concentrated neighborhoods to healthcare facilities, as well as driving routes for each participant from their residential areas to their designated healthcare providers. Additionally, bus routes in Louisville were mapped to show access to transportation within these regions.

All geospatial data were collected from U.S. Census 2010 data (unless specified otherwise) and the use of spatial reference data such as zipcodes or specific addresses of facilities, such as those collected from the descriptive survey form (Gatrell, 2002). All data were open for public access and anonymity and confidentiality was maintained through de-identification of census data and the use of geo-coded data. Using GIS technology for geospatial analysis of data significantly strengthened this study because it provided a mechanism to visually depict large amounts of census data using maps (Albert, Gesler, Wittie, 2000). Furthermore, GIS technology has been identified as an effective measure to evaluate patterns of primary healthcare access and to examine health inequities within various geographic settings (Dulin et al., 2012; Phillips, Kinman, Schnitzer, Lindbloom, Ewigman, 2000). The ability of GIS to identify particular health and social service facilities assists in identifying service delivery regions, and the demographic characteristics of these regions. Geospatial analysis and community mapping provided essential information to fulfill measurement of geospatial barriers and facilitators that influence healthcare access under the CFAAHS dimension of *accessibility*. These maps were compared and contrasted with other existing community maps to provide further insight into HLI populations that may have been underrepresented in census data. All data analysis was undertaken with the consultation of the investigator's identified advisor, qualitative methodologist, and a GIS technology specialist.

Ethical Considerations

Maintaining reliability and validity in qualitative research has been debated over the years. Critical ethnography as a method of research is subjected to scrutiny in maintaining reliability and validity due to

its value-laden characteristics, political stance, and influence of investigator biases (Carspecken, 1996). Furthermore, the epistemological constructs of CE place the critical ethnographer in an emancipatory position to recognize subjugated knowledges of the oppressed, by revealing underlying structures of power, domination, and injustices that impede social equality for the oppressed. As a result of the emancipatory role of the critical ethnographer and the value-laden, subjective, and political nature of CE, it is essential to recognize the influences of biases on the research process, by addressing issues of positionality, otherness, and critical reflexivity (Carspecken, 1996; Hammersley & Atkinson, 1995; Madison, 2005). Addressing subjectivities of the investigator that may influence the dialogical relationship with the participants (or the Other) requires engagement in critical reflexivity.

With strong theoretical and methodological underpinnings in critical perspectives, the investigator took significant measure in this dissertation to address issues of validity, trustworthiness, and reflexivity both in the methodological approach of CE and related qualitative methods guiding the study (Lincoln & Guba, 1985). In CE, the use of methodological congruence and reflexivity of the investigator enhances this verification process (Thomas, 1993). In this study, overall validity and rigor was established through methodological congruence, which refers to the fit between method, data, and data analysis techniques (Richards & Morse, 2007). Trustworthiness of data was maintained through: 1) prolonged engagement in the field, triangulation, and member checking (credibility and dependability); 2) purposeful sampling techniques and thick description (transferability); and, 3) audit trails (confirmability) (Carspecken, 1996; Denzin & Lincoln, 2005; Lincoln & Guba, 1985; Merriam, 1988; Miles & Huberman, 1994; Patton, 2002; Spradley, 1980). The use of these strategies supported scientific adequacy of translations and findings. Addressing issues of critical reflexivity, in conjunction with positionality and otherness, contributed to the credibility of critical ethnographic methodologies and research findings of this study.

Validity and Trustworthiness

Following the selection of a research topic based on the ontological and epistemological assumptions of CE, an integral, subsequent step in the research process is the selection of methods that closely align with these critical assumptions. In CE, data collection is not a neutral process; therefore, the data sources can dramatically influence the critical potential of the study (Thomas, 1993). In order to ensure rigor in qualitative research methods, it is essential to maintain validity through each step of the

research process. In qualitative inquiry, issues of reliability and validity are based on criteria that vary greatly from quantitative methods (Lincoln & Guba, 1985). The general method of maintaining overall validity and rigor of qualitative studies is through establishing methodological congruence, which refers to the fit between method, data, and data analysis techniques (Richards & Morse, 2007). Methodological congruence provides a mechanism for CE methods to be aligned to critical paradigms at every stage of the research process. Maintaining validity in qualitative research requires the use of several strategies that establish trustworthiness based on the epistemology of naturalistic inquiry. These strategies were maintained throughout this study.

Trustworthiness. In qualitative research, issues of reliability and validity are represented in four aspects of trustworthiness, which include credibility, transferability, dependability, and confirmability (Carspecken, 1996; Lincoln & Guba, 1985). Trustworthiness is an essential component of establishing validity in qualitative, ethnographic data as it maintains the dialogical relationship between the investigator and the participants in the field (Guba & Lincoln, 1988; Hall & Stevens, 1991). Various methodological strategies that demonstrate rigor in qualitative research such as triangulation, member checks, peer debriefing, negative case analysis, and referential material adequacy, fall under the four main strategies of maintaining trustworthiness (Guba & Lincoln, 1981; Guba & Lincoln, 1982; Lincoln & Guba, 1985). Each of these verification strategies are aptly guided by corresponding epistemological standards of trustworthiness, including truth value, applicability, consistency, and neutrality. In this study, strategies that were used to maintain validity under the criteria of trustworthiness were achieved in light of these epistemological standpoints.

Credibility. Driven by the ethical responsibility of both the researcher and the research process, credibility aims to establish the truth value or the accurate representation of study findings as they are lived and experienced by participants (Lincoln & Guba, 1985). As an essential component of the ethical conduct of research, the maintenance of credibility is accomplished through numerous strategies; however, the most useful and applicable verification techniques that were used in this study included prolonged engagement, triangulation, and member checking.

Prolonged engagement allows the investigator to have continued observation in the field, improving the investigator's capacity to gain an in-depth, emic and etic perspective of the phenomena

under study (Carspecken, 1996; Lincoln & Guba, 1985). Additionally, this provides the investigator with an opportunity to gain and build trust with participants. In this study, the investigator employed participant observation data collection techniques to allow for both prolonged engagement and detailed observations that were maintained through extensive field notes and memos (Spradley, 1980). This allowed the investigator to move from being an outside observer to an inside participant (Jorgensen, 1989). The investigator collaborated with local agencies that provided health and social services for HLI, and volunteered at various institutions in order to have increased exposure to potential participants and study setting. Prolonged engagement and immersion in the field assisted in the recruitment of participants utilizing purposeful sampling methods, which is discussed in further detail under the strategy of maintaining transferability (Patton, 2002).

Along with data collection methods such as participant observation and field notes, this study used face-to-face in-depth interviews, document reviews, surveys and community mapping. This technique of using multiple sources of data to promote further understanding of the phenomena under study is known as triangulation (Lincoln & Guba, 1985). Apart from utilizing different data sources, triangulation is also based on the corroboration of evidence from different methods, researchers, and theories (Miles & Huberman, 1994; Patton, 2002). For example, Carspecken (1996) establishes triangulation through the use of multiple recording devices during data collection, including tape recorders and external observers, as a means to compare both sources of data for accuracy. In this study, data collected during interviews included audiotaped transcripts, to allow for constant checking and rechecking of information. This method of triangulation helped maintain accuracy of data and provided a solid foundation from which conceptual and cognitive linkages were built (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Additionally, as this study was guided by critical epistemology, formal interviews were conducted in an interactive and dialogic manner with full self-disclosure on the part of the investigator. According to Lather (1991), conducting interviews in such a manner is essential in encouraging reciprocity, which enhances credibility of data.

Further credibility of this study was maintained through use of member checking (Lincoln & Guba, 1985). This method involves a process in which data, analytic and thematic categories, interpretations, and conclusions are returned to corresponding participants to verify accuracy of findings and to promote further discussion and interpretation (Merriam, 1988; Miles & Huberman, 1994).

Conducted both formally and informally, this technique is considered by Lincoln and Guba (1985) to be the “most critical technique for establishing credibility” (p.314). For this validity strategy, the investigator restated and summarized information collected during interviews and shared it with corresponding participants to determine accuracy (Creswell, 2007). Member checking was conducted with all participants simultaneously during the interviews and also after data analysis. Participants agreed that the analysis was an authentic representation of their perspectives, affirming the credibility of this study (Lincoln & Guba, 1985).

Transferability. Guided by the epistemological, trustworthiness standard of applicability, transferability refers to the degree to which study findings can be applied to larger populations and different contexts (Lincoln & Guba, 1985). Positivist interpretations of transferability do not accurately translate into naturalistic methods of inquiry, where generalizability of findings is not of ultimate importance (Glesne & Peshkin, 1992). Therefore, in qualitative research, this strategy of trustworthiness intends to provide the reader with sufficient knowledge to determine transferability of data based on sample selection, data saturation, and through the use of thick description.

With the intention of meeting these criteria, this study used purposeful sampling strategies, to select information-rich cases or participants from the HLI community (Patton, 2002). These key informants provided in-depth analyses of their experiences with healthcare access. Additionally, sample size was not determined by a power analysis as in quantitative inquiry, but was determined through data saturation, which refers to the theoretical saturation of data (Denzin and Lincoln, 2005). Qualitative inquiry values the quality of the sample over quantity, by establishing an adequate sample size sufficient enough to provide an in-depth, case-oriented analysis, and large enough to provide a varied understanding of experiences (Sandelowski, 1995).

The final contribution of this study towards determining transferability was the use of rich, thick description, which provided a detailed account of the participants and setting under study (Lincoln & Guba, 1985; Merriam, 1988). With its basis in critical ethnographic methodology and postcolonial theoretical perspectives, this study was highly contextualized, and therefore warranted a thick description of the historical, sociocultural, economic, and political contexts that influenced the research process. Additionally, it was essential to understand the experiences of healthcare access among HLI in Louisville within these

contexts. Therefore, the investigator provided a thick description of both the setting and the participants in the introduction to research findings in chapter three, which enables readers to transfer information to other settings based on shared demographic and contextual characteristics (Erlandson, Harris, Skipper, Allen, 1993).

Dependability. According to Lincoln & Guba (1985), it is not necessary to demonstrate dependability of a study separately, if validity through credibility has been established. However, in order to maintain consistency in the replication of the study, several indirect and direct criteria must be met. Indirect criteria are accomplished through the measure of credibility, which include triangulation, prolonged engagement, and member checking. Direct measures of dependability include stepwise replication and triangulation of methods and participants. Stepwise replication is analogous to utilizing test reliability techniques in quantitative research, where two inquiry teams are utilized to collect data independently. However, as both naturalistic inquiry and critical perspectives are based on an emergent process, stepwise replication is both cumbersome and unnecessary. Therefore, this study did not use the stepwise process and instead established dependability through triangulation. As mentioned earlier, triangulation was achieved in this study through the collection of multiple sources of data and methods of data collection (Lincoln & Guba, 1985).

Confirmability. The final verification strategy of confirmability is based on neutrality, representing unbiased accounts of both the research process and findings (Lincoln & Guba, 1985). Confirmability is maintained through triangulation of methods and participants, and confirmability audits or audit trails. The latter is identified as an essential component for establishing confirmability by providing a systematic record of different aspects of the research process. According to Halpern (1983), the six vital audit trail categories include raw data, data reduction and analysis products, data reconstruction and synthesis products, process notes, materials relating to research intentions, and instrument development information. In this research study an audit trail was maintained on all six auditing categories, which included audiotaped recordings and transcripts; field notes and theoretical notes on the hypothesis and concepts; thematic and analytic categories, findings, relationships, and interpretations; methodological congruence, trustworthiness, and audit trail notes; and, reflexive notes on expected research findings. Maintaining a clear audit trail helped establish methodological congruence of data and confirmability.

Additionally, it gave the investigator the ability to identify and recognize sources of bias that may have influenced research findings.

Clarifying researcher bias is an essential component of qualitative inquiry that provides the reader with an understanding of the investigator's positionality, bias, or assumptions that may influence findings (Merriam, 1988). Although Lincoln & Guba (1985) do not explicitly address this component as a validity strategy, numerous qualitative investigators and critical ethnographers have gone to extreme measures to include these criteria in research processes. Based on ontological and epistemological assumptions of critical inquiry, the investigator remained cognizant of the significant areas of bias in critical ethnographic methodologies based on postcolonial theory by reflecting on discourses of critical reflexivity, positionality and other (ness).

Critical Reflexivity

Due to the value-laden, political nature of CE, and the interpretive, emancipatory role of the critical ethnographer, recognition of investigator bias and positionality becomes a crucial concept to this methodology (Hammersley & Atkinson, 1995). Therefore, critical reflexivity is necessary to maintain rigor in ethnographic research by providing reflexive accounts that promote flexibility throughout the research process (Carspecken, 1996). Reflexivity refers to the ethnographer's ability to reflect on how their understanding of the Self and culture affects the research process (Aamodt, 1991; Davies, 1999). Freire (1970) referred to this continual process of self-examination by the investigator as "critical consciousness". In CE, reflexivity takes on a critical stance, where the focus is on the dialectic relationship between the investigator and the Other, which is shaped by a investigator's historical, sociocultural, economic, and political positions (Anderson, 1989).

In his works with conducting ethnographic research based on critical, cultural-Marxist, and feminist perspectives, Foley (2002, 1998) describes four types of reflexivity: confessional, theoretical, textual, and deconstructive. However, deconstructive reflexivity is most applicable to postmodern and critical perspectives (Derrida, 1976). Postmodern ethnographers utilize deconstructive methods in the critical reflexivity process to provide an open and transparent account of the research process (Lather, 2001). As products of postmodernism, postcolonial theory and critical ethnographic methodologies that guided this study necessitated the use of critical reflexivity. Therefore, the investigator utilized critical self-

reflections based on deconstructive reflexivity. This process was guided by methodological strategies used in Foley's (1990) ethnographic accounts that focused predominantly on marginalized Hispanic, Latino, and Native American populations in the U.S.

Critical self-reflection assists in maintaining epistemological and ontological assumptions of CE that emphasize flexibility and adaptability in the research process, and the positionality of the investigator (Burns and Grove, 2001; Carspecken, 1996; Giddens, 1984). In this study, the investigator developed further understanding of her Self in relation to the Other (HLI). Understanding her positionality influenced her dialogical relationship with the HLI participants, while enhancing her ability to self-reflect on the research process. This was accomplished through the monitoring of internal actions and thoughts of the investigator through field, methodological, and theoretical notes. Knowledge constructed by the investigator was documented and analyzed with respect to the geographical location and the context of study setting; the theoretical lens of postcolonialism; and, the power relationships between the investigator and the participants (Allen, Benner, & Dickelmann, 1986; Muecke, 1994; Thomas, 1993). Additionally, several reflexive questions based on critical ethnographic assumptions were adopted to maintain consistency throughout the research process in this study. These questions included: How do the cultural background and immigrant experiences of the investigator shape her understanding of Hispanic Latino immigrant cultures? What are the investigator's assumptions in understanding the barriers to healthcare access among HLI? Are cultural understandings of health and healthcare access shared or individual perspectives? By asking these questions throughout the research process, the investigator was able to maintain critical reflexivity on her positionality and its influence on the dialogical relationship with the participants.

Positionality

With the ethical responsibility of representing voices and experiences of the subjugated or the Other, it is essential for critical ethnographers to discuss their positionality in relation to the research process (Carspecken, 1996; Madison, 2005). Positionality refers to the ability of the ethnographer to self-reflect on his or her own power, privilege, and biases that may influence the intentions, methods, and findings of the research process. Acknowledging positionality is an essential responsibility of the investigator in adequately representing and interpreting study findings. According to Habermas (1971), the

central positions of investigators in qualitative, ethnographic inquiry are based on the three models: natural science, historical and interpretive, and critical theory.

Under the natural science model, the ethnographer merely conveys information from a neutral, unbiased stance (Fine, 1994; Habermas, 1971). Similarly, the historical and interpretive model provides a vague representation of the ethnographer's positionality. The critical theory model, however, provides a clear description of the investigator's positionality, where marginalized voices and experiences are discerned for the political purpose of emancipation. The positionality of critical ethnographers falls under the critical theory mode, making them vehicles of subjugated voices. With this high level of responsibility, Noblit et al. (2004) state that "critical ethnographers must explicitly consider how their own acts of studying and representing people and situations are acts of domination even as critical ethnographers reveal the same in what they study" (p.3). Reflecting on the investigator's positionality relative to the research participants, theoretical paradigms, and representations and interpretations of findings is an essential, continual process in critical ethnographic research.

In this study, the investigator reflected on her own positionality, making herself accountable for every aspect of the research process from stating the study's purpose to representing its findings. Utilizing techniques of critical reflexivity, also known as postcritical ethnography (Davies, 1999; Noblit et al., 2004), the investigator was able to explore the notion of subjectivity in influencing the research process. The investigator's position as an immigrant from an oppressed minority group and personal experiences with colonization from her native country influenced both the purpose and the target population of this study. In addition to these positions, her background as a healthcare provider and investigator influenced the critical aspects of the research process. Being aware of this positionality is central to establishing validity of the study methods and findings, and therefore was maintained and recorded consistently through fieldwork. By contextualizing the positionality stance, the viewpoints of critical ethnographers become more accessible, apparent, and open to judgment and evaluation, placing them in an elevated level of ethical responsibility to accurately represent and interpret the voice of the Other.

Other and Otherness

The epistemological assumptions of both CE and postcolonial theoretical perspectives emphasize the emancipatory role of researchers in giving voice to subjugated voices and knowledges of the oppressed

(Freire, 1970; Hammersley & Atkinson, 1995; Spivak, 1994). Derived from the term *Orientalism*, coined by postcolonial theorist Edward Said (1978), ‘otherness’ represents the marginalization of indigenous populations under colonial rule.¹⁴ The subjugated knowledges of the colonized were muted or made obsolete relative to the knowledge created by colonial powers. The marginalization of the indigenous centered the colonizer and created a sense of ‘otherness’, where the colonized were considered to be inferior or less than human (Said, 1978). Said (1994) proposes discourse analysis as a method of making connections between what is seen and not seen, the Other and the colonizer, and the dominant and the marginalized. Therefore, discourse analysis or dialogue represents the encounters and conversations with the Other, which is the essence of critical ethnographic research and methods.

Dialogue with the Other is represented in CE fieldwork methods, through the conversations with research participants (Fine, 1994; Madison, 2005). The investigator’s concern for the Other demands attention to (the investigator’s) positionality, which must transcend his or her subjectivity. According to Madison (2005), a critical ethnographer must attend to how “subjectivity in relation to the Other informs and is informed by...engagement and representation of the Other” (p.9). In this study, the investigator’s positionality in relation to the Other (HLI) was reflected throughout the research process. Open and ongoing dialogue between the investigator and HLI was accomplished through prolonged immersion in the field, participant observations, and individual interviews. The dialogical processes with the participants were not conducted in a linear fashion, but rather through a dynamic, reciprocal process of giving and receiving (Freire, 1970). This was accomplished through the use of adaptive, semi-structured interview techniques that allowed for open dialogue between the investigator and participants. Building strong connections with the Other allowed the investigator to have an enhanced understanding of (her) Self, and in turn be more open to gaining a fuller understanding of the healthcare experiences of HLI (Davies, 1999). The ability of the critical ethnographer to reflect on her positionality, and its influence on the dialogue with the Other in an adaptive research process, was also accomplished by maintaining critical reflexivity.

Conclusion

This study, which explored the social determinants of healthcare access among HLI within historical, sociocultural, economic, and political contexts, utilized CE to illuminate the social inequities that

¹⁴ Conceptual definition of terms can be found in Appendix D

serve as barriers to healthcare access among this marginalized and underserved population. The methodology was used to guide selection of study settings and participants, data collection techniques (interviews, participant observation, document reviews, GIS), data collection tools (semi-structured interview guide, descriptive survey form), and critical interpretation of data. Issues of validity and trustworthiness, reflexivity, positionality and otherness in CE were addressed throughout the conduct of the study and study techniques. By addressing issues of critical reflexivity, in conjunction with positionality and otherness, the investigator provided evidence for the credibility of critical ethnographic methodologies and research findings of this study. Along with maintaining validity of qualitative research through the elements of trustworthiness, the study ensured overall rigor of the research process based on the ontological and epistemological standpoints of critical ethnographic research. Additionally, the expertise of the dissertation committee members assisted in adhering to the scientific rigor of this study as each member provided insight that strengthened the theoretical, methodological and practical aspects of the research process.

CHAPTER IV

RESEARCH FINDINGS

Introduction

In order to provide a rich and contextualized understanding of the barriers and facilitators to healthcare access from the perspective of HLI participants, research findings were represented in several integral parts. Part one provides a thick description of the setting and the sample to establish the foundation of the study. Part two addresses research question 1 by providing perceptions on the health concerns, meaning of health and cultural influences on health among participants and HLI in Louisville. Part three addresses research questions 2 and 3 by providing participant's narratives on barriers and facilitators to healthcare access by using the voice of participants. This approach was used to provide cultural accounts without interpretation on the part of the investigator and/or other factors external to the participant's experience and voice. Part four addresses research question 4 by providing a contextualization of participants' narratives developed through an analysis of interview transcripts, participant observations, document reviews and geospatial data. This allowed for the understanding of barriers and facilitators as perceived by HLI within historical, sociocultural, economic, and political contexts, which represented the social determinants of healthcare access. Data findings were rich and varied and the investigator discussed those that were most integral to understanding barriers and facilitators to access within a postcolonial framework.

PART I. DESCRIBING THE SETTING AND POPULATION

Demographic Description of the Community

Over the last decade the HLI population has grown considerably, representing one of the largest immigrant groups in Louisville, KY. Hispanics and Latinos were one of the fastest-growing immigrant populations in Louisville representing 4% percent of the total population (Office of Policy Planning and Evaluation, 2012; White, 2011). The Hispanic population in Louisville has almost doubled in size since 2000 from an estimated 12,370 to 23,715 in 2010 (U.S. Census Bureau, 2010). Findings revealed that HLI in Louisville represent various nationalities, but predominantly come from Mexico, and countries in Central America (Guatemala, Ecuador, Honduras) and the Caribbean (Cuba and Puerto Rico). However, exact numbers and breakdown of HLI by country of origin were often very difficult to obtain from census data and other data sources. Even more challenging, however, was obtaining the number of undocumented HLI living in Louisville. The latest available estimates from the Urban Institute indicated that in 2000, around 18% of the Louisville immigrant population was undocumented, with the majority coming from Mexico and other Latin American countries (Capps et al., 2006). Although exact numbers were hard to determine, interviews with participants and community members revealed that the number of undocumented HLI in Louisville continues to grow. Hispanic Latino immigrant communities in Louisville were found to be concentrated in the southern regions of the city. Geospatial data and existing community maps helped identify the geographic distribution of HLI, along with other key socioeconomic factors, such as poverty, income, education and language that shaped both the physical and social positioning of HLI in Louisville.

Hispanic Latino Immigrants

To allow for a further understanding of the demographic distribution of U.S. born Hispanic Latino populations and foreign-born populations in Louisville, comparisons were made between existing community maps (Center for Health Equity, 2011) and thematic maps from geospatial analysis conducted in this study. Figure 13 indicated that Hispanic Latino populations were predominantly concentrated in southern regions of Louisville including neighborhood areas of South Louisville, South Central Louisville, Fairdale, Buechel-Newburg-Indian Trail, Highview- Okolona and Fern Creek. However, results also revealed that these populations were expanding in other regions of the city, especially in northeastern regions including Jeffersontown and Northeast Jefferson.

Percent of Population by Neighborhood Who Are Hispanic or Latino, of Any Race
2005-2009 ACS Estimate

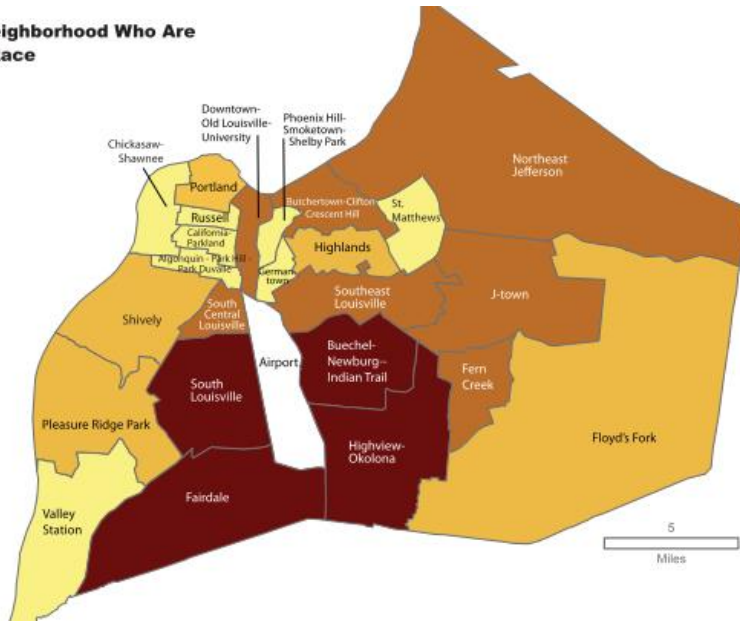
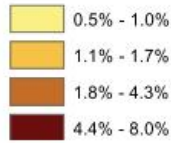


Figure 13. Distribution of Hispanic Latino population in Louisville (Center for Health Equity, 2011, p. 4).

Figure 14 distinctly indicated that a larger concentration of foreign-born populations resided in South Louisville and Buechel-Newburg-Indian Trail, Southeast Louisville, J-town and Northeast Jefferson neighborhoods, which were also identified as areas with large Hispanic Latino populations (See Figure 13). Therefore, it can be assumed that a significant number of HLI reside in South Louisville.

Percent of Foreign Born Population by Neighborhood
2005-2009 ACS Estimate

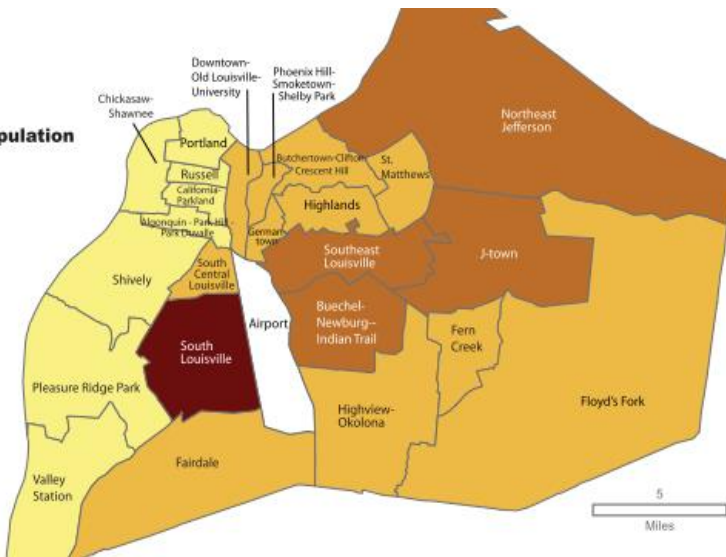
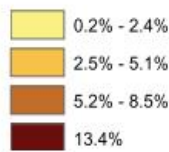


Figure 14. Distribution of foreign born population in Louisville (Center for Health Equity, 2011, p. 11).

Using geo-coded data of the 2010 Census, the physical location of HLI in Louisville were mapped according to census tracts in Jefferson County for this study (Figure 15). Similar to existing community

maps showing southern neighborhood areas with high HLI concentration (see Figures 13 & 14), geospatial analysis conducted for this study indicated that HLI predominantly resided in census tracts 56, 90, 120.02, 114.04, 114.05, 113.02, 110.02, 110.04 and 119.06. Surrounding census tract areas also had a high concentration of HLI and largely represented neighborhood areas of South Louisville, South Central Louisville, Buechel-Newburg-Indian Trail and Southeast Louisville.

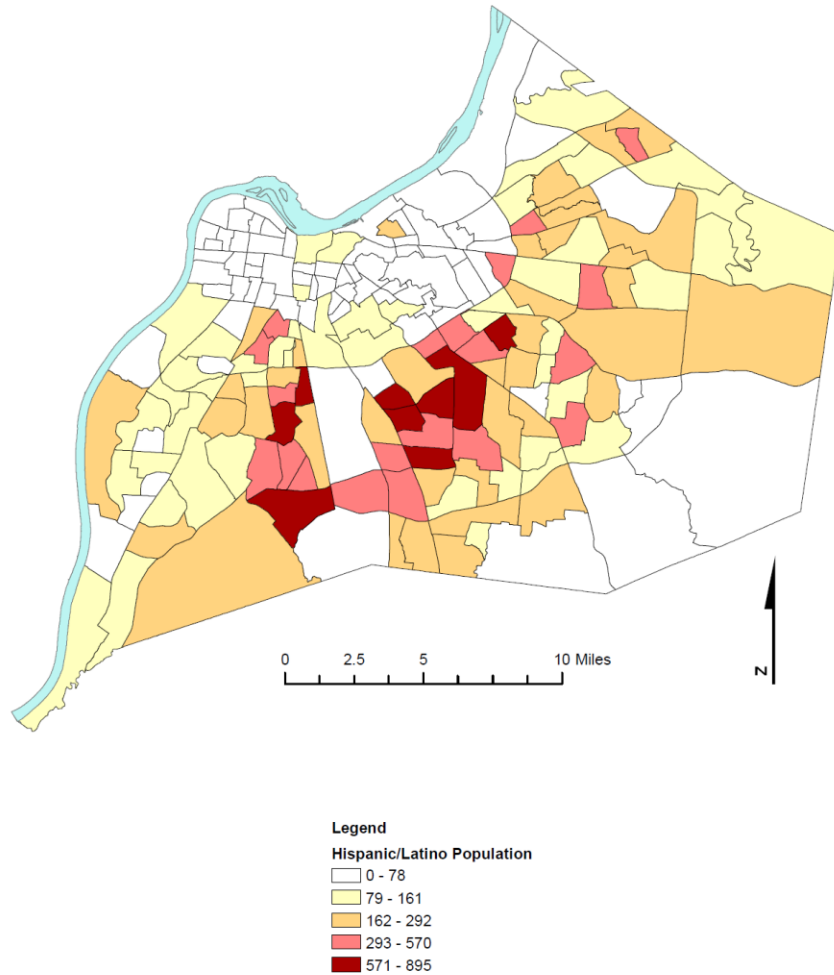


Figure 15. Hispanic Latino population by census tract in Louisville.

Geocoding of HLI population by zipcodes in Jefferson County also indicated a large HLI concentration in the identified southern neighborhoods of Louisville, mainly in zipcodes 40214 and 40219 (Figure 16). Geospatial data and community maps indicated distinct physical demarcations of HLI populations by neighborhoods, census tracts and zipcodes in Louisville. Findings also revealed that while HLI populations were predominantly concentrated in southern regions of Louisville, these groups were also growing at an increasing rate in northeastern regions of the city.

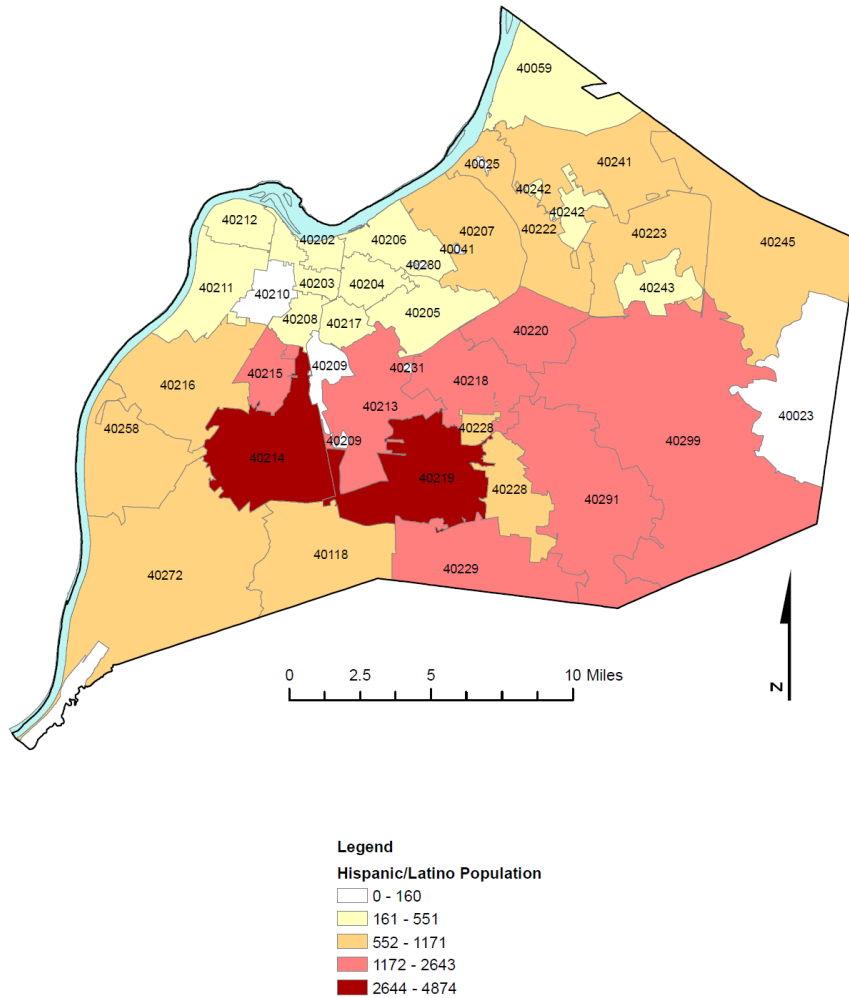


Figure 16. Hispanic Latino population by zipcode in Louisville.

Thematic maps were also used to demonstrate socioeconomic factors of HLI such as levels of poverty, income, education and language. In 2012, the USDHHS (2012) estimated the poverty level at \$23,050 (annual income) for a family of four. The U.S. Census Bureau (2013) estimated that from 2007-2010, an average of 17.5 % of residents in Louisville were living below the poverty level. Additionally, 41% of Hispanic Latinos in Louisville had incomes below the poverty level (City-Data, 2013). Geospatial analysis revealed that HLI living in poverty were primarily concentrated in the census tracts 56 and 90, but were also located in census tracts 112.02, 91.05, 119.01, 119.06, 115.05 and 110.02 (Figure 17). Census tracts 56 and 90 are located in the neighborhoods of South Louisville and South Central Louisville (Figure 14) and in zipcodes 40214 and 40215 (Figure 16).

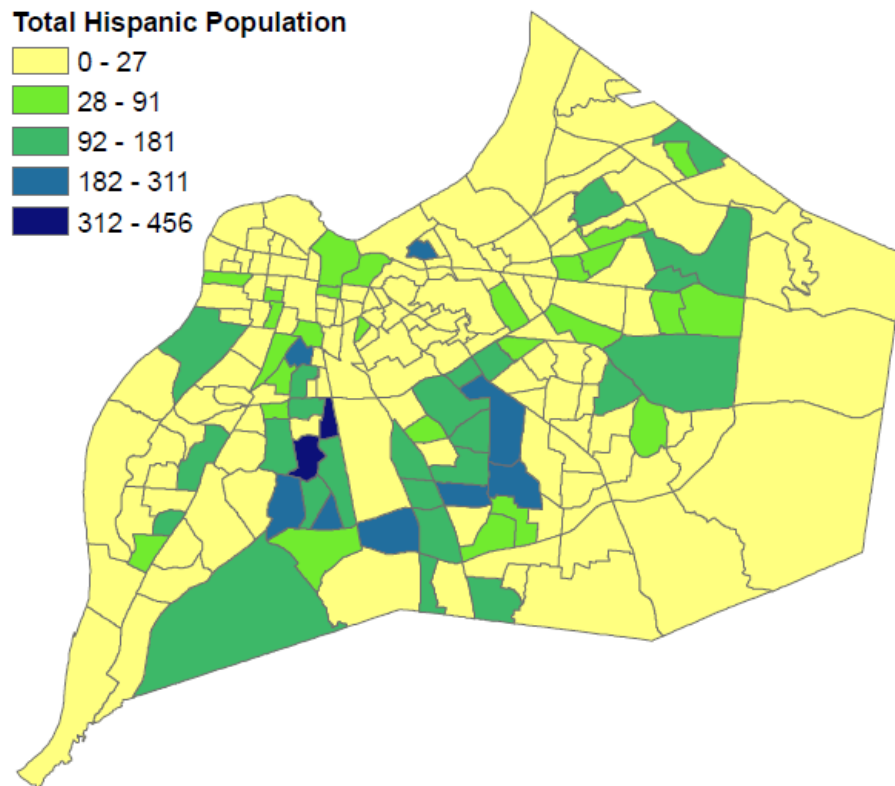


Figure 17. Hispanic Latino population with income below poverty level in Louisville.

Figure 18 shows the distribution of HLI in Louisville based on median household income. It must be noted that this thematic map was developed using American Community Survey data from 2005 to 2009 and census tract boundaries for HLI based on 2000 census data, due to insufficient 2010 census data on this measure (D. Biddle, personal communication, February 13, 2013). Geospatial analysis revealed that the majority of HLI with household incomes below \$26, 509 resided in census tracts 56, 90, 91.03, 119.04, 119.06, 114.06, 110.02 and 115.05 (Figure 18). As indicated in Figure 17, these census tracts also have a larger number of HLI living below the poverty level. South Louisville, Fairdale, Buechel-Newburg-Indian Trail and parts of Highview-Okolona neighborhoods represented the areas with lowest levels of income among HLI. Generally, HLI with higher levels of income were shown to reside predominantly in Fern Creek, J-town and Northeast Jefferson neighborhoods. Therefore, HLI with low levels of income and those living below the poverty level were primarily concentrated in southern regions of Louisville as indicated by geospatial analysis that revealed distinct physical demarcations of these populations within identified areas.

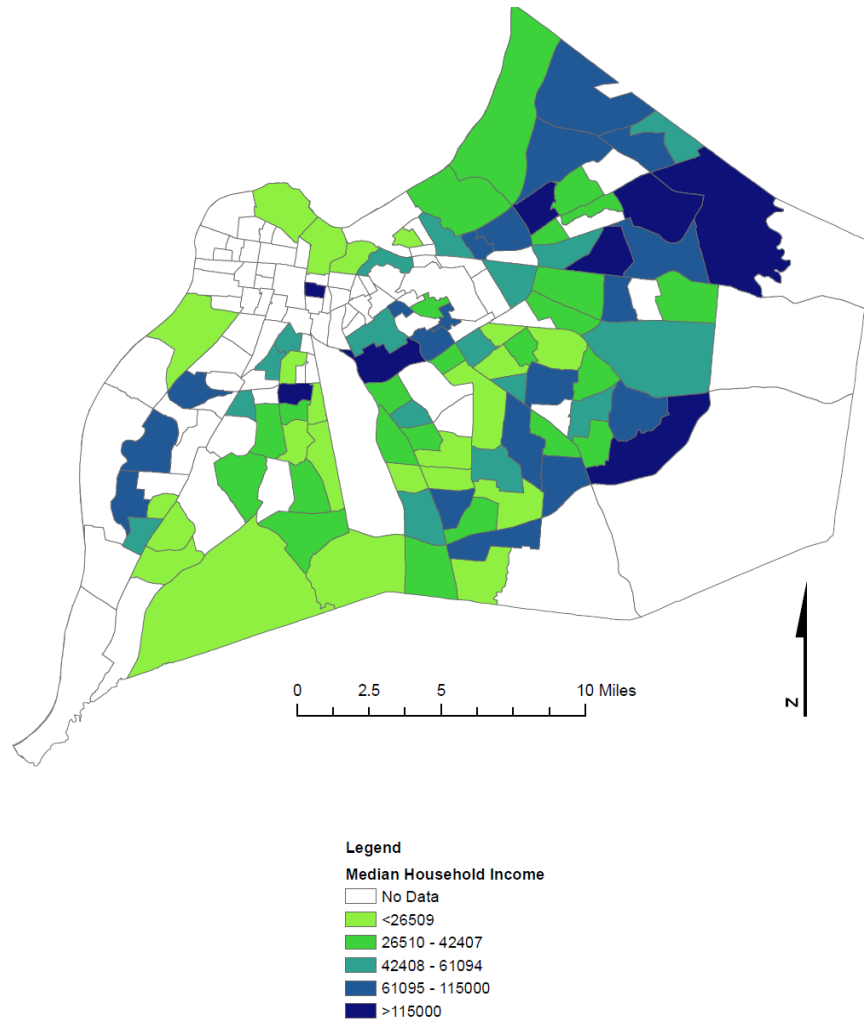


Figure 18. Median household income for Hispanic Latino population in Louisville.

Geospatial analysis revealed that distribution of HLI in Louisville also varied according to levels of educational attainment (Figure 19). Figure 19 shows the percentage of the total Hispanic Latino male and female populations (over 18 years of age) for each category of educational attainment: *less than high school diploma*, *high school diploma* and *bachelor's degree*. Findings revealed that census tracts with the lowest levels of educational attainment among HLI males and females were scattered across the city, but were generally located in previously identified southern regions of Louisville. Hispanic Latino immigrants residing in eastern regions of Louisville were more likely to have a bachelor's degree and HLI living in southern regions of Louisville were less likely to have a bachelor's degree. The distribution of educational levels were shown to correspond with income and poverty maps, indicating that areas with less educated HLI also had a significant number of HLI with incomes below poverty level.

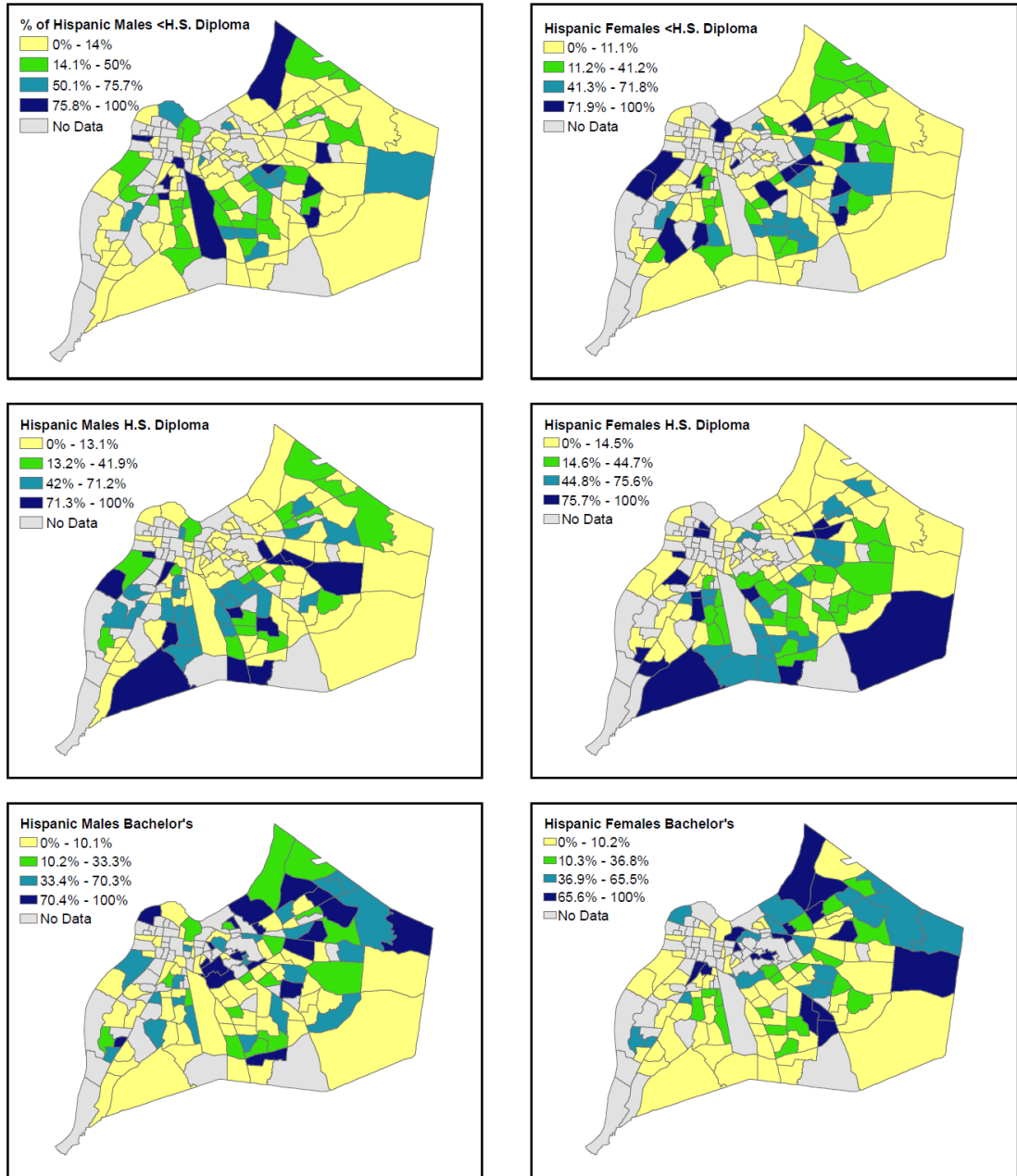


Figure 19. Educational levels of Hispanic Latino population in Louisville.

Language was another demographic characteristic that was shown to geographically vary across Louisville. Figure 20 shows that 0-20% of the total HLI population residing in South Louisville, South Central Louisville, Buechel-Newburg-Indian Trail and surrounding neighborhoods spoke only English at home. Correspondingly, these areas were also shown to have higher concentrations of HLI speaking only Spanish as their primary language at home.

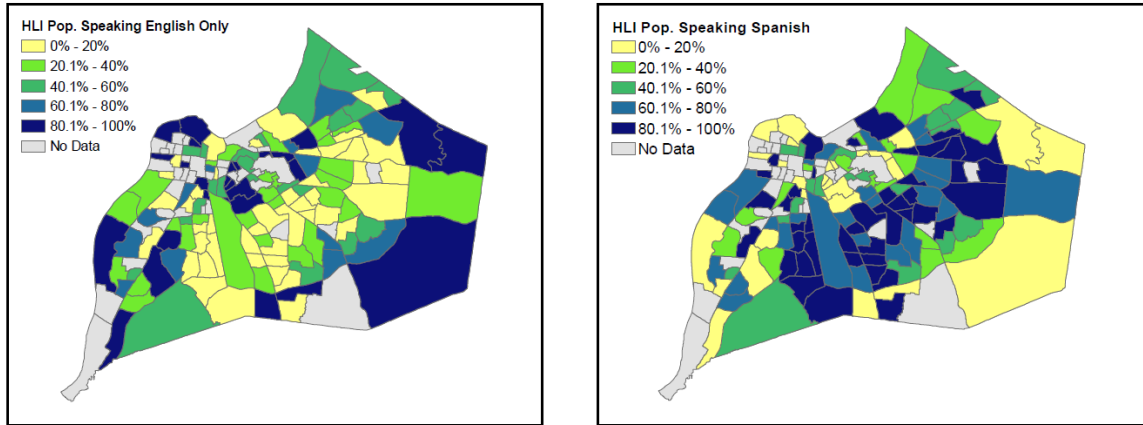


Figure 20. Hispanic Latino population speaking only English or Spanish at home in Louisville.

Geospatial analysis also revealed that differences in the ability to speak English among HLI geographically positioned them in southern regions of Louisville (Figure 21). Hispanic Latinos residing in these areas were less likely to speak English *Very Well* or *Well*. Roughly 20% to 40% of HLI residing in census tracts 56, 90, 114.04, 114.06 and 118 did not speak any English at all. Census tracts and neighborhoods with lower levels of English proficiency corresponded to highly concentrated HLI census tracts with lower income and educational levels and higher levels of poverty.

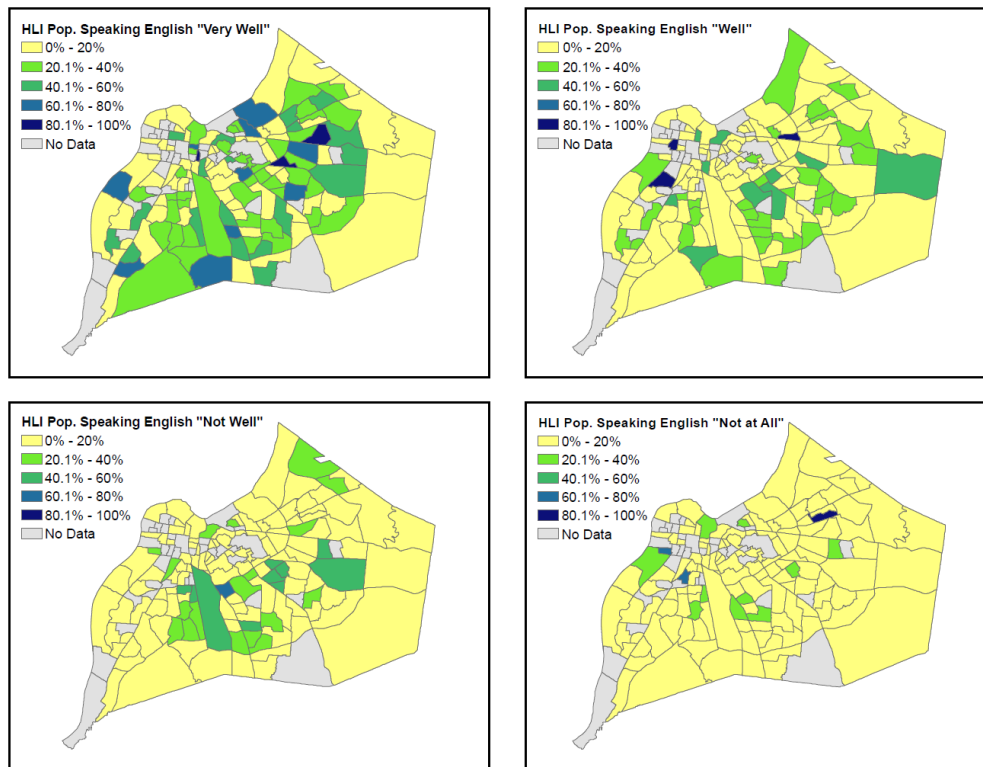


Figure 21. English Language skills of Hispanic Latino population in Louisville.

Recruitment and Study Setting

Data collection occurred at three different study sites including, 1) a local community center that provided social services to immigrants and refugees, 2) an infectious disease clinic that served HLI who were HIV positive, and 3) a primary healthcare clinic that served migrant workers in the horse racing industries. The community center and primary healthcare clinic were both located in the southern regions of Louisville (see Figures 15 & 16), where geospatial data indicated higher concentrations of HLI who were impoverished, had lower levels of income and education, and were more likely to have LEP (see Figures 17 to 21). Although the infectious disease clinic was not located in these identified regions, participants who accessed services at the clinic predominantly resided in these southern regions. All three sites provided rich perspectives on the variations in experiences of diverse HLI subgroups in Louisville.

The community center was a non-profit organization focused on meeting general immigrant and refugee needs through youth and adult programs geared towards educating and empowering individuals. Located in South Louisville (see Figure 13) or zipcode 40219 (see Figure 16), the community center predominantly served immigrants and refugees from African and Asian countries. Interestingly, it was found that relatively fewer HLI accessed services at this center. One of the program directors at the center stated:

Currently, there are very few Hispanic Latino families that access services at the community center. This is mainly due to the fact that most Mexicans live in Fairdale and have difficulties getting transportation to get here. And Cubans have many other resources in the community, so they don't need additional services. Also, many families are reluctant to even come out of their homes or communities for fear of ICE (Immigration and Customs Enforcement) and deportation... Recently ICE has been entering their homes with warrants and detaining people at the Boone county prison. Our director goes there periodically to talk with the detainees and advocate for them. Sometimes these people are imprisoned and detained illegally, over something as trivial as getting pulled over. So we try to advocate for them and our aim is to increase HLI outreach at the community center.

The community center provided ESL classes as well as a family education program, which were held bi-weekly to teach parents about availability of social services and increased awareness among parents regarding their children's education. These programs also offered parent-teacher conference preparation classes to help educate parents about the importance of communicating with teachers and being informed about their children's education. Interpreters were available on-site at the community center to assist parents with LEP to communicate effectively with teachers. Through the help of the on-site interpreter, the

investigator was able to hand out flyers and provide information sessions to recruit participants for the study from the community center.

Similar to the community center, the primary healthcare clinic was also located in a densely concentrated area of HLI in South Central Louisville (see Figure 13) or zipcode 40215 (see Figure 16). This clinic provided free primary healthcare services for horse racing industry employees, which were predominantly comprised of Spanish-speaking migrant workers. Employees were only allowed to access services from the clinic contingent upon their employment status, which changed according to horse racing seasons. The investigator was able to gain access to this site through the director of the clinic who was a nurse practitioner. Study recruitment times did not correspond to the seasonal horse racing schedules as most employees had moved down south to Arkansas seeking employment. However, the nurse practitioner at the clinic was able to assist in recruitment of several individuals who were identified as key informants, providing interesting insights into healthcare access for those working at the horse racing industry.

The third study site was an infectious disease clinic that provided bilingual healthcare services for a large community of HLI in Louisville who were HIV positive. The clinic was located in the downtown region of Louisville (zipcode 40202), directly north of South Central and South Louisville (see Figure 13). Through fieldwork, it was identified that HIV was a growing and often overlooked healthcare concern among HLI in Louisville. Therefore, it became crucial to the investigator to represent this population in the study sample. The infectious disease clinic received federal funding to provide affordable HIV-related health services and medications to promote management of disease for those who could not afford it. Access to these services for over one-hundred Spanish-speaking individuals was facilitated through the help of a bilingual medical case manager, who over the years has built strong patient-provider relationships with the HLI clientele at the clinic. Recruitment at this site was made possible with the help of the medical case manager, who also served as the interpreter on this study. The increased levels of trust and familiarity between the medical case manager and the patients at the clinic provided for open communication, where participants were more candid and comfortable in sharing their perspectives.

Sample Demographics

Table 9 displays the demographics characteristics of the 20 study participants collected in the descriptive survey form (see Appendix B).

Table 9

Demographic Characteristics of Study Participants

Participant	Age	Gender	Country	Race	Ethnicity	Number of years in US	Easy to Speak English	Occupation	Weekly salary range	Highest level of education
1	41	M	Cuba	Latino	Don't know	10	Not at all	Custodian	>\$375	Some high school
2	42	M	Guatemala	Latino	Hispanic	18	Somewhat	Janitor	\$250-374	High school diploma
3	52	M	Cuba	Latino	Latino	13	Somewhat	Unemployed	\$0- 124	Technical College
4	33	M	Mexico	Hispanic	Don't know	10	Somewhat	Janitor	>\$375	Grades 1-8
5	31	F	Mexico	Latina	Don't know	4	Somewhat	Laundry Service	\$250-374	High school diploma
6	39	M	Guatemala	Hispanic	Don't know	12	Somewhat	Tire changer	>\$375	Some high school
7	27	F	Mexico	Hispanic	Don't know	6	Somewhat	Janitor	\$250-374	High school diploma
8	28	F	Mexico	Hispanic	Latino	14	Somewhat	Unemployed	\$0- 124	Some high school
9	47	M	Puerto Rico	Hispanic	Hispanic	26	Very	Customer Service	>\$375	Some College
10	36	M	Cuba	White	Hispanic	2	Very	Interpreter	\$125-249	4-year College degree
11	42	M	Puerto Rico	Hispanic	Latino	15	Very	District manager of janitorial services	>\$375	2-year College degree
12	45	F	Ecuador	Mestizo	Hispanic	14	Somewhat	Janitor	\$125-249	Technical College
13	57	F	Cuba	White	Hispanic	11	Not at all	Operator	\$250-374	Technical College
14	57	M	Cuba	White	Latino	11	Somewhat	Operator	\$250-374	High school diploma
15	21	M	Guatemala	Hispanic	Don't know	1	Somewhat	Works for Notary of KY	\$125-249	Some College
16	47	F	Honduras	Hispanic	Hispanic	1	Somewhat	Janitor	\$125-249	Grades 1-8
17	39	F	Guatemala	Hispanic	Hispanic	18	Not at all	Horse groomer	>\$375	Grades 1-8
18	51	F	Mexico	Hispanic	Mexican	16	Somewhat	Hot walker for horses	\$250-374	Some high school
19	36	F	Guatemala	Hispanic	Blanco	12	Somewhat	Hot walker for horses	\$125-249	Grades 1-8
20	44	F	Guatemala	Hispanic	Don't know	20	Somewhat	Horse groomer	\$250-374	Grades 1-8

Table 9 indicated that although the ethnicity of all participants was Hispanic or Latino, only 55% of the participants (n=11) identified their ethnicity as Hispanic or Latino. The remaining 45% of participants (n=9) stated that they “did not know” their ethnic background. Similarly, over 80% of participants (n=16) identified their race as Hispanic or Latino; 15% (n= 3) stated that they were “*blanco*” or white; and, one participant stated that she was “*Mestizo*”, which is a person from mixed Spanish (Spain) and Latin American heritage. Fifteen-percent of participants (n=3) stated that they did not speak any English at all, while 70% (n=14) stated that they spoke very little English. It should be noted that only four interviews were conducted in English, and all others required the use of a Spanish interpreter.

The largest variations in attributes related to healthcare access were associated with country of origin, immigration status (undocumented vs. documented) and socioeconomic factors (income and number of dependents). Therefore, these differences are displayed in detail in Table 10. It must be noted that although the majority of participants said they had a healthcare provided in the U.S., only six participants had a regular primary healthcare provider through either a private doctor’s office (n= 5), a public health clinic (n=2) or through the primary healthcare clinic at the horse racing industry (n=4). Eight participants accessed health services at the infectious disease clinic, which only provides health services related to HIV and does not provide primary healthcare services in general. Despite this fact, many participants identified the infectious disease clinic as their primary healthcare provider and accessed the emergency room for all other immediate health concerns.

Descriptive data in Table 10 also indicated that all participants who were undocumented came from Guatemala (n=3) or Mexico (n=3). Among participants who were undocumented none had health insurance and six participants had HIV. Participants from Mexico and Guatemala were shown to be less likely to have health insurance (n=11) than Cubans and Puerto Ricans (n=2). The majority of participants (n=12) reported experiencing some form of discrimination in the healthcare setting based on their race and ethnicity, immigration status, language and/or HIV status. Sixty-five percent of participants (n=13) had a healthcare provider in their home countries, while the remaining participants identified their mothers or traditional healers as alternative sources of healthcare. Additionally, the majority of participants (n=12) identified their family as the most important person to them when they are sick.

Table 10

Country of Origin, Documentation Status and Income in Relation to Factors of Healthcare Access

Country of Origin	Immigration Status	Weekly salary range	# of dependents	HCP in Country of origin	HCP in US	Health insurance	Health concerns	Most important person when sick	Discrimination in Healthcare setting
Guatemala	Undocumented	\$250-374	1	No	Yes	None	HIV	HCP	Yes
		≥\$375	3	No	Yes	None	HIV	Family	No
		\$125-249	0	Yes	Yes	None	HIV	HCP	No
	Documented	≥\$375	3	Yes	Yes	Employer	Muscle pain	Family	Yes
		\$125-249	4	Yes	Yes	None	Ovarian cysts and fibroids	Family	Yes
Mexico	Undocumented	\$250-374	1	No	Yes	None	Vaginal bleeding	Family	No
		≥\$375	2	Yes	Yes	None	HIV	Family	No
		\$250-374	3	Yes	Yes	None	HIV	HCP	Yes
	Documented	\$0-124	3	No	No	None	Anemia; Flu	Family	Yes
		\$250-374	3	Yes	Yes	None	Gastrointestinal	Family	No
		\$250-374	5	Yes	Yes	Employer	Gastrointestinal	Family	Yes
Cuba	Documented	≥\$375	1	No	Yes	Employer	HIV	Family	Yes
		\$0-124	0	Yes	Yes	None	HIV	HCP	Yes
		\$125-249	3	Yes	Yes	None	Varicoceles	Family	No
		\$250-374	2	Yes	Yes	Employer	Breast cancer; High cholesterol	HCP	No
		\$250-374	2	Yes	Yes	Employer	Cardiac; Hypertension	HCP	No
Puerto Rico	Documented	≥\$375	0	No	Yes	Employer	HIV	Employer	Yes
		≥\$375	2	No	Yes	Employer	Diabetes	Family	Yes
Ecuador	Documented	\$125-249	3	Yes	Yes	None	Bronchitis; Asthma	HCP	Yes
Honduras	Documented	\$125-249	2	Yes	Yes	Employer	Thyroid problems	Family	Yes

PART II. CULTURAL INTERPRETATIONS OF HEALTH

Research findings presented in this part of chapter four addressed research question 1: *What are the perceptions of HLI on health, healthcare, and healthcare access?* Findings revealed that the culture played a significant role in shaping the meaning of health and the types of health concerns that were most commonly experienced by HLI in Louisville. The first three core questions of the study's interview guide (see Appendix B) pertained to understanding the meaning of health or *being healthy* and cultural influences on health outcomes and health-seeking behaviors of participants. The majority of participants (n=11) defined *being healthy* as the absence of any chronic diseases or other illnesses. Two participants identified not having pain as their definition of being healthy. The remaining participants discussed health as an overall balance between physical and mental health, which includes eating right and exercising. One Cuban participant's perspective summarized these definitions:

First of all to be healthy means not to be sick, not to be ill, and to enjoy a great quality of life, physically and mentally. Not to suffer from any ailment or disease. So everything you do in life you do it in comfort, not having pain, not having something that interferes with your daily routine.

Findings revealed that the HLI community in Louisville had several health concerns with diabetes, hypertension and high cholesterol identified as some of the most frequently experienced chronic health conditions. In addition, respiratory and cardiac related illnesses were common among HLI. Data indicated that respiratory problems were related to the high level of allergens in the Louisville atmosphere, which is located in the Ohio valley. Cardiac problems were shown to be related to unmanaged hypertension, lack of exercise and improper diet. Access to dental care was identified as a significant problem in the HLI community as most individuals did not have insurance coverage or couldn't afford dental services. These barriers also applied to accessing specialty health services such as eye care. Participants shared similar health concerns, but interestingly, the condition that occurred most frequently in the study sample was HIV (see Table 10). Other sources of data revealed that HIV was a growing health concern in Louisville, but it was often unaccounted for and disregarded as an important health concern among HLI. The infectious disease clinic received newly diagnosed immigrant patients throughout the year. Diagnosis of HIV in its later stages was especially common among the HLI community. As HIV is asymptomatic in its early stages, many HLI did not learn of their condition until they had an opportunistic infection which prompted them to seek emergency hospital services, where the disease was diagnosed in its advanced stages.

Reasons for delayed presentation and diagnosis of HIV among HLI were related to lack of awareness of the disease process and to negative cultural stigma towards HIV. Out of the eight participants with HIV, seven stated that they were diagnosed after they arrived in the U.S. Many participants found out about their condition when they were in the hospital with advanced symptoms related to opportunistic infections or full-blown AIDS. Several participants stated that they were unaware of the need to test for HIV and other STDs in their home countries, and were often discouraged from doing so as a result of the negative cultural stigma associated with the disease. Additionally, as homosexuality was strongly associated with HIV, participants expressed barriers in testing for HIV and other STDs in their countries because it contradicted the cultural notion of *machismo*, or the strong sense of masculinity that was revered in HLI cultures. This was reflected in one participant's statement:

In Puerto Rico they were not accepting of male to male relationships or HIV. It is important to keep in mind that the Latino culture is also machismo and religious, which influences their views on homosexuality and HIV...HIV is a subject that they don't want to touch. If you are HIV positive unless you have a group support, they will not be concerned about you because they are not understanding of what it means to be HIV positive.

As a result of negative cultural stigma, many participants were unable or ashamed to share their HIV status with family members or the community for fear of being perceived or treated differently. Therefore, culture was shown to play a central role in the occurrence and management of HIV for participants in this study.

Culture also had a significant impact on healthy behaviors and management of illnesses, as many participants indicated that their cultural values encouraged them to consume natural foods, such as fresh fruits and vegetables. One participant stated:

My culture influences my health by telling me to eat the right way and allowing me to know how to make healthy choices. Above all, eating fresh fruits and vegetables is very important. In Honduras, we were taught how to eat healthy through the media.

Similarly, other participants practiced healthy behaviors that were traditionally instilled in them by their family members. Family was also influential in passing down generations of home remedies and traditional medicinal practices to maintain healthy lifestyles. Participants from Mexico, Guatemala and Ecuador identified these traditional practices as essential methods of managing illnesses in their culture. In these countries, the use of *curanderos/curanderas* or traditional healers was a common practice as they were readily available, affordable and easy to access within the community. Generations of traditional medicinal practices and home remedies remained strong among HLI in Louisville and indicated the retention of

cultural values despite immigrating to the U.S. Although traditional healers were not always available in Louisville, participants were able to find community members who practiced homeopathic and other naturalist healing methods as an alternative means of healthcare.

The retention of the cultural ideology of *familism* was also central in defining health and healthcare access for participants, as family support was identified as a major factor to being healthy. *Familism*, which is a principal characteristic of Hispanic Latino cultures, refers to the strong family orientation and emphasis on social support received from family networks (Franzini, Ribble, & Keddie, 2001; Mindel, 1980; Vega & Miranda, 1985). The influence of familism and other cultural factors on healthcare access are further discussed under sociocultural contexts.

Overall, the definitions of health among participants were shown to be relative to cultural factors that influenced healthy behaviors. The most significant health concerns among participants were HIV, chronic illnesses, respiratory and gastrointestinal problems. Data indicated that numerous other health concerns were commonly experienced by Hispanic Latino populations in Louisville. The *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012) revealed that the primary health conditions responsible for inpatient hospitalizations among Hispanics in 2009 were mental or emotional diagnosis (532 deaths), heart disease (177 deaths), drug induced morbidity (143 deaths), chronic obstructive pulmonary disease (131 deaths), perinatal conditions (108 deaths), and asthma (100 deaths). Infant mortality among Hispanics was 7%, which was relatively lower than whites (7.6%) and blacks (13.1%). Additionally, 31.4% of Hispanic mothers were not receiving prenatal care in their first trimester (Office of Policy Planning and Evaluation, 2012). However, these statistics must be interpreted with caution because of inaccurate data on HLI populations. As a result, the majority of data provided in the *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012) were focused predominantly on blacks and whites, providing statistics on causes of death, chronic illnesses, behavioral risk factors, mental health, injury and violence and communicable diseases among other vital statistics. The lack of epidemiologic data on HLI in Louisville does not indicate the health problems do not exist in this community, but rather warrants the need for further studies to fully comprehend the scope of health outcomes and disparities among HLI in Louisville.

PART III. BARRIERS AND FACILITATORS TO HEALTHCARE ACCESS

Research findings presented in this part of chapter four addressed research questions 2 and 3:

What are the identified barriers to accessing healthcare services for HLI and what are the identified facilitators to accessing healthcare services for HLI? The purpose of this section was to focus on the voice of the HLI participants and represent findings from the interview data that were linked to the literature and theoretical underpinnings of this study. Barriers and facilitators to healthcare access were coded under the four dimensions availability, accessibility, affordability and acceptability under the CFAAHS framework (Peters et al., 2008). As previously detailed, each step of the analysis process was conducted systematically using line-by-line coding, content analysis and constant comparative techniques. The investigator provided visual depictions of how major themes and subthemes were derived from coded data using cluster analysis under each access dimension in chapter three. After data were sorted and categorized, it was then reconstructed and represented in meaningful and comprehensible ways for the reader to understand using tables (Jorgensen, 1989). This analytic cycle was followed for each access dimension under barriers and facilitators, and each contextual factor discussed in part four of this chapter. Central themes and corresponding codes are discussed in further detail to give voice to participant experiences and perspectives in this section.

Barriers to Healthcare Access

Availability Barriers

The major themes under availability barriers were *Time and Availability*, *Healthcare Personnel Characteristics*, *Patient-Provider Communication* and *Navigating the Healthcare System* represented in Table 1 (see page 55).

Time and Availability. Initially, participants faced significant challenges entering the healthcare system as a result of limited clinic operating times and availability of appointments. A fundamental theme under the availability barrier of access was the lack of time and availability within the healthcare system. The centrality of this theme is evident in its influential relationship with other themes and subthemes under this dimension of access.

Limited clinic operating hours and availability of appointments. Participants voiced significant concerns with difficulties entering the healthcare system due to the limited operating times of healthcare

facilities that did not correspond to their work schedules and as a result of limited availability of appointments. In general, the majority of health clinics and doctors' offices operated during 8am to 5pm work hours. However, most participants worked in jobs where work hours went well beyond these traditional office hours, serving as a barrier to accessing healthcare services. One participant, who works as a janitor said:

We Latinos...even if we have the clinics right in front of our faces we're not going to go because we don't have time because we have to work, work and work.

Participants that access health services from clinics that are amenable to their work schedules, face an additional barrier to access as a result of limited availability of appointment times. One participant, who was a U.S. citizen, had health insurance coverage and a primary healthcare provider expressed his persistent difficulties in obtaining an appointment to be seen by his doctor:

I wasn't feeling well and I called my doctor 4 times to make an appointment and he wasn't there. I even went to his office and I still never saw my doctor. So I went to another clinic and I had problems trying to see a doctor. So they sent me to the emergency room and found out I had pancreatitis. They told me when I get out of the hospital I need to see my doctor within 5 days. He was unavailable and so I had to wait 3 weeks before I actually saw my doctor.

During times of emergencies, it is more challenging to make appointments as most clinics and doctor's offices are booked for several months in advance. Often, this leaves only one option or seeking services at hospital emergency rooms, as indicated in another participant's experience:

The last time I had a fever for more than two days, my throat was very swollen and I couldn't swallow. So I went to the emergency room because I didn't make an appointment and if you don't make an appointment you can't be seen at the clinic.

Barriers in obtaining appointments with healthcare provider delayed vital treatment resulting in the advancement of the disease process and other serious health consequences.

I had a bad experience with my daughter. I noticed my daughter had a black hole between her two front teeth, so I made an appointment and took her to the dentist. But the doctor told her that she just had to clean her mouth well and it will be ok. However, after some time the problem wasn't resolved so I tried to make an appointment through the same nurse for a doctor. She said "I gave you an appointment just one month ago; I can't give you an appointment now!" But I said "My daughter has a bigger black hole between her two teeth." Eventually I got a second appointment and the doctors said "Wow! Now she has an infection and we have to extract those two front teeth".

Attempts at taking precautionary and preventive measure by patients were not encouraged by healthcare providers. Worsening health as a result of delayed healthcare access resulted in increased healthcare costs and was also a source of emotional distress, frustration, and anxiety.

It is very overwhelming when you have to pay so much for your service and you have to wait until they are available for you. They charge me so much money and I have to wait all this time! I get 10 minutes of your time. They don't spend enough time with you. They put it in a computer and forget about you. And they give you a paper and say, read this and if you have any questions call us. When you call they are not available.

Long waiting times and limited contact with healthcare providers. Once the individual entered into the healthcare system, there were barriers that further impeded navigating through the healthcare system including long waiting times to be seen and limited time and contact with healthcare providers when they were seen. One participant made a comparison of waiting times in the U.S. to those in Cuba to illustrate this point:

In the U.S. it takes a lot of time for the doctor to see you, especially in the emergency room. Here you spend a whole lot of time with the nurses before you see the doctor. In Cuba, any time you go to the doctor, say whatever you will, any kind or all kinds of events, they always try a way to resolve your problem or make you feel better.

Long waiting times were identified as significant barriers to access, especially in emergency situations, where delay in receiving medical attention can lead to fatalities:

Once my step-father went to the emergency room with chest pain and waited for more than 40 minutes to be seen. They always say this is a real emergency because when somebody dies they say, "if you would have come five minutes before you could have avoided this." When you get to the emergency room you don't understand how crucial five minutes can be. You cannot spend your time waiting there without attention. That's what I think.

Negative experiences with long waiting times discouraged healthcare access and influenced future decisions to seek healthcare services at particular facilities. After sustaining injuries from an accident falling off a horse at work, one participant described her negative experiences when seeking healthcare at an emergency room:

A nurse would come in every so often, but not the doctor...not so much. I don't know if there were a lot of people in the emergency room, but later the doctor came. Really they took a long time just to attend to a person. Almost three hours it took to see me. They took three hours to take an x-ray. I left before they could take the x-ray. I had to leave because I took my daughters with me and they were hungry, so I left. I didn't really get any help... It was very bad because I left the emergency room, I didn't like how they treated me.

Delay in receiving medical attention, especially in emergency rooms, gave participants the perception that either there were a limited number of healthcare providers or that the healthcare providers didn't have a sense of urgency to help those in need:

Once I was in the emergency room at the [hospital] and I was waiting for a while. There was a man whose arm was bleeding a lot. I thought at that time that it was a real emergency and that the doctors and nurses should see him quickly, but they didn't. So I said to my husband, I would go and clean the blood off that man myself because he needs attention very fast.

During emergency situations, patients are in a state of heightened physical and emotional stress looking to their healthcare providers for comfort and help with easing their symptoms. Often times, illnesses can be life altering and requires closer attention and care from healthcare providers. When he experienced his first symptoms of AIDS before knowing of his HIV status, one participant described the emotional toll of waiting and not having contact with a healthcare provider:

Before I was diagnosed with HIV, I was experiencing the first symptoms of AIDS for the first time. I thought it was due to the food that I ate, because I didn't know I had HIV. I went to the hospital. Nothing would pass down my esophagus. So I went to the ER and waited for 10 hours before somebody was able to see me. It was a rough experience. This was back in 1995 May. They were not prepared with how to treat AIDS patients so it was not a great experience. 10 hours became 24 hours as I was lying in the hallway in a stretcher.

Another significant barrier to access related to time and availability pertained to the limited amount of time and contact participants had with their healthcare provider and in particular with their doctor, who was identified as primary healthcare provider for all participants. During an emergency room visit for varicoceles, one participant described his experiences with limited contact and levels of communication with his doctor:

So the person from the lab came and she told me what she was going to do and she took a sample. Somebody else came to give me a robe and get me in a room with monitors. I saw the doctor twice. The first time she came to do a physical examination and told me just that nothing was wrong, besides the varicoceles. The second time she came back with the results of the vasography. But, just that! No more information or contact. Very little time.

Limited contact with healthcare providers resulted in impersonal experiences for participants, who expected to receive more time and attention to meet their health needs. One participant questioned the quality of healthcare services to the cost of services provided in the limited amount of time seen by a doctor:

I don't care if I have to pay or not. All I care about is if I pay, am I going to get the service that I want? Believe it or not, if you go the doctor for half an hour, out of that time you wait 20 minutes and see the doctor for 10 minutes. Then the bill comes through, which is huge! You ask yourself, does it really cost this much to be seen for only 10 minutes?

Time and availability leads to significant barriers to healthcare access. Participants perceived delayed healthcare services as being treated like a number by the healthcare system and personnel:

They treat it like a business. It is like a drive through. It is so fast. I just don't understand why doctors today charge so much but give you so little.

Furthermore, the unavailability of doctors or healthcare providers during a time of emergency for the patient was identified as a source of frustration. One participant's experiences illustrated his frustrations as he compared how treatment from healthcare providers in the U.S. differed from Puerto Rico:

Yes, when I went to the doctor for the pancreatitis I was upset because I called my doctor many times and they told me that he was not available. They said he was busy. So practically it felt like I don't care if you are sick or not I'm sorry. That makes you think why are you paying so much money for your doctor and he is not there when you need it. In my country you get to see the doctor directly. They make the time for you when you are sick and you don't even have to pay. And here, it costs so much money and you have to work around their schedule.

Healthcare personnel. Once in the healthcare system, participants had additional difficulties communicating with healthcare providers as a result of limited availability of interpreters, bilingual healthcare personnel, and individual language barriers (LEP). Characteristics of the healthcare providers and other personnel served as a significant barrier to healthcare access for participants primarily as a result of language barriers. Participants voiced their challenges in accessing care as a result of the lack of linguistically and culturally competent healthcare providers and interpreters.

Interpreter availability and training. The limited availability of trained interpreters was identified as a significant availability barrier to healthcare access as it restricted communication and understanding during healthcare encounters.

For me, one of the main issues with healthcare is not having enough interpreters because I have had several bad experiences with that. For example, I was called for an appointment and they didn't have an interpreter, so I didn't understand what they were telling me. Or sometimes they call and leave a message on the phone and when I listen to it I don't understand what they're saying. Sometimes I want to call back to ask for further information and they get angry...they don't like that. They usually don't have an interpreter available. It should be important that they provide information in Spanish or interpreters so all the information can be understood. Perhaps it's not an obligation. Isn't it a constitutional right to have an interpreter?

In facilities that do provide interpreter services, often times access to interpreters requires prior scheduling as services are not available on-site. Interpreter services were sometimes needed during unforeseen circumstances, and were not provided because of scheduling conflicts with interpreter and patient appointment times:

I had an experience when I took my daughter to the hospital and she had surgery on her eyes. At the beginning the doctor asked me if I was going to need an interpreter and I said "well I don't know, perhaps not". Later, I realized I might need it and then I told the doctor I need an interpreter. But the doctor said "you said you didn't need an interpreter initially?" And I said "well I need an interpreter now". But the doctor was confronting me about initially saying I didn't need an interpreter. I need an interpreter now, because I don't understand. That's the point.

One participant who lived in Maryland compared access to bilingual workers in Maryland to Louisville, indicating that the need for interpreters was a significant issue in Louisville and Kentucky:

In Maryland it's hard to find a place that doesn't have a bilingual interpreter or bilingual personnel. Whoever is cleaning the floor; they will just call them over and ask them. And the person who is cleaning the floor will come over and serve as an interpreter. In Kentucky it's hard to find people working in service positions, bilingual people working in service positions. For example, Maryland has three or four young people working and at least one of them is going to speak Spanish. Yes, there were also interpreters. If you ask for it they will give you one. But always someone is always...workers...who serve as interpreters.

This participant expressed that even if certified interpreters were unavailable, in diverse settings, it was easier to merely access Spanish speakers (instead of certified interpreters) to help translate and enhance communication during healthcare encounters. He believed that some communication is better than none.

This participant was HIV positive and accessed health services from the infectious disease clinic that provides a bilingual medical case manager and interpreter. He goes on to say:

I've not seen any non-health professional workers here that speak Spanish, just you (pointing to study interpreter). And in the emergency room it's the same thing. They didn't provide me with an interpreter or a phone interpreter in the emergency room. The doctor was telling me that the infection was at an advanced stage, but I didn't understand. I try to understand. If they talk to me in very basic terms I understand, but when they give me big long explanations, that's when I get mixed up.

Negative experiences with interpreters were also a source of frustration for participants who felt that they were not being understood or were not able to understand what is being communicated. This is especially true with the use of telephone interpreters, where the lack of personal contact and absence of non-verbal cues significantly undermined communication. One participant described his experiences of using telephone interpreter services that resulted in increased miscommunication and frustrations:

I went to the dermatologist for my lipomas and they said I had to pay \$80 for each incision and they wanted me to decide which of the lipomas they wanted to take out. So the specialist was explaining to me what was going to go on, but was afraid of telling me what the risks were going to be. No one spoke Spanish. They used the telephone to call a bilingual person to interpret for me. It was very tense. Neither the doctor nor the interpreter could explain to me or tell me for sure what was going to happen to me when I go to the surgery. They were supposed to explain the risks. They had to explain it to me before and they didn't explain any of it. At the end of this they gave me back the \$80...

Another participant voiced his concern about using telephone interpreters or interpreters who were not well trained, as it led to miscommunication and lack of trust:

I have used a telephone interpreter before, but I prefer a person. A lot of different interpreters have a different way of asking different questions. Sometimes you feel like they are making up a story and not telling the whole truth. That's why I always like to look at the interpreters in their eyes.

Lack of bilingual healthcare personnel. Along with the lack of trained interpreters, another catalyst to the language barriers in healthcare access was the lack of bilingual healthcare personnel (healthcare providers and staff). One participant identified what she believed was the reason for these language barriers:

Perhaps doctors who don't speak Spanish and the lack of interpreters. I know a person who used to live in the neighborhood- an 85 year old man who used to live alone. When he needed to go to the doctor he couldn't speak English and he was not understood.

Lack of bilingual healthcare providers also coincides with availability of appointment times, identified as a barrier to access in and of itself. One participant's statement indicated that if bilingual healthcare providers are unavailable, it is imperative for interpreters to be available to assist in communication and understanding between the healthcare provider and the patient:

Mainly, the doctor that sees my daughter speaks Spanish. He is a Spanish speaker, but he is not always available. So sometimes I have made appointments with the doctor's office or hospital... the Spanish speaking doctor is not there. But they don't have interpreters. I have limitation with English and cannot communicate well. So I like to reschedule the appointment to a time when the Spanish speaking doctor is there, because there is no communication otherwise. Of course using an interpreter or a bilingual healthcare provider makes communication much better.

Lack of cultural competence. Understanding that patients with LEP need language and interpreter services to enhance their healthcare encounter and communication is an essential component of the cultural competency training of healthcare providers. Cultural competence, which is a core component of providing healthcare services in all medical fields, requires providers to be cognizant of the cultural needs of patients. This entails acknowledging and being sensitive to culture, language and other factors that can lead to communication barriers. One participant described his attempts to overcome language barriers by using alternative methods to enhance communication during his healthcare encounters:

I try to make myself understood sometimes even without an interpreter. Sometimes it's hard, it's difficult. And sometimes it's not important like a blood test, I'll read over it and I understand everything. In the emergency room yes, they make it a little bit harder. It's as if they don't want to understand. Like with Hispanics, I feel like they put some sort of difficulty there between them and the Hispanics. Because I lived in Maryland for many years, I've noticed a lot of differences between Maryland and Louisville.

This participant's experiences depicted that even if language barriers can be overcome, cultural barriers that are not adequately addressed can be a significant barrier to patient-provider communication. When patients perceive the lack of cultural competence from healthcare providers, they are often discouraged from

accessing care. Another participant gives an example of his wife's doctor not being sensitive to the cultural background of the patient and instead making a judgment on the patient's ability to speak English:

My wife has been having treatment for her pancreas now. They told me to take her to a clinic and I said I don't know where it is and the doctor said something very bad. "Why do you need a translator, you have been living in the US for so long" ...I didn't like that. I didn't feel comfortable.

The healthcare provider's role is to facilitate the healthcare encounter by providing culturally and linguistically competent care. Cultural competency training is essential for healthcare providers as it enhances communication and builds trust in the patient-provider relationship.

Patient-provider communication. The lack of linguistically and culturally competent healthcare providers and interpreters and the limited time and availability of healthcare providers had direct effects on the patient-provider relationship. Participants expressed limitations in both time and means of communication that lead to mistrust in healthcare providers and the system. Furthermore, lack of communication was identified as a barrier to healthcare access by participants because they felt they were often looked over, rushed and did not get their healthcare needs completely met.

Lack of communication. Limited time and availability within the healthcare system and limited contact with healthcare professionals results in the lack of communication and understanding between healthcare providers and recipients.

Most likely I talk to the nurse practitioner. She is the one who takes my information and asks me all my questions. Then the doctor just looks at the computer to see what she wrote. So practically he is seeing me for only 5 or 10 minutes, which is no time at all. You ask them questions and their answer is "well, you know you can do this or do that." They don't get deep and make sure you understand. They act like I asked them "how the weather was". The service is very impersonal.

Communication is central to the healthcare encounter because it helps patients understand their health conditions and encourages medication and treatment compliance. However, participants experience severed communication with their healthcare providers as a result of language barriers:

Something to make the healthcare system better is to have more interpreters at the time you go to see a doctor because it's pretty difficult for you if the doctor asks you any important question about something that you might have, do you feel headache or do you feel dizzy and you don't understand what the doctor is asking you. Or you want to say something to the doctor that this information for the doctor should be important to diagnose what you have.

Participants expressed that when they received services from new doctors or doctors they were unfamiliar with (such as specialists), often times there was limited communication, trust and familiarity.

When my doctor relocated to Fort Knox, he told me I had to find someone else and recommended a doctor from Indiana. I went there and I knew that the treatment was going to be different, but I

didn't know what I was getting into. He was a general doctor but also took care of infectious disease. You leave with the impression that he is not understanding of you because every time you go to see him he would ask you the same question and he wouldn't recognize you. He would have to pull a file. You were pretty much a patient that he couldn't remember.

The patient-provider relationship is highly dependent on communication, which helps build trust and familiarity. Lack of communication and trust serves as a barrier to healthcare access, as patients are less likely to seek healthcare services. Lack of communication, feelings of not being understood and not being able to express oneself was identified as a source of frustration by one participant, who has very limited English proficiency:

Sometimes I speak English and sometimes I need an interpreter. I want to be understood all the time and I get frustrated if I don't... Sometimes they can understand me better with an interpreter.

Language barriers and lost in translation. Language barriers that stem from an individual's ability to speak English also served as barriers to healthcare access. When asked to identify the most significant barriers to healthcare access in Louisville, one female participant from Cuba responded:

The language...because you want to be understood by the doctor, but the doctor cannot understand you. It is frustrating to say something and you cannot be understood... It's not very easy for me because I need an interpreter... I don't have any barriers with medical insurance, but some other people have that. For me language is the biggest barrier.

The healthcare language in and of itself is difficult for individuals to understand, even those with high levels of English proficiency. As a result, even those who speak English fluently have trouble communicating with their healthcare provider. Therefore, it is essential for Spanish speakers to have trained interpreters available to assist in communication. However, often times, HLI use family members to communicate with their healthcare providers when interpreters are not available. One participant's statement illustrated this point:

Sometimes you go to the doctor or a man goes to the doctor with his son or daughter who speaks English a lot, but the point is they don't know the exact medical terms so you cannot expect to understand, even your language because you don't know the medical terms.

When asked if a Spanish-speaker should use an interpreter when speaking to a bilingual healthcare professional, one participant responded:

Definitely! I speak English. But there are medical terms in English that I do not know but I do know them in Spanish. Sometimes it is kind of a hassle.

Facilitating complete and thorough translation requires time and consideration on the part of the healthcare provider to explain and facilitate understanding for the patient. This communication barrier is further

enhanced for those who don't speak English or with LEP, which necessitates the presence of trained interpreters. The importance of having trained interpreters is emphasized when discussing vital information that can be misinterpreted or lost in the translation process. Even if interpreters and bilingual healthcare personnel were available for participants, they feared that the true meaning of their words may be lost in translation. One female participant described the importance of clear communication and understanding during the healthcare encounter:

For example, when you are talking about medical terms you should be very careful because the doctor might be telling you something in English and there should be a trained interpreter telling you what you should do with your baby. The explanation should be crystal clear by the doctor and by the interpreter. They need to make sure that I understand because I am the mother and I am going to carry out the treatment for the baby. It's not only the explanation from the doctor and the interpreter, but they should make sure that I understand as the mother all the things that I should do for treatment, because one little mistake can be fatal.

Navigating the healthcare system. Barriers to availability of healthcare services resulted from limited paperwork and lack of advertising of public resources that impeded an individual's ability to navigate the healthcare system. Paperwork or documentation was a recurring theme, especially when participants who were uninsured and undocumented shared their experiences of accessing healthcare. Several participants discussed their concerns with the importance of medical history paperwork in the U.S. healthcare system, which often times was a direct barrier to accessing healthcare services. One male from Cuba shared his experience:

Once I was working and I had an accident where I cut my hand with a knife. I was very shocked when I was bleeding a lot. I was taken to a clinic that belongs to the company and for 40 minutes I was filling out forms and papers and was asked about numbers and medical insurance while the hand was bleeding all over the place. So attention should be given first to my hand and then later the paperwork can come. Here in America first you have to do the paperwork and the payments and then you get medical attention. But not in Cuba. No papers. Nothing. They take care of your health first.

Other participants shared similar experiences where they were turned away from accessing healthcare services because providers did not have adequate medical history paperwork. One woman shared her experiences of taking her daughter (undocumented), who was in serious need of medical attention to a clinic that refused to provide care because they didn't have medical history paperwork:

Yes. In the women's clinic where they have birth control. I had an experience at a women's health clinic left me very angry and mad at them. So the clinic told me to take my daughter up there to be seen. But when I got there they said she didn't have a medical history with them so she couldn't be seen...I went there because it was a special day where they were seeing children and adolescents for free. And I got angry because my daughter was in a lot of pain and they couldn't see her that day.

Participants also expressed that the lack of advertising through media, public radio and television regarding public resources and health information in the community impeded access to available health services. One major reason for this disparity was the lack of local Spanish radio and television stations:

There's not much information out there in Spanish. In Kentucky there's no free Spanish television channel. There's no Telemundo, there's nothing in Spanish. In other places it's free and not here in Kentucky.

Culturally, having access to media such as radio and television was identified as an essential component in the Hispanic culture by many participants. Therefore, vital information regarding public resources can be disseminated to HLI using these forms of communication. Another participant who is a U.S. citizen from Puerto Rico and speaks English fluently stated:

I believe there are local and free English channels such as KET. I don't see much promotion about healthcare or anything for families that need help especially with bilingual access. I don't see much of that advertised.

Accessibility Barriers

The major themes under accessibility barriers were *Documentation*, *Emergency Room* and *Type of Healthcare Facility* represented in Table 2 (see page 56).

Documentation. As mentioned earlier in the availability theme of *navigating the healthcare system*, the emphasis on documentation, especially documents pertaining to health insurance and immigration status were identified by most participants as significant barriers to accessing healthcare services.

Lack of health insurance. Participants who did not have health insurance identified it as a significant and at times sole barrier to accessing healthcare services in the U.S.

The most fundamental barrier to healthcare access is medical insurance. I don't have access to health insurance. That's the most fundamental difficulty.

Having health insurance is also contingent upon job status and type of employment. Two participants who were U.S. citizens and worked as phone operators at a local company voiced their concerns about losing health insurance coverage through their employment:

The company we work with now is going to close at the beginning of February and we will not have jobs and will not have medical insurance anymore. I had those troubles in the past with cancer and I have to go to the doctor every year for checkups frequently, and without medical insurance I cannot do that anymore, so my health is going to be at risk.

Being uninsured affected an individual's ability to access primary healthcare services as well as specialty services. One participant described being turned away from accessing healthcare services as a result of his lack of health insurance coverage:

In my gastroenterologist's office if you didn't have medical coverage or health insurance they wouldn't do the procedure. So if you need an endoscopy and you don't have medical insurance when you're seen at the time they won't help you. I don't have insurance for my mouth (dental) so they won't fix it. You see so many young people, 20 or so old, 20 years old or so and they have ugly teeth. In Cuba it doesn't happen.

The ability to access health insurance is also dependent on the type of immigration status of the individual.

Being undocumented affected the ability to access federal assisted health insurance programs such as Medicaid. One woman distinguished between her two daughters and their ability to access the Passport Health Plan (Louisville/Jefferson County's Medicaid Program):

My daughter who was born here has a social security number and is insured through Passport. My other daughter, who was not born here, I take her to the ER, if it's a cold or whatever. I try to make payments so I can pay them. Without health insurance it's difficult to pay.

A female participant from Honduras who has lived in the U.S. for over 14 years said:

The biggest difficulty for me when accessing healthcare was when I didn't have medical insurance. Now I feel better that I have medical insurance when I have to go to the doctor. But it's really hard for some of my family members who don't have medical insurance...because they have to think a lot to go to see a doctor when they don't have papers.

This narrative explicates the importance of having health insurance, but also addresses the need to have legal immigration documents in order to obtain health insurance, and consequently to be able to access healthcare services.

Lack of legal immigration documents. Legal immigration documents are essential in obtaining a social security number, which serves as a basis for receiving healthcare services in the U.S. Participants expressed that their undocumented immigration status affected their ability to purchase health insurance, and consequently served as a barrier for accessing healthcare. Not having a social security number significantly impeded access to healthcare services and also influenced the health-seeking behaviors of the undocumented. One undocumented participant from Guatemala said:

The first thing that they ask you at the front desk is, "What is your Social Security number?" That's the first thing. This makes it more complicated. There is no explanation and explaining your migratory status is difficult. A lot of times I just say I left it at home or have it at home and I just don't have it with me...But if they ask for social security paperwork then I never go back to that place.

Participants expressed that the majority of the time, clinics and doctor's offices asked for social security cards and turned individuals away if they did not have documentation. However, certain emergency rooms were an exception, as they tended to all patients regardless of documentation status. When asked if she had to show legal documentation to receive healthcare services, one undocumented female participant from Mexico responded:

Yes. Social security card. I don't have a social security number or a license from here. That's what they ask from me in order to see me. I say I don't have it and they tell me they can't treat me or see me. This is not the case in the emergency room, but yes in other clinics.

The disparate treatment and differences in healthcare access for documented and undocumented HLI were clearly apparent through participant experiences. One female participant who recently obtained her U.S. residency compared how she was treated when undocumented and how her access to healthcare changed when she obtained her residency:

I'm legal here. So I just give my social security number. When I came here first I didn't have documents and it was hard, more difficult to get healthcare services. When I was pregnant, it was pretty hard for them to see me and treat me, because they told me I hadn't been in the U.S. for long enough at that time. Somebody told me to go to another place where they helped me.

Emergency room. Although participants indicated that emergency rooms did not ask for documentation to access health services, they did express long waiting times and increased expenses when obtaining emergency room services, as evidenced under availability barriers. These negative experiences in emergency rooms that were often identified as significant sources of healthcare by undocumented and uninsured participants, served as a barrier to healthcare access. During an emergency room visit after an accident falling off a horse one undocumented participant described her experiences:

Really they took a long time just to attend to a person. Almost three hours it took to see me. They took three hours to take an x-ray. I left before they could take the x-ray. I had to leave because I took my daughters with me and they were hungry, so I left. I didn't really get any help... It was very bad because I had to leave the emergency room, I didn't like how they treated me.

The healthcare costs incurred from receiving emergency health services were a significant affordability barrier as demonstrated by the experiences of a participant who was both uninsured and undocumented:

For example, last year, when I got grease on my leg at work I had an outbreak of something on my legs...I went to the [hospital]. I am still paying the bills because it cost almost \$1000 dollars. It was in the emergency room at ...hospital. And I'm still paying every month in installments.

Another participant with HIV expressed his negative experiences in accessing emergency room services:

I had a horrible experience in going to the public hospital...With the second admission to the ER within two months. I was waiting, knowing that I would have to wait 10-12 hours to be seen.

When asked how this experience affected his decision to seek healthcare services at the emergency room again, the same participant responded:

Actually I did not have any choice. That was the local hospital and I didn't have any other choice at that point. I had lost a job so I had to go there. I went to the local agency. The system will help you saying how to medicate. I continued to go there because I had no choice.

Type of healthcare facility. Similar to their unique experiences in emergency rooms, participants expressed barriers to accessing healthcare services in public health clinics and specialty health facilities. Barriers to public health clinics were related to limited availability of appointment times and limitation in the types of health services provided, which required referrals to specialty healthcare providers. Participants faced additional barriers in accessing specialty health services related to availability, costs and health insurance coverage.

Public health clinics and specialty health services. Public health clinics in Louisville provide healthcare services based on an individual's income using a sliding scale fee. These centers are accessed by a large underserved, low-income population across the city and often are unable to meet the high-demand for their affordable services:

For example like one month ago I had to go to the emergency room at the [public hospital] and I know that the question I have in my mind or the doubts regarding my condition...I knew if I go here to the [public health center]they don't have the ability to take care of this condition. So they have to coordinate and refer me a place to go. And at that time I thought it was a waste of time going there, so I went directly to the [hospital] and they told me what I had and said "you don't have what you think you might have". So it made me feel a little bit better knowing that I don't have what I thought I had. That's why I didn't go to the [public health center], because if I go there they're going to say, "Ok I think you need to see a specialist or an urologist" and I was already feeling bad.

Accessing specialty healthcare services is essential for HLI, especially because most public clinics and emergency rooms do not provide such services. Obtaining referrals to specialty healthcare providers requires time and money, as most services are expensive and require health insurance coverage. One participant from Cuba, who has suffered from varicoceles for the majority of his life, was very knowledgeable about his condition. However, he recognized the challenges in being able to afford specialty health services and expressed his plans to acquire surgery in Cuba to alleviate his condition:

When I was released from the emergency room, my doctor said "you should go see a urologist, you don't need medical insurance". But I was checked and seen by an urologist in Cuba and I know they will do another physical examination and a vasography again. I know the only way to

solve or eliminate varicoceles is through surgery. The urologist is going to tell me you need a surgery. So how much is it going to be... 50, 000 dollars! So I'm waiting for my residency so that I can go to Cuba. I have many friends, many doctors in Cuba, surgeons, great surgeons! I have to live with the pain, but I need to go to Cuba to have the surgery. I can't afford it here. If I spent six hours in the emergency room and the bill was almost 6000 dollars... even if he's (the urologist) going to check me and see me without medical insurance but what about the surgery? It's going to be or 50 or 100 I don't know how many thousands of dollars. But in my country I wouldn't have to spend for this.

Affordability Barriers

The major themes under affordability barriers were *Financial Barriers, Knowledge and Awareness* and *Resources* represented in Table 3 (see page 56).

Financial barriers. The majority of participants worked in minimum wage, labor industry jobs, with multiple dependents, which represented affordability barriers to healthcare access. Five participants were financially supporting family members in their home countries, while taking care of daily living expenses in the U.S. Participants expressed that limited financial resources restricted their ability to afford healthcare expenses, as well as purchase health insurance, which was identified as an imperative factor when accessing healthcare in the U.S.

Expensive healthcare costs and limited income or financial resources. Participants described expensive healthcare costs and limited income as significant barriers to accessing healthcare in Louisville. Several participants expressed how their inability to directly pay for health services affected their ability to access healthcare:

Here, in the U.S. you have to pay for healthcare services. It is very important because if you don't pay you cannot get medical attention. So, it's important to pay. It's not free. You have to do it.

Another participant from Ecuador who works as a part-time janitor echoed this concern stating, *"It is important, because if I don't pay they are not going to see me."* Often times, participants were discouraged from accessing healthcare based on their anticipation of not being able to afford healthcare expenses. One participant expressed this concern, emphasizing the importance of health and wellness over the ability to pay:

Sometimes here in the U.S. I'm afraid of going to the hospital because I don't know the amount of money I have to pay. The sicker you are perhaps the less you can work better. And to get money you have to work to pay your bills. So it's difficult here in the U.S. ...You are thinking all the time about your health. So, it doesn't matter if you get sick in Russia, America or Cuba, of course you have to pay money. But it's not a matter of money when you get sick. It shouldn't be a matter of money.

Anticipation of the unknown or uncertainty of costs that will be incurred discouraged participants from accessing health services. However, they understood that in order for the healthcare provider to have a thorough understanding of the condition or to make an accurate diagnosis of their condition, various costly tests were required:

Sometimes you stop yourself from going to see the doctor because you're afraid of the amount of money that you're going to spend. For example, if I go to the doctor because I have pain and the doctor says well we have to take another test or something else, you cannot say "No, no, don't do that", because you can't avoid that.

Participants tried to gauge their healthcare expenses based on prior experiences. Although some participants mentioned that they would forego accessing healthcare services depending on the severity of their condition, priority was given in situations of pregnancy or child care. A female participant from Mexico, who was the only interviewee without a healthcare provider in the U.S. stated:

When I used to go to the hospital during my pregnancy, I paid. But there was a small amount of money to be paid so I did it. But if I think I have to go see a doctor, and the bill is going to be pretty high I wouldn't have any way of paying. So I wouldn't go.

Often times, federal services are available for pregnant mothers for limited periods of their pregnancy regardless of immigration and/or health insurance status. Following this limited period access to other sources of federal funding are only available for the child who gains citizenship by being born in the U.S.

No health insurance coverage. Affordability barriers to healthcare access were also largely affected by the health insurance status of participants. Participants were uninsured because they couldn't afford to buy health insurance coverage. Consequently, this affected their ability to afford healthcare services. A documented female participant from Cuba stated:

Medical insurance here is very necessary and very important. I can pay it because I have a job. I also think about the people who don't have a job or medical insurance. They cannot afford to pay medical insurance.

Not having health insurance coverage was identified as a significant barrier to accessing healthcare services for HLI in Louisville, especially for those participants who were unemployed or worked in part-time jobs.

Often times, HLI are employed in part-time jobs where employers do not provide health insurance coverage for their employees. Additionally, participants expressed that working in these part-time jobs yielded low wages that were insufficient to cover cost of living along with medical expenses:

The biggest barriers when accessing healthcare in Louisville is that we won't have enough money to pay medical insurance. If you work a part time job you don't get medical insurance from the place you work, and you are not paid much. That money is not enough to pay medical insurance.

These examples demonstrated the influence of employment status and types of employment on HLI and their ability to afford health insurance and consequently on the ability to afford costs incurred from accessing healthcare services.

Knowledge and awareness. Participants faced significant affordability barriers to healthcare access as a result of their limited income, expensive healthcare costs and lack of health insurance coverage to cover medical expenses. However, participants were also unaware of other options in the city that provides free or affordable healthcare services. When asked what he would do if he couldn't pay for healthcare services that he needed, one participant who is HIV positive and only accessed the infectious disease clinic as his primary healthcare provider jokingly said, *"I don't know what I'd do. Maybe my medical case manager can pay me?"*

Participants who were HIV positive utilized the infectious disease clinic as their primary healthcare provider and the majority of them stated that if they needed medical attention, they contacted the clinic to access healthcare. Another participant who accessed health services at the infectious disease clinic stated: *"I don't even know if they have a free clinic here in Louisville. Sometimes when I need help this is very important to know."*

There are a limited number of clinics that provided free healthcare services to underserved, low-income populations in Louisville. Even if these clinics were available, individuals were unable to access these services due to limited clinic hours and availability of personnel; lack of knowledge regarding services; and, limited ability to access clinics due to travelling distance and lack of transportation.

Resources. Many participants came from countries where governments take complete or partial responsibility for providing healthcare for its citizens. Adapting to the privatized healthcare system in the U.S. was difficult for many participants, especially when they were unable to afford high healthcare costs with their limited income. One Cuban participant expressed his concerns about the lack of government support, despite their knowledge of existing healthcare access problems:

I think access to healthcare in the U.S. should be better or free. The government knows that free is better. They know it should be less expensive, that medication is going to be expensive and people don't have medical insurance. They know that. Before we say these things, they know it happens. So why don't they do something to fix it if they know it happens.

Acceptability Barriers

The major themes under acceptability barriers were *Discrimination, Cultural Barriers, Health-seeking behaviors, Mental health* and *Healthcare Business* represented in Table 4 (see page 57).

Discrimination. Recurring subthemes under acceptability barriers to healthcare access included discrimination based on race, ethnicity, immigration status, language, health insurance and HIV status. Participants indicated that discrimination was a significant barrier to healthcare access because it resulted in emotional distress and negative feelings that discouraged health-seeking behaviors, and consequently healthcare access.

Discrimination based on race and ethnicity. Participants acknowledged being viewed and treated differently when accessing healthcare services, especially in waiting rooms of clinics and by auxiliary healthcare staff. One participant from Guatemala said:

Yes, sometimes you noticed the service. The majority of places that I go to, the majority of people are white and I am the only Latin person that goes there. One day when I walked into the waiting room the, everybody turned around and looked at me. But I thought, this is a clinic and it should be normal to see a Latin person.

Experiences of discrimination resulted in negative stressors and emotions that affected health-seeking behaviors of participants. When accessing health services for her son at a childrens hospital, a female participant from Guatemala shared her experiences:

We got to the hospital at 9pm and my son had a high temperature... I know nurses are busy helping with patients and I know at the hospital when you get to the emergency room you have to wait. I know that. But other people got there with the same problem later than me and I started to see that the people who had come after me passed me in line and were tended to before me. They were American people. So when the third person who had gotten there after me was called before me, I got up and asked "why were the people who got here after me seen before me." The nurse said "understand that it's an emergency and we're not going to attend to you at the time that you want." By that time it was 1 am and she told me you have to wait about 2 hours more. I waited thirty minutes more and got up and said to her "you know something I'm leaving". And I said "I'm going I'm leaving, but I have your name and if something happens to my daughter it's your responsibility"... And I left and never came back. I never went back there.

Experiences of discrimination, especially in healthcare settings where participants were seeking help for their children, caused heightened levels of stress and emotional distress that often discouraged them from returning to access healthcare services. Another woman from Ecuador, who experienced discrimination when accessing healthcare for her daughter, was severely affected by the negative experiences that influenced her decision return to that particular clinic:

It happened once when I took my daughter to the doctor and we were in line, she was the only Hispanic one and they said they lost her papers. She was the only one whose paper got lost, and they never called to see her. Sorry tomorrow we will see her then. They never found the papers. These were the initial forms you fill out when you go to the [public health clinic]. They lost the paper and couldn't give her care. Because we went at three and at five they were closing. I never took my daughter back there.

Another undocumented female participant had a similar experience with discrimination when accessing care for her daughter:

They told me they couldn't see my daughter that she didn't have a medical history there at the clinic and because she wasn't born here. That's very bad...Seems like discrimination. I left really mad, because the school called me and told me where to take her.

Discrimination based on language. Language was identified as a significant barrier to healthcare access under the dimension of availability. However, discrimination based on language was identified by participants as an acceptability barrier. Being judged on language ability, accents and LEP, and the inadequate provision of language services, such as interpreters and bilingual staff served as critical barriers to healthcare access. When asked to share his experiences of being treated differently when accessing healthcare, one male participant who was a U.S. citizen from Puerto Rico said:

I know they treat me differently when they ask me where I'm from. I know that I have an accent but they don't need to ask me where I'm from. I don't ask you where you're from. Because of things like that they treat me a little different. Because my name is in Spanish they treat me differently automatically. They talk to me slow. I'm like "Hello, I speak English! And just because I'm Hispanic it doesn't mean I don't know your language"... Most of the time they treat me a little slower. After I tell them I speak English, they try to be nicer.

When sharing his experiences of being treated differently because of his language, one participant attempted to rationalize this differential treatment to the lack of education or awareness of the auxiliary healthcare staff:

The nurses and doctors are very professional. The differences I experienced have been in the reception area where they don't know your language and they treat you differently. Anyhow, they don't have the same level of education or information as a medical doctor or a nurse. That should have a little bit of influence.

Discrimination based on HIV status. The majority of participants who were HIV positive experienced some form of discrimination based on their HIV status from the community and/or from healthcare providers. As challenging as it is to live with this condition, participants with HIV were faced with an additional burden of discrimination by healthcare providers, who should be knowledgeable about the transmission of the disease and precautionary methods. Participants with HIV were discouraged from accessing care from providers who treated them differently because of their condition:

I had an experience this year when I went to the dentist here at the [hospital]. I was sitting in a chair lying down. So, a male dental student walked in with my record. He already had on gloves and when he saw that I was HIV positive he put on another pair of gloves and he was touching me as if I was not a human being and I was very uncomfortable. In the middle of that appointment, the doctor in charge came with normal gloves and he started checking my mouth over. The dental student asked me a question and I didn't answer because I was in shock at how he was treating me and he thought that I didn't understand English. And he looks at the doctor and says "this person is HIV positive". He thought that I didn't understand English. And he said "be careful. This person is HIV positive" ... I wanted to get up and leave from the chair.

Lack of awareness regarding HIV transmission among healthcare providers resulted in feelings of not being understood, discouraging participants from seeking healthcare services from these facilities. Similarly, lack of awareness in the community regarding HIV was also identified as a source of discrimination.

Participants expressed that discrimination based on HIV status resulted in feelings of social isolation, which influenced their health-seeking behaviors. One participant described the emotional distress that was worsened by discriminatory treatment when he was first diagnosed with HIV and was experiencing the symptoms of AIDS:

I was waiting in the emergency room of a public hospital and I had my mask on as at that time I had full blown AIDS. I could barely breathe. They told me with a protective mask it would protect me from viruses from everybody. There was a couple with a new born child and they asked me if the condition that I had was going to be dangerous to their child. I said it's not going to be dangerous. They didn't ask me in a really nice way. They shouted out so everyone understood. They wanted to make sure they were addressing me and that I wouldn't pass anything on to the child. I moved to a different location. It was very demeaning and it felt really odd and confusing. I could barely speak.

Cultural barriers. Individual characteristics, traditions and beliefs were also shown to significantly influence acceptability barriers to healthcare access. Cultural stigma associated with sexually transmitted diseases such as HIV, the use of traditional healing methods and self-medication were identified as cultural barriers to healthcare access. Participants often turned to traditional medicines and used self-medication as a result of other barriers to healthcare access. However, in some circumstances this resulted in delayed access to vital healthcare services.

Stigma associated with HIV. Negative cultural stigma associated with HIV significantly affected how participants sought preventive care, participated in screenings and adhered to treatment. When asked how her culture influences her health a female participant responded:

Bad. With respect to my sickness, I'm HIV positive, if they know somebody had this illness then they don't talk to you. They discriminate a lot. They try not to pay attention to you.

One participant from Puerto Rico attributed negative cultural stigma towards HIV to HLI cultural views on homosexuality, ideas of *machismo* and the emphasis on religion:

In Puerto Rico they were not accepting of male to male relationships or HIV. Knowing the culture as machismo and religion-based as well influences this. What I have heard up until now is that HIV is a subject that they don't want to touch. If you are HIV positive unless you have a group support, they will be concerned about you because they are not understanding of what it means to be HIV positive. We are talking about the old generation, old families.

Several participants also expressed their concerns about keeping their HIV status confidential, because they didn't want to be judged by their community or their families. One participant expressed his fears stemming from negative cultural stigma towards HIV that discouraged him from interacting with the community:

The Latino community is very discriminatory with regards to the condition that I have (HIV). So when they offer flu shots etc., I don't go. Other than my wife no one knows the sickness that I have. I don't want to take a risk and cut myself. I have to be very careful.

While some participants were able to gain family support despite negative cultural stigma, others were unable to disclose their HIV status to family members. A 21 year old participant from Guatemala said his family was unaware of his condition and he had to be separated from them in order to take care of himself:

I moved to Louisville because I don't want my family to know about my problem. I won't feel good if they know. I feel better here. I tried to depend upon myself. I would be doing it anyway, even if I was home.

Traditional medicine and self-medication. It is very common practice in Hispanic Latino cultures to use traditional, naturalistic and homeopathic medicines, and home remedies to treat health conditions. However, participants indicated that these traditional practices can be a barrier to seeking healthcare that may be timely and appropriate for different conditions. A participant from Guatemala expressed his views on traditional medicine:

In our culture, there are a lot of myths. People in general don't get checkups and don't go to the doctor. What they do is take more home remedies. One myth, for example is if you go to see a doctor supposedly you go in walking and you come out on a stretcher. That's what the people think.

Cultural beliefs and myths in accessing conventional healthcare services is particularly significant to HLI in the U.S. because of limited access to traditional, homeopathic healthcare providers who provide culturally appropriate care for HLI. One woman from Ecuador, who frequently accessed traditional healthcare and homeopathic therapies when ill, stated there were a limited number of traditional healthcare providers in

Louisville. However, this participant expressed how the inability of homeopathic medicines to effectively treat her respiratory condition resulted in further complications:

Three months ago I was having a cough or flu but it really was bronchitis. I tried to heal myself using homeopathic medicine...Usually I get healed or I recover from sicknesses with homemade remedies, and homeopathic medicine, but the last time three months ago, it didn't turn out the way I expected it to be.

Self-medication and lack of treatment effectiveness. Self-medication with traditional, homeopathic medicines was described to be a barrier to accessing timely and appropriate healthcare in circumstances where advanced medical therapies were required. As a result of increased costs when accessing conventional healthcare in the U.S., many participants decided to take their health into their own hands, which resulted in self-diagnosis and self-medication.

There is a big contrast between the U.S. and Cuba, because we don't pay in Cuba and you're openly free to go see the doctors and the doctors are forced to see you. If I would have been in Cuba and I had a pain here in my stomach I would have seen the doctor, but here you can't. It's going to be really expensive. So I have to try to deal with my pain by self-medicating or trying something else to relieve my pain.

When medications are prescribed to patients, it is essential for healthcare providers to explain and educate the patient on dosage, side effects and other vital information to assure safety and compliance. However, with the limited time and availability of healthcare providers, often medication information is not relayed appropriately leading to self-medication. One participant's experience illustrated how lack of time, availability and communication with healthcare providers can discourage patients from accessing healthcare, resulting in self-diagnosis and self-medication:

The problem is that everything happens so quickly. You go to the doctor and you only realize what is going on when you are in your car driving home. They give you all these medicines and when you go home you are like wow, I have all these medicines? It is scary when you have a lot of medicines you have to buy and you don't even understand why. Then you have to sit down and go the pharmacy where you get a little booklet about what is what. The doctor is getting paid to tell you that. When you walk out of that door you need to be a 100% sure about what is your situation in your health and they don't do that. You have to do your homework. If I can do that, I could do my own homework myself and buy my own medicine.

Lack of treatment effectiveness was identified as a reason for self-medication by many participants. One participant, who suffered from gastritis and reflux explained how he had to wait for long periods of time and incurred high expenses at the doctor's office for tests, procedures and medications that were ineffective. So he decided to increase his dosage, without his doctor's advice:

I suffer from gastritis and reflux, and I had to wait a long time to do all sorts of procedures like the endoscopy and all sorts of stuff and I had to wait that long. But then when the doctor was done he prescribes to me Nexium, a bottle of 30 pills which costs \$169. I didn't get better and Medicaid didn't cover it so I had to go back to the doctor. So he prescribed me Omeprazole. I treated myself and I took two pills of Omeprazole verses one, because the doctor ordered one pill, but it didn't do anything. And I read on the internet that there are prescriptions of 40 mgs Omeprazole and I asked myself why my doctor didn't prescribe me the 40 mg pill instead of the 20 mg pill. So I self-medicated myself to help me and took two 20 mg pills. Why should I keep on going to these appointments if he didn't resolve my problems and didn't cure what I have? It was the 40 mgs Omeprazole dose that really helped me. I self-medicated, so that's what helped me.

This narrative is a powerful indicator of the severity of self-medicating on prescription medications without accurate medical advice. The internet is a popular source of health information for many, but must be utilized cautiously as information is not always accurate. However, many turn to this source as a result of increasing healthcare costs and limited availability of healthcare services that serve as barriers to accessing appropriate care.

Health-seeking behaviors. Acceptability barriers to healthcare access were also related to individual health-seeking behaviors. This was influenced by participants' prioritization of healthcare that influenced the timely and appropriate accesses to healthcare services. Delaying access to healthcare was also related to lack of awareness or education regarding health conditions, the healthcare system and preventive health measures.

Prioritization and delaying access of care. Accessing healthcare was not a priority for several participants, who placed greater emphasis on family and work. Even with health insurance coverage, one male participant stated that he prioritized work over health:

Two years ago I had a very sharp pain in my chest, but when I started feeling the pain I didn't want to go to the doctor. I was having the pain for 8 hours and I didn't want to go. Even with that sharp pain I went to work. I thought that if I was able to work then I was ok. Right after we finished working, then I went to the hospital. That's a priority, going to work over going to the hospital.

Prioritization of work over healthcare was greatly related to affordability barriers, such as low-income, long working hours and high cost of healthcare and medical insurance. One participant observed:

People that don't have medical insurance try to wait to go to see a doctor, which is why they waste or loose time. Perhaps they can be saved or healed if they went earlier. They might go to the hospital and it's too late. It's very hard. The most important thing is that your life depends on your health, but your health depends on work or money.

Affordability barriers influenced prioritization of healthcare and resulted in delayed health-seeking behaviors. In some circumstances, participants expressed living with pain and other severe symptoms before seeking healthcare services. One female participant who did not have health insurance stated:

The last time I got sick was for a stomach disorder. I was in severe pain. I waited several days but the pain didn't go away. So I went to see the doctor because it was impossible for me to fall asleep.

This participant was later diagnosed with a severe stomach disorder (which she did not want to share with the investigator) that required multiple surgeries and resulted in increased healthcare expenses.

Immigration status and the fear of deportation were significant contributors to delayed health-seeking behaviors. Often times, participants were concerned that healthcare providers, who required social security numbers as a basis for accessing healthcare services, would report those who were undocumented to Immigration and Customs Enforcement (ICE). One participant shared an example:

I knew of a case of a lady who had appendicitis and that lady didn't want to go to the doctor. She was scared that they were going to send her back to her country. I told her two-hundred times that this was not going to happen. But she was like "no, they are going to get my information and pass it along to immigration." You know, the same way companies get your information and sell it to marketing people to make money? That's what they think is going to happen in hospitals. Hispanics think that the hospitals are going to send your information to immigration and they will have enough information about you to send you back to your country.

Lack of awareness, education and prevention. Health-seeking behaviors were also influenced by lack of awareness and knowledge regarding health, healthcare and preventive measures. HIV was identified as a significant health issue affecting the HLI community in Louisville. Out of the eight participants who were HIV positive, seven of them learned of their HIV status after immigrating to the U.S. Many indicated that they found out about their condition after routine testing required for legal immigration, such as applying for residency. Others were only aware of their HIV status when experiencing the first advanced symptoms of the disease process, which resulted in emergency room visits. One participant who was HIV positive and learned of his status after coming to the U.S. expressed how his lack of awareness regarding the condition was related to cultural factors:

I think that in my race, the Latin race, many people don't know they are infected with HIV and they don't get a test done. And when they finally do get a test they are in the final stages of the condition. Or when they find out they find out in the hospital. I've seen three cases of when people come to the hospital with some problems and they end up finding out what they have. So when they're in the hospital the doctors tell the family "your family member is HIV positive and it's possible that the person won't come out of the hospital because it is in its terminal stages."

Participants also indicated that they were not well informed about the U.S. healthcare system, including availability of interpreters and places to access affordable information and resources. When asked if HLI are aware of interpreter availability, a female participant said:

No I don't think so. Many Hispanics and Latinos do not know that you have the right to ask for an interpreter. It is very important for the Hispanic community to know their rights about these things like interpreters. We didn't know about this before.

Knowledge and awareness of free resources, such as clinics, was also limited among participants. Although there is only one currently active free health clinic in the Louisville community, none of the participants were aware of these free services. Limited knowledge regarding resources in the community and health conditions significantly affected the ability of participants to access preventive health services, such as screenings. This was a significant issue among the HLI population with HIV, as illustrated by one Cuban participant's narrative:

My country is third world and very poor and it's very hard to get gonorrhea or syphilis. Very difficult. For 40 years I was in Cuba and I had never gotten any of that. When I was young we never used condoms. No AIDS, no HIV. And I was very promiscuous. But I never had any illness like that and my country is third world. And imagine in this country, these things happen. That's ugly.

Lack of awareness of preventive measures such as contraceptive use, screenings and testing for sexually transmitted diseases including HIV was identified as a significant health concern in the HLI community, and was often related to cultural barriers. Several participants expressed limited community measures, such as educational programs, to increased awareness regarding health and healthcare access. This served as an additional barrier to promote preventive health behaviors and healthcare access:

Many people don't know about the different preventive measures that are available in the community. People don't know about the places where to go to get free healthcare services and other preventive tests. People don't read papers or watch TV and are not in tune with what is available to them.

Mental health. Immigrating and integrating to a new culture has many challenges and can lead to stressors that have shown to significantly affect the mental health of immigrants. When talking to participants and HLI in the community, verbal and non-verbal cues provided evidence for the emotional distress experienced as a result of immigrating to the U.S. Non-verbal cues included changes in voice intonations, hand gestures, eye movements and tearing up. However, participants also expressed emotional

distress and discomfort as a result of factors such as discrimination, significantly affected their decision making process to access healthcare.

Discrimination causes discomfort. Discrimination based on race and ethnicity, language, and HIV status triggered negative emotions that affected health and health-seeking behaviors of participants. One male participant who experienced discrimination as a result of his LEP expressed his feelings:

It made me feel very, very bad. That is a very serious lack of respect. Very bad. It bothers you for a long time because you think this is not fair. This treatment is not fair. But not all people are the same. People are impatient at times to pay attention to you. I didn't like that. I didn't feel comfortable.

Several participants who were HIV positive and experienced discrimination based on their HIV status at healthcare facilities expressed negative emotional feelings that were vividly portrayed in their expressions and emotions while being interviewed. One participant who experienced discrimination in the emergency room described it as “*very demeaning and it felt really odd and confusing. I could barely speak*”. Another participant experienced discrimination at a dental clinic based on his HIV status and stated that “*...when something like that happens I never return to that place.*” This statement indicated the powerful influence that negative emotional experiences stemming from discrimination can have on health-seeking behaviors that serve as an acceptability barrier to accessing care.

Emotional distress that discouraged access also stemmed from negative experiences when accessing care. One Mexican female participant who was undocumented stated that she did not access healthcare in the U.S. except during her pregnancy. Her sole interaction with the healthcare system caused emotional distress and negative feelings regarding the attention she received from her healthcare providers during a stressful time:

I had my baby at the [hospital] in Louisville and I had a very bad experience that time. The same day I was about to give birth there were like six nurses in the room with me. Suddenly, they went out, they disappeared and I stayed alone in the room and I was worried about that. My husband was with me. I was having sharp pain and I knew I was going to give birth at that moment. And then I was more afraid because only my husband was here and he's not ready or prepared, he doesn't have gloves on his hands. So I started to cry and yell and the nurses came and the head of the baby was already out, and I was in panic. It was a very bad experience because of that. I think that when you are in such a situation, doctors and nurses shouldn't leave the patient alone in such a situation.

Healthcare business. The view that healthcare in the U.S. was more of a commercialized form of “business” or “trade” was a central theme in acceptability barriers to healthcare access. When comparing the healthcare system in the U.S. to those in their countries, participants often perceived the treatment of

patients as customers instead of humans in the U.S. These feelings occurred as a result of participant perceptions that healthcare providers did not care about their health and wellbeing, inhumane treatment and lack of social support.

Patient vs. customer. Participants emphasized their belief that healthcare is a human need and should not be treated as a business, as they perceive it to be in the U.S. A male participant from Cuba stated:

In my country I was a patient, as far as health goes. But then I came to the U.S. and now I'm a customer. A sick person is a face here. I don't know how to explain it. Because you pay them, they see you and they listen to you. Health is a human necessity, a human need, but here healthcare is a business.

Reasons for these perceptions stemmed from various negative experiences when interacting with the healthcare system, but were significantly related to time, availability, communication and financial barriers to healthcare access. A participant from Puerto Rico gave reasons for his view on the healthcare business idea:

It all comes down to money in America. They want you to be there when they don't have any appointments. That's why they schedule you beforehand. But once they have their schedule full, they don't care. Sorry I don't have time for you. The reason why doctors are so impersonal is because they want to make the most money they can in one day. They want to have a really big turnover. They want to give you only ten minutes. While the doctor is talking to you the nurse practitioner is taking care of all the patients. So in a day if you just count ten minutes for an hour it's a lot of money. Basically when they want you to do tests... everything is done through tests. I don't have a clue why I need to get a blood test for. So it is very overwhelming. You are scared about it but you go and do it and everything comes out fine. You still have to pay for it.

Accepting the healthcare business mentality in the U.S. is particularly difficult for HLI because of the vastly different healthcare systems they were accustomed to in their countries of origin. Compared to others, Cuban participants were very vocal about how the healthcare business perspective served as a barrier to healthcare access. After going to multiple visits to his healthcare provider and incurring expensive healthcare costs, one Cuban participant came to a realization:

Why should I keep on going to these appointments if he didn't resolve my problems, didn't cure what I have... That's when I started to realize that it's a business. If the money wasn't so calling to them, the professionals would be more conscious. My country didn't give me one penny for my health, but the medical doctors were more professional. The nurses get very little salary, tiny! A Cuban doctor earns thirty to forty dollars a month; the conversion would be around five-hundred or six-hundred pesos a month. And when you're sitting there they treat you with a lot of pleasure, doesn't matter if you're brown, white, dirty, or if you come stinky. They treat you with the same sweetness and respect.

This statement revealed the participant's perception that money was central to the healthcare system and among healthcare providers in the U.S., whereas in Cuba, where the healthcare system is socialized, providers are more concerned about patient health and wellbeing over income. As financial factors were identified as a significant affordability barrier to healthcare access, the strong view of healthcare as a business in the U.S. influenced participant acceptability of healthcare systems and health-seeking behaviors. These narratives also revealed issues of equality in treatment by healthcare providers, which ties into the inhumane treatment and perceptions of healthcare providers desire to help.

No desire to help from healthcare provider and inhumane treatment. The perspective that the healthcare system is more of a business versus a humanitarian service was amplified by participant's views that healthcare providers lacked the desire to help patients, or in extreme cases treated patients inhumanely.

A female from Ecuador stated:

Medical doctors and hospitals...for these kinds of health providers the most important thing for them is making money. Not to help people, to treat people, or to heal people. So it's like a trade or a business. There's not a sense of it being a human service that helps people, which it should have.

Other participants voiced similar concerns when seeking health services at emergency rooms and doctor's offices, especially when they did not receive adequate language services to promote communication during healthcare encounters. Participants expressed the importance of having healthcare providers who are caring and considerate of the patient's language needs. Inequality in treatment of individuals based on language differences exemplifies the limited desire of healthcare providers to help.

When participants perceived that healthcare providers did not have a strong desire to help them or care about their wellbeing it resulted in feelings of insignificance and isolation. This narrative illustrated the negative experiences of one participant when accessing care from a specialty healthcare provider that resulted in ineffective patient-provider communication and emotional distress:

The specialist looked me over examined me but I felt like the specialist was just examining an animal or a number, just a number or just another patient...It was very tense...And I went down to the building downstairs outside and sat down and cried. I said how can there be people like this who lie? They didn't try to communicate with me and there wasn't an interpreter available for me.

Summary

Under the four dimensions of barriers to healthcare access, there were several recurring patterns that were overlapping, indicating the interrelated nature of the various themes. The investigator systematically categorized themes and subthemes to highlight areas that participants perceived to be

significant barriers to healthcare access. Under availability barriers, *Time and availability*, *Healthcare personnel characteristics*, *Patient-provider communication* and *Navigating the healthcare system* were the most pertinent themes. *Documentation*, *Emergency room* and *Type of healthcare facility* were recurrent themes under accessibility barriers. Affordability barriers were exemplified under the themes of *Financial barriers*, *Knowledge and awareness* and *Resources*. *Discrimination*, *Cultural Barriers*, *Health-seeking behaviors*, *Mental health* and *Healthcare Business* were the predominant themes under accessibility barriers.

Facilitators to Healthcare Access

Availability Facilitators

The major themes under availability facilitators were *Healthcare Personnel*, *Patient-Provider communication* and *Resources* represented in Table 5 (see page 58).

Healthcare personnel. Participants identified the availability of trained interpreters and bilingual healthcare providers to be significant facilitators to healthcare access because it eliminated language barriers and facilitated communication. Other healthcare professionals who were identified to be integral to facilitating healthcare access were nurses and medical case managers. Nurses and medical case managers took the effort and time to help participants with their health concerns and assisted them in navigating the healthcare system to access appropriate healthcare services.

Interpreters and bilingual healthcare providers. Although participants identified the lack of interpreters and bilingual healthcare personnel to be a significant availability barrier to healthcare access, they also identified the availability of trained interpreters and bilingual healthcare providers as a facilitator to healthcare access. The availability of interpreters and bilingual providers helped build trusting relationships and encouraged health-seeking behaviors through increased communication. A female participant described her experiences when using an interpreter at the hospital:

When I went to the hospital for my colonoscopy they gave me an interpreter. The experience was good. It was easier to understand what was being said with the interpreter there. The man has a lot of experience in this field of interpretation, so he was very affectionate and he's very professional. I felt fine.

As participants only had a short amount of time to familiarize themselves with the interpreters, the interpreter's level of training, expertise and people skills were integral to developing an understanding, professional relationship. The availability of face-to-face interpreters was crucial to accessing healthcare

services, especially in circumstances where patients were undergoing procedures that were invasive or caused higher levels of stress. Participants expressed increased levels of communication and comfort when using face-to-face interpreters as opposed to phone interpreters. One participant stated:

Sometimes when I have gone to get a mammography sometimes there is no interpreter and they call somebody through the phone and we do interpretation. The experience was good. Of course it's much better to have an interpreter in person, but anyways it was helpful.

Another participant who accessed interpreter services both by phone and in person expressed the importance of having an interpreter:

I can see that having an interpreter can be very useful because of the limitations we have for speaking and communicating in English. Those places that Latinos go they need interpreter services in those places and institutions. They should have people available most of the time to help communicate with the doctors.

Accessing healthcare can be a very stressful event during a patient's life. The inability to communicate with doctors and other healthcare providers increases levels of stress, as the patient is unaware of their condition and the types of medical procedures that will be conducted. Participants identified better communication with doctors with the help of interpreters:

I feel very nice when I communicate with my doctors and they are very nice as well. And they always provide me with an interpreter so I can communicate very well. When I get to the hospital there is an interpreter available there.

All participants, including those who spoke English fluently, identified the importance of having an interpreter to facilitate communication with healthcare providers. Participants also expressed that access to bilingual healthcare providers further increased communication and promoted trust and familiarity. One participant emphasized the importance of having a bilingual healthcare provider:

Mainly, the doctor that sees my daughter speaks Spanish. He is a Spanish speaker, but he is not always available. So sometimes I have made appointments with the doctor's office or hospital... the Spanish speaking doctor is not there... So I like to reschedule the appointment to a time when the Spanish speaking doctor is there, because there is no communication otherwise. Of course using an interpreter or a bilingual healthcare provider makes communication much better.

Although the availability of bilingual healthcare providers was limited, participants took the extra effort to find Spanish speaking doctors to help facilitate communication and access. Bilingual healthcare providers facilitated access to healthcare services for many participants with LEP:

It's not very easy for me because I need an interpreter. We always try to find a doctor who speaks Spanish. It's much better for us to communicate.

Another participant who didn't speak English stated:

Of course it is much easier to have a bilingual doctor. I changed my doctor and she is Hispanic and she speaks Spanish so the communication was very good and easier, better for us.

Access to bilingual healthcare providers increased communication between the patient and the provider, especially when language barriers and other limitations served as a barrier to accessing healthcare services. Additionally, cultural factors influenced the level of communication and type of relationship that participants had with their healthcare providers. One participant made a comparison between her relationship with her healthcare provider in the U.S. and Ecuador:

I think my relationship with my healthcare provider in the U.S. is different from the one in Ecuador. In our country we treat the doctors with a certain kind of affection and there is great communication. Here, you are limited because of language, so when you find a doctor who speaks Spanish it is much better for you.

Nurses. In several circumstances where time and availability served as barriers to healthcare access, participants identified nurses as facilitators to healthcare access. As identified in availability barriers, participants stated that doctors did not have sufficient time to communicate with patients, whereas nurses were more attentive and spent relatively increased amount of time patients. One participant stated:

In the United States, it takes a lot of time for the doctor to see you here, especially in the emergency room. Here you spend a whole lot of time with the nurses before you see the doctor.

Another participant expressed similar views while experiencing long waiting times in the emergency room stating that “A nurse would come in every so often, but a doctor no. Not so much.” The availability of nurses and the attention received from nurses were positive influences on healthcare access for many participants, especially when nurses were identified as a significant source of healthcare services. One participant shared his views:

Most likely I talk to the nurse practitioner. She is the one who takes my information and asks me all my questions. Then the doctor just looks at the computer to see what she wrote. So practically he is seeing me for only 5 or 10 minutes. Which is no time at all... While the doctor is talking to you the nurse practitioner is taking care of all the patients.

Nurses were also identified as individuals who provided important health information for participants. Increased communication with patients provided opportunities for nurses to relay vital health information regarding treatment, medications, and preventive health measure to promote healthy behaviors. When taking her daughter to the dentist, one participant said:

The dentist only tells me what my daughter has. But for example the nurse told me that my daughter shouldn't drink soda or other soft drinks; that children may not always brush their teeth

correctly, and that I should do it for them. Mainly, the doctor or dentist never tells me anything, never talks to me. The nurses talk to me.

Medical case managers. Another significant facilitator to healthcare access was the availability of medical case managers, especially in the circumstance of participants with HIV. Medical case managers were central in facilitating navigation through federal and healthcare systems for individuals with HIV. The individual who served as an interpreter and assisted with recruitment in this study also worked as a bilingual medical case manager at the infectious disease clinic (one of the identified study sites). The level of communication, familiarity and trust that participants shared with their medical case manager was evident in their willingness to participate in the study, mannerisms and narratives. When asked what he would do if he needed immediate healthcare services one participant stated:

Thank god I haven't needed to. I wake up every morning. I call Joshua (medical case manager) to see if he can help me see a doctor or call him to see a doctor. Or on the other hand, if I have to, I go to the emergency room.

Several participants identified their medical case manager as an essential channel to enter and navigate through the healthcare system, as this individual facilitated access to HIV medications, preventive resources, tests and screenings and most importantly social support. When asked who the most important person to him was when sick the U.S., one participant responded:

Joshua, my medical case manager. I call him when I'm sick and I get health services at [the infectious disease clinic].

Medical case managers facilitate healthcare access for patients who are HIV positive through several federally funded programs across the nation. In Kentucky, the Kentucky Aids Drug Assistance Program (KADAP) takes primary responsibility in providing HIV medications and other resource support for individuals who cannot afford them (Department of Pharmacy Policy, 2012). One participant who moved from Florida to Kentucky shared his experiences:

The first state that I moved to was Florida and then I transitioned to a program here in Lexington in 1999. I had already arranged it in Florida and I registered in the local agency in Lexington. Probably within a month I was with a case manager. It was a fluent process here in Kentucky but not so much in Florida... From the experiences I had I have been very blessed with not only the medical case workers I had but the doctors in Louisville too.

Patient-provider communication. Along with availability of interpreters and bilingual healthcare providers, patient-provider communication was additionally enhanced through several provider and recipient characteristics. Participants were more likely to access healthcare when their healthcare provider

was cognizant and respectful of their cultural needs resulting in the development of familiarity and trust. Increased communication as a result of an individual's ability to speak English and the use of family members who speak English as interpreters also facilitated healthcare access.

Familiarity, trust and cultural identification. Participants who accessed healthcare at the infectious disease clinic and the primary healthcare clinic indicated higher levels of trust as a result of increased patient-provider communication and culturally competent care. Additionally, familiarity with providers increased trust and enhanced the patient-provider relationship. One patient who was HIV positive and accessed services at the infectious disease clinic described his experience:

It's always easy to come here and that's why I always come here. In the clinic they tell me everything that I have, they tend to me well. And every time I come here I feel good. They look at my patient history, so it's become very easy to come here.

The infectious disease and primary healthcare clinics also provided interpreters and access to bilingual healthcare providers, which was an integral factor that promoted health-seeking behaviors and healthcare access among participants. One participant who was HIV positive described the level of communication with his healthcare provider at the clinic:

Very easy, because my doctor speaks my language. And I feel more comfortable with him and more confidence in him. We all speak openly about everything.

Along with language access, most participants who accessed care at these clinics also expressed that their providers were able to identify with their culture and were understanding of culture needs. Cultural competency is an essential component of being an effective healthcare provider in almost any healthcare setting. The strength and effectiveness of cultural identification is illustrated in this narrative where one participant with LEP expressed how he was able to have a trusting relationship with his healthcare provider even without the help of an interpreter:

I almost never use an interpreter with my doctor because I have very good communication with my doctor. She knows how to speak to me very slowly. And when I don't understand a word I say I don't understand. She knows that I can read a little bit more in English, so sometimes she writes it down. There is more certainty. We have a good relationship. That's why I don't use an interpreter. There aren't many bilingual, Spanish to English doctors. I have a very good relationship with my doctor.

Participants stated that they felt more confident and trusting in their patient-provider relationship when healthcare providers were inclined to take efforts to understand them, despite language and time barriers. This is another component of cultural competency, where non-verbal communication that exudes the caring

and compassionate nature of healthcare providers encourages communication, enhances patient-provider relationships, and facilitates healthcare access. One participant statement exemplified the strength of cultural identification and non-verbal communication on building trust and familiarity:

So when a doctor or nurse is taking care of a patient and takes their time and gives you a smile or some kind of sign of good will, a patient feels more trusted, understood, more comfortable. They feel comfortable and trust their doctors to tell them about everything that they're going through when they're kind and compassionate and take time to communicate with the patient.

Being treated equally by healthcare providers was also viewed as an essential component of being a culturally competent and caring provider, further enhancing the patient-provider relationship. A female participant who experienced discrimination based on her language and ethnicity from healthcare providers stated:

There are doctors and nurses who are very amicable, very friendly. I see they are like that with everybody, not just with me. I agree with that because if I'm a person who deals with the public I'm going to treat everybody the same- treat everyone equally.

Ability to speak English and use of family as interpreters. Participants expressed that their ability to converse in English facilitated communication with their healthcare providers. Even participants with LEP, sometimes took efforts to facilitate communication with their healthcare providers. One participant who was HIV positive stated:

When I go to the clinic I have to speak, but sometimes they have people who speak both languages. But sometimes I can do it myself- I can communicate. Sometimes they ask me "do you need help", but I try to do it myself. Like now, I'm trying to speak in English. Sometimes when I don't understand very well, I will ask somebody to explain to me very well. Like now when I need to know very well what they're saying I ask the interpreter to help.

It must be noted however that although an interpreter was available during the interview, this participant was determined to conduct the interview in English and did not solicit the help of the interpreter. The participant's efforts were admirable; however, he often found it very difficult to express his perspectives, leading to frustration and lack of communication with the investigator. Therefore, it is evident that even though participants may take efforts to communicate with their providers in English vital information can be lost in translation.

Another facilitator to healthcare access was the use of family members as interpreters during healthcare visits, when trained interpreters are unavailable. Several participants with LEP stated that they always took their English-speaking family members with them in order to facilitate communication and

understanding with their healthcare provider. One participant with LEP stated, “*Most of the time I come with my wife and we help each other understand.*” In situations where interpreters and bilingual healthcare providers are unavailable, having some form of communication with providers assisted participants in accessing services. In some circumstances, participants expressed using children (who were second generation HLI and more likely to speak English) as their interpreters. One participant said:

They don't provide me with an interpreter at other places. So, I take my brother. He is 12 years old and speaks English very well. When I take him to places, people don't have a problem having him interpret for me.

Although participants identified it as a facilitator to healthcare access, using family members as interpreters has several limitations and ethical issues, especially with the use of young children. As indicated in the availability barriers, important health information and terminology is not easily understood, even by those who speak English fluently. Therefore, family members who are not certified interpreters may not be able to translate accurate health information to patients. Additionally, using children as interpreters when accessing services, which is a common phenomenon in the HLI population as a result of language barriers, poses significant problems. Using children as interpreters is a major issue not only because of limitations in translations, but because it is unethical to expose children to stressful environments as they may not be able to understand or cope with the health conditions of their family members.

Resources. Availability of resources such as medications, health fairs and screenings served as facilitators to healthcare access for many participants. Participants who were HIV positive were especially expressive about their ability to access affordable and sometimes free HIV medications that are essential to keeping their viral counts within normal limits:

Now I'm doing well because the clinic has helped me a lot. My medication doesn't cost me anything to buy. However, everything I get from the other nurse I have to buy myself every month.

For patients with HIV, maintaining health in the U.S. is facilitated as a result of the resources available for people with this condition. Medications for HIV are expensive and often unavailable in other regions of the world, where cultural stigma and lack of resources impedes an individual's ability to live healthy lifestyles with this condition. When comparing access to HIV medications in the U.S. to Mexico, one female participant stated:

The medications are more advanced here and not so much in Mexico. I was trying to research if there was any way I could go back to Mexico to live, but the medications I'm taking here are not available in Mexico. So I have to stay here in Kentucky.

Along with medications, other resources within the community that facilitate healthcare access include health fairs and screenings. One annual event that two participants were aware of and accessed was the Hispanic Latino health fair:

The only health fair that I know of is when health screenings are provided every year, where a bus from [hospital] comes to Americana where they give mammography and other cancer screenings. They bring a bus outside so all women can go there for screenings for free. It helps a lot.

The Hispanic Latino health fair is organized and supported by local organizations and hospitals to provide free healthcare services such as cancer, blood pressure, blood glucose, and cholesterol check-ups to anyone in the community, but is targeted towards HLI. Similar annual health fairs and screenings that participants identified to be popular among HLI were also provided at different settings including churches and other community organizations. These health fairs were often identified as the only source of healthcare for many HLI in Louisville, especially among those who were low-income, uninsured and undocumented.

Accessibility Facilitators

The major themes under accessibility facilitators were *HIV, Type of Healthcare Facility, Documentation and Quality of Care* represented in Table 6 (see page 59).

HIV. One facilitator to healthcare access that was new and unexpected in the research findings was HIV. Participants who were HIV positive verbalized how their condition enabled them to access vital health services and other resources through the infectious disease clinics designed to help disadvantaged individuals with HIV.

HIV and the infectious disease clinic. Participants who were HIV positive were knowledgeable about their health conditions and aware of the need to maintain treatment and medication compliance in order to maintain low viral counts. They took additional precautionary measures to stay healthy and visited their healthcare provider in three to six month intervals, or as indicated by their healthcare provider. One male participant who moved to the U.S. with the intent of accessing better resources for HIV said:

I go to the clinic every three months. The last visit was for a blood test and lab work. I like to always go get checkups to see what's going on with my body. Every three months.

Participants also expressed that they were more inclined to access health services to meet their HIV needs when compared to other healthcare services:

Nowadays I visit the doctor just for HIV and not other health services. And I always come to my appointments with my doctor here. And I take my medications. I try to keep myself healthy.

Being diagnosed with HIV was a traumatic experience for all participants who were HIV positive. However, having this condition often encouraged them to be more proactive about their health and promoted health-seeking behaviors. Availability of free HIV resources such as medications and community support programs in the U.S. also facilitated healthcare access and overall health and wellbeing of participants with HIV. Healthcare visits to the infectious disease clinic cost a minimum cover fee of \$15 dollars, depending on the patient's monthly income. (If patients are considered to be a class six on the gold card or sliding fee card, which is the lowest class, they are required to pay the \$15 cover fee). One participant who was undocumented and sought services at the clinic stated:

While I'm here in the U.S., I feel fine. I'm afraid that someday it will change because I might have to move out of the country because I'm illegal. I know that within the country there are always going to be organizations that help with HIV services within the US... I don't know what I would do to access healthcare in Guatemala because I've never had to. I never had to access healthcare because I got sick with HIV here.

The availability of services at the infectious disease clinic was identified as a significant facilitator to healthcare access among participants who were HIV positive. Often times, the clinic was identified as a vital source of health and social support, especially for immigrants who become aware of their HIV status after they entered the U.S. One participant shared his experiences of accessing help for his newly diagnosed condition after emigrating from Cuba:

In 2003, when I did my physical exam for U.S. residency I found out about my sickness. It was a problem because I didn't have anywhere to go it was a bad experience. I almost committed a stupid act and I thought of killing myself. But then I was recommended services about [the clinic]. There is help for people who want to live longer and don't want to kill themselves because of their conscience. They go to [the clinic]. They help us and make us aware of what we need to do. There is no problem with accessing medication. It's up to us. We need to be conscientious if we want to get ahead... When I found out about [the clinic] I felt better... That is what helped me survive until now. I'm a fighter.

The clinic provides affordable health services and access to free medication, testing and other resources for individuals who are HIV positive regardless of insurance and or immigration status. Other contributory facilitators to the infectious disease clinic that also served as availability facilitators included availability of interpreters, medical case managers, and bilingual healthcare providers, increased communication and

building of trust and familiarity. All these facilitators enhanced patient-provider relationships between participants and their healthcare providers at the clinic. One participant who only accessed health services at the clinic said:

Actually, every time I go to the clinic I haven't encountered any problems. I think they understand me, my culture and my health needs. Every time I come here they treat me well.

Individuals who access services at the clinic have developed trusting relationships with their healthcare providers because of the availability of interpreters, bilingual healthcare providers, medical case managers and providers who care about their health and wellbeing. The clinic had considerable positive influences on healthcare access for one participant who expressed the need for these types of affordable services and social support in other areas of health:

Friends of mine, they see me come to the clinic and ask me, "Hey how do you come to this clinic and they don't charge you anything." It's difficult to hide from people that I come here because I'm HIV positive. But they want to know if I can give them the telephone number to the clinic because they want to call to get help. My friend's husband found out he had cancer and no one was willing to see him anywhere. If he could come here (to the clinic) they would be able to help and support him. In that aspect the government does help, since there's more support or more medical attention for HIV.

Interestingly, the majority of participants accessed the clinic as their primary source of healthcare. Several participants contacted their medical case manager when they were sick to see if the clinic could provide primary healthcare services to treat them. If the clinic was unable to take care of their health condition, most participants accessed the emergency room because they were uninsured and did not have a primary healthcare provider. However, regardless of their condition, many participants expressed that healthcare providers and medical case managers at the clinic made every effort to help them seek further medical treatment for their healthcare needs. One participant stated:

I come here to the clinic four or five times a year. I don't go anywhere else, depends if I need it. Very rarely do I go somewhere else.

Type of healthcare facility. Participants experienced variations in the level of ease in accessing healthcare services depending on the type of healthcare facility. Emergency rooms, public health clinics and other primary healthcare clinics served as facilitators to healthcare access because it helped overcome barriers of documentation, time and availability, lack of health insurance and financial barriers.

Emergency rooms. Although emergency rooms were identified as an accessibility barrier to healthcare access as a result of negative experiences such as long waiting times and lack of communication,

these healthcare facilities also served as facilitators to healthcare access especially for low-income participants who were undocumented and/or uninsured. Participants who were undocumented indicated that although other primary healthcare clinics asked for identification and social security numbers as a prerequisite to accessing healthcare services, emergency rooms did not ask for this type of documentation. When asked what type of legal documentation she had to show in order to access healthcare services, one participant stated:

None. Well they ask you if you have social security number, but it doesn't make any difference if you have it or if you don't have it, they are going to see you here in the ER.

Another participant who was uninsured had similar experiences:

If I feel really bad I go to the emergency room it doesn't matter if you're legal or illegal, if you have medical insurance or not. So they treat you. If it's an emergency they help you. So it's not difficult to see a doctor in that case. It's not difficult to be seen by somebody, but the point is if you don't have medical insurance to cover your treatment then that's what influences your decision to go to the doctor. If you can pay or not.

Visiting the emergency room allowed participants to experience alleviation from symptoms of their healthcare problems in a relatively faster time than waiting to be seen at a primary healthcare clinic, which has limited availability of appointments. One female participant described being diagnosed with serious health conditions as a result of visiting the emergency room on three occasions:

I went three times to the emergency room when I had a problem with my back and they told me I had renal, kidney stones. The third time they told me it was a problem with my spine. It was a disc muscle.

Limited time and availability of healthcare providers often led participants to seek healthcare services at the emergency room, where despite barriers of time and money, participants were able to find relief from their symptoms. When he was unable to set up an appointment to see his primary healthcare doctor, one participant was sent to the emergency room from a nurse practitioner clinic for pancreatitis:

It was scary because I didn't know what was going on. I didn't know what pancreatitis was until they explained it to me. So they put me on 24 hours only on water and IV, and they gave me Jell-O and bullion and stuff like that. Then they sent me home the third day.

Another participant from Cuba had a similar situation:

The last time I had a fever for more than two days, my throat was very inflamed and I couldn't swallow. So I went to the emergency room because I didn't make an appointment and if you don't make an appointment you can't be seen at a clinic.

Although emergency rooms were identified as an accessibility facilitator as it allowed participants to get immediate medical attention, it must be noted that participants also expressed receiving expensive emergency room bills that they could not afford. Therefore, although emergency rooms facilitated access and served as a vital source of healthcare for many participants, barriers related to availability and affordability continued to restrict access. This was further discussed under accessibility barriers

Public health clinics and primary healthcare clinics. Several participants accessed primary healthcare services from public health clinics that provided services using an income-based sliding scale fee program. All participants who accessed healthcare services at the public health clinics were documented, but did not have health insurance coverage. Participants expressed that although it may take several months to get an initial appointment with the public health clinics, subsequent visits were easier to schedule once they were in the patient database. One participant said, *“If I feel bad I can go to the [public health clinic] and I stay there and they see me the same day. I get the attention that I need.”* Another female participant echoed this perspective regarding attentiveness at the public health clinics stating, *“They were very attentive and as soon as I called they gave me an appointment at the [public health clinic].”*

As a facilitator to healthcare access, the public health clinics are often the first choice for individuals who are eligible to receive services from these clinics. One participant from Ecuador stated:

The first thing I do when I’m sick or ill is I go to see a naturalist and use traditional medicine and try to heal with that. If not I go to [public health clinics].

When asked what types of barriers she faces when accessing care in Louisville, one participant from Mexico who primarily accessed healthcare services from the public health clinics stated:

I don’t have any kind of difficulties or hard time, because every time I call for an appointment at [the public health clinic] for the children I get an appointment and they call me back and tell me availabilities. I don’t have any barriers. As soon as I call they give me an appointment and in my personal case I don’t have any trouble getting an appointment. And they always have the medical records of my children and always have the information available so they call me back.

Another facilitator to healthcare access was the primary healthcare clinic that provided healthcare services to employees of the horse racing industry, which also served as a study site for this dissertation. The clinic functions with the help of nurse practitioners, nurses and interpreters who volunteer their time to provide services for employees of the race track. All four participants who accessed healthcare services from the primary healthcare clinic expressed ease in accessing services at the clinic, especially because of the availability of nurse practitioners, bilingual staff and interpreters. The clinic makes referrals to specialty

health services and facilitates access to other clinics for patients. One participant who was suffering from incessant vaginal bleeding that resulted in low hemoglobin levels stated that her nurse practitioner at the clinic helped her in accessing the appropriate treatment and healthcare:

I came here to the race track to see [my nurse practitioner] and she gave me medication and I'm still doing follow-ups with her for the vaginal bleeding. In December I came every week because my blood level and hemoglobin was low. Now every two weeks I come to check and see how my blood is doing. They help me a lot in the clinic.

Documentation. Having immigration paperwork that identifies an individual's legal immigration status was identified as a significant facilitator to healthcare access. This includes having a social security card, green card or U.S. driver's license. Many healthcare facilities require patients to show proof of identification and/or social security cards in order to receive healthcare services. Those individuals who have a work visa, refugee status, permanent residency, citizenship and/or other paperwork as proof of their legal immigration status in the U.S. are able to apply for an identification card, driver's license and social security number. This in turn allows them to access health insurance coverage and healthcare services. One participant who came from Cuba on a Family Reunification Parole Visa (temporary refugee status) and was waiting for his permanent residency to be granted stated:

When I came here, when I went to the refugee organization they told me I had to go come to [the public health clinic] for my initial physical assessment and screening which is done there for all refugees... It was not because I wanted to come, it's because they told me to come and that was the first time I've visited the doctor here. The second time it was when I went to the emergency room. In a year and seven months I've visited the doctor two times. When I applied for my permanent residency I had to go to a hospital again to get a physical examination, blood tests, and TB test. Everything was ok, but it was an obligatory test to apply for your residence in the U.S.

The government provides mechanisms for individuals with refugee status to have access to healthcare services for a limited amount of time, after which individuals are responsible for obtaining their own health insurance and healthcare services. Participants who had legal immigration paperwork expressed the ease in which they were able to access services, without the fear of being caught or deported:

I'm legal here. So I just give my social security number. When I came here first I didn't have documents and it was hard, more difficult to get healthcare services.

There is a significant difference in the level of healthcare access between documented and undocumented immigrants. This difference is illustrated in the narrative of another participant who makes a comparison between her two daughters- one who was born in the U.S. and one born in Mexico:

My daughter doesn't get any assistance from the government. She was born in Mexico. My other daughter was born in the US. Because she was born here, it makes everything easier for her. She has insurance through Passport (Medicaid).

Participants with legal immigration paperwork were also able to access health insurance coverage, which serves as a significant facilitator to healthcare access. Often times, these services were vital to the health and wellbeing of the participants as it was in the case of a participant with HIV who was a U.S. citizen from Puerto Rico:

KADAP takes care of the medication copayments after the insurance pays for it. They bill me for any out-of-pocket expenses I need to pay for medical services. What I need right now is the medication and I'm happy with it.

Quality of care. Participants identified that the better quality of care and access to healthier options in the U.S. as opposed to their home countries supported healthier lifestyles and health-seeking behaviors that facilitate healthcare access.

Better quality of care. Many participants expressed significant differences in the quality of healthcare services in the U.S. compared to their countries, indicating that better quality of care facilitated healthcare access. When asked how an individual would access care when sick in Puerto Rico, one participant stated:

They will still go to the emergency room, primary care and outpatient centers, but the quality of care is not going to be the same as you are getting here in the U.S. You are still going to be seen in the hospital but again it is going to be a totally different experience.

Quality of care was often measured by participants based on the use and availability of technology, advanced diagnostic measures and preventive screening methods that detect serious health conditions. A female participant from Cuba shared her experiences of being diagnosed with breast cancer:

When the doctors detected and found that I had cancer it was because of their routine check-up, because I didn't have any kind of symptoms before. I didn't detect in my self-exam any cysts or anything suspicious. It was detected by a mammogram. In Cuba I never did a mammogram. That kind of device or equipment that takes a mammogram in Cuba is only available when the doctors do a physical examination or you have symptoms and ask for a mammography. It's not as routine as it is in the U.S. for prevention. It's very hard to have a mammogram in Cuba. It only happens with if they notice symptoms and the next step is a mammogram. But it's not as preventive as here...I wouldn't have known I had breast cancer if the doctor hadn't found it.

The healthcare system in Honduras was also identified as having fewer technological resources and healthcare facilities as indicated by one participant's narrative:

The healthcare system in Honduras is different from the U.S. The biggest differences are that here in the US there are many clinics and hospitals and in the hospitals there are many devices and

equipment to diagnose your health problems. In Honduras there are not so many hospitals and clinics and they don't have as much equipment or devices to diagnose what you have.

Participants expressed that access to better quality healthcare often assisted in early detection of health problems that were preventable and treatable at the stage in which it was diagnosed. The advanced diagnostic tools and knowledge available to healthcare providers in the U.S. makes it easier for them to “get to the heart of the matter”, as one participant stated.

Better access to healthier options. In addition to higher quality of healthcare, a few participants expressed that there were better opportunities to access healthier dietary options to maintain healthy lifestyles in the U.S. Access to healthier diet options encouraged healthy lifestyles and preventive behaviors. One participant from Cuba stated:

Most of all, to be healthy or to have a healthy body what we need the most is to have a healthy diet or to eat certain kinds of foods that in our culture we don't usually do. Here we have the kinds of food to create a healthy diet, but in our country we don't have it, it's really hard to find that. For example, in our country we have certain kinds of food where we can get calcium, but we cannot afford it so easily. Here we can.

Another participant from Guatemala said:

The biggest difference between taking care of your health in the U.S. and Guatemala is that here we have more opportunities to make healthier choices to eat healthier.

Affordability Facilitators

The major themes under affordability facilitators were *Government Resources, Resources and Financial Assistance* represented in Table 7 (see page 59).

Government resources. Affordability facilitators to healthcare access included direct and indirect government funding for participants that increased their ability to access healthcare services. Government resources included funding for programs and clinics that provided health and related social services for low-income individuals, and welfare benefits including Medicaid and KADAP.

Government funded financial resources. Financial support from government agencies was identified as a significant factor in providing health services for underserved, disadvantaged populations. Participants expressed their increased ability to access government funded programs in the U.S. When comparing differences in healthcare access in Guatemala to the U.S. one participant stated:

There's a big difference because there's a lot of economic help and money in the U.S., but not in Guatemala. Someone told me that you have to have lots of money there in Guatemala and you have to pay a lot of money in order to survive.

Participants identified the provision of increased government resources within the community in the U.S. to assist underserved and disadvantaged populations. Often times, this level of government funding is not available in certain countries as expressed by participants from Guatemala, Mexico and Honduras. One participant from Guatemala shared a story of his friend who received help for cancer treatment:

I know a friend who got cancer in the blood and an association or organization took care of him. For people with that kind of problem, people with cancer, there are places that help. And he is very happy, because he is almost better now. He is doing very well.

Welfare benefits. The two main welfare programs that several participants were able access included the Passport Health plan (Louisville/Jefferson County's Medicaid program) and KADAP. Participants who accessed Medicaid services were permanent residents and U.S. citizens, or had children who obtained U.S. citizenship by birth, which are prerequisites to accessing most federally funded programs. A female participant from Honduras whose daughter was born in the U.S. said:

My daughter has Passport insurance. When my husband and I get sick we go to [the public health clinic]. We pay the amount of money they tell us to pay based on a sliding scale fee. They check how much I make every month and use a scale to establish the fee.

Individuals who were permanent residents and/or U.S. citizens were also able to access Medicaid services.

A Cuban participant shared his experiences with the benefits he received from federal funds:

I got here on 1999 and came to Miami. And they gave me many things. They treated me wonderfully the first year. First they give you Medicaid, food stamps, they help you look for work, and they give you special attention. So I love this country for that.

Participants who were HIV positive were able to access welfare benefits through the Kentucky HIV/AIDS Care Coordinator Program (KHCCP) and the infectious disease clinic that provided services and access to free medications through the KADAP assistance program. Under the Federal Ryan White funding program, KADAP provides medication assistance for those who can show proof of their HIV positive status, low-income, ineligibility for assistance from other entities and state residency (Kentucky Cabinet for Health and Family Services, 2012). Therefore, the program does not discriminate based on immigration status. As a result, many undocumented HLI with HIV were able to access funds from this program to assist them in accessing HIV services and medications. Participants who met these criteria were eligible for receiving financial assistance for their HIV medications. One participant from Puerto Rico, who

worked as a customer service representative at a health insurance company stated, “*If I didn’t have the KADAP program I wouldn’t be able to afford the HIV medications that I’m using.*”

This statement indicated that HIV medication were very expensive and difficult to afford, even for those at moderate income levels. The KADAP program offers financial assistance to access HIV medications for low-income individuals. Another participant who received assistance from this program stated:

I pay a fee for the counseling or medical appointments. The medications I don’t pay for. They are very expensive... The only help I need is to pay for the medication...

Resources. Other resources that were identified by participants included general community resources and programs that helped them access affordable supportive health and social services. Participants who were seasonal migrant workers at the horse race track industries were provided access to free healthcare services through their employers during the racing seasons. Additionally, participants expressed the importance of and need for free or socialized healthcare services to facilitate healthcare access for all.

General resource. Participants identified several community resources available in the city including a local women’s center that provided assistance for victims of domestic violence and an organization that supported race track workers in accessing health and social services. One participant from Guatemala who was a victim of domestic violence shared her experiences with accessing services:

I have travelled to many cities, but I really like Louisville the best, because here there’s a lot of domestic violence help for single mothers.... Some people will just sit back and wait instead of going and looking for help. But you have to go out and look for help because there are services out there to help with domestic violence. When I went through the experience there were a lot of people willing to help... So when a woman takes the first step by overcoming the fear, then everything is a lot easier. Everything is a lot easier... I was in therapy at the women’s center and that helped a lot. The truth is the city of Louisville I like it a lot. To live this is a very peaceful city.

Access to such social services is vital for an individual’s mental health and overall wellbeing, especially immigrants who are already exposed to higher levels of stress as a result of immigration and integration into a new culture. Services such as these promote health and wellbeing for individuals through continued community and social support, including legal services, welfare benefits and accessing healthcare.

Free, socialized healthcare. The five participants from Cuba, who came from a socialized healthcare system, emphasized the importance and need to provide free healthcare services for all individuals in the U.S., but especially for the disadvantaged. Several participants, including those from

other countries, provided healthcare system, government and community recommendations to improve healthcare access by providing free and/or affordable services. One participant from Cuba stated:

I think it should be better or free healthcare. The government knows that free is better. Less expensive, they know it should be less expensive, that medication is going to be expensive and people don't have medical insurance, they know that. Before we say these things, they know it happens. So why don't they do something to fix it. They know it happens.

Another participant from Ecuador who was a permanent resident, but did not have insurance stated:

The government or medical institutions should provide something where you can pay for health insurance or healthcare with your own money. Because we have tried to find medical insurance for me and my husband and they ask to pay 500 dollars a month and it's too expensive for us. So it's in disagreement with our compensation. So we cannot afford that. So they should provide something that we can pay and make it easier for everybody to buy health insurance. My husband is self-employed so he doesn't have health insurance.

Reducing healthcare costs were identified as the responsibility of the federal, state and local governments, as well as private institutions and hospitals. Interestingly, participants rarely discussed the upcoming changes in the healthcare system with the implementation of the PPACA (Pub. Law No. 111-148., 2010), which could bring significant changes in healthcare access for this population. This was further illuminated in the discussion of the healthcare policies under political contexts.

Financial assistance. While federal funding and programs facilitated access to healthcare services by reducing costs of health services, medications and other resources, financial assistance programs also provided ways to help participants pay for incurred healthcare costs. Health insurance coverage, medical assistance and billing help and financial planning were factors served as affordability facilitators. When participants were aware of the availability of financial resources they were more inclined to access healthcare services knowing that they would be able to afford it.

Health insurance. Having health insurance coverage was identified as a significant facilitator to healthcare access both under accessibility and affordability facilitators. Many participants expressed their inability to access services solely because they did not have health insurance. A female participant from Honduras who was undocumented upon her arrival to the U.S. expressed her difficulties in accessing healthcare, which dramatically improved as soon as she was provided health insurance through her employer:

Sometimes just having medical insurance is something that makes you feel better. Just knowing that you have medical insurance...I had difficulties when I first came to this country, but now I feel much better having the medical insurance.

Several participants indicated that having some form of health insurance facilitated their access to care and encouraged health-seeking behaviors. One participant stated:

Giving everybody medical insurance would make it much easier for Hispanics. Giving people better healthcare and make sure people are not afraid to access services just because they don't have medical insurance.

Medical assistance and billing help. As mentioned in prior sections, medical assistance was often accessed by participants through various federally funded programs and services. Participants who did not have access to these federal funds were able to access financial assistance for their medical expenses from other sources. For example, after going to the emergency room and receiving a bill for \$6000 one participant from Cuba who was uninsured said:

When I left the hospital, somebody gave me some forms to fill for financial help. So I sent this application and received a letter from Chamberlin Edmonds, it's a company that helps people pay medical bills...When I didn't hear back from them I called them and they told me "Ok...I'm going to reduce your medical expenses by 79%, so you're going to pay like 25 dollars every month." So from 6000 dollars I had to pay 1600 dollars, in 25 dollar payments every month. They also said that "if you need further assistance, the hospital might be able to help you or they might even pay the whole bill. We don't know. If that happens then you don't have to pay." I'm not sure what's happening with that. I'm. I'm still waiting on the hospital to send the bill.

Chamberlin Edmonds is a company that "provides patient advocacy based eligibility and enrollment services that are proven to provide clients with an effective solution to manage their uninsured patient base and to generate meaningful incremental cash flow" (Chamberlin Edmonds, 2013). Although the company provides direct services to healthcare providers themselves, they indirectly help patients to manage their healthcare bills and find affordable solutions to cover their healthcare expenses. However, it was not clear as to which patients are eligible to apply for financial assistance through such companies, as other participants who were undocumented and uninsured did not mention receiving financial assistance for their emergency room bills. Therefore, although medical assistance may be available, vagueness regarding eligibility criteria often served as a barrier to accessing these services.

Financial planning. When participants incurred large bills from the emergency rooms and other hospital facilities, the majority of participants used monthly installment payment methods offered through the financial planning programs at various healthcare facilities. Knowledge of the availability of these services greatly facilitated healthcare access for participants who were more inclined to seek health services, especially in emergency situations. One participant from Guatemala stated, "When I have to pay

bills I can't pay much, but I try to pay the most I can in installments." Paying in installments made it more manageable for participants to afford healthcare expenses, as they were given the opportunity to balance their income with their bills. This also offered them time to look for other sources of financial assistance means to help pay their medical expenses. One female participant from Mexico described the benefits of financial planning options available in the U.S.:

I like it more here in the U.S. than Mexico. It's much different. It's different and I prefer it here because you have different ways of payment. They send the bill home to your house so you can make different payments according to you income. I think it's more affordable in the US.

Another female participant from Mexico echoed this sentiment:

The big difference is that in Mexico most of the places where you go you have to pay in cash in advance before the doctors see you. Here in U.S., you can go to some hospitals and then you have different ways of paying your fees. So you're offered some means to pay.

Although healthcare costs were identified by participants to be very expensive and unaffordable, they also expressed the importance of being able to get immediate medical care when needed and having to worry about paying the bills later. Having to pay in advance, especially in emergency situations or during unforeseen healthcare visits puts a severe strain on an individual's ability to access healthcare services.

Acceptability Facilitators

The major themes under acceptability facilitators were *Knowledge and Awareness* and *Social Circumstances* represented in Table 8 (see page 60).

Knowledge and awareness. Participants who were aware of their health conditions and healthcare needs took proactive and preventive measures to access healthcare services. These health-seeking behaviors along with medication and treatment compliance significantly facilitated healthcare access for participants.

Health-seeking behaviors. Several participants, especially those who experienced health problems that required maintenance through medications, screenings and tests, prioritized their health over other areas in their lives and gave importance to accessing healthcare services. When asked how important it was for him to be able to pay for health services one participant with HIV said that "*There is nothing more important because without medical services you can't live.*" Participants also expressed their eagerness to gain knowledge about their conditions and to have a complete understanding of their health needs. One participant stated:

I'm an anxious person. So when I'm not satisfied with one answer I look for another- making sure that things happen to take care of my health.

Additional resources were utilized by participants to understand their symptoms and illnesses. One HIV positive participant from Guatemala said:

If I am sick I research on the internet. Later, with this information I find the place that would be most appropriate to get help. I find out what my symptoms are before I go, in order to explain well to the doctor. It actually helps me in that sense.

Participants were knowledgeable about their health conditions that allowed them to understand their need for certain diagnostic tests and the effects of medications on their health. A participant who was suffering from a cough, flu and sharp chest pain said:

I went to the doctor who did a physical examination, using stethoscope, and checked my throat. I heard a noise in the lungs, and I thought I needed an x-ray and I asked to have one. But they told me it was unnecessary. It took me three months to get healed because after that I suffered from laryngitis, flu and cough. Furthermore, to treat the bronchitis they prescribed me antibiotics and steroids, which suppressed my immune system.

Knowledge about their health conditions allowed participants to be more vocal about their needs and proactive about their healthcare. Participants with chronic illnesses such as diabetes and those who were HIV positive were very aware of being proactive about their healthcare needs as they maintained frequent visits to their healthcare provider. A Puerto Rican participant with diabetes said, *"I have to go every three months to get checked for my diabetes and I go to the dentist as well."* This participant did not have access to primary healthcare or dental services in Puerto Rico and for most of his life in the U.S., as he did not have health insurance, sufficient income and did not prioritize healthcare. After understanding the importance of maintaining his blood sugar levels and his dental needs, this participant became more proactive about going for regular check-ups with his healthcare provider. Similarly, a female participant who had a double-mastectomy as a result of breast cancer became more proactive with her health and maintained yearly check-ups with her family doctor:

Every year I have to go for a check up with the doctor, the oncologist. Sometime ago I used to go to the doctor every six months, but now I go once a year to get my check up. I also go to the family doctor once a year, to check my cholesterol and have lab tests and other basic tests.

Medication and treatment compliance. As indicated through their health-seeking behaviors, participants who were more inclined to be compliant to medications and treatment modalities were more likely to access healthcare services for their immediate and chronic healthcare needs. This was especially

true for participants with HIV, who depended on their medications and frequent doctor visits to maintain their viral counts and live healthy lifestyles. One participant with HIV said:

I do my treatment that my doctor tells me to. I take my life day to day and minute by minute... No one should be scared of HIV. It's like a cancer, but you can control it. I treat my sickness like a cold. If I control it, it doesn't hurt you. I go to parties; I drink my beer, and act responsibly. But my medication is always there.

Participants who understood the importance of being compliant to medications and treatments were more likely to continue seeking and accessing healthcare services. Another participant with HIV stated the difference between medication and treatment compliance in the U.S. and Guatemala:

It's different because you can have more control over your HIV here. In Guatemala there is some control but it's not a lot. Maybe four times per year you get testing. Here, for me it is one time every two months I keep control of lab numbers or results. I can keep control about everything.

Social circumstances. Social factors that served as facilitators to healthcare access included support from family and community members that encouraged health-seeking behaviors. Although it didn't directly facilitate healthcare access, individuals who were understanding or accepting of social circumstances such as discrimination, were able to overcome negative emotions that may have discouraged them from accessing care.

Family and social support. Family support was highly regarded by participants as a significant source of encouragement and support, especially in relation to health. When asked what factors made it easier for him to take care of his health, one participant stated: *"My wife. She is very dedicated. I am worried about her and she is worried about me. If we feel bad we take care of each other."* Having family members who are equally concerned about an individual's health as they are is an essential component to maintaining healthy lifestyles and promoting health-seeking behaviors. When making important healthcare decisions one participant from Cuba said *"The first person I talk to is my mom. I ask "Mom what do you think I should do?", and she advises me."*

Family and community were emphasized by all participants as playing an integral role in their lives, especially in relation to health. Participants expressed that social and community support facilitated healthcare access by encouraging health-seeking behaviors as well as providing them with important referrals and recommendations to healthcare resources. Patients with HIV were able to garner this information from their medical case manager and the infectious disease clinics. Other participants received social support from various churches in the community that provided health and social services specially

targeting HLI. Some participants were able to obtain basic health screenings from several community events and programs that were conducted by local churches that aimed to serve the healthcare needs of a large undocumented HLI population.

Understanding or accepting of discrimination. Many participants experienced discrimination based on race, ethnicity, language, insurance status and HIV status during their healthcare encounters. Although many were discouraged from accessing health services after these negative experiences, a few participants were understanding and/or accepting of being treated differently. Individuals who were able to rationalize this type of treatment were often not negatively affected or discouraged from seeking healthcare services. After experiencing discrimination from a doctor based on his inability to speak English, one participant from Cuba stated that he wasn't discouraged from returning to access health services from this doctor:

I thought that maybe he is a good doctor but he just had a bad moment. After we went back to him again he treated us well.

Several participants said that they were aware that sometimes people can be "good" and sometimes people can be "bad", but that the most important thing was to understand this difference and not let these people affect you negatively. After experiencing discrimination based on her ethnicity and language one female participant said:

Although I've had bad experiences I've had good experiences too... I try to see and understand the negative, why people would think negatively and treat people that way. Maybe they had a bad day or something bad happened to them.

Although participants should not be subjected to situations where discrimination is viewed as an acceptable social norm, their ability to rationalize why an individual may be treating them differently helped ease their levels of mental and emotional distress. A female participant who experienced discrimination during a healthcare visit described her experiences:

It happened to me personally when I was at the [hospital]. The doctor came and I was waiting in the room, she came in speaking English to me and I said "I don't speak English" and she answered me "I don't speak Spanish," in a very aggressive and rude manner. I knew my rights because I've been in the U.S. so I said "contact an interpreter." After 15 minutes when she left, she didn't say "I'll be back" or anything. So I left, took my purse and went out... and came back for another appointment later on and I told them what had happened and they gave me an interpreter.

Summary

Analysis of facilitators to healthcare access revealed fewer recurring themes and participant narratives when compared to healthcare access barriers. The most pertinent themes under availability facilitators were *Healthcare personnel*, *Patient-provider communication* and *Resources*. *HIV*, *Type of healthcare facility*, *Documentation* and *Quality of care* were recurrent themes under accessibility facilitators. Affordability facilitators were strongly represented under the themes of *Government resources*, *Financial assistance* and *General resources*. *Knowledge and awareness* and *Social circumstances* were the two predominant themes under accessibility facilitators.

PART IV. CONTEXTUALIZING HEALTHCARE ACCESS BARRIERS AND FACILITATORS

Research findings presented in this part of chapter four addressed research question 4: *What are the historical, sociocultural, economic, and political contexts that shape the social determinants of healthcare access within this population?* Findings indicated numerous historical, sociocultural, economic and political factors that contributed to shaping the social determinants of healthcare access for HLI in Louisville. In order to provide an in-depth understanding of contextual factors, findings from participant interviews, and participant observations and document reviews were represented in tables respectively for sociocultural, economic and political factors. These themes were then cross-examined and compared to derive the major themes that influenced the barriers and facilitators to healthcare access. This process was guided by the WHO's SDH Conceptual Framework (Figure 1) and focused on factors such as socioeconomic and political context, governance, policy, cultural and societal norms and values, social position (education, occupation, income), and ethnicity and race. Postcolonial theoretical perspectives were also used to identify contextual factors pertinent to understanding the HLI experience. As there were no significant themes among participant interviews that pertained to historical contexts, this section focused on historical factors represented in participant observations and document reviews that helped shape the historical contexts of healthcare access for HLI in Louisville. Contextual analysis of data served as a basis for the discussion on postcolonial influences on understanding the social determinants of healthcare access in chapter five.

Historical Contexts

Barriers and facilitators to healthcare access as perceived by HLI were further explicated through their contextualization within a historical frame. It was challenging for the investigator to find data that underlined the historical influences that directly shaped HLI health experiences in Louisville, Kentucky. Recent history on the characteristics of the first HLI populations to arrive to the state was scarce. However, the history of Kentucky in and of itself provided a rich perspective on the historical contexts that shaped the current sociocultural, economic and political conditions of HLI in Louisville today. History, dating back Kentucky's Native Americans, colonization and slavery, and civil rights movements helped understand how race and ethnicity have and continue to influence inequalities in socioeconomic status of minorities, including HLI. This chapter outlines the historical data that were pertinent to understanding disparities in

healthcare access for HLI, beginning with a description of Native American presence in Kentucky and concluding with changes in the demographic profile of the state with the arrival of HLI.

Unlike other contextual factors, participants' perspectives did not directly contribute to the understanding of historical influences on their ability to access healthcare services. Therefore, findings were based solely on document reviews of historical reports, panel discussions, briefings and meetings. Findings were categorized under the major themes of *Kentucky Native Americans, European Colonization and Slavery, Racism, Discrimination and Segregation, Civil Rights* and *Hispanic Latino Immigration*. These themes served as a foundation for understanding the sociocultural, economic and political contextual factors that affected healthcare access for HLI in Louisville. Table 11 displays these central historical contextual themes and their relationship to specific barriers and facilitators to healthcare access as identified by document reviews and participant observations. As it is beyond the scope of this study to provide a detailed historical portrayal of Kentucky, a concise description of relevant historical accounts pertinent to understanding the HLI experience in Louisville and Kentucky were discussed. A brief timeline is provided in Appendix F to assist the reader in understanding the pivotal moments in Kentucky history pertaining to civil rights and Hispanic Latino immigration.

Table 11

Understanding Barriers and Facilitators to Healthcare Access within Historical Contexts

Access Dimension	Themes and Subthemes		Historical Context
Accessibility	Barriers	Documentation (Lack of Health Insurance; Lack of legal immigration documents)	Hispanic Latino Immigration Civil Rights (Equal Employment Opportunities)
Affordability	Barriers	Financial Barriers (Expensive healthcare costs; No health insurance coverage; Limited income or financial resources; Dependents)	Civil Rights (Equal educational opportunities; Equal employment opportunities) Hispanic Latino Immigration
		Resources (Lack of Government support or intervention)	Racism, Discrimination and Segregation
Acceptability	Barriers	Discrimination (Discrimination based on race and ethnicity; Discrimination based on language)	Kentucky Native Americans European colonization and slavery Racism, Discrimination and Segregation
		Health-seeking behaviors (Delaying accessing care; Prioritization ; lack of awareness or education; lack of prevention)	Civil Rights (Equal educational opportunities; Equal employment opportunities)
		Mental health (Emotional distress discourages access; Discrimination causes discomfort)	Racism, Discrimination and Segregation
		Healthcare business (Patient vs. Customer ; No desire to help from healthcare provider ; Inhumane treatment; Lack of social support)	Racism, Discrimination and Segregation

Kentucky Native American History and Influences on HLI

In the beginning I was here...in harmony with the Great Spirit, honoring all life around me. In this land Kan-tu-kee, the great meadow, the dark and bloody ground, I was known as Shawnee. I was also known by other names, Cherokee, Chickasaw, Iroquois, Lanapota, Creek...I am Native American, the indigenous tribes of this land, the American Indian. (KYCHR, 2008, p.22)

Study findings revealed that despite the presence of Native Americans in the state of Kentucky, details of their history in the state were inaccurate as their earlier occupation of this region was undocumented and consequently unrecognized. However, research, genealogical data and stories of Kentucky Native Americans themselves provided evidence for the historical and current presence of Native Americans in Kentucky. Indian Tribal Records indicated that before the first colonial European settlers occupied Kentucky, it was home to more than twenty indigenous Native American tribes, including Cherokee, Chickasaw, Chippewa, Mosopelea, Delaware, Shawnee, Haudenosaunee and Yuchi (KYCHR, 2008). After frequent bloody clashes between the Native Americans and white settlers, which resulted in the annihilation of many tribes, Kentucky was declared as the 15th state of the United States in 1792. The Indian Removal Act of 1838 forced more than 2,500 indigenous people out of Kentucky and numerous others from states across the nation to reservations in the West. Several Kentucky Native Americans were able to escape to the mountains of eastern Kentucky, and preserve their history and culture (KYCHR, 2008)

Currently, the U.S Census Bureau identifies only 0.2 percent of Kentucky's population as American Indian, representing 34 different tribes with Cherokee Nation being the largest (KYCHR, 2008). However, members of a Kentucky Native American panel hosted by WFPL's *State of Affairs* program indicated that as many as 35,000 to 40,000 Native Americans are currently living in Kentucky.

Kentucky's Native American population is at a concentration that rivals regions in Oklahoma and North Carolina, but not 300 years ago like one would think. Our fighting men in WWI rushed to the call of duty and registered for the draft and maybe to some of the men's surprise they seemed to be registered in regards to their heritage. One county's registration documents show us that Southeastern Kentucky was populated by Native Americans, then and always. The WWI registration only helps prove what many have been saying for years; Southeastern Kentucky is Native American! In 1917 our fathers, grandfathers and uncles registered for the draft and many Native [Americans] went classified as White, but a ton registered as Native Americans, either by choice (which I doubt, your lands would have been confiscated) or by force. Racial bias existed in those days and if you had a choice, you would rather register as white. (KYCHR, 2008, p.23)

The history of Native Americans in the state of Kentucky is essentially erased, but Kentucky Native Americans are fighting for recognition. At the KYCHR (2008) advocacy hearing, Kentucky Native Americans and their advocates lobbied for official state recognition of the various American Indians and

tribes in Kentucky that would support funding to keep the culture and traditions of the people alive. However, the challenges still remain in providing equal rights and recognition to Kentucky Native Americans were reflected in the lack of current statistics, census data and other records on the concentration of this population in the state (KYCHR, 2008). Momfeather Erickson, a Kentucky Native American who served on the panel for WFPL's *State of Affairs* program said:

The problem is, we have never even been properly identified as a people in this state, and if you are not full blooded or live on a reservation, you are not considered Indian...There are lots of Native American groups clustered here and there in every part of Kentucky. You never hear about them, does that say anything? It tells me that again we are not noticed but are still quietly hidden away in the social closet. (KYCHR, 2008, p.23)

The forgotten history and struggles of Native Americans in the state of Kentucky was foundational for the next two-hundred years of segregation, integration, and immigration in Kentucky, impacting human and civil rights until current times (Aguirre-Molina, Molina & Zambrana, 2001; IOM, 2003; Perea et al., 2007). Once the original inhabitants of this North American region, Native Americans have been subjected to colonial and imperial hegemonic forces that have led to the decline of these populations in numbers as well as in health and social status. Today, they continue to fight for recognition and equal rights, but they share their plight with other unrecognized and disadvantaged minority groups, including HLI. This apparent erasing of the history of Native Americans is also evident in historical accounts of HLI, where findings indicated the lack of historical accounts on the characteristics of the first HLI groups to arrive in Kentucky. These discrepancies have placed additional barriers on the ability of HLI to gain equal rights within a community that is unaware of their unique history. Study findings indicated that many HLI in the Louisville community also feel that their existence and contributions to society were unrecognized and "taken for granted." This idea was summed up in one statement by a HLI living in Louisville:

I'm a woman. I'm an immigrant like you I have dreams, but you don't see them because for you I don't exist. (Mujica, 2011)

The historical struggle of Native Americans, African Americans and other minority groups in Kentucky were shown to have effects on the current social positioning of HLI in Louisville and throughout the state (Aguirre-Molina et al., 2001; IOM, 2003; Perea et al., 2007). Although HLI interviewed in this study did not identify having direct ancestral roots to Native American tribes in the state of Kentucky or in the U.S., several of them identified having ancestors from Spain and Africa, indicating the influence of European colonization and slavery on their ethnic and racial identity.

European Colonization and Slavery

The history of colonialism and slavery in Kentucky were shown to have significant effects on the current sociocultural, political and economic structures that shape the experiences of minorities and HLI (Zuniga & Hernandez-Leon, 2005). As indicated under Native American history, when the first white settlers arrived in the region of Kentucky, there was war and bloodshed over occupation of the land. Native American tribes were forced to move westward, as new white colonies were established in the state. The first slaves to arrive in the commonwealth came with these white settlers (Kentucky Educational Television, 2013). According to the data published by the Filson Historical Society (2009) in Louisville, by 1860 Kentucky had one of the largest numbers of slaveholders in the southern states.

Kentucky's economy was inarguably slave powered. In agriculture, plantation owners and small farmers used slaves to raise cash crops of hemp and tobacco, as well as a variety of livestock and crops used for food and cloth fiber. Manufacturers also benefitted from the slave system. Slaves worked in a variety of industries, including salt and textiles. In Lexington and the surrounding area, slaves provided much of the labor in hemp processing factories. Culturally, owning slaves served as an important status symbol. As in the Cotton South, most whites did not own slaves, but most aspired to join the slaveholding elite. (The Filson Historical Society, 2009)

While slaves played a significant role in the economic development of Kentucky, they remained as an oppressed group, subjected to subhuman conditions. Slavery, which symbolizes the deprivation of basic human rights, has been a significant barrier to the economic and social development of African Americans throughout the history of Kentucky. The effects of slavery on limiting the progression of civil rights, equality and social justice were evident through the historical events that followed it, which included the Civil War secession from the Union, Jim Crow segregation laws, and civil rights movements. As a border slave state, Kentucky was geographically and politically divided amid civil wars and civil rights movements throughout history (Center for Health Equity, 2012; IOM, 2003). This partition served as the foundation for Kentucky's conservative economic and social policies that continues to influence the acceptance of change in its communities. These historical factors also served as the basis for understanding the notable absence of HLI presence in the state of Kentucky and other southeastern regions of the U.S. (Cabell, 2007; Zuniga & Hernandez-Leon, 2005). Similar to the experiences of Native Americans and African Americans, historical events specific to Kentucky have considerable effects on the current social positioning and experiences of HLI in Louisville and throughout the state.

Racism, Discrimination, Segregation

Colonialism and slavery were foundational in shaping the cultural factors of racism, discrimination and segregation that influenced the current health and social experiences of HLI in Louisville (Center for Health Equity, 2012; IOM, 2003; Perea et al., 2007). As African Americans and other minority groups fought for equal rights, guerilla warfare led by groups such as the Ku Klux Klan (KKK), neo-Nazis and other white supremacist movements continued to thwart these efforts through the use of violence. These societies still continue to exist within the state of Kentucky, fighting against equal rights for minorities and immigrants (Zuniga & Hernandez-Leon, 2005). In 2012, local KKK and neo-Nazi members rallied against illegal immigration at the Kentucky Capitol in Frankfort. Collectively and formally known as the National Socialist Movement (NSM), these white supremacist movements have taken immigration and undocumented immigrants on their current agenda:

The NSM's core beliefs include defending the rights of white people everywhere, preservation of our European culture and heritage, strengthening family values, economic self-sufficiency, reform of illegal immigration policies, immediate withdrawal of our national military from an illegal Middle Eastern occupation, and promotion of white separation. (NSM, 2013)

For over a hundred years, these white supremacist movements and the idea of white separation have defined the meaning of racial inequality in the southern states of the U.S. The existence of such movements and beliefs embedded in racism, are indicative of the lack of social progression in the state of Kentucky and other southern states. With the rapid growth in immigrant populations in southern cities like Louisville, anti-immigration movements and other discriminatory activities have also started to increase in this area. As evidenced by participant narratives on their experiences of discrimination under acceptability barriers and sociocultural contexts, these events have had devastating psychological effects on HLI populations, especially those subjected to racism on a daily basis.

Historically, racism and segregation were blatantly represented in laws and policies, which kept African Americans and other minority groups separated from whites in Louisville. The struggle for equality was evident in the institutional structures, where structural racism further restricted these individuals from having equal access to public services.

Structural racism examines racial and ethnic impacts that stem from a history of disenfranchisement and policies that favored those in power. Consequently, the origins of urban inequality for communities of color cannot be separated from structural racism. An example is the history of federal housing policies that not only denied homeownership to urban African-

Americans but physically destroyed many black neighborhoods under the policies of urban renewal. (Center for Health Equity, 2012, p.4)

Findings indicated that subtle forms of structural racism continue to exist in current society, especially in regards to equal rights for minority and immigrant populations. All twenty participants in this study experienced some form of racism and/or discrimination when accessing public services in Louisville. Some participants identified this as a normal and expected occurrence in U.S. society. One participant from Puerto Rico stated, “I never knew about racism until I came to the U.S. and to Kentucky.” Experiences of discrimination in healthcare settings served as a significant barrier to healthcare access as it was shown to cause negative emotions that discouraged health-seeking behaviors. However, the existence of structural racism within private and public institutions were also shown to suppress HLI and other immigrants from having equal access to health and social services as other dominant groups.

Civil Rights

Although historical data on HLI presence in Kentucky and Louisville was limited, there was evidence for the state’s struggle with issues of segregation, racism and discrimination, and its historical fight for equality and civil rights. Civil rights movements in Kentucky were also indicative of the lack of progression in policies and acceptance of differences in the social, cultural and political atmosphere of the state (Center for Health Equity, 2012). These factors were shown to have a substantial impact on the historical contexts that shape the current experiences of HLI in Louisville, especially in relation to equal access to health and social services. The challenges in fighting for equality were mainly related to the underlying structures of racism and discrimination that continued to oppress minorities in Kentucky. In 1997, the Kentucky Advisory Committee to the U.S. Commission on Civil Rights provided insight into the various types of major ethnic groups in Kentucky through its reports on bias and bigotry in Kentucky:

There appears to be an expansion in the groups targeted for bigotry-related violence (e.g., Jews, Asians, African Americans, interracial couples, black-on-white, and white-on-black). The increasing numbers of new ethnic minorities (e.g. Vietnamese refugees in Louisville, Asians in Lexington, Hispanic migrant workers in Bowling Green) appears to trigger increased bias and bigotry related incidents. (Kentucky Advisory Committee to the U.S. Commission on Civil Rights, 1997, p.1)

Underlying influences of racism and discrimination continued to affect the fight for equality and social justice among minorities in Kentucky. This was especially evident through historical accounts of inequities in equal educational and employment opportunities for minorities.

Equal education opportunities. Before 1954, racial inequities in educational opportunities were accepted notions in social and educational structures throughout the country. However, in 1954 *Brown v. Board of Education* (347 U.S. 483, 1954) mandated equal educational opportunity on a non-segregated basis for all students. The U.S. Supreme Court's ruling that segregation based on race was in violation of the 14th amendment was identified as the central impetus for furthering civil rights regulations pertaining to education. Despite these monumental changes, structural racism continued to exist in society as discrimination on the basis of race and ethnicity was not prohibited until the passing of the Kentucky Civil Rights Act in 1966.

Findings indicated that equality in education among racial and ethnic minorities continues to impact current society, where underserved African American and Hispanic groups struggle to gain equal bearing in educational achievements. This was shown to be related to their subjection to lower socioeconomic status and other oppressive factors. Almost fifty years after *Brown v. Board of Education*, the KYCHR (2003) released a report on equal education in the state of Kentucky:

The Commission reported that race continued to be a major factor related to the achievement levels of Kentucky's public school students. Mean scores and the scale score indexes and gaps showed African American students were more than 15 percent behind their white counterparts in all subjects in both proficient and novice performance levels...Hispanic students, similar to African American students have about a 15 per cent gap in all subjects for proficient and novice (performance levels). Similarly there is a strong apparent correlation between students in poverty and African American students. (p. 5)

Hispanics and African Americans continue to rank substantially below whites in educational achievement, mainly as a result of their lower social positioning in a society that subjects them to limited opportunities and resources. Data indicated that lower educational levels among HLI were also shown to be in relation to their socioeconomic situations (lack of financial resources) as well as their immigration status (being undocumented). The effects of lower levels of educational attainment among HLI are further discussed under educational factors that shape economic contexts of barriers to healthcare access. However, it is important to note that over the last fifty years, progression in civil rights pertaining to equal educational opportunities has been slow and in some cases has even regressed, especially in the conditions of undocumented immigrants in the U.S. Inequities in access to education among HLI were shown to affect their ability have a voice and be empowered in advocating for their rights to equal access to health and social services.

Equal employment opportunities. Similar to challenges in equal educational opportunities, minorities in Kentucky have had a history of being subjected to inequities in employment opportunities.

Earliest accounts of these inequities were indicated in a report by the Kentucky State Police in 1977:

Among the State's 3.2 million residents, 7 percent are black and over 50 percent are women. Approximately 11,100 persons of Spanish heritage live in the State, as do approximately 1,300 Native Americans. Forty percent of the State's black residents live below the poverty level, compared to only 22 percent of the white residents. As is true throughout the country, the minority woman, who is often a single head of household, ranks at the bottom of the pay scale... As of April 1, 1977, the bureau of State police employed 448 sworn personnel. Over 97.8 percent or 927 were white men. Twenty-one or 2.2 per-cent of the sworn force were minority males (19 black, 2 Spanish surname)... minority persons who are employed as commissioned officers rank (are) at the bottom of the bureau's chain of command; none ranks higher than trooper. (Kentucky Advisory Committee to the U.S. Commission on Civil Rights, 1978, p.16)

These findings indicated the notable absence of Hispanic Latino populations within Kentucky in the 1970's, the socioeconomic positioning of African Americans and the underrepresentation of minorities in the police workforce during those years. In 1989, the report on *The Employment of Minorities and Women by Kentucky State Government* showed substantial growth in the employment of African Americans and women in state institutions stating that

...though there was a steady increase in the percentage of full-time black employees in Kentucky State government between 1971 and 1981 from 4.9 percent to 7.2 percent, the proportion then remained relatively unchanged through 1987... (Kentucky Advisory Committee to the U.S. Commission on Civil Rights, 1989, p.2)

By law, government institutions were mandated on some level to provide equal employment opportunities for minorities. However, these reports indicate a significant dearth of minority employees in state institutions, representing a lack of progress in employment since the 1977 Kentucky State Police report. The lack of minority representation in government institutions was indicative of similar inequities in employment opportunities in other labor sectors during the 1970s, 1980s and into the 1990s.

In the 1990s, despite the new growth of immigrant populations, civil rights reports continued to focus on the inequities facing African Americans, who have been the largest representation of minorities in Kentucky over the years. The conditions of minorities in the state had progressed slowly, with a higher percentage of minorities being employed in various labor sectors. The 1997 report on Bias and Bigotry in the Kentucky indicated that despite this growth, minorities continued to remain on the bottom of the hierarchical workforce structure:

There are over 1000 faculty members at the U of L (University of Louisville), but in his 16 years there, the number of African American faculty has hovered between 20 and 35; and, African

American faculty are denied tenure at a higher rate than white faculty. (Kentucky Advisory Committee to the U.S. Commission on Civil Rights, 1997, p.8)

The historical influences of inequities in education and employment are also extant in current societal conditions as evidenced by study findings. The lack of representation of diversity or minorities in leadership positions significantly affected the levels of cultural competence and the ability of health and social service providers to meet the needs of diverse populations. A hospital administrator and advocate for diversity and cultural competence stated:

Louisville and Kentucky are very conservative and things are run differently here. People don't like to hear numbers about race and ethnicity and how that plays a significant role in health and healthcare access. As a predominantly white state, there are many white people in leadership positions, especially in health and service industries. The healthcare culture in Louisville is also very hierarchical. Doctors don't get along with nurses; higher administration doesn't take advice from those below. The hierarchical nature of the healthcare industry is very much a product of the political and historical contexts of Louisville and Kentucky. We are progressing very slowly here and always meet obstacles to advance, as you can see by the fact the minorities are still struggling to make it in higher leadership positions.

This statement is not only indicative of the lack of minority representation in the professional workforce, but also of the influences of the historical structures of power and oppression based on race and ethnicity that continue to impact Kentucky's progression. As was the case with African Americans, HLI are subjected to these inequities and have substantial difficulties in gaining equal ground on the basis of education, employment and other socioeconomic indicators. These indicators were also shown to influence barriers to accessing health and social services for HLI in Louisville.

Hispanic Latino Immigration

The 1990's saw a significant growth in immigrant populations throughout the nation. However, recorded historical accounts of HLI presence in the state of Kentucky was not noted until the late 1980s and early 1990s with the arrival of Mexican immigrant labor for growing horse breeding and tobacco farming industries in the state (Zuniga & Hernandez-Leon, 2005). The growing presence of diverse HLI groups was often detected with the increased rate of racial and ethnic tensions between predominant white and minority populations in Kentucky. For over 30 years, the KYCHR has been the foremost authority and reporter of civil rights issues arising from racial and ethnic conflicts in Kentucky. The commission's first indicator of HLI presence in Kentucky was in their reference to increased cases of bias and bigotry towards Hispanic migrant workers in Bowling Green, Kentucky (Kentucky Advisory Committee to the U.S. Commission on Civil Rights, 1997). Data revealed that although HLI may have arrived in Kentucky in earlier years through

farming and other agricultural industries, their actual presence in Louisville was not acknowledged until recent years. The latest report on the Profile of the Foreign-born in the Louisville Metropolitan Area stated:

Prior to the 1980s, Louisville had a small population of immigrants, most of who were older and came from Canada and Europe. But starting in the 1990s, Louisville—like many other cities of the same size in the Southeast and Midwest— became home to increasing numbers of immigrants arriving from across the globe. The recent and diverse character of immigration flows to Louisville makes it important to understand the demographics of the area’s immigrants, as well as their contributions, service delivery needs, and economic and social impact. (Capps et al., 2006, p.10)

Other sources of data provided evidence for earlier HLI presence in the Kentucky as migrant workers were solicited to promote economic growth in agricultural and farming industries such as tobacco farms and horse farms, especially with the expansion of these industries in rural areas of the South (Zuniga & Hernandez-Leon, 2005). However, the arrival of new agricultural technology that reduced the need for manual labor promoted HLI to seek employment in other labor-intensive industries. These industries were predominantly low-skilled, low-wage economic sectors such as construction, agriculture, meat-packing, and manufacturing, which were related to the lower educational and English proficiency levels of HLI (Bump et al., 2005). Currently, HLI in Louisville and Kentucky predominantly work in these industries, faced with the additional barrier of undocumented immigration status, which influence the sociocultural, economic and political contexts that shape their social positioning. These factors are further discussed in the following contextual analyses of research findings.

With the rapid influx in immigrant populations in metropolitan cities such as Louisville, state and local level institutions have continued to struggle with implementing culturally appropriate mechanisms to address the health and social needs of this diverse population. In 2002, the report on Immigration in Kentucky stated:

Until a few years ago, Kentucky was inexperienced in immigration issues, but like other states in the southeast and the rest of the nation, is learning to address a “new population.” Just as public agencies are responding to these immigrants—primarily from south of the U.S. border, but other nationalities as well—private entities are reacting. It appears that private or private/public organizations and groups are focusing mostly on immigrants in the state who are from countries in Latin America, and it also seems that most of the activities are taking place in central Kentucky. (Legislative Research Commission, 2002, p.88)

Today, inequities in civil rights and access to health and social services are common attributes of immigrant communities in Louisville. Representing the largest immigrant group, HLI were shown to be in a substantially prominent disadvantaged position as a result of various sociocultural, economic and political

factors that are embedded in the historical accounts of colonialism, slavery, racism and discrimination, segregation and civil rights in Kentucky. These mechanisms also provided for an in-depth understanding of current social structures that serve as barriers to healthcare access for this underserved population.

Sociocultural Contexts

Barriers and facilitators to healthcare access as perceived by HLI were further explicated through their contextualization within in a sociocultural frame. The process of categorizing themes under sociocultural contexts was an arduous task, as there were numerous factors that were pertinent to understanding the experiences of HLI. Categorization into central themes were guided by the WHO’s SDH Conceptual Framework (Figure 1), the CFAAHS (Figure 3) and postcolonial theory. Tables 12 and 13 represent the sociocultural contextual factors analyzed from interview data, and participant observations and document reviews respectively.

Table 12

Sociocultural Contextual Factors from Participant Interviews

Themes from Interviews	Subthemes (References, Sources)*
Geographic Factors	Louisville vs. Other Cities (26, 14)
Societal Factors	Racism and Discrimination (24, 17); Seeking respect (6, 6); Discrimination within Hispanic community (4, 4)
Immigration	Undocumented (13, 7); Immigration concerns in Louisville (13, 10); Fear of deportation (12, 7); Crossing the Border (4, 4)
Cultural Factors	Communalism (18, 9); Familism (10, 7); Social Isolation and separation from family (10, 9); Sacrificing dreams to come to the U.S. (2, 2); Survival (8, 6)
Language	Language Access (14,7)
Outreach and Advocacy	Lack of Spanish communication channels (4, 4); Need to promote diversity, language and cultural competence (4, 3)

*Note: *See Appendix C for NVivo Functions*

Table 13

Sociocultural Contextual Factors from Participant Observations and Document Reviews

Themes from Participant Observations & Document Reviews	Subthemes (References, Sources)*
Geographic Factors	Environment (8, 6); SDH (10, 6); Physical Segregation (5, 4)
Societal Factors	Racism and Discrimination (10, 7); Social Isolation (7, 7); Domestic Violence (7, 5); No progression in Kentucky (3, 2)
Immigration	Fear of Deportation (6, 6); Acculturation (3, 2); Crossing the Border (2, 2)
Cultural Factors	Individualism vs. Communalism (2, 2); Traditional medicinal practices (16, 10)
Language	Language Access (16, 7); Language Barriers (15, 9); Language Facilitators (8, 6)
Outreach and Advocacy	Community Advocacy and Outreach (28, 19); Community and social services (34, 27); Church Support (12, 7); Promoting Diversity and Cultural Competence (20, 13); Lack of collaboration and community involvement (12, 9)

Note: *See Appendix C for NVivo Functions

Based on these results, the major themes that were concurrent in all three sources of data were identified. Factors that shaped the sociocultural contexts that influenced availability, accessibility, affordability and acceptability barriers and facilitators to healthcare access were categorized under the themes of *Geographic factors, Societal Factors, Immigration, Cultural Factors, Language and Outreach and Advocacy*. Table 14 displays the central sociocultural contextual themes and their relationship to specific barriers and facilitators to healthcare access as identified by participants. The association between barriers, facilitators and relevant sociocultural contexts are further discussed to provide a contextual understanding of healthcare access for HLI in Louisville.

Geographic Factors

Barriers to healthcare access. Findings from surveys, document reviews, participant observations and geospatial analysis indicated that geographic factors significantly influenced barriers to healthcare access for HLI in Louisville. These barriers are represented under the subthemes of *Environment, Physical Segregation, and SDH*. Difficulties in accessing healthcare and maintaining healthy lifestyles were evident through geospatial analysis that revealed the influence of environmental factors and physical segregation on the health of HLI populations in southern Louisville.

Table 14

Understanding Barriers and Facilitators to Healthcare Access within Sociocultural Contexts

Access Dimension	Themes	Sociocultural Context
Availability	Barriers	<p>Time and Availability (Limited time and contact with doctor; long waiting times; Treated like a number)</p> <p>Healthcare Personnel (Interpreter availability and training; Lack of cultural competence; Lack of Bilingual Healthcare Personnel)</p> <p>Patient-Provider Communication (Lack of communication; Lost in Translation; Language Barrier-LEP of Participant)</p> <p>Navigating the Healthcare System (Lack of advertising public resources)</p>
	Facilitators	<p>Healthcare Personnel (Interpreters; Bilingual healthcare personnel; Nurses; Medical case manager)</p> <p>Patient-Provider Communication (Familiarity and Trust; Cultural Identification)</p> <p>Resources (Health fairs and screenings)</p>
	Cultural Factors (Individualism vs. Communalism)	<p>Language (Language Barriers)</p> <p>Outreach and Advocacy (Need to promote diversity, language and cultural competence)</p>
	Language (Language Barriers)	Outreach and Advocacy (Lack of Spanish communication channels)
	Language (Language access)	Outreach and Advocacy (Promoting Diversity and Cultural Competence)
	Outreach and Advocacy (Community and Social Support; Church Support; Promoting Diversity and Cultural Competence) Language (Language Access; ESL classes) Cultural Factors (Communalism; Familism)	Outreach and Advocacy (Community and Social Support; Church Support)
Accessibility	Barriers	Documentation (Lack of Health Insurance; Lack of Immigration (Undocumented; Fear of deportation)

		legal immigration documents)	
		Emergency Room (Negative Emergency room experiences)	Cultural Factors (Individualism vs. Communalism)
		Type of Healthcare Facility (Emergency room; Specialty Health Services)	Geographic (Environment; Physical Segregation)
	Facilitators	HIV (HIV facilitates access; Infectious disease clinic) Quality of Care (Better quality of care; Better access to healthier options)	Outreach and Advocacy (Community and social services; Promoting diversity and cultural competence)
		Type of Healthcare Facility (Public health clinic; Primary healthcare clinic)	Language (Language access; Language facilitators)
Affordability	Barriers	Financial Barriers (Expensive healthcare costs; No health insurance coverage; Limited income or financial resources; Dependents)	Immigration (Undocumented) Geographic (SDH; Physical segregation)
		Knowledge and Awareness (Unaware of affordable options)	Outreach and Advocacy (Lack of Spanish communication channels; Lack of collaboration and community involvement)
		Resources (Lack of Government support or intervention)	Societal Factors (Social Isolation) Geographic (SDH; Physical segregation)
	Facilitators	Government Resources (Government funded financial resources; Welfare benefits)	Outreach and Advocacy (Community and social services)
		Resources (General resources; Free Socialized Healthcare)	Outreach and Advocacy (Community and social services; Church support)
Acceptability	Barriers	Discrimination (Discrimination based on race and ethnicity; Discrimination based on language)	Societal Factors (Racism and discrimination; Social Isolation) Immigration (Undocumented; Fear of deportation)

		Geographic (Louisville vs. Other Cities; SDH; Physical segregation)
	Cultural Barriers (Traditional medicine; self-medication)	Cultural Factors (Traditional medicinal practices)
	Health-seeking behaviors (Delaying accessing care ; Prioritization; lack of awareness or education ; lack of prevention)	Cultural Factors (Traditional medicinal practices)
	Mental health (Emotional distress discourages access; Discrimination causes discomfort)	Immigration (Undocumented; Fear of deportation) Societal Factors (Racism and discrimination; Social Isolation)
	Healthcare business (Patient vs. Customer ; No desire to help from healthcare provider ; Inhumane treatment; Lack of social support)	Cultural Factors (Individualism vs. Communalism) Outreach and Advocacy (Lack of collaboration and community involvement; Need to promote diversity, language and cultural competence)
Facilitators	Social Circumstances (Family and Social Support; Understanding or accepting of discrimination)	Cultural Factors (Community; Familism) Outreach and Advocacy (Community and social services; Church support)

Influenced by its history of ethnic and racial tension, the city of Louisville continues to be physically segregated markedly by race, ethnicity and socioeconomic factors, which shape the SDH. In the renowned documentary *Unnatural Causes: Is Inequality Making Us Sick*, the opening episode centers on how patterns of health and illness in Louisville were influenced by underlying structures of class, socioeconomic status and racial inequalities (California Newsreel, 2008). Dr. Troutman, the former Director of Louisville Metro, Public Health & Wellness, guides viewers in recognizing the segregation in Louisville as evidenced by the 9th street wall:

There's almost a cultural demarcation in the city where on one side of this particular street, Ninth Street, there's a tremendous amount of new development going on, condos rising up. The downtown business environment is very much alive. And right across the street on Ninth Street, is where the beginnings of the first set of projects are, public housing projects...Very little business in this area, primarily fast foods, small business, barbershops, beauty salons, pawn brokers, nail parlors, check cashing, liquor stores...And it seems like every city has a Ninth Street, whether it's 110th Street in Harlem or South Side of Chicago. (California Newsreel, 2008, p.5)

This statement and other findings in the documentary provided evidence for the physical and social segregation of Louisville that generated disparities in socioeconomic conditions and health status of segregated groups, who were predominantly identified as ethnic and racial minorities, low-income populations and immigrants.

In the *Louisville Metro Health Equity Report* (Center for Health Equity, 2011) life expectancy rates of Louisville neighborhoods were shown to be higher in many western and southwestern regions of Louisville (Figure 22). West and southwestern regions, with high concentration of HLI populations had lower life expectancy rates.

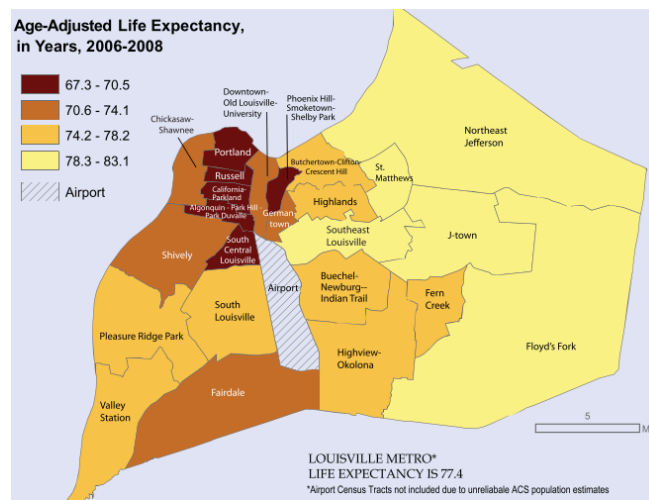


Figure 22. Age-adjusted life expectancy rates in Louisville Metro.

According to the Center for Health Equity (2012):

In Jefferson County, the neighborhood in which one lives can serve as a predictor of life expectancy. Neighborhoods that have the lowest life expectancies are the same neighborhoods with high levels of poverty, crime, vacancies, payday lenders, and fast food retailers. These associations provide strong evidence that the quality of the social and physical environment may play an important role in determining the health of community resident. (p.5)

This statement indicated that lower socioeconomic status was closely associated with poorer health outcomes in the Louisville population (Center for Health Equity, 2012). Also known as the wealth-health gradient, social gradients in disease and illness promote understanding of the social determinants that influence health for HLI in Louisville (California Reel, 2008). Geospatial analysis of study data and community maps retrieved from The *Louisville Metro Health Equity Report* (Center for Health Equity, 2012) reflected the influence of segregation, environmental factors and the social determinants on health and healthcare access of HLI in Louisville.

As previously indicated in the description of the study setting, geospatial data revealed that HLI populations were predominantly concentrated in southern regions of Louisville (see Figures 13 to 16). These regions also had higher rates of poverty (see Figure 17), lower levels of income (see Figure 18), lower educational levels (see Figure 19) and lower levels of English proficiency (see Figure 21), when compared to other northern and northeastern regions in Louisville. Community maps indicated noticeable geospatial differences in these socioeconomic factors, which were also related to health status and access to health and social services. This was evident when comparing rates of poverty, income, education and other socioeconomic measures to death rates associated with illnesses.

Findings indicated that Louisville areas with higher rates of illness related deaths also had the highest concentration of HLI populations as indicated in Figures 13, 15 and 16. From 2006 to 2008, deaths due to all causes were higher in Fairdale (1528 deaths), South Central Louisville (1217 deaths) and South Louisville (899 deaths) when compared to Jeffersontown (661 deaths), Northeast Jefferson (617 deaths) and the overall Louisville Metro rates (832 deaths) (Center for Health Equity, 2012). Deaths related to heart disease, cancer and diabetes were also higher in these regions when compared to northeastern regions and overall Louisville Metro rates. Among other health concerns, diabetes was identified as a significant problem in the HLI community especially in regards to diet and exercise, lifestyle and lack of preventive healthcare. Deaths related to diabetes were significantly higher in South Central Louisville (48 deaths),

Fairdale (46 deaths) and South Louisville (31 deaths) when compared to Northeast Jefferson (16 deaths) and Jeffersontown (16 deaths). These stark disparities in health outcomes are closely related to the wealth-health gradient:

In America, the wealth health gradient looks like this: Over 70% of affluent Americans report very good to excellent health – almost twice as many as poor Americans. No surprise. But in the middle levels, good health decreases significantly. This translates into a reverse slope for chronic disease [such as] diabetes, where low-income Americans have twice the rate of disease as the affluent. And for those in the middle, it's still almost twice the rate. A similar pattern holds for stroke, heart disease, eventually contributing to excess death¹⁵, especially for middle and low income Americans. Low-income Americans have twice the rate of disease as the affluent. And for those in the middle, it's still almost twice the rate. A similar pattern holds for stroke, heart disease, eventually contributing to excess death, especially for middle and low income American. (California Newsreel, 2008, p.4)

Findings indicated that the wealth-health gradient applies to HLI living in underserved, southern regions of Louisville that were shown to have lower income and educational levels, higher rates of poverty, and higher number of deaths related to chronic illnesses. Deaths related to heart disease, cancer and diabetes can be reduced with proper preventive health measure, which includes screenings to help identify health problems and access to primary healthcare services to manage chronic illnesses. However, geospatial analysis uncovered geographic barriers to accessing to these vital healthcare services for HLI in Louisville. Limited distribution of hospitals, public health centers, free clinics and other primary healthcare facilities in southern regions of Louisville play a significant role in shaping the geospatial factors that serve as barriers to healthcare access. Community maps resulting from geospatial analysis are embedded within the narrative of sociocultural contexts to provide the reader with a visual guide to geospatial barriers and facilitators to healthcare access.

Geospatial factors that served as barriers to healthcare access included physical access to healthcare facilities, travelling distance and transportation. The distribution of hospitals and pharmacies significantly diminished in the southern regions of Louisville with high concentrations of HLI (Figures 23 & 24). There were no hospitals located in major populated census tracts in South Louisville, Fairdale, Buechel-Newburg-Indian Trail and Highview-Okolona areas, which were also identified as impoverished regions of the city (Figure 23). However, several hospitals were clustered in major populated census tracts in downtown regions and eastern areas of the city, where HLI populations were identified to have higher levels of income, education and English proficiency levels.

¹⁵ Operational definition of terms can be found in Appendix D

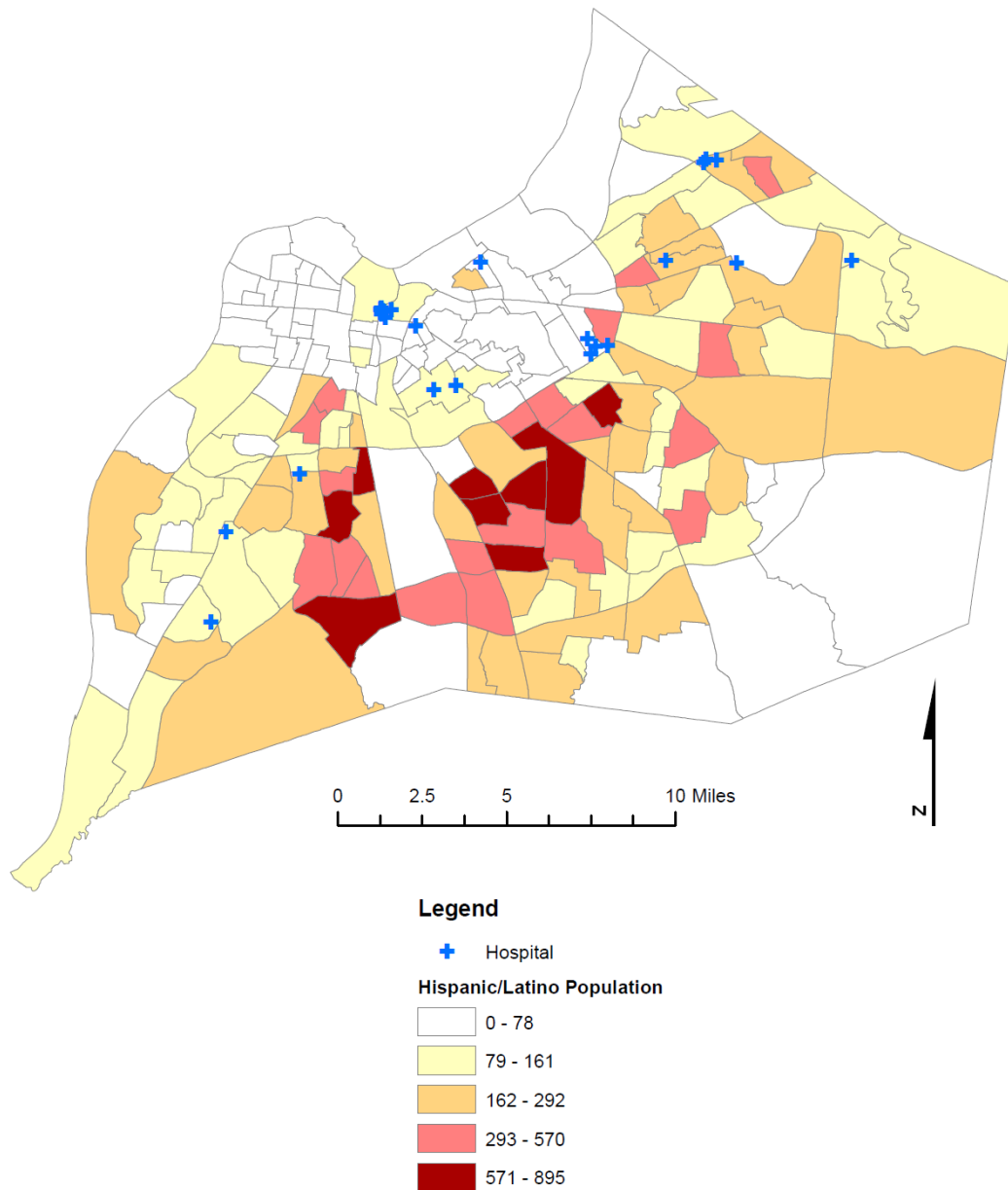


Figure 23. Louisville Hospital Locations and Hispanic Latino population by Census Tract

While major hospitals were predominantly located in north and northeastern regions of the city with relatively lower concentrations of HLI, pharmacies were located sporadically in areas with higher concentrations of HLI (Figure 24). Although point map data were able to identify the location of pharmacies, it did not identify the characteristics of pharmacies, such as the provision of Spanish language service (interpreters and translated materials). Therefore, although pharmacies were located in major HLI populated census tracts, other barriers to accessing services must be taken into consideration when interpreting these findings.

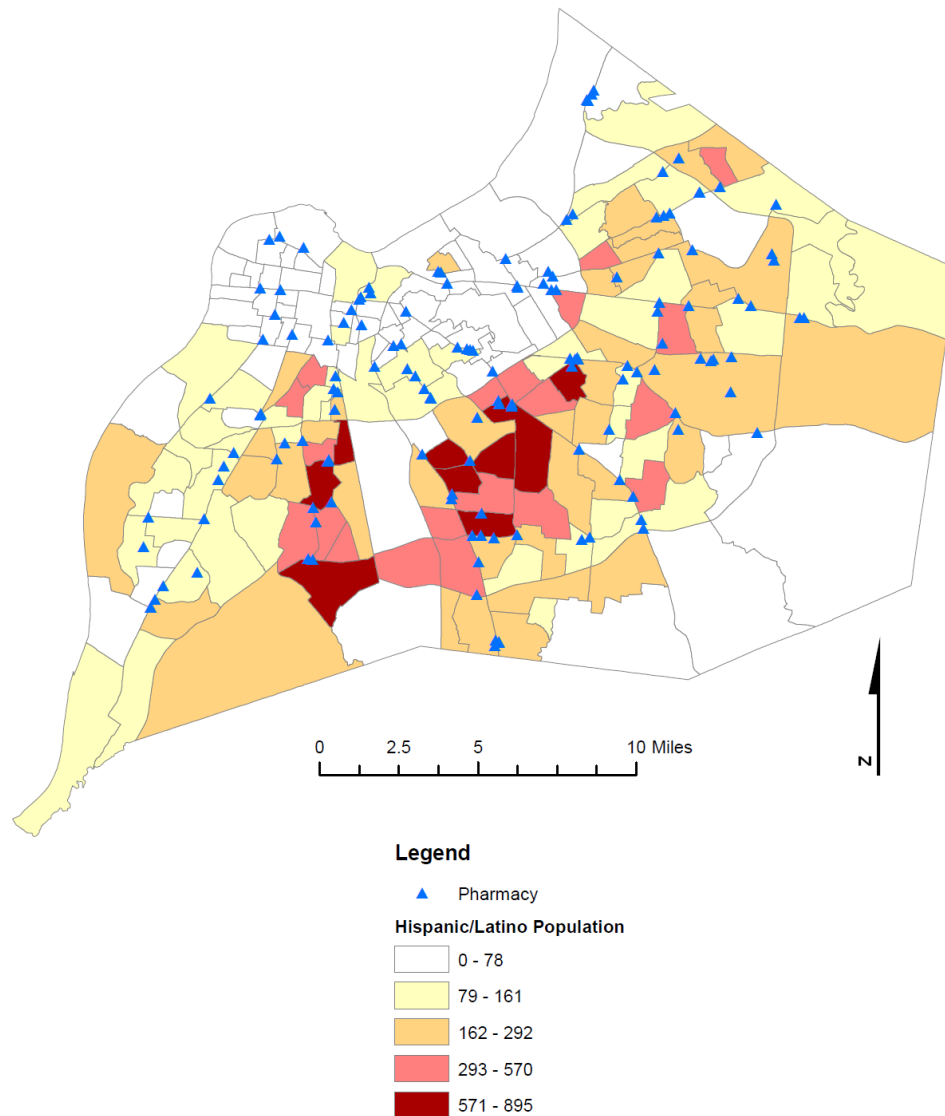


Figure 24. Louisville pharmacy locations and Hispanic Latino population by census tract.

Similar to the limited distribution of hospitals, the distribution of other healthcare providers and facilities such as pediatricians, dentists, family health centers, family planning clinics and family medicine practices, nurse practitioners, eye care providers, general practice clinics, OBGYN and internal medicine practices was scarce in southern regions of Louisville (Figures 25 and 26). Figures 25 and 26 depicted the physical location of healthcare facilities who offered interpreter services targeted at Spanish-speaking patients. Pediatric and dental services were dispersed across the city; however, Family Health Centers, family planning clinics and family medicine practices were concentrated in northwestern regions of the Louisville. It is important to note that although there were Family Health Centers (or public health centers)

located in the South Louisville area, there were no centers located in the Buechel-Newburg-Indian Trail and Highview- Okolona, which also had a large number of HLI populations living in poverty. Additionally, there were no services in the census tracts that were identified to have higher concentrations of HLI living in poverty and with limited English proficiency. Discrepancies in the physical location of medical services relative to areas with significant HLI populations were indicative of limited physical access to medical services and inability of healthcare facilities to expand services for HLI populations residing in areas of need.

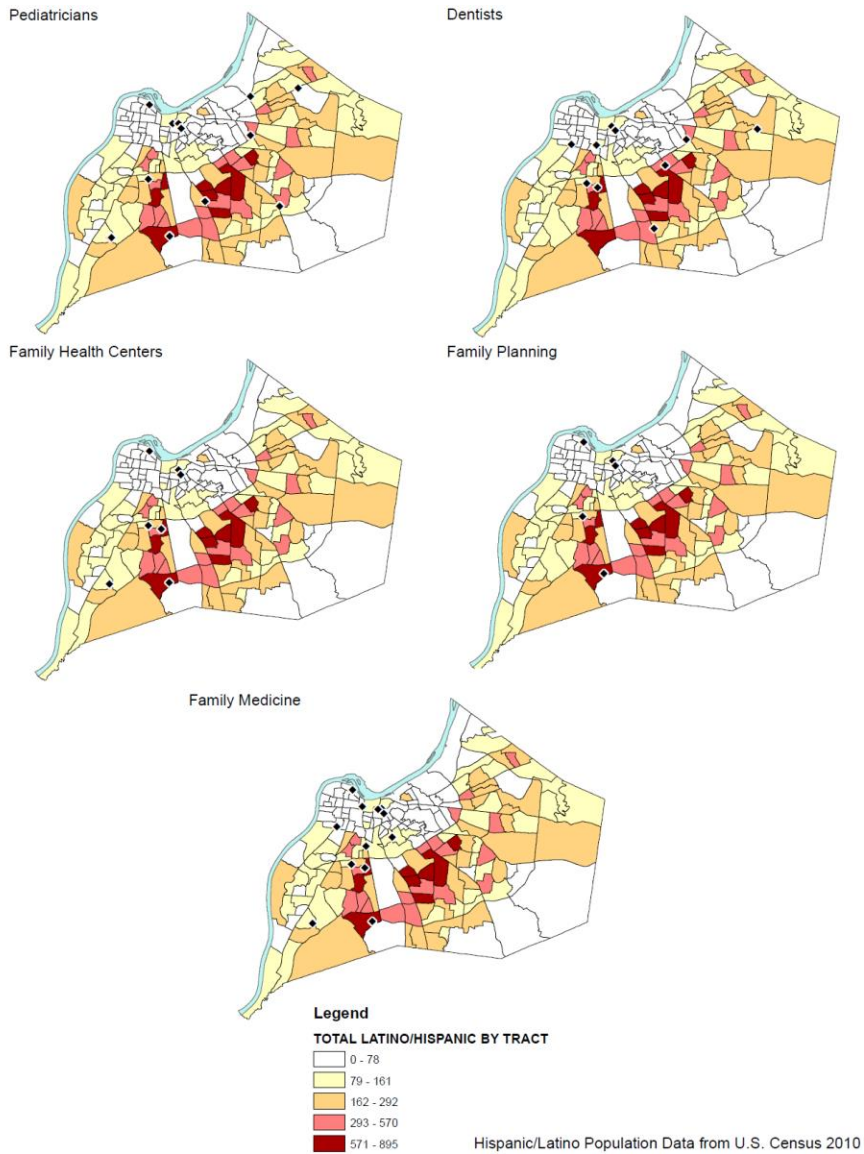


Figure 25. Distribution of healthcare facilities for Hispanic Latino population in Louisville.

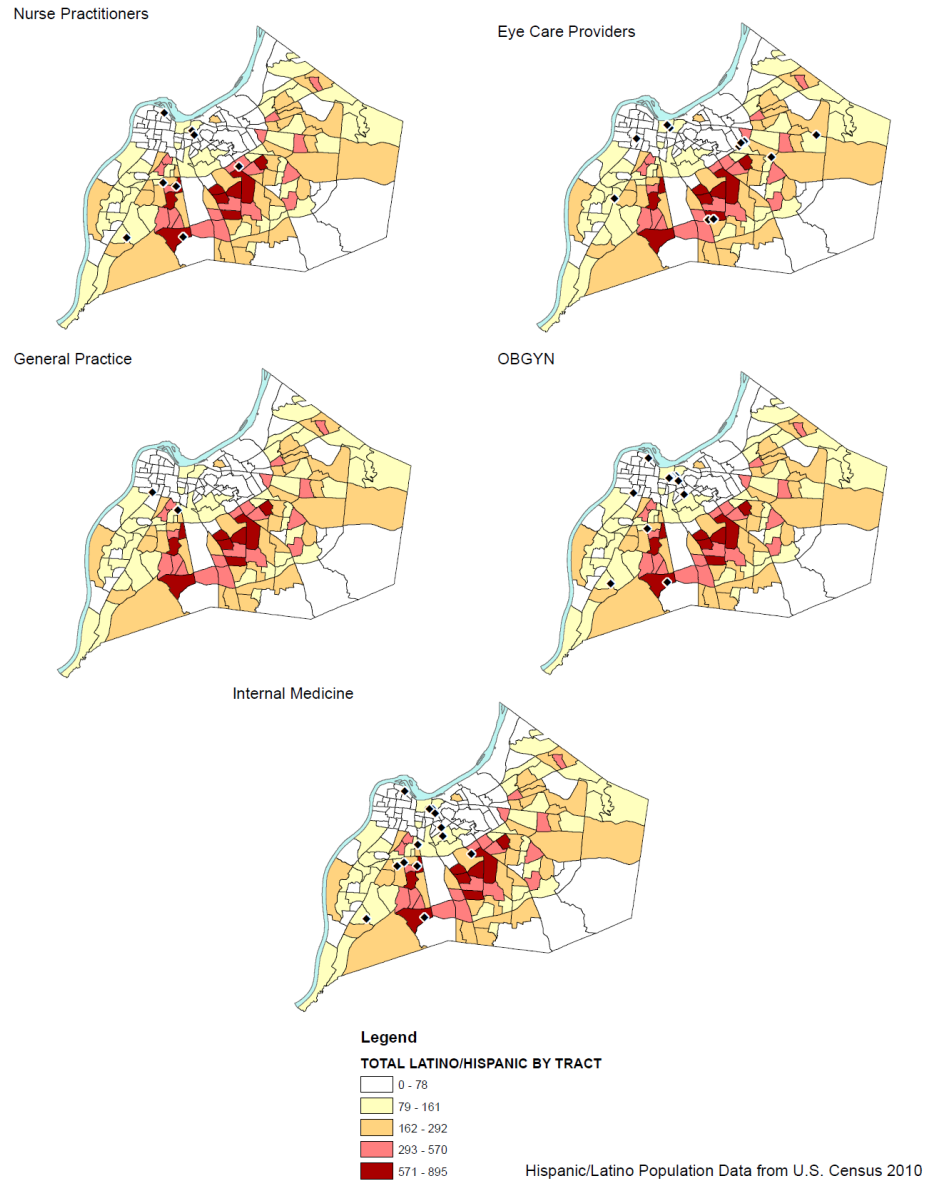


Figure 26. Distribution of healthcare facilities for Hispanic Latino population in Louisville.

Figure 23 and 25 indicated that there were no hospitals and few Family Health Centers conveniently located in major HLI populated census tracts. Distance measure maps (Figures 27 & 28) indicated that several census tracts in southern Louisville regions were farthest away from accessing hospital services. Figure 27 illustrated that HLI residing in South and South Central Louisville areas had to drive an average of four to eight minutes to access hospital services, while HLI in Fairdale, Buechel-Newburg-Indian Trail and Highview- Okolona areas had to drive anywhere from six minutes to over ten minutes to access a hospital.

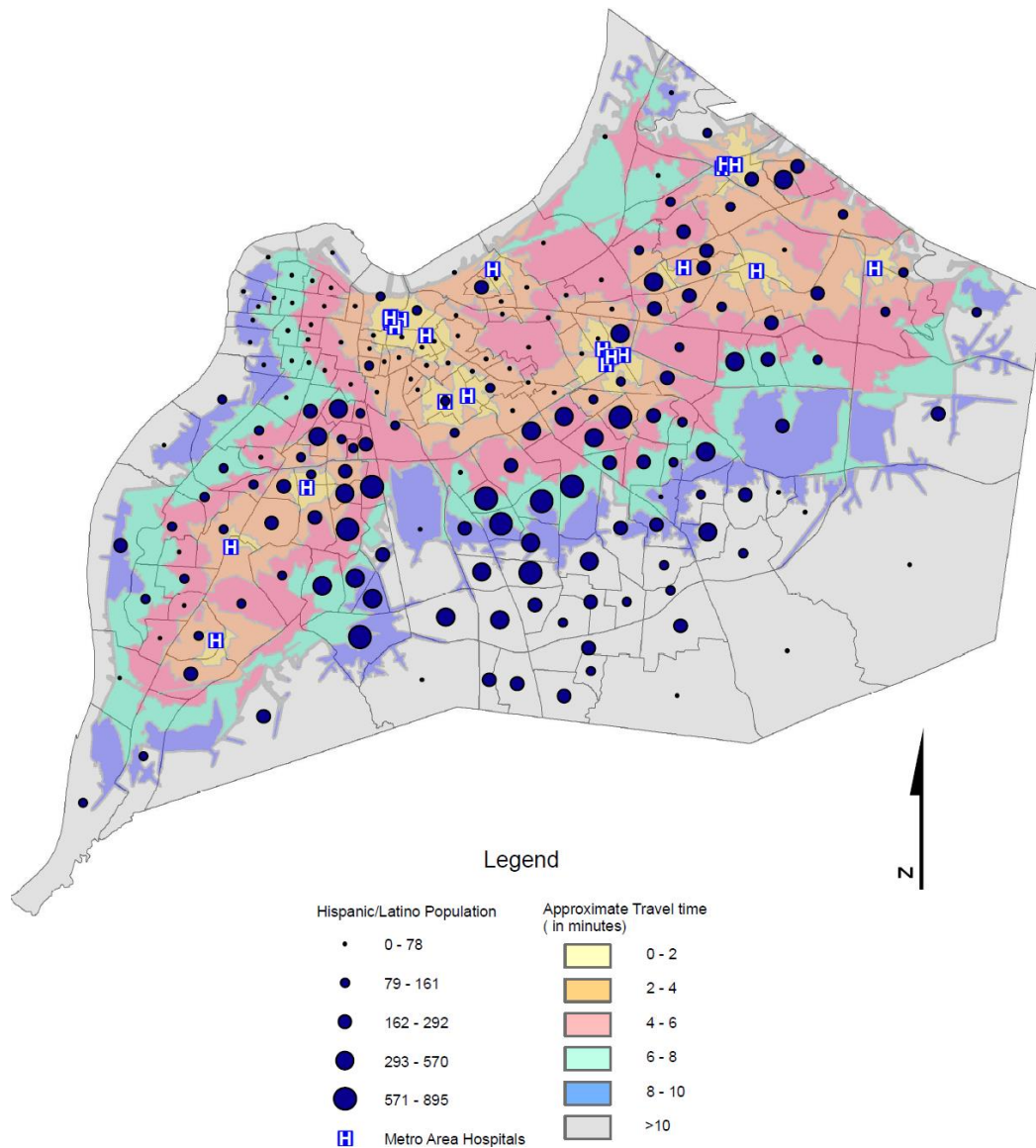


Figure 27. Drive time to hospitals for Hispanic Latino population in Louisville.

Figure 28 indicated that drive times to accessing Family Health Centers was also relatively faster for HLI residing in South and South Central Louisville and for Fairdale areas when compared to Buechel-Newburg-Indian Trail and Highview-Okolona neighborhoods. This map also indicated the location of a free primary healthcare clinic in the Butchertown-Clifton-Crescent Hill neighborhood (see Figure 13). This neighborhood had a relatively lower concentration of HLI and was located over ten minutes away for many southern, underserved HLI communities. These findings provide evidence for the increased distance and travel time required for HLI populations in southern regions to access affordable or free medical services at Family Health Centers or at the free clinic.

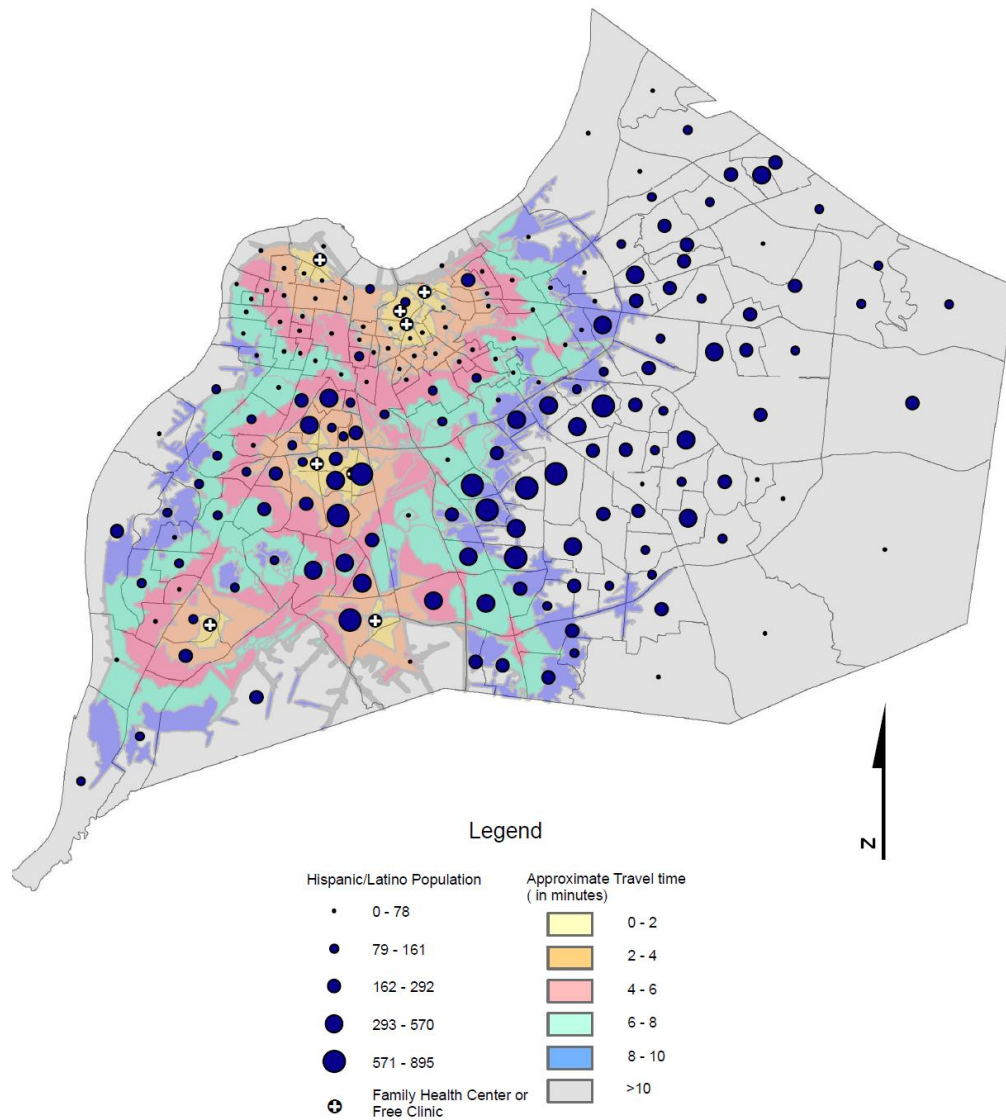


Figure 28. Drive time to Family Health Centers and Free Clinic for Hispanic Latino population.

Drive times to access primary healthcare services for the twenty participants in this study were illustrated in Figure 29. This distance measure map, which was developed using descriptive survey findings, illustrated the driving routes and distances (in miles) that each study participant had to travel to get from their place of residence to their identified healthcare provider. It must be noted that several driving routes were overlapping and are may not be visible because of similarities in participant residential locations and their associated healthcare provider locations. Similarly, as many participants had the same zipcode and/or healthcare provider, their location points of references are overlapping and were shown as one point. Despite these limitations, Figure 29 showed that participants travel time to access health services

ranged from 2 to over 15 miles. Additionally, survey findings indicated that participants had to travel an average of twenty minutes to access healthcare services from their designated healthcare providers.

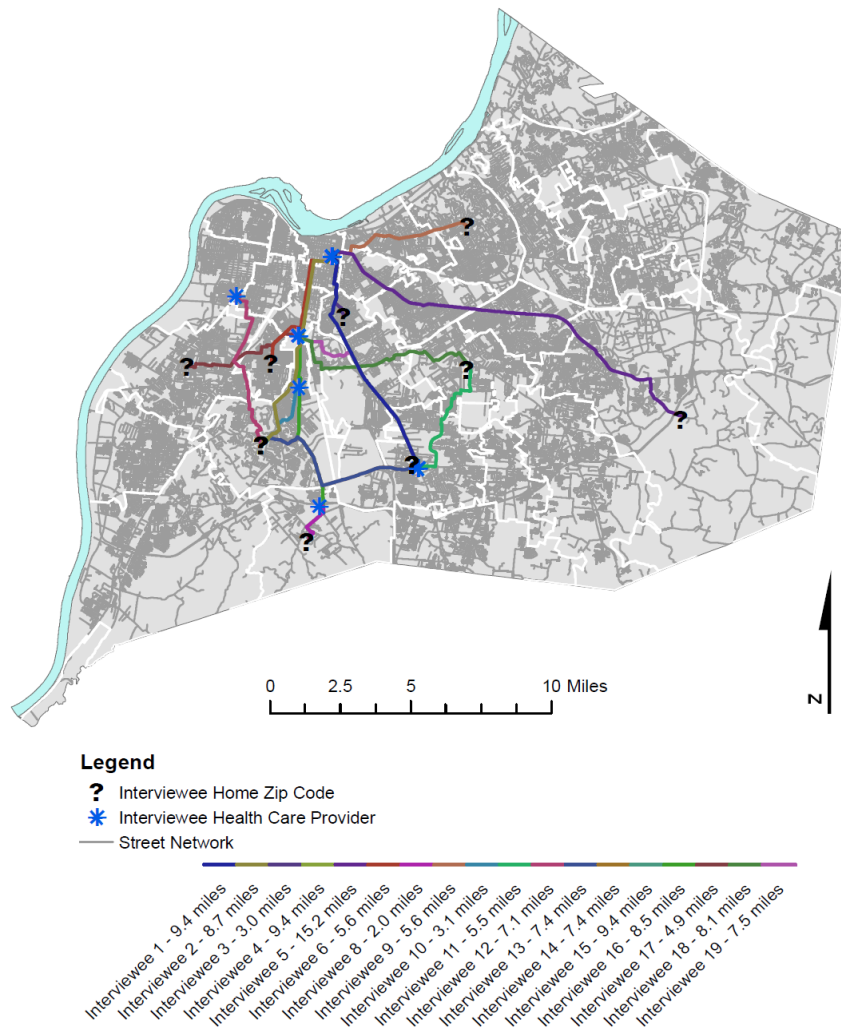


Figure 29. Study participants driving routes to selected healthcare providers.

Although several healthcare facilities may have been located within southern regions of Louisville, many HLI did not have adequate transportation to access these services. While the majority of study participants relied on cars as their primary means of transportation (n= 16), other participants and HLI in Louisville relied on the local bus system or Transit Authority of River city (TARC) as their main means of transportation. The TARC bus system was frequently used by many community members, especially for those with low-income and living in poverty. However, findings indicated that TARC services had limited routes and schedules in highly concentrated HLI regions of southern Louisville (Figure 30). The four study participants who used the TARC bus system stated that they travelled roughly thirty to

forty-five minutes by bus to access healthcare services. Therefore, limited bus routes served as an additional transportation barrier to accessing health services, especially from hospitals and other medical services that were not centrally located in southern regions of Louisville.

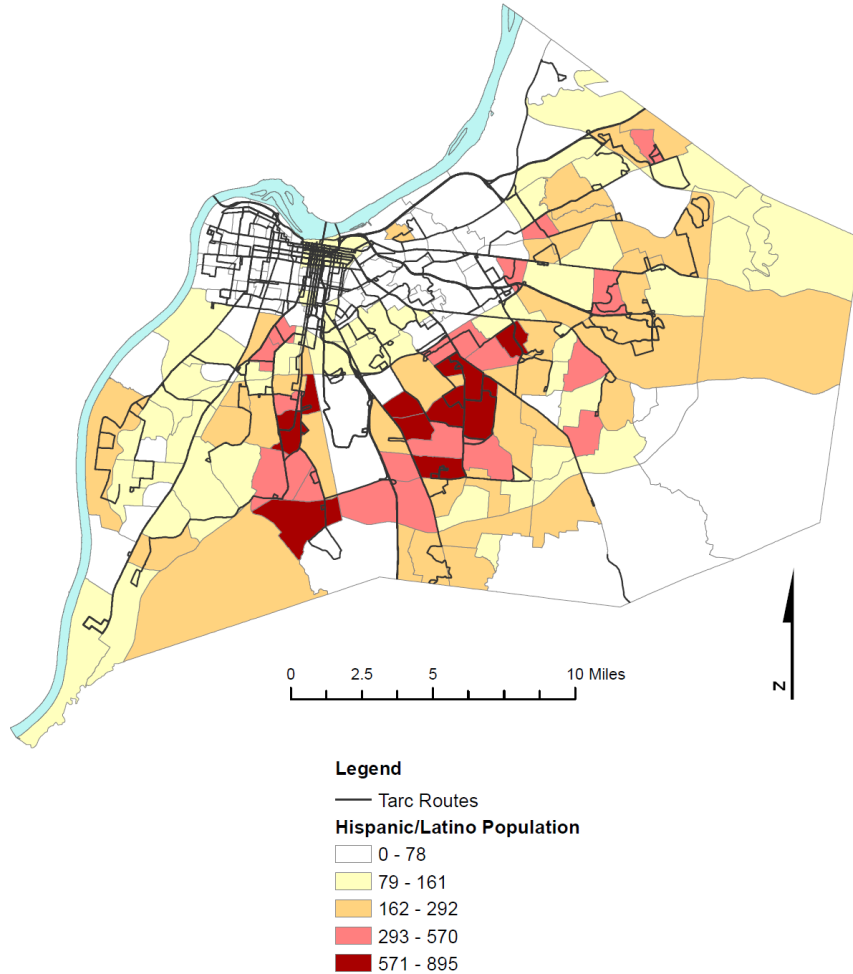


Figure 30. TARC bus access for Hispanic Latino population in Louisville.

Geospatial analysis and community maps indicated that geographic factors such as physical location, distance and transportation played a significant role in shaping the barriers to healthcare access for HLI in highly concentrated southern regions of Louisville. Southern Louisville regions with higher concentrations of HLI had fewer affordable medical service facilities, such as public health center and/or free clinics. Facilities that provided interpreter services for the Spanish-speaking population were not centrally located in areas of need and HLI had to travel long distances to acquire healthcare services at these locations. Furthermore, limited bus routes and transportation served as additional barriers to accessing

healthcare services for HLI communities with the highest need for affordable and linguistically competent services.

Societal Factors

Barriers to healthcare access. Similar to geographic factors, themes under societal factors were shown to significantly influence barriers to healthcare access. Important themes included *Racism and Discrimination* and *Seeking Respect*. Experiences of racism and discrimination by HLI in healthcare settings served as a direct barrier to healthcare access, as it resulted in emotional distress and discouraged health-seeking behaviors. However, racism and discrimination were also integral to shaping the larger sociocultural contexts of Louisville. One participant who moved to Louisville from Maryland stated:

In Louisville, there is a lot of racism. A lot of racism. They are two-faced. I experienced it myself before. But not in Maryland. In Maryland it's different, there is racism, but in Kentucky and Indiana it's more perceivable. I've experienced it.

Other participants expressed feelings of not being accepted or understood because of their language both within and outside of the healthcare setting. One participant who did not speak English had an experience at a car dealership where there was miscommunication over billing for services as a result of language barriers:

The manager treated me in a very rude and impolite way. "We are in America!" he kept yelling out "we are in America", as if to say that in America only English is spoken. And I told him "it doesn't make us inferior because we don't speak English."

Discrimination based on language occurred less frequently than discrimination based on race and ethnicity, which was more physically perceivable than language differences. Blatant racist and discriminatory remarks and treatment in public settings were often everyday occurrences for several participants. One participant from Guatemala stated:

I don't think they treat us bad because of the language that we speak. Sometimes when they see you and you look Hispanic, they start to treat you differently. I think if the language has nothing to do with it, but they just look at you and see that you're Hispanic they start to say things, certain things. For example, about a month ago I was at a red light and a white guy about forty years old, who was with his wife started to shout to me bad words, calling me Mexican and I didn't like it. Another time there were four or five American guys who were driving through my neighborhood and started yelling at me, calling me Mexican and other names.

Another participant from Guatemala said:

Louisville is a little bit conservative. Once I was in the check-out line in a store and the lady in front of me said "Go back to Mexico!" I told her "I'm not Mexican." With the English that I could get out I said "I'm not bothering you. I am buying something in the store." But sometimes you just

get angry. So when she took out her credit card and paid while standing there staring at me I said "Señora, you're paying with a card with money that you don't have and I'm paying with cash with money that I've earned from working hard."

Similar to historical contexts that shaped the fight for equal rights among minorities, discrimination that affects equal educational and employment opportunities continue to impact the ability of HLI to be viewed and treated equally as members of society. One female participant from Ecuador, who helps her husband manage their private business stated:

There is a lot of racism. And Hispanics and Latinos, we can't develop what we want to do or grow into who we want to be. This treatment doesn't let us grow and be a part of the community. Americans, they think Hispanics or Latinos cannot do the things they want to do here in this society and because of that we can't fulfill our targets and goals and we can't climb up. It's not a matter of not being able to do it, but a matter that they don't allow us to do it.

A male participant's narrative reflected this view that racism and discrimination continues to retain HLI in lower, oppressed social positions:

I experience discrimination all the time, especially with my work. I once tried to do a cross-over business partnership. As soon as I opened my mouth to speak they asked me where I'm from. Just because I'm Hispanic they automatically think that I am not good enough. They even told me "I don't need your people here"

This participant, who experienced several hardships in seeing growth in his personal business, which he attributes to discrimination, expressed his desire to be treated equally and with respect in the community:

Fifty-one percent or more of business owners in Louisville is Latino or Hispanic owners. We are not going anywhere and we are growing. We are going to be taking over if you don't give us the opportunity to work with you. We come here and start as dishwashers and five to ten years later we own our own business. If you don't work with us, then we are going to end up being your competition. That is what is happening. You are taking us for granted. You are underestimating that we can learn your language and we can play your game.

Document reviews identified several other cases of discrimination in places of business reported to the KYCHR. The KYCHR publishes annual reports of programs, events and legal cases related to civil rights. One representative from this organization stated:

We have received several calls regarding discrimination at the health clinics in Louisville with Hispanics and Latinos. Although it is not a focus of our office, I help with consultations for people who are trying to apply for publicly fund social services, like WIC or food stamps, based on their immigrant status or even sometimes with immigration paperwork.

Annual reports revealed that over the last four years, four civil rights cases were processed through the KYCHR for HLI who filed complaints on the basis of discrimination. One such case was Nicholson v. Paul & Chong Corp (Luigi's Pizza):

The complainant alleged he was discriminated against in violation of the Kentucky and United States Civil Rights acts in that he was the subject of harassment based on his sex and national origin, Hispanic. He alleged he reported the behavior, but no action was taken in response to his complaints, and that he was then discharged. He also alleged his employer retaliated against him for reporting the incidents. The respondent denied all allegations of unlawful discrimination and asserted the complainant was terminated in accordance with its policies. Prior to completion of the investigation, a conciliation agreement was signed by both parties. The company compensated Mr. Nicholson in the amount of \$7,500.00, and agreed to undergo compliance training and monitoring for three years. (KYCHR, 2010, p.19)

Although the data indicated numerous experiences of discrimination, HLI were less likely to report such behavior to advocacy groups or governmental bodies such as the KYCHR. The ability to advocate for themselves and have their voice heard is a privilege for many HLI, especially for the undocumented who are unable to do so related to fears of deportation. A photo-ethnography of Latina immigrants in Louisville by a cultural anthropologist and diversity consultant from Peru portrayed the voices of several undocumented Latinas and their experiences of discrimination (Mujica, 2011). One Latina from Guatemala stated:

The hardest things about being an immigrant is the gender-based obstacles that one may confront and, on some occasions, the color of my skin. What I like the most about living in this country is the opportunities that the country has to offer. After overcoming the language barrier, the doors to opportunity open wide, the likes of which are hard to obtain in our native countries. (Mujica, 2011)

Although many immigrants come to the U.S. in search of better opportunities and quality of life, they are often subjected to racism and discrimination which serve as barriers to achieving this American Dream. Various sources of data indicated that the societal factors of racism and discrimination and the struggle for seeking respect and equality is an additional sociocultural factor affecting the barriers to healthcare access for HLI. Analysis of barriers to healthcare access within this sociocultural context facilitated understanding of underlying social structures or race, ethnicity, power and dominance that influenced the HLI experience in the U.S.

Immigration

Barriers to healthcare access. Sociocultural contexts are also shaped by experiences of migrating to the U.S. and living as an immigrant in the community. The subthemes under *Immigration* included *Crossing the Border, Undocumented, Acculturation, Immigration Issues in Louisville, and Fear of Deportation*. Immigration factors were identified as integral barriers to accessing healthcare services in the U.S., especially in relation to those who were undocumented. When border fortifications were implemented

in the 1990s, immigrants wanting to cross the border turned to human smugglers, also known as coyotes, who charged thousands of U.S. dollars to smuggle a single individual across the border illegally. One participant who crossed the border from Mexico said that ten years ago he paid close to \$3000 to be smuggled across the border by coyotes, but now the rates have gone up to \$5000. Stories of participants who crossed the U.S.-Mexico border were riveting and moving, where many were willing to risk their lives for the wellbeing of their families. One male participant who crossed the border from Guatemala said:

It was a little bit hard because it took us 25 days of walking from Guatemala to the border. Going through Mexico was very difficult because there were a lot of thieves and killers. But one has it in his mind that I have to do this for myself and for my family.

Another female participant from Guatemala, who has lived in the U.S. for over twelve years, shared her experiences:

My brothers who lived in the U.S. kept saying “come here, come here to the US.” And I said “no because I wanted to be free and I don’t want to hide. And if I go there without documents, I would be illegal and hiding myself all the time.” I always told that to my brothers when they told me to come. One Thursday morning I decided to come here...I suffered a lot to get here. I walked a lot at night time in Mexico. I was for four days and five nights in the desert. I was eating canned food and that was making me sick to my stomach. And I am very scared of snakes and in the desert there were so many snakes. And I felt like fainting, I don’t know if it was because of the food or if it was fear. It was a horrible experience.

Crossing the border is a very a dangerous, life-threatening experience, which today has become riskier as a result of vigilante groups who have taken it upon themselves to patrol the borders and kill immigrants who they believe to be undocumented. By instilling fear through violence and control, these vigilante groups that predominantly existed in southwestern regions of the U.S. have started to emerge in southeastern regions, with the growth of immigrant populations. One female participant who worked at the horse racing industry shared her experiences with security guards and vigilantes who take it upon themselves to enforce immigration laws by means of domination, violence and fear:

Vigilantes and guards at my job go after people who don't have licenses to work. To get the work license you have to show a social security card, so you have to show legal immigration papers. I've gone with these people without licenses to work and it's very scary because they hide, they try to hide themselves because they don't want to be deported. If they don't have a license they come in hiding, by jumping the fences or something. So the security guards spy in the horse stables and they grab these people and ask for documents. And if they don't have them they throw them out. Some have to hide or run so they don't get caught because they don't have documents. They can't even go out to buy food or anything because they are scared of getting deported. Many of them live in the stables with the horses, and everything they have, own or know is in those fences. I've seen people get deported and they have to leave their cars here and all their belongings, bank accounts, money they saved up, everything. They take away everything, even the clothes off their backs. They have to stay in jail for three months before they can go back to their country. I heard it's very cold in jail and they treat them very poorly. Not having documents is very sad.

The plight of migrant workers who come on legal work visas and fall out of legal status is shared by other undocumented HLI in the community. The fear that is experienced when crossing the border is persistent throughout the life of an undocumented immigrant, as many continue to live with the fear of deportation resulting from the lack of legal immigration paperwork. This persistent fear was shown to impact levels of acculturative stress, acculturation and overall mental health and wellbeing of HLI. One local community advocate and immigrant from Argentina stated:

Another piece in our city that we have is we don't have access to what we call mental health here. It's doesn't mean that you are crazy, it's about the anxiety, pressure, losses...we are talking about how your emotions are on an emotional roller-coaster every day. How you cannot go to sleep in peace, how you are tense all the time, how your blood pressure is going through the roof, and there are no or few practitioners who can help Hispanics to go through the emotions and try to understand.

Without legal immigration documents, HLI cannot obtain social security numbers, driver's licenses, employment and/or health insurance, consequently resulting in lack of access to vital health and social services, especially specialty services such as mental health. Undocumented HLI often fear that they will be reported to law enforcement or immigration authorities when seeking health and social services, if they are unable to provide a social security number or other proof of their legal immigration status. One participant from Puerto Rico stated:

For those who don't have papers and they are illegal, it is all about fear. Everyone has fear to go to the doctor... Illegal people fear doing that now because they feel that once you put yourself in the computer record, they are scared that the doctors can pass along that information to immigration and they can get in trouble. That's why they don't do it. The consequences of that are that they don't go get check-ups and they get sicker. They prefer to jeopardize their life before they jeopardize the future of their family or little ones. That's something you see that... when you go to the doctor when you don't have any papers. That has nothing to do with your health. But they don't know it. They need to be educated about that kind of stuff.

Findings indicated that HLI who were undocumented worked in low-wage, service industries, under employers who were aware of their undocumented status. On some occasions, employers use the undocumented status of HLI to their advantage by providing wages that are considerably lower than other, documented employees. With lower income levels, the undocumented face additional barriers to accessing healthcare services because of their inability to afford medical expenses. The lack of documentation required to access certain healthcare services is an additional barrier to access, which often leads to delayed health-seeking behaviors. Immigration related issues continue to shape the sociocultural and economic contexts of HLI in Louisville as evidenced by one participant's statement:

Immigration is an issue in Louisville. The person who doesn't have documents, this person is discriminated. You cannot get a job or get a license because you don't have documents. Immigration issues are important here in Louisville. Having residency is important. I know many people who fear this every day, not having documents. I have employment permission because I am legal here but I fear it anyway. The most important thing is having residency.

These immigration factors significantly influenced access to healthcare services and were central in shaping the sociocultural contexts of healthcare access. This analysis provides a basis for understanding the influences of power, control and domination manifested through fear on the experiences of HLI, especially of the undocumented living in Louisville.

Cultural Factors

Barriers to healthcare access. Cultural factors that helped create the sociocultural contexts of barriers to healthcare access included *Communalism vs. Individualism, Familism, Social Isolation and Separation from Family* and *Traditional medicinal practices*. Many HLI and their cultures focus on the wellbeing of the community as a whole, emphasizing the importance of social and family support. In this context communalism refers to the coming together of community members and groups to work towards common goals and overall wellbeing of the community as opposed to focusing on the individual. Contributing to the idea of communalism is *familism*, which is a central characteristic of Hispanic Latino cultures that prioritizes family over the individual needs (Franzini, Ribble, & Keddie, 2001; Mindel, 1980; Vega & Miranda, 1985). Therefore, HLI are often challenged with integrating into U.S. societies whose social and cultural structures are predominantly engrained with principles of capitalism and individualism. The influence of individualistic tendencies of U.S. society on efforts to promote overall community health and wellbeing were recurrent themes in research findings. In the documentary, *Unnatural Causes: Is inequality making us sick?* one source stated:

We live in an individualistic society. We believe that people are individually and personally responsible for their own fate. We enact our laws that way; we create our social policy that way. (California Newsreel, 2008)

While U.S. society and culture is based on the principle of individualism, HLI cultures uphold community and family wellbeing as the epitome of survival, especially during challenging life situations. Stressors associated with immigrating and integrating into a new culture were exasperated without adequate community and family support. Study participants expressed how they yearn to have a sense of community,

which they were accustomed to in their home countries. In describing the differences between his lifestyle in Cuba and the U.S. one participant stated:

It's very different. Neighborhoods in my country and here in the U.S. are different. So in Cuba you talk to your neighbor and everybody in your neighborhood. And you share coffee and you sit down at night and talk a lot! You share experiences and you play dominos, but you also work 8 hour days like here in the U.S. and sometimes even more in Cuba. But there is always time to share with my friends. There is a different environment there and it makes you feel supported. It's the country, your culture.

Another participant from Puerto Rico expressed his views:

It's not just in Kentucky but in the whole country. The whole country is very spoilt and they treat us like we inferior, but they have never been through what we have been through. I know that this has nothing to do with this topic, but look what happened during the 9/11 attacks. The U.S. thought nobody is going to touch them and look what happened. That was a wakeup call that you are not that untouchable. So we the Latinos are here to stay. Don't do the same thing with us, because eventually we are going to take over in numbers... You know what I would love to have the Americans say "let's work together. How can I help you to be a part of the community and grow in our business?"

Being treated unequally and isolated from the community makes it more difficult for HLI to gain community and social support to enhance their social positions in U.S. society. Furthermore, many HLI were unable to uphold their cultural inclinations towards communalism and *familism* because they are separated from their families and socially isolated from members of Hispanic communities and mainstream society. A survey of nearly 200 Hispanics in Louisville that examined access to healthcare for this specific population indicated that separation from family and social isolation were among the many factors that impacted the mental health and wellbeing of HLI:

Like many others, the survey found, the immigrants surveyed cited problems with depression and anxiety, exacerbated by unemployment. But other factors were unique to immigrants: culture shock, the pain of being separated from family and their home countries, and a fear of deportation among those here illegally. (White, 2011, p. 2)

A female study participant from Cuba described her challenges with not having family support throughout cancer treatment:

When I came here to the U.S. I didn't have any relatives here. The reason I came from Cuba here to America is because I wanted to help my children and my mother who are still in Cuba. We have been a very united family. The most important thing is the love we profess for one another. We have had to sacrifice our love by living apart and moving to help one another. This has been very hard on me. I was alone here in America when I got cancer and it was very hard. I didn't want to tell my children and my mother in Cuba because they were going to get exasperated and they couldn't do anything.

Living in an individualistic society as an immigrant often forced HLI to adapt to American cultural norms, in order to survive. Most participants identified living in isolation as an innate characteristic for survival as an immigrant. For example, when asked who the most important person was when he is sick in the U.S. one participant from Guatemala stated:

No one. No one, it's because we learn to take care of ourselves. As immigrants we come by ourselves, so we can't count on our families. And here everyone is focused on their own things.

The emphasis of communalism and *familism* in many Hispanic Latino cultures was also related to the political, social and healthcare systems that they come from. For example, participants from Cuba, who were accustomed to a socialized healthcare system, were more vocal about expressing the need for accessing free healthcare services in the U.S. Contrary to Cuba, participants from Mexico, Guatemala and other central American countries expressed the insurmountable costs of healthcare services in their home countries that made it impossible to access care for many. One participant from Mexico stated:

If you have money in the U.S. you can be seen. In Mexico if you don't have money you can't be seen. If the person works they can get medical insurance. If they don't work they have to have money to get healthcare.

In comparing the healthcare system in the U.S. to Guatemala one participant stated:

There are huge differences. One difference is that here in the U.S. there is access all year-round for any kind of sickness. In my country, because I live in the southern border of El Salvador I have to travel six hours to get to a hospital. In my country if you have money, that means you have access to health systems that are better quality and access to medicine. If you don't have money, then you get access to a worse system or a lower system.

Despite access to higher quality and quantity of healthcare services in the U.S., these participants still faced difficulties in accessing healthcare in the U.S., especially in relation to financial barriers. To overcome these financial barriers, both in their home countries and in the U.S., many HLI turned to traditional healthcare or medicinal practices. *Familism* was also a central theme in the use of traditional healthcare as participants identified their family members as primary sources of healthcare in their home countries. Often times, mothers and grandmothers were the family matriarchs that practiced and handed down generations of traditional medicinal practices and home remedies, still used by HLI to cure illnesses. Ten participants stated that they used traditional and/or homeopathic medicines and home remedies as their initial treatment for illnesses. Other sources of data also indicated that immigrants from Mexico, Guatemala and Ecuador frequently used traditional medicine for their illnesses. *Curanderos* and *curanderas* or

traditional spiritual healers, inherent in many Latin American countries were identified as sources of healthcare for HLI. These traditional healers promoted the use of herbal and folk remedies to cure illnesses. Once in the U.S., access to traditional healers was limited for HLI, who often resorted to home remedies.

One participant who used traditional medicine in Ecuador shared her experiences:

The first thing I do when I'm sick or ill is I go to see a naturalist or use traditional medicine and try to heal myself with that... I take Echinacea with orange juice, when I feel I'm sick. I also drink ayurvedic waters that clean the inside of your body. I think it really helps me and keeps me healthy so I don't have to visit a doctor.

One Guatemalan indicated reasons for using traditional and naturalistic healing methods:

In Guatemala people are dedicated to natural, healing with plants, using natural remedies or medicinal plants for example. I think in the U.S. healthcare system has a lot of technology, and there's a lot more here than in Guatemala. That's why people in Guatemala prefer medicinal plants as opposed to going to a hospital. It's not very sophisticated, or well looked upon to be at a hospital, so a lot of people don't go to the hospital.

Although the use of traditional medicines was indicated as a barrier to healthcare access, it is important to acknowledge the origin of these cultural factors that shape sociocultural contexts of barriers to accessing healthcare for HLI. Traditional practices and differences in healthcare systems are essential in understanding the influence of these factors on cultural barriers and health-seeking behaviors and to identify culturally competent methods to reduce these barriers. Cultural factors of communalism and *familism* provide a contextual basis for understanding participants' perspectives on *Time and availability*, *Emergency room*, *Healthcare business* and *Social circumstances*, which served as barriers to healthcare access.

Language

Barriers to healthcare access. Sociocultural factors that influenced language barriers to healthcare access were categorized under *Language access* and *Language barriers*. As the demographics of the Louisville community dramatically changed with the arrival of new immigrant groups, its language profile also changed considerably. According to the *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012), the percent of residents who did not speak English well or at all was estimated to be 1.6% in 2009. 7.4% of the population spoke a language other than English, with Spanish being the most commonly spoken language. Despite the large growth in HLI and the Spanish-

speaking population, findings indicated that Louisville struggled to provide linguistically competent services for these changing demographics.

This palpable difference in language use was also seen in the sample population of this study. Seventy percent of the participants in this study (n=14) stated that they spoke very little English and 15% (n=3) said they didn't speak any English at all. Ninety percent of participants (n=18) predominantly spoke Spanish at home. Consequently, some of the largest barriers these individuals faced in the community especially when accessing healthcare were related to language access. Many participants indicated that their inability to communicate in English became a substantial problem when seeking community services. One woman from Cuba who didn't speak any English stated:

Sometimes you can perceive or notice when you go to some places and people get angry or mad because they don't want to or sometimes they can't understand what you say. They become angry because you cannot express yourself in the same language they speak.

Other HLI in Louisville found that accessing Spanish interpreters and healthcare providers to be significant language barriers when accessing health services. Findings from a community survey on Hispanics and access to healthcare reported that the largest barriers to healthcare access were related to linguistic and cultural barriers:

Mexican native Lupe Rebollo, who came to Louisville in 1987 and works as a self-employed housekeeper, said she has struggled first-hand with the challenges of getting proper medical care. She said that when she and her husband arrived, they initially met only a handful of people in the city who spoke Spanish — and none were health-care professionals “When I took my husband to the Portland clinic [Family Health Clinic], we couldn't talk to a doctor,” she said. “That was kind of hard.” But things have improved since then, she said, even for people like her who don't have health insurance. (White, 2011, p.1)

Over the years, access to language services in the healthcare industry has been a constant battle for many immigrants. The influence of policies on language access was a central theme in the findings of this study and is discussed further under political contexts. However, inconsistencies in implementing and enforcing language access policies, the unavailability of trained interpreters, the lack of resources and information in Spanish, and allowing children to serve as interpreters were identified as essential barriers to language access. Although using family members as interpreters was identified as a facilitator to healthcare access as it enabled some level of patient-provider communication, many providers realized that it was unethical and inappropriate to use young children as interpreters. Many HLI resort to using their children

and other family members as interpreters as a result of availability barriers including lack of interpreter availability, training, bilingual healthcare personnel and lack of patient-provider communication.

Facilitators to healthcare access. Sociocultural factors that shaped language facilitators to healthcare access were categorized under *Language access* and *Language facilitators*. Community efforts to provide linguistically competent services helped facilitate language access for HLI in Louisville. These efforts were predominantly seen in the establishment of English as a Second Language (ESL) classes through the Jefferson County Public Schools (JCPS) Adult Education program, the Americana Community Center, Kentucky Refugee Ministries, Iroquois library, Backside Learning Center, and Wesley House community center. Despite the establishment of these programs to promote the English language, it was found that several HLI groups did not attend these classes as a result of lack of awareness, ineligibility for certain programs, inability to pay for those that required fees, conflicts in work and class schedules, and difficulties with learning languages. Several participants in this study expressed their desires to study English, but were unable to do so because of the above-mentioned barriers. One participant who works at the horse racing industry had access to the ESL classes offered through the Backside Learning Center, but stated:

I understand because it's our obligation to learn English, but we don't have time, because of work. They offer English classes at the Backside learning center. Before they used to be very expensive for the classes, but I don't know how much they are now. But I have two jobs and I'm busy so I can't even make it to the classes. Sometimes when I do attend the classes, with two jobs often times I will be tired in class and I can't focus so I don't learn anything.

While HLI themselves made efforts to eliminate language barriers by learning English, community organizations also took measures to provide linguistically competent services by providing basic Spanish classes to their employees:

Like law enforcement agencies, ambulance services and fire departments have initiated changes to communicate with individuals who have limited English proficiency. According to a published report, an Ashland firefighter gave an example of responding to a house fire where a child might have been inside. If firefighters are unable to communicate with the family outside the structure, a life could be lost. Another published report noted that Louisville area county police joined firefighters and emergency medical services agencies in basic Spanish classes. (Legislative Research Commission, 2002, p.88)

Increasing communication with LEP individuals is essential in building trust and familiarity, which is essential to the patient-provider relationship in healthcare. Although limited, some health and social service organizations also provided interpreter or bilingual services to meet the needs of their HLI clients, which

many participants identified as facilitators to healthcare access. For example, the bilingual medical case manager at the HIV infectious disease clinic was identified as a sole facilitator to healthcare access for the participants who were HIV positive in this study. Other facilitators to healthcare access identified under *Type of Healthcare Facility* included public health and primary healthcare clinics, where access to interpreters and bilingual staff was identified as a significant facilitator to access. Public health clinics which are federally funded are required by law to provide language services to LEP clients. One report indicated:

In 2006, more than 30 percent of the patients seen in these federally qualified community health centers (public health centers) were served in a language other than English. Most patients at these centers reported that their care provider spoke their language. (Kentucky Youth Advocates, 2009, p. 5)

As federally funded programs are required to provide language access services under Title VI of the federal Civil Rights Act of 1964, many hospitals and larger healthcare facilities that receive federal funding have established programs and departments overseeing language and cultural competence. Findings from this study indicated that out of the four major hospital systems in Louisville, two facilities (one private and one public) have established either a distinct department for diversity and inclusion or for providing language services. The private hospital, which houses the department for diversity and inclusion, provided language services through the use of telephone and video-remote interpreters who are available 24/7 and on-site interpreters who were available by appointments through partnership with local agencies providing interpreter services. The public hospital also provided telephone and video-remote interpreter services, but also employed two full-time and two part-time Spanish-speaking onsite interpreters to provide services for their HLI clientele. During an interview, the language services supervisor at this site stated:

Cultural and language issues are a major barrier to access as Hispanic immigrants don't understand how to navigate the healthcare system in the U.S. as it is very different from the systems in their home countries. Therefore, we try to provide language services both in the hospital and throughout the community. Many Spanish-speaking patients in the community will call us directly to try to find out where they can access health services, because we can communicate directly to them in Spanish. Our staff providing in-patient care are very keen on using available language services, but we are still facing difficulties providing services at our out-patient locations, especially at doctors' offices.

Although efforts were being taken by community organizations to facilitate language access, many HLI continued to face barriers to accessing linguistically competent healthcare services. Continued efforts in promoting language access are essential in facilitating healthcare access for HLI. Findings indicated that

differences in language played a significant role in shaping the sociocultural contexts of healthcare access. Language barriers and inability to communicate in English resulted in feelings of not being understood, not feeling cared for, or feelings of inferiority and subordination for many participants. These findings illuminate the continued oppression of HLI through the mechanisms of language.

Outreach and Advocacy

Barriers to healthcare access. Factors pertaining to *Outreach and Advocacy* that shaped the sociocultural contexts of barriers to healthcare access included the *Lack of Spanish communication channels, Need to promote diversity, language and cultural competence, and Lack of collaboration and community involvement.* Access to available health and social services for HLI in Louisville was highly influenced by the limited availability of Spanish media sources. In its 2008 Annual Report, the KYCHR identified several Hispanic media outlets throughout Kentucky that were used to promote the commissions outreach programs and information on civil rights:

The media outlets include Hoy en las Américas in Shelbyville, La Vereda in Owensboro, La Voz de Kentucky Lexington, Al Día en América in Louisville, the magazine Actualidad in Lexington, and Spanish radio La Caliente in Louisville and the Radio Vida in Paris. The commission is very appreciative for the partnership of the Hispanic media outlets. (KYCHR, 2008, p. 51)

Despite having one of the largest HLI populations in the state, Louisville only has two Spanish radio stations (La Caliente and La Poderosa) and one Spanish newspaper (Al Día en América). Many sources indicated that both of these media outlets were predominantly geared towards Mexicans in Louisville, which was also identified as one of the largest HLI subgroups. State-wide publications like El Kentubano targeted Cuban populations, as evidenced by the document review findings. The affiliation of these media outlets to specific HLI subgroups greatly affected their circulation and limited their ability to communicate information to a widespread audience as evidenced by this statement by a Cuban immigrant in Louisville:

La Caliente and Al Día en América are for Mexicans. Cubans in Louisville don't have any way to get information specific to them. Cubans are not going to read a Mexican newspaper or listen to their station.

This statement makes it essential to understand the importance of being respectful of the cultural distinctions between various Hispanic Latino cultures, as each subgroup has unique features that distinguish them from others. It is important to recognize the various media outlets and their respective target audiences so that culturally appropriate information can be provided depending on these affiliations.

Despite the provision of limited media sources many HLI were unaware that there were media sources, especially those that were available outside the city, on a state-wide basis. Additionally, participants expressed that limited access to bilingual media sources served as a significant barrier to obtaining pertinent health information regarding free health fairs, screenings and clinics. One English speaking participant stated:

I don't see much promotion about healthcare or anything for families that need help especially with bilingual access. I don't see much of that advertised. I really don't know how other immigrants who just come from other countries like Mexico get that outreach and help without going to the local agencies. Because other than that how would they know? The literature available to them here is all in English. So it becomes your responsibility to reach out and look for better access. It starts from Metro Louisville. They are in charge.

These limitations in access to Spanish media sources emphasized the need to promote diversity, language and cultural competence throughout the city, both in private and public sectors. Participants identified the lack of language and cultural competence of healthcare providers and feelings of being treated inhumanely as significant availability and acceptability barriers to healthcare access. Several health and social service providers acknowledged the challenges in providing language and culturally competent care. A director of an organization that provided community and social services in south Louisville stated:

We had a rough start with the Latino community as far as word of mouth and having culturally competent programs, staff and lack of training of staff on Latino issues and how to approach and serve the Latino community. As far as immigrants are concerned we need to do all we can to help them. You have to meet people halfway. Since then we have tried to provide programs geared towards the Latino community which makes up almost 45% of the population accessing our services.

Providing culturally competent services is especially important for HLI when accessing healthcare services, as non-verbal cues were central to enhancing the patient-provider relationship within this culture.

A healthcare provider and researcher advocated for providing culturally competent care for HLI in Louisville through her research findings:

Access to care was a big issue especially with healthcare providers not being personable and friendly. In my research the women talked about a face or "personalismo", which means a face that is personable and friendly. The healthcare providers try to be professional and this doesn't read well in the cultural translation to Latinas, because they are looking for a friendly face, a smile, recognition. We also found there were long waiting times to be seen at the public health clinics and at the WIC centers. The women couldn't wait that long and it was discouraging for them to access services.

This statement is indicative of the confounding effects of time and availability, healthcare personnel, and healthcare business barriers on the need to promote linguistic and culturally competent healthcare services.

Several sources of data indicated that the lack of competent care is often directly linked to the lack of workforce diversity, or the limited representation of health and social service providers who are HLI. Limited representation of minorities in the professional workforce and leadership positions stems from historical factors (as discussed under historical contexts). The director of diversity and inclusion at a local healthcare facility stated:

Although I'm not directly involved in recruitment of diverse workforce, I try to influence Human Resources by emphasizing the need for and importance of having a diverse workforce of healthcare professionals. My goal is to develop and maintain the community involvement and collaboration through a council of leaders, but it's almost impossible to find and recruit leaders from minority backgrounds. There is a significantly lower percentage of minorities in leadership positions, especially in Louisville. Hospitals in Louisville are also struggling to embrace the importance of diversity and having a diverse workforce.

A diverse workforce was identified as an essential component in promoting culturally competent health services for a diverse patient-base which continues to grow exponentially in Louisville. Limitations in outreach and advocacy for HLI were also associated with the lack of collaboration and involvement of community organizations and members. The idea of healthcare as being more of a business than an essential human service was a significant acceptability barrier to healthcare access. Findings from interviews with several community advocates and hospital administrative staff indicated that healthcare facilities and providers often worked in competition with one-another, as opposed to working in collaboration. One provider indicated:

It's hard to communicate and collaborate with other hospitals and clinics because of this sense of competition. You won't believe it, but one hospital did not want to share their model for their cultural competency or language services program, because they wanted to preserve their Spanish-speaking clientele. It comes down to the money in the end.

Another social service provider and local community advocate emphasized the lack of community collaboration, introducing the lack of cohesiveness within Hispanic groups as an additional barrier to providing comprehensive outreach and advocacy programs:

Although there are many advocacy groups started by people who want to be active in the community, often times there is lack of communication and collaboration between these individuals to have a cohesive successful group. Also, Cubans and Mexicans won't come together in these groups. There is separation and distinction among the different nationalities as well. So although some say the Hispanic community in Louisville does come together, and is united and supportive, there is still some level of competition or not getting along.

Facilitators to healthcare access. Significant *Outreach and advocacy* factors contributing to facilitators to healthcare access within sociocultural contexts included *Community and Social Services* and

Church Support. Findings indicated numerous governmental and non-governmental community organizations and groups that advocated for equal rights for HLI and provided access to affordable health and social services. These services aim to promote diversity and cultural understanding within the Louisville community. The Office of Globalization, under the Louisville Metro Government was established to raise awareness and encourage growth of international communities through advocacy and outreach programs (City of Louisville, 2013a). The metro government also supports equity in health through its Center for Health Equity which provides innovative methods to addressing public health concerns, by addressing “the root causes of health disparities by supporting projects, policies and research working to change the correlation between health and longevity and socioeconomic status” (City of Louisville, 2013b).

Another government organization that was pivotal in advocating for HLI rights was the KYCHR. Through various programs and events the commission aims to increase communication and collaboration between immigrant groups and governmental bodies (KYCHR, 2008). The Kentucky Hispanic and Immigrant Networking Summit, which is held annually, helped meet the commission’s goal of advocating for immigrants:

The commission organized this unique event to foster mutual understanding and increase communication and collaboration between the federal, state and local governments with Kentucky’s foreign-born communities. Participants had the opportunity to network with Hispanic educators and entrepreneurs, directors of Kentucky Latino centers and refugee agencies, and members of the Hispanic media from across the commonwealth. (KYCHR, 2008, p.52)

Despite the efforts of local and state governments to oversee the promotion of diversity and health and wellness within the Louisville community, limited data were available to indicate the level of metro government involvement in providing direct community services in areas of health and healthcare access for HLI. Numerous sources of data, however, indicated that non-governmental organizations and churches took further initiatives to advocate for HLI and provide social services. These state and local organizations included the Kentucky Foundation for Health, the Center for Health Equity, Kentucky Coalition for Immigrant and Refugee Rights, Wesley House, Hispanic Latino Coalition (HLC), La Casita Center, St. Joseph, St. Rita and St. Bartholomew Catholic churches, the Hispanic Latino Business Coalition (HLBC), La Camara and the Americana Community Center. A member of the HLC, which played a vital role in promoting outreach and advocacy for HLI groups in Louisville stated:

The Hispanic Latino Coalition has two main purposes: advocacy and health. So we provide a free health fair and legal advocacy. Recently with the elections there has been a mental change in local politics and community groups are stepping up. There is a push to start the friendly city or compassionate city movement which promotes an attitude of being open to other communities. The HLC is working on supporting that.

Local organizations and churches took further measures to promote healthcare access for underserved, disadvantaged populations through free health fairs, screenings and clinics. These providers were often identified as the only source of healthcare for many HLI in the community. Study participants identified using the infectious disease clinic and the primary healthcare clinic as their primary sources of healthcare. However, the infectious disease clinic only provided services for eligible participants who were HIV positive and the primary healthcare clinic only provided services for participants who were employed at the horse racing industry. Apart from their respective clinics, the majority of participants did not access healthcare from other healthcare facilities. Other sources of data revealed that some HLI only received healthcare services when offered through local health fairs or screenings sponsored by social, religious and health organizations. Two annual health fairs and one screening event were identified in the community as integral, and at times the only source of healthcare for many HLI in Louisville. One screening event, which was provided by nursing students at St. Rita's church located in zip code 40219, was frequented by HLI and a relatively large number of undocumented immigrants. Students provided limited health screenings (blood pressure and blood glucose levels) and advocated for individuals to get appointments at local clinics, if they needed to be seen urgently. A healthcare provider and supervisor of the health fair stated:

We see mostly undocumented individuals who come to this health fair as their only source of healthcare every year and it is very discouraging for me because I can't do more to help them. They can't access services elsewhere, and the only free clinics are very, very far from them so transportation is an issue. The other areas that we need significant help in are dental and vision, which we as nurses cannot provide services for. We have put ads in newspapers, but no physician or school has come up to us from dental or vision asking if they can help in any way. I don't know why no one has stepped up but that is disappointing. Other issues in the HLI population include uncontrolled high blood pressure and sugar. When they come to us their numbers are through the roof and when we try to call in and get an appointment through the [public health centers], the [public health centers] won't take them because they're numbers are too high. They say, "Please send them to the emergency room." But these people cannot afford to go to the emergency room and don't have insurance, so they live with their conditions until it is too late. I'm talking about blood pressures in the 200s and blood sugars through the roof.

An annual health fair targeting HLI in Louisville held in collaboration with local organizations and hospitals also provided vital health screenings, education and information. This health fair provided screenings for cholesterol, blood glucose, HIV, pap smears and mammograms and bone density scans.

Exhibitors at the event included local health and social providers, government organizations, and insurance agencies among others. Findings revealed that roughly two-hundred and sixteen HLI attended the health fair represented by ninety Mexicans, sixty-five Cubans, sixteen Dominicans, ten Peruvians, ten Venezuelans, nine Guatemalans, eight Colombians, four Salvadorans, two Ecuadorians and two Hondurans (Hispanic Latino Coalition, 2012). Ninety-nine individuals received cholesterol and blood glucose screenings, thirty-one women received pap smears and thirty-three women received mammograms. Additionally, findings revealed that individuals who attended the health fair resided predominantly in zip codes 40214 (65 individuals), 40219 (53 individuals) and 40215 (14 individuals), corresponding to the community maps in Figure 16. One organizer of the fair stated:

The spatial analysis results of the health fair attendees showed that the northeast region of Louisville is growing in population with Hispanics. However, one area that is underrepresented with the low-income Hispanic population is in the south, in zip code 40209. South of the dumpsters there's a trailer community. Income levels were shown to be way below the average for this population. I know families that live down there.

Findings indicated that these free health fairs and screenings were the only source of healthcare for many HLI, who are unable to overcome the affordability and accessibility barriers to healthcare access. Another source of free healthcare in Louisville that was frequented by HLI was the Family Community Clinic, which also serves a large number of uninsured, low-income individuals. This clinic runs solely on a volunteer basis with doctors, nurse practitioners, nurses, interpreters, administrative staff and assistant staff. It is open two days a week on Saturday mornings and Tuesday evenings to accommodate to its client-base. While volunteering at the clinic as a triage nurse, the investigator gained a deeper perspective on the healthcare access needs of this particular population. On one Saturday morning, a total of 22 patients were seen at the clinic, with over 60% HLI clients out of which roughly 40% spoke only Spanish. Participant observation data indicated that the majority of individuals that accessed services at the clinic were HLI, many without health insurance or jobs to afford services at other clinics. Similar to the situations in health fairs and screenings, individuals who accessed the clinic as their primary source of healthcare sometimes arrived in critical conditions, with alarming levels of unmanaged hypertension and diabetes.

Access to free health fairs, screenings and clinics helped facilitate healthcare access for many HLI and promoted health-seeking behaviors. Continued outreach and advocacy through various organizations helped empower HLI to understand their rights, allowing them to take health and social circumstances into

their own control. These factors represented sociocultural contextual factors that enhanced healthcare access for HLI in Louisville.

Economic Contexts

Barriers and facilitators to healthcare access as perceived by HLI were further explicated through their contextualization within in an economic frame. Unlike categorizing themes under sociocultural contexts, the process of categorization under economic contexts was direct and concise. Categorization into central themes were guided by the WHO’s SDH Conceptual Framework (Figure 1), the CFAAHS (Figure 3) and the postcolonial theory. Tables 15 and 16 represent the economic contextual factors analyzed from participant interview data, and participant observations and document reviews respectively.

Table 15

Economic Contextual Factors from Participant Interviews

Themes from Interviews	Subthemes (References, Sources)*
Employment	Type of employment (20,9); Hardworking (19, 9); Taking jobs myth (3, 2)
Capitalism	Capitalism (4, 3)
Federal System	Eligibility for welfare and Medicaid benefits (7, 5); Immigrating from Cuba (4,3); Difficulty navigating federal system (2,1)

Note: *See Appendix C for NVivo Functions

Table 16

Economic Contextual Factors from Participant Observations and Document Reviews

Themes from Document Reviews and Participant Observations	Subthemes (References, Sources)*
Employment	Low-wage service job (13, 8); Type of employment (12, 11); Horse racing industry (12, 7); Agricultural Industry (4, 2)
Education	Education impacts employment and income (12, 3); Immigration influences education (4, 1)
Healthcare Business	Healthcare Business (9, 6); Advertisements for Insurance (10, 9); Emergency Room (2, 2); Lack of promoting preventive health (1, 1)
Federal System	Government funding and support (8, 7)

Note: *See Appendix C for NVivo Functions

Based on these results, the major themes that were concurrent in all three sources of data were identified. Factors that shaped the economic contexts that influenced availability, accessibility, affordability and acceptability barriers and facilitators to healthcare access were categorized under the themes of *Healthcare Business, Education, Employment and Federal Systems*. Table 17 displays the central

economic contextual themes and their relationship to specific barriers and facilitators to healthcare access as identified by participants. The association between barriers, facilitators and relevant economic contexts were further discussed to provide a contextual understanding of healthcare access for HLI in Louisville.

Healthcare Business

Barriers to healthcare access. The theme of *Healthcare Business* helped shape the economic contexts of barriers to healthcare access. The idea of healthcare being a business rather than a human service was identified by participants as an acceptability barrier to healthcare access. However, understanding of participant experiences of limited time and contact with doctors, limited availability of appointments, feelings of being treated like a number or inhumanely are enhanced within the healthcare business idea, which was critical in shaping the economic contexts of healthcare access. One participant summarized the perspectives that were shared by many participants on the healthcare business concept:

It all comes down to money...The reason why doctors are so impersonal is because they want to make the most money they can in one day. They want to have a really big turnover. They want to give you only ten minutes. While the doctor is talking to you the nurse practitioner is taking care of all the patients. So in a day if you just count ten minutes for an hour it's a lot of money...

Findings indicated that when comparing U.S. healthcare systems to other systems globally, there is strong evidence for the distinct economic power that the healthcare industry asserts on the U.S. economy. As a necessary and vital service, healthcare has and will continue to be in high demand, making it one of the most coveted goods in the U.S. consumer market. It is important to note, however, that this level of power is unique to the economic structures of the U.S. as developed countries across the globe view healthcare as a human service rather than a business or an economic fact. In making a distinction between healthcare systems in Europe and the U.S. one Peruvian immigrant stated:

I'm not trying to criticize, but I want to point out that in other countries like Europe there is more sensitivity from the government, or government involvement, a more social approach. For example, in Spain, it doesn't matter where you're from even if you are from another country and you need to go to the hospital, it's ok, you don't have to pay a bill. I know friends had a bill from the hospital and they said they didn't worry because it's paid by the state. There is some kind of different approach to healthcare between the U.S. and Europe.

Spain, like the United Kingdom and other European nations functions on a free, universal healthcare system. Some form of universal healthcare systems, either fully or partially subsidized by the government were adopted by many countries surround the U.S., including Canada and Latin American countries such as

Table 17

Understanding Barriers and Facilitators to Healthcare Access within Economic Contexts

Access Dimensions	Themes and Subthemes		Economic Contexts
Availability	Barriers	<p>Time and Availability (Limited time and contact with doctor; limited availability of appointments; long waiting times; Treated like a number; Limited clinic operating hours)</p> <p>Patient-Provider Communication Lack of communication; Lost in Translation; Language Barrier-LEP of Participant</p>	<p>Healthcare Business (Emergency room; lack of promoting preventive health)</p> <p>Education (Immigration influences education)</p>
	Facilitators	<p>Resources (Medications; Health fairs and screenings)</p>	<p>Federal system (Government funding and support)</p>
Accessibility	Barriers	<p>Documentation (Lack of Health Insurance; Lack of legal immigration documents)</p>	<p>Employment (Type of employment, low-wage jobs service jobs, agricultural industry)</p> <p>Education (Immigration influences education; education impacts employment and income)</p> <p>Federal system (Eligibility for Welfare and Medicaid benefits; Immigrating from Cuba)</p>
		<p>Emergency Room (Negative Emergency room experiences)</p>	<p>Healthcare Business (Emergency Room; Lack of promoting preventive health)</p>
	Facilitators	<p>HIV (HIV facilitates access; Infectious disease clinic)</p>	<p>Federal system (Government funding and support)</p>
		<p>Type of Healthcare Facility (Public health clinic; Primary healthcare clinic)</p>	<p>Employment (Horse racing industry)</p> <p>Federal system (Government funding and support; Welfare and Medicaid benefits)</p>
	<p>Documentation (Legal immigration paperwork)</p> <p>Quality of Care (Better quality of care; Better access to</p>	<p>Employment (Horse racing industry)</p> <p>Federal system (Government funding and support;</p>	

		healthier options)	
Affordability	Barriers	Financial Barriers (Expensive healthcare costs; No health insurance coverage; Limited income or financial resources; Dependents)	Healthcare Business Employment (Type of employment; low-wage service jobs) Education (Immigration influences education; education impacts employment and income) Federal System (Eligibility for welfare and Medicaid benefits; Immigrating from Cuba)
		Knowledge and Awareness (Unaware of affordable options)	Federal System (Difficulty navigating federal system)
	Facilitators	Government Resources (Government funded financial resources; Welfare benefits)	Federal System (Government funding and support; Immigrating from Cuba)
		Resources (General resources; Free Socialized Healthcare)	Federal System (Government funding and support)
Acceptability	Barriers	Financial Assistance (Health insurance; Medical assistance and billing help)	Employment (Type of employment; Horse racing industry)
		Health-seeking behaviors (Delaying accessing care; Prioritization)	Employment (Type of employment; low-wage service job)
	Facilitators	Healthcare business (Patient vs. Customer; No desire to help from healthcare provider; Inhumane treatment)	Healthcare Business
		Knowledge and Awareness (Health-seeking behaviors; Medication and treatment compliance)	Federal System (Government funding and support)

Cuba and Mexico. In this study, participants who were accustomed to universal healthcare systems found it increasingly difficult to adapt to the privatized healthcare system in the U.S. One participant from Cuba stated:

In my country I was a patient, as far as health goes. But then I came to the U.S. and now I'm a customer. A sick person is a face here. I don't know how to explain it. Because you pay them, they see you and they listen to you. Health is a human necessity, a human need, but here healthcare is a business.

In universal healthcare systems where government subsidies help promote access to healthcare services, individuals have options to access health services when needed, without the fear of being unable to afford medical expenses. The U.S. does not have a universal healthcare system, but has been taking measures to improve equitable access to care by providing access to health insurance through the PPACA (Pub. Law No. 111-148, 2010), which will take full effect in 2014. Over the years, health insurance has started to become one of the most highly-coveted goods in the U.S. market, especially as companies prepare for the new changes with the PPACA. This was made evident in the research findings by the large number of advertisements on television and radio stations, and Spanish publications regarding insurance companies. Insurance were also targeting the Spanish-speaking population by using insurance agents who were HLI. However, even with federally mandated health insurance coverage the healthcare business perspective will continue to exist and serve as a barrier to healthcare access, especially for those undocumented HLI who will be ineligible to participate in this new program. (Further discussion of healthcare reform policy can be found under political contexts.)

Education

Barriers to healthcare access. Educational factors that shape the economic contexts of barriers to healthcare access are discussed before employment factors because the lack of education was shown to have direct effects on the type of employment, level of income and consequently the ability to afford healthcare for many HLI in Louisville. As a result of this association, the theme of *Education* played a central role in defining the economic contexts that shaped barriers to healthcare access. These barriers are represented under the subthemes *Immigration influences education* and *Education impacts employment and income*. Findings indicated that lack of education and lower levels of educational attainment were significant problems in the HLI population on local, state and national levels. Compared to the rest of the nation, Kentucky's Latino population was found to be half as likely to obtain a minimum of a two-year

college degree (U.S. Census Bureau, 2010). Ben Ruiz, an immigrant from Mexico and local community advocate who supported grassroots efforts aimed at promoting the education of Hispanic Latino students in local school systems stated:

Fifty-six percent of Kentucky's Latino population is represented in the two largest cities in the state, along with their surrounding counties. Currently, only 19 percent of those individuals in Kentucky have an associate's degree or higher. (Ruiz, 2012)

Survey data indicated that forty-five percent of the participants in this study (n=9) had less than a high school diploma and only two participants had an associates or bachelor's degree. Out of those participants that had less than a high school diploma, three participants reported they did not speak any English and seven participants said they spoke a little English. Data indicated that the reasons for lower rates of education among HLI were multifaceted, resulting from unique issues such as language, cultural and financial barriers, and immigration status. An excerpt from a recent article *Kentucky Latino Population Lagging in College Degrees*, expressed the views of several HLI:

Many students believe that universities will reject their application because they are undocumented, Montano-Smith said, explaining that in her experience even if the student is accepted, they are limited in their scholarship options and cannot apply for federal financial aid. "I think a lot of (my friends) kind of lost hope during high school when they learned of their illegal status," said Baca, who is also a team leader representing the Kentucky Dream Coalition for Kentucky Latino Education Alliance. Of her friends who entered college, Baca said many found it too difficult to work long hours while balancing school, leading many of them to drop out (Miraval, 2012, p.2)

This statement indicates the strong relationship between levels of education, employment and immigration status. Pursuing an education is often not an option for many HLI who often have to work multiple jobs to take care of themselves and their families. Limited education, which also impacts English proficiency levels, further restricts employment options for HLI, who predominantly work in low-wage, service, construction and horse racing industry jobs in Louisville. Inadequate levels of income made it impossible for HLI to access healthcare services or health insurance coverage, resulting in delayed health-seeking behaviors and lack of preventive healthcare practices leading to worsening health conditions. Limited education and English levels also influenced patient-provider communication, which served as an availability barrier to healthcare access. Furthermore, findings indicated that HLI were restricted from accessing education as a result of their undocumented status, despite the acceptance of undocumented immigrants into state colleges and the passing of the Development, Relief, and Education for Alien Minors Act in 2012 (DREAM Act; SB 1291, 2001). Before the passing of the Dream Act one news source stated:

The Dream Act could change the futures of about 65, 000 kids yearly who graduate from high school- many of them standout students in the top 10 percent of their class and eager to go to college. The only problem? They're here illegally. Even if they receive an acceptance letter from the college of their choice, chances are, many will never attend. For one, many can't afford the tuition and don't qualify for the most private scholarships or state and federal grants and loans. Never mind that they also can't work legally to pay their way through college. (The Dallas Morning News, 2006)

Therefore, it is evident that undocumented immigrants faced numerous barriers in attaining education, which consequently limited their ability to obtain high-paying jobs and opportunities to advance their careers. The same was true for legal HLI in Louisville, whose socioeconomic status was impacted by their lack of education. This was illustrated in Figures 17 to 21, where southern regions with high concentrations of HLI also had lower educational, income and English proficiency levels, along with high rates of poverty. The combination of these various factors further influenced the barriers to healthcare access.

Employment

Barriers to healthcare access. Employment factors that shaped the economic contexts of barriers to healthcare access included *Type of Employment, Low-wage service jobs, Taking jobs myth, and Hardworking*. Findings indicated that the type of employment affected levels of income, insurance coverage, ability to afford healthcare expenses and overall access to healthcare services for HLI in Louisville. Accordingly to the National Council of La Raza (NCLR, 2013), “Hispanics are disproportionately employed in service and support occupations. More than one in four (26%) work in service occupations; 21% in sales and office jobs; 16% in natural resources, construction, and maintenance jobs; and 17% in production, transportation, and material-moving occupations.” Study findings indicated that many HLI in Louisville worked predominantly in service industries; however a large population represented migrant workers in agricultural and horse racing industries. Historical data identified that some of the first Hispanics and Latinos to arrive in Kentucky came as migrant workers, especially during the flourishing years of the agricultural industry. The *Profile of Foreign-born in Louisville* report stated:

The labor-driven migration wave to the Southeast was composed largely of Latin American immigrants, who found jobs mostly in lower-skilled, low-wage sectors of the economy such as manufacturing, agriculture and construction. These jobs matched the relatively low levels of English proficiency and educational attainment among recent Latin American immigrants, many of whom are undocumented. (Capps or Urban institute, 2006, p. 13)

Data indicated that although limited populations of agricultural migrant workers resided in Louisville due to its urban setting, these populations continue to exist in rural areas of Kentucky. However, it was indicated that the thoroughbred horse racing industry, with over five-hundred thoroughbred farms across Kentucky were composed of over 75% of immigrant employees (Legislative Research Commission, 2002). Louisville, being the home of the Kentucky Derby and one of the leading thoroughbred race tracks in the nation, is also home to many migrant workers of the horse racing industry. In this study, fourteen participants (70%) worked in the service industry such as cleaning, janitorial and customer service jobs. The majority of these participants had salaries ranging from roughly \$125 to \$374 per week and had over four dependents to take care of, putting them well below the poverty line. Four participants (20%) worked at the horse racing industry as groomers or hot walkers, and two participants were unemployed. Out of those that worked in service industries, only six participants received health insurance coverage from their employers and nine participants didn't have any source of health insurance. These results indicated that those who were working in low-wage service jobs received minimal income and health insurance coverage. This quote from a government employee revealed that this trend was also reflective of the HLI population in Louisville:

The majority of Hispanics in Louisville work in hospitality and food industries. These areas do not employ them full time and therefore don't provide any health benefits or health insurance. There are also those who work on farms who don't have these services and have difficulties with accessing healthcare. For example, Wal-Mart and Cracker Barrel will employ many individuals and keep them part-time so that they don't have to give them health benefits. They are cheating the system and the employees.

Focusing more on their businesses than the wellbeing of their employees, employers have developed ways to save costs by providing minimum number of work hours that do not require the provision of employee health insurance coverage. Lack of health insurance was identified as a significant affordability barrier to healthcare access. Data analysis also indicated that HLI were among the lowest earning minority groups in the state of Kentucky. The *Status of Minorities and Women in State Government Report* (KYCHR, 2007) indicated that:

Among racial/ethnic groups, the average White salary is the highest in each of the ten cabinets. The average White salary in the ten cabinets averages out to be 0.42% higher than employees who identify themselves as "Other;" 10.83% higher than the average salary of African American employees; 11.67% higher than Asian American employees; 15.96% higher than American Indian employees; and 16.86% higher than Hispanic employees. (p.39)

Reasons for these varying differences in earnings were attributed to lower levels of educational attainment and English proficiency, undocumented immigration status and sociocultural factors of racism and discrimination. It was also found that HLI were often willing to take low-skilled, low-wage jobs because of these barriers, but also because of their hard-working cultural ethics. The hard-working ethic of HLI has led to the debate about immigrants taking American jobs. However, many sources indicated that U.S. citizens were sometimes unwilling to work in low-wage positions, without benefits and sometimes in the harsh work conditions. An article in the local newspaper quoted the Executive Director of the Kentucky Thoroughbred Association, David Switzer:

All of us are in a position of needing employees. We don't want to hire illegals...A significant number of foreign born are working in our industry... At some of our farms, they have not had a Caucasian or African American apply for a job in eight years. Nobody applies. What are we supposed to do? (Downs, 2011, p.1)

Immigrants are often more willing to work in these types of jobs and working conditions because many of them come to the U.S. with hopes of providing economic support for their families in their home countries. Many immigrants who cross the border illegally leave behind spouses, children and parents, hoping to find some form of income and working hard to take care of their families. One of the study participants stated:

I understand that maybe they don't want us here. But when you sit down in a restaurant and you see those beautiful fajitas with those peppers and onions. Who do you think picks up those peppers and onions. It's people like us. They work hard and make so little. So maybe you don't want us here but you need us. So don't underestimate the impact we make in this country. We take the jobs that you don't want. If you really want that job, make an application and go for it. I bet you if it was an American, they won't last an hour picking up peppers. They would quit. So if you enjoy the contribution that we bring to this country at least gives us the opportunities to be equal. But they see us as Latino and say we are not supposed to be here, and what are you doing in this job and it mounts into a bigger thing and they say it is racism. But if you look back you are taking us for granted.

This participant made poignant remarks on the type of employment and economic conditions that HLI are willing to endure, emphasizing the need for equal treatment and employment opportunities. Historical contextual factors indicated that the struggle for equality in education and employment continues to plague minority groups, especially HLI, who remain at the bottom of the socioeconomic ladder in Kentucky. Factors related to education and employment played a significant role in shaping the economic contexts of barriers to healthcare access.

Facilitators to healthcare access. Employment factors that shaped the economic contexts of facilitators to healthcare access included *Type of Employment* and *Horse racing industry*. As indicated

earlier, the horse racing industry in Louisville employs a large number of HLI. In 2002, it was reported that an estimated 80 to 90% of workers at the Kentucky Thoroughbred Association (which includes thoroughbred horse farms and horse racing industries) were immigrants, the majority of whom were Hispanic men (Legislative Research Commission, 2002). Four participants in this study, who were all female, worked in this industry as groomers and/or hot walkers, earning an estimated minimum of \$125 per week to a maximum of \$375 per week. Although, it is not one of the highest paying jobs in the labor industry, working in the horse racing business provided several benefits for HLI, including legal immigration documents through work visas and access to health and social services. The Backside Learning Center was established to “serve and actively participate in the civic, economic and education opportunities of the backside workers at Churchill Downs” (Backside Learning Center, 2013). The center aimed to promote a better quality of life through various social programs for their employees, the majority of whom were Spanish-speaking HLI.

In addition, employees had access to healthcare services through the Kentucky Racing Health Services Center funded by the Kentucky Racing Health & Welfare Fund, which provides primary healthcare services for workers of the horse racing industry. Participants who accessed services at this primary healthcare clinic stated that healthcare services were more accessible and affordable and that interpreters or bilingual staff were always available to assist in making the healthcare encounter a fluid process. The horse racing industry also organized an annual health fair for its employees, which has been established for fifteen years in collaboration with local health and social organizations. The health fair provided essential preventive services including mammograms, vision exams, HIV testing, flu vaccines and dental services (Al Día en América, 2012). The race track also provided health insurance for some of its employees based on the number of working hours (i.e. being part-time or full-time). One female employee from El Salvador stated:

There's a big difference between U.S. and El Salvador. The hospitals in the US offer me much better medical access and treatment. I've had a lot of sicknesses. I go to hospitals for help in the U.S. Through the help of Churchill downs health insurance, where I work, I have access to healthcare. They've covered all of my operations. And all the different types of problems of issues I've had are covered by Churchill downs insurance...and that is very important for me, because if not I would have to pay for health insurance and until now I have not had to pay in other places. The insurance from the racetrack has helped me out a whole lot.

Identified as significant facilitators to healthcare, the primary healthcare clinic, health fair and health insurance coverage were only accessible for employees of the horse racing industry. It must be noted that many race track workers are not employed on a full-time basis throughout the year, because of the seasonal changes in horse racing. Findings indicated that the majority of workers were employed for an estimated minimum of five months, with three months during the Kentucky Derby season (April to June) and two months in the fall season (September and October). During these intervals, workers are forced to find alternative forms of employment to maintain an income. Also during these intervals, workers are not able to access health services at the primary healthcare clinic because they are not employed at the race track industry. It is important to recognize that not all race track workers are provided health insurance coverage, which is also dependent on employment periods. Despite these limitations, the primary healthcare clinic and the health fair were a vital source of healthcare for many employees, who couldn't access services elsewhere due to lack of health insurance coverage and income.

Federal System

Facilitators to healthcare access. Government funding and support also helped shape the economic contexts of facilitators to healthcare access, by providing funding for programs affiliated with immigrants and welfare benefits for those immigrants who were eligible to receive them. Although not all HLI were eligible to access federal funds and services, it was found that for those who were eligible, government funding and support served as significant affordability, accessibility and acceptability facilitators to healthcare access. (Eligibility issues that serve as barriers for accessing government funds and services are further discussed in light of welfare policies under political contexts). The Cabinet for Health and Family Services (CHFS) is the main governmental body that oversees the state of human services and healthcare programs. Findings from an interview with a CHFS social service provider indicated that Medicaid, identified as Passport in Louisville, and the Kentucky Temporary Assistance Program (KTAP) were services that were most frequently accessed by HLI in Louisville. Some of the benefits provided under Medicaid included access to Passport health insurance plans and monthly food stamps based on the number of children per household. Services provided through KTAP included access to a medical card, food stamps, job training, ESL lessons, day care and other programs. These services were predominantly

accessed by HLI whose eligibility was based on need and immigration status. One Spanish-speaking employee of the CHFS, who predominantly provided services to the HLI population stated:

First a distinction should be made between Cubans and pretty much anyone from any other Latin country. There are two main Latin groups represented in Louisville- Mexicans and Guatemalans (with traces of Argentinians, Peruvians, Hondurans) and Cubans. Cubans do not mix with other Latins, are highly educated and come from fairly low levels of crime in Cuba. These Cubans who leave Cuba and come to the U.S. are known as "Gusanos", which literally translates in English as a worm or maggot. Ironically, these Cubans are mostly republican, but are also the highest users of federal services for immigrants that are not supported by the Republican Party. Cubans are 90% automatically eligible for federal services. The U.S. makes it very easy for Cubans to come here. Cubans do not even need a criminal background check.

Political policies and foreign relations are major factors in determining the level of federal support received by Cubans and Puerto Ricans, who are provided various immigration, social and health benefits from the U.S. government. All five Cuban and two Puerto Rican participants in this study were residents or citizens of the U.S., making them eligible to receive federal funds and access federally funded programs. However, only one participant from Cuba, who was a U.S. resident, accessed Medicaid services. In addition, several participants from Mexico, Guatemala, and Ecuador reported that their U.S. born children received Passport (Medicaid) and other federal funding because of their citizenship eligibility. Interestingly, several sources indicated that HLI who were ineligible for these programs as a result of their undocumented immigration status, were able to obtain fake social security cards and green cards for less than \$200 in the black market. One federal social service provider stated:

Many undocumented immigrants access our services using fake social security numbers and they get away with it because the federal system has no way of tracking this information. Also, legally, federal agencies cannot ask for legal documentation to determine eligibility. They can ask for the social security number once and that's it. If the individual cannot provide one, we are not allowed to keep questioning them and we have to continue providing services.

Government funding also supported the KHCCP and KADAP, which provides medical assistance to individuals with HIV regardless of their immigration status (Kentucky Cabinet for Health and Family Services, 2012). Findings indicated that government funding and support facilitated healthcare access for HLI who were HIV positive, and who could show proof of their U.S. residency or citizenship either with real or fake forms of identification. Despite loopholes in the federal system, government funded programs had some influence in facilitated healthcare access for HLI by helping them overcome affordability and accessibility barriers.

Political Contexts

Barriers and facilitators to healthcare access as perceived by HLI were further explicated through their contextualization within in a political frame. The process of categorizing themes under political contexts focused predominantly on policies that were pertinent to understanding the experiences of HLI. Categorization into central themes were guided by the WHO’s SDH Conceptual Framework (Figure 1), the CFAAHS (Figure 3) and the postcolonial theory. Tables 18 and 19 represent the political contextual factors analyzed from participant interview data, and participant observations and document reviews respectively.

Table 18

Political Contextual Factors from Participant Interviews

Themes from Interviews	Subthemes (References, Sources)*
Immigration Issues	Undocumented (9, 7)
Language Policies	Not upholding Title VI (4, 4)
Politics and Governance	Government resources (19, 7); Need for Government reform (6, 3); Conservative Politics (3, 3)
Health policies	Healthcare reform (3, 3)
Advocacy and Outreach	Lack of Advocacy for HLI (4, 4)

Note: *See Appendix C for NVivo Functions

Table 19

Political Contextual Factors from Participant Observations and Document Reviews

Themes from Document Reviews and Participant Observations	Subthemes (References, Sources)
Immigration	Undocumented (18, 12)
Politics and Governance	Governance (20, 12); Power and Control (4, 2)
Policies	Immigration policies (72, 20); Health policies (37, 14); Social and Economic policies (7, 3); Welfare policies (10, 8)
Advocacy and Outreach	Advocacy and Outreach (45, 27); Empowerment (11, 9); Immigration legal services (46, 10); Education empowerment (20, 14); Civil rights advocacy (17, 14)

Note: *See Appendix C for NVivo Functions

Based on these results, the major themes that were concurrent in all three major sources of data were identified. Factors that shaped the political contexts influencing availability, accessibility, affordability and acceptability barriers and facilitators to healthcare access were categorized under the themes of *Immigration, Politics and Governance, Policies* and *Advocacy and Outreach*. Table 20 displays

the central political contextual themes and their relationship to specific barriers and facilitators to healthcare access as identified by participants. The association between barriers, facilitators and relevant political contexts are further discussed to provide a contextual understanding of healthcare access for HLI in Louisville.

Immigration

Barriers to healthcare access. The plight of undocumented immigrants was and continues to be a major topic of policy debate across the nation, especially in relation to equal rights in accessing education, employment, and health and social services. The debate over undocumented immigrants was a significant factor that shaped the political contexts of barriers to healthcare access. The importance of immigration status among HLI on understanding barriers and facilitators to healthcare access is highlighted through its underlying presence in discussions of historical, sociocultural, economic and political contexts throughout the course of this study. Data indicated that a common misconception about undocumented immigrants was that they were burdening the health and social infrastructure of the U.S. economy.

With the recent economic downturn, further steps have been taken to reduce healthcare expenditures, while continuing to provide adequate coverage for U.S. citizens and legal immigrants. However, undocumented immigrants have been restricted from obtaining these services due to the common misconception that they incur higher healthcare costs than non-immigrants. Recent studies have attempted to dispel these beliefs, indicating that undocumented immigrant may not be contributing to the increase in healthcare costs in the U.S. and that addressing healthcare needs of this population could in fact reduce costs (Mohanty, Woolander, Himmelstein, et al., 2005; Stimpson, Wilson & Eschbach, 2010). Research findings from this study also dispelled these common misconceptions, indicating that undocumented immigrants were more advantageous to the U.S. economy, especially in states like Kentucky.

According to data obtained from the Immigration Policy Center (2011), undocumented immigrants and their families make significant contributions to Kentucky's economy. In 2010, it was reported that undocumented immigrants in Kentucky paid \$85.1 million in state and local taxes (Immigration Policy Center, 2011). In addition, it was reported that the removal of all undocumented immigrants from Kentucky would cost the state \$1.7 billion in economic activity and \$756.8 million in

Table 20

Understanding Barriers and Facilitators to Healthcare Access within Political Contexts

Access Dimension	Themes	Political Context
Availability	Barriers Healthcare Personnel (Interpreter availability and training; Lack of cultural competence; Lack of Bilingual Healthcare Personnel)	Language policies (Not upholding Title VI)
	Patient-Provider Communication (Lack of communication; Lost in Translation; Language Barrier-LEP of Participant)	Language policies (Not upholding Title VI)
	Facilitators Healthcare Personnel (Interpreters; Bilingual healthcare personnel; Nurses; Medical case manager)	Advocacy and Outreach (Advocacy and Outreach; Empowerment)
	Patient-Provider Communication (Familiarity and Trust; Cultural Identification; Ability to speak English)	Advocacy and Outreach (Education empowerment)
Accessibility	Resources (Medications; Health fairs and screenings)	Advocacy and Outreach (Advocacy and Outreach)
	Barriers Documentation (Lack of Health Insurance; Lack of legal immigration documents)	Policies (Immigration policies; Welfare policies; Health policies) Immigration (Undocumented)
	Emergency Room (Negative Emergency room experiences)	Governance (Conservative Politics; Power and control) Language policies (Not upholding Title VI)
	Type of Healthcare Facility (Public health clinics; Specialty Health Services)	Policies (Welfare policies)
	Facilitators HIV (HIV facilitates access; Infectious disease clinic) Type of Healthcare Facility (Emergency room; Public health clinic; primary healthcare clinic)	Policies (Welfare policies)
	Documentation (Legal immigration paperwork)	Governance and Politics (Government resources)

			Immigration (Undocumented)
		Quality of Care (Better quality of care; Better access to healthier options)	Advocacy and Outreach (Immigration legal services) Policies (health policies)
Affordability	Barriers	Financial Barriers (Expensive healthcare costs; No health insurance coverage; Limited income or financial resources)	Policies (Health policies; Welfare policies)
		Resources (Lack of Government support or intervention)	Politics and Governance (Government resources; Need for government reform; Conservative Politics; Power and Control)
	Facilitators	Government Resources (Government funded financial resources; Welfare benefits)	Policies (Welfare policies) Politics and Governance (Governance)
		Resources (General resources; Free Socialized Healthcare)	Advocacy and Outreach (Empowerment) Health policies (Healthcare reform)
		Financial Assistance (Health insurance; Medical assistance and billing help; Financial planning)	Policies (Health policies; Welfare policies)
Acceptability	Barriers	Discrimination (Discrimination based on race and ethnicity; Discrimination based on language)	Language policies (Not upholding Title VI)
		Health-seeking behaviors (Delaying accessing care; Prioritization; lack of awareness or education; lack of prevention)	Immigration (Undocumented)
		Mental health (Emotional distress discourages access; Discrimination causes discomfort)	Immigration (Undocumented) Policies (Immigration policies)
		Healthcare business (Patient vs. Customer ; No desire to help from healthcare provider ; Inhumane treatment; Lack of social support)	Policies (Health policies; Welfare policies) Immigration (Undocumented)

Facilitators **Social Circumstances** (Family and Social Support;
Understanding or accepting of discrimination)

Advocacy and Outreach (Civil rights; Immigration legal services)

gross state product (Perryman Group, 2008). These data indicated the high level of economic contributions that undocumented immigrants make to the state of Kentucky. Despite these facts, undocumented immigrants continue to be viewed in a negative light in social, economic and political arenas, resulting in discrimination and unequal treatment.

Findings indicated that being undocumented made it increasingly difficult for HLI to be participating and active members in the Louisville community, as many individuals lived in fear of being identified as undocumented, being detained by police and immigration enforcement and eventually deported to their countries. A study participant from Mexico stated:

There's a lot of fear regarding immigration because you left your country and you don't have anything there now. So we came to the U.S. and we are better here. If they make us go back at my age there is no work in Mexico. Being separated from the family is harder. I have to be here with my other sons. Thinking about immigration makes it scary. Every day we think, maybe today they will take us or tomorrow they will take us.

Social and economic conditions of HLI were further impacted as a result of immigration policies, which are discussed in detail under the theme of *Policies*. Fears of deportation were heightened with new policies that established law enforcement as a mechanism of immigration reform. A local member and advocate for HLI stated:

I think they're trying to create a political environment where anything but enforcement is unacceptable. They want an enforcement scheme, arrest everybody and take them out of the country as soon as possible. Instead of looking at the problem in a more comprehensive way and asking, what are the main problems with the immigration system and trying to solve them in a more rational manner?

The political climate and the focus on undocumented immigrants were based on stereotyping rhetoric that portrayed immigrants in a negative light as intruders and criminals. However, it was found that the majority of undocumented immigrants come to the U.S., not to take advantage of the system, but to improve their economic situations and provide financial support for their families, who they most often leave behind in their countries. Therefore, it was evident that there was a lack of awareness or advocacy on behalf of undocumented immigrants, especially because it continues to be a controversial topic of political debate. The fear of being undocumented was a common and recurrent theme throughout the study findings. These findings supported the need to repeal legislations that restrict HLI access to healthcare and promote policies that improve access to health services.

Politics and Governance

Barriers to healthcare access. *Politics and Governance* were other central issues in shaping the political contexts of barriers to healthcare access, especially in Kentucky, which was identified as a predominantly Republican state for over fifty years. As such, some of the subthemes that emerged from the data included *Conservative Politics, Power and Control, and Need for Government Reform*. National, state and local level politics and politicians greatly contributed to shaping political contexts. The latest presidential elections shed light on the perspectives of political leaders on immigration and the rights of HLI in the U.S. The presidential elections of 2012 indicated the presence and level of influence that HLI voters had on the political atmosphere. According to the Pew Hispanic Center (2012), 24% of Hispanic eligible voters in Kentucky were naturalized U.S. citizens. An article in the local Spanish publication, *Al Día en América* depicted the influence of the Hispanic Latino vote on the presidential elections:

Jim Messina, the head of the Obama campaign, classified Romney as the most extreme presidential candidate in the history of immigration. This idea is important for these elections, since the highest number of Latinos in history will be voting in this election. The loss of the Hispanic vote is a huge error for the Romney campaign. The Romney campaign recognizes that there are problems with communication with Latino voters. In the latest study done by the group Latino decisions, Obama is ahead of Romney 73% to 21%. The Latino vote is especially in these elections due to the large Hispanic population. (Al Día en América, 2012, p. 32)

President Obama took several efforts during his campaign to meet with Hispanic Latino leaders and community members, and advocated for laws and policy reform in favor of the HLI community. These liberal political views aided in influencing the Hispanic Latino vote. Contrarily, conservative immigration political views of Senator Romney did not reflect the concerns of HLI communities. Conservative political views that hindered immigration policies and equal rights for immigrants were significant factors in influencing the Hispanic Latino vote. Similarly, conservative political views of state level leaders were also shown to influence the political climate for HLI in Louisville. Senator Mitch McConnell, U.S. Republican Leader and Senator for Kentucky, strongly stands behind his conservative political views especially in regards to economic growth and healthcare reform (McConnell, 2013). Despite his stoic conservative views on healthcare reform, McConnell has relatively moderate views on immigration reform. Contrary to McConnell's views, Senator Rand Paul of Kentucky holds strong and often controversial views on immigration and healthcare. Senator Paul does not support amnesty and promotes fortified border

enforcement as a form of immigration reform (Paul, 2013). On access to health insurance for undocumented immigrants Paul stated:

We had 45 million people nationwide that were not receiving or didn't have health insurance. A third of them were in the country illegally and were illegal aliens. And I don't think we should be giving illegal aliens health insurance. (Fox News Sundays, 2010)

Unlike the conservative political climate of the state, the local government in Louisville is in a position to embrace liberal views toward immigration, because of its growing diverse population. Local level political leaders in Louisville have started to embrace the diverse contributions of immigrants as evidenced by the Mayor Greg Fischer's push towards creating a collaborative community in Louisville that promotes cultural diversity and equality. This was also seen through the metro government's establishment of the Office of Globalization and other programs to boost economic conditions and quality of life of immigrants and the overall Louisville community. One community member and advocate for HLI said:

Recently with the elections there has been a mental change in local politics and community groups are stepping up. There is a push to start the friendly city or compassionate city movement which promotes an attitude of being open to other communities.

Despite these efforts however, findings also indicated that internal politics or struggles within local political organizations have stunted the implementation and growth of several local governmental programs. Recent changes in local administration, especially in the areas of public health were identified as significant factors shaping the political contexts of healthcare access for HLI. Regarding the latest *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012) one local healthcare provider stated:

Everything in this report is focused on black and white, African Americans and Caucasians. There is very limited data or focus on Hispanics. Why aren't they represented in the epidemiologic data that is collected through the department of public health?

Interviews with local community leaders and advocates for health equity echoed these concerns, attributing this oversight both to the lack of available census data and on the limited efforts of the metro government in reaching out to immigrant communities, especially HLI. Community members were especially concerned about the changing administration and the ineffectiveness of one sector of the department of public health.

A health advocate of the HLI community remarked on this particular sector:

We have had very sporadic involvement or responses from [this sector] especially with the new administration. It was better with Dr. Troutman (former director of public health) and his wife who oversaw health equity.

Another healthcare provider echoed this concern describing this sector as being “*very unfriendly and hard to reach and I don’t know why they are so difficult to get a hold of.*” Although it is identified to play a significant role in promoting equity in health and healthcare access, this sector was found to be inactive in HLI communities, showing limited efforts to collaborate and communicate with local groups. Reasons for these discrepancies were often hard to identify, but most community advocates were frustrated about the political rhetoric that often governed the administration of public health and social services for HLI, especially the undocumented in Louisville. Internal politics that affected local government institutions, especially those pertaining to health and healthcare access for underserved populations played a significant role in shaping the political factors that served as barriers to healthcare access.

Policies

Immigration, welfare and healthcare policies served as both barriers and facilitators to healthcare access. Findings revealed that policies and laws pertaining to immigration and welfare predominantly represented barriers to health and social services for HLI, while health and language policies represented both barriers and facilitators to access. Dealing with issues of access to health and social services for immigrants in general has been an ongoing struggle for policymakers in immigration, welfare and health reform (Wishnie, 2004; Sonfield, 2007). Since the 2001 terrorist attacks, there has been a heightened level of attention and debate over the provision of public services to immigrants, especially the undocumented. Although inaccurate, increased blame has been placed on immigrants for higher healthcare expenditures (Mohanty et al., 2005; Stimpson, Wilson & Eschbach, 2010). Attempts to address these community concerns have been viewed as more of a political strategy rather than a public welfare concern. As a result, constant policy changes in immigration, welfare and health policies have taken place over the last two decades that have continued to influence the ability of HLI to access healthcare services.

Barriers to healthcare access

Immigration policies. Data indicated that key immigration policies are central in shaping the current conditions of HLI in the nation and in Louisville. The Immigration Act of 1990 (Pub. Law No. 101-649, 1990) changed the admission and priority levels of immigrants, bringing a significant influx of immigrants to boost the workforce and economy of the U.S. As levels of diversity started to increase, disparities in health and socioeconomic status continued to grow in the community. Federal and state

legislations started to focus on immigration reform in an attempt to curb the rates of illegal immigration in the U.S. With the option of being more restrictive than the federal government, states continued their efforts to further restrict immigrants from accessing state-wide services (Sonfield, 2007). The first wave of anti-immigration policies started with Proposition 187, that was passed in California to prohibit undocumented immigrants from accessing any public services, including healthcare and education . Although this bill was later deemed unconstitutional and overturned by a federal court, causing Congress to make several modifications to existing policies, the trend of state legislations exclusion of immigrants from public services continued into the 2000s.

Following the September 11 attacks, federal law enforcement agencies responded through the mechanisms provided by the Congress and the US Department of Justice to enlist police in the enforcement of immigration laws (Wishnie, 2004). In 2010, the Support Our Law Enforcement and Safe Neighborhoods Act was passed in Arizona, giving law enforcement officers the authority to determine immigration status of individuals if they have “reasonable suspicion” (Senate Bill 1070, 2010, p.4) that the immigrant is illegally residing in the U.S. This was of great concern to many local HLI in Louisville, especially after Senate Bill 6, modeled after the Senate Bill 1070 passed the Senate in Kentucky. Local community advocates voiced their concerns:

What anti-immigrant legislators in Arizona initially passed was an unconstitutional profiling statute allowing police to stop anybody on street. Because of the outrage that occurred they tweaked it and said you can't be stopped because you might look undocumented or Latino or whatever basis they used to stop someone, but that there had to be another lawful reason to stop someone. Their intention was very clear. I can't believe officers are going to try to utilize this law in unconstitutional ways. That's going to lead to a lot of abuse...It creates problems for people who might be helping or advocating for them as well. It a terrible threat to working people. It's inconceivable that 2010 we're going back to this kind of situation. (Yo Soy Louisville, 2010)

Although Senate Bill 6 was not approved, the effects of this policy and continued political debates took a toll on the local HLI communities, especially the undocumented, by increasing their levels of fear and heightened feelings of discrimination. Local civil rights advocates acknowledged the barriers that are placed on immigrant communities as a result of policies, which can significantly affect how immigrants are viewed in society, their level of integration and feelings of acceptance, and their overall mental health and wellbeing. At the KYCHR's Hispanic and Immigrant Networking Summit in 2009, which was aimed at promoting understanding, communication and collaboration between federal, state and local governments and immigrant communities, the executive director of the commission, John J. Johnson stated:

News reports reveal that national, state and local immigration policies are causing a disturbing pattern of abuses that threaten the livelihood and safety of entire families in their communities. (KYCHR, 2010, p.30)

Data indicated that national and state level immigration policies have focused on curbing undocumented immigrants from residing in the U.S. by restricting them from accessing vital services such as healthcare and proposing policies to give local law enforcement the power to enact immigration reform. These policies threatened the livelihood of HLI, especially those who are undocumented by excluding them from employment and education opportunities, which served as affordability barriers to healthcare access. These immigration policies also played a significant role in shaping the political contexts that influenced accessibility barriers to healthcare access by creating fear among immigrants that their undocumented status will be revealed by accessing healthcare services.

Welfare policies. Over the years, welfare policies have also restricted immigrants from accessing health and social services based on their immigration status. In 1996, the PRWORA (Pub. Law No. 104-193, 1996) restricted legal immigrants from accessing federally funded health services through Medicaid by delaying eligibility until permanent resident status was attained for five years (Derose et al., 2009). Undocumented and non-permanent residents were denied of any benefits through Medicaid. Although twenty-five states provided full coverage for immigrants who did not qualify for Medicaid or State Children's Health Insurance Program (SCHIP) in 2004, studies have shown that states that failed to meet this gap resulted in poor access to healthcare and coverage for immigrants further discouraging seeking care (Kaushal & Kaestner, 2005; Borjas, 2003). Despite budget constraints, several states managed to provide healthcare through public services for ineligible immigrants. However, these attempts were short-lived with the next wave of immigration and health policy reform in the 2000s.

In 2006, the Deficit Reduction Act (DRA; Pub. Law No. 109-171, 2006) required both state and local Medicaid agencies to obtain proof of citizenship and identity from those who applied for these services (Ku & Pervez, 2010; Pub. Law No. 109-171, 2006; Sonfield, 2007). Passed by Congress in 2006, the DRA attempted to preserve services for citizens by reducing levels of fraud by undocumented immigrants. Interestingly, evidence suggests that a significant threat of fraud by immigrants does not exist, shedding light on alternative motives of the DRA. According to Sonfield (2007) an estimated 1 to 2 million, low-income American citizens will be forced to delay care and eligibility through Medicaid due to

the difficulties and associated costs in obtaining documentation. As a result of the DRA, nearly fourteen new legislations were passed in eleven states that either restricted or expanded eligibility for public services for immigrants. Even with changes in documentation requirements that accepted social security numbers to meet eligibility requirements, undocumented immigrants continue to be barred from receiving services as the Social Security system does not include undocumented immigrants.

There is a persistent struggle among states with expanding Medicaid coverage for undocumented immigrants and immigrants as a whole, while meeting federal laws and regulations. Findings indicated that Kentucky also faced issues with maintaining eligibility criteria for access to welfare funds. Welfare policies that restrict access to health and social services through Medicaid, KTAP and other state-wide programs significantly affected HLI in Louisville, especially those who were undocumented. Without adequate income and access to federal funds and support, many HLI face barriers in accessing and affording healthcare services.

Facilitators to healthcare access. Healthcare policies and language policies are discussed under political contextual factors that shaped facilitators to healthcare access. However, healthcare policies also served as barrier to healthcare access, especially for undocumented immigrants who are ineligible under new healthcare reform laws. Additionally, federal, local and institutional language access policies were also important facilitators to healthcare access, but were often not implemented adequately, serving as a barrier to healthcare access. Healthcare and language policies are further discussed in light of these differences.

Healthcare policies. Over the years, both state and federal level policymakers have addressed the issue of immigrants and access to healthcare. However, laws continue to alter and adapt to changes in administrative and congressional agenda. In 2010, the Obama administration introduced into law the PCAA that requires all citizens and legal immigrants residing in the U.S. to have health insurance (Pub. Law No. 111-148, 2010). Under this law, HLI will have access to health insurance coverage through federally mandated systems, but will continue to be restricted from accessing certain federal funds such as Medicaid and Medicare if they do not meet eligibility criteria. As legal immigrants are subjected to a five-year waiting period for Medicaid eligibility, the healthcare reform provides states with the option of implementing a Basic Health Program (BHP), which can expand healthcare coverage for legal immigrants with incomes below 133% of the federal poverty level (NCLR, 2011). States that chose to adopt the BHP

can significantly increase healthcare access for HLI. However, when healthcare coverage becomes mandatory in 2014, those who remain uninsured will predominantly comprise of undocumented immigrants as they will not be allowed to purchase private health insurance at full costs in state established exchanges (National Immigration Law Center- NILC, 2010; Stewart, 2011). Table 21 shows the main differences in access to healthcare coverage between legal (documented) and undocumented immigrants. It must be noted that despite being documented, legal immigrants are barred from accessing welfare service such as Medicaid, CHIP and Medicare. Coverage under these programs can be expanded for immigrants if states adopt changes in their eligibility requirement laws and policies.

Table 21

Healthcare coverage for legal and undocumented immigrants

Type of Coverage	Immigration Status	
	Legal	Undocumented
Individual mandate and related tax penalty	Eligible	Not Eligible
Purchasing from state insurance exchanges	Eligible	Not Eligible
Temporary high-risk pools and basic health plans offered by state	Eligible	Not Eligible
Premium tax credits or cost-sharing reductions	Eligible	Not Eligible
Medicaid	-Eligible if eligibility requirements per state law met - Citizens of Compact Free Association states residing in US are ineligible	Not Eligible Eligible for emergency Medicaid if low-income
Children's Health Insurance Program (CHIP)	Eligible if eligibility requirements per state law met	Not Eligible
Medicare	Eligible if eligibility requirements per state law met	Not Eligible

Note. Information included in table adapted from the National Immigration Law Center (2010).

The current healthcare reform employs a stringent verification system that requires all those who enter into state exchanges to provide proof of citizenship or legal status. This has created a new fear among

undocumented immigrants nationwide, as their lack of insurance will be a direct indicator of their lack of legal immigration paperwork. Additionally, the healthcare reform act establishes several barriers to federally funded healthcare programs and insurance coverage for undocumented immigrants.

Undocumented immigrants are exempt from health insurance exchanges even if they are able to pay out of pocket. Despite the lack of restraints on accessing emergency rooms and other community health clinics, undocumented immigrants are less likely to utilize emergency rooms than U.S.-born citizens (Huang, Yu, & Ledsky, 2006). With the establishment of these new laws, undocumented immigrants are further discouraged from seeking healthcare due to fears and confusion over rules of eligibility (California Immigrant Policy Center, 2006). Restricting access to healthcare in an attempt to deter the rates of undocumented immigration places increases danger on public health and results in higher healthcare costs. Realization of these negative consequences has caused concern among healthcare providers and policymakers, highlighting the need for immigrant health policy reform.

Hispanic Latino immigrants represent the majority of undocumented immigrants in Louisville, and will feel the effects of the PPACA when it takes full effect in 2014. However, data indicated that many HLI in Louisville were unaware of the various stipulations of the healthcare reform act, and few measures were taken to relay this information to the community. One study participant from Cuba, who was a permanent resident of the U.S. stated:

President Obama's plan is a good plan, but at the same time there are also people who are against it. So I think I need to get more informed about it. That worries me a little bit. Because I think why are so many people against it and they don't want that health insurance. As little as I know about it, I think the plan would be good, especially for people like me that have low income. Healthcare is important, not for people who are just sick but for everyone.

This statement indicates the need for community outreach and education among the HLI population in Louisville on healthcare reform and how it will affect their access to healthcare services. As the new policy starts to be implemented, undocumented immigrants will be further restricted from acquiring health insurance and will not be entitled to receive healthcare and other federally funded, public welfare programs, posing a severe threat to the health of immigrants and the nation as a whole.

Language policies. The promotion of policies pertaining to language access was critical in shaping the political contexts of healthcare access for HLI, especially in promoting interpreter availability and training, and patient-provider communication. Hospitals and clinics that mandated institutional

language policies and national language access policies, such as Title VI of the Civil Rights Act of 1964 were pivotal in promoting healthcare access for their HLI patients. Among the four major hospital systems in Louisville, those that received any form of federal funding were required by law to abide to Title VI.

This law states:

No person in the United States shall, on the ground of race, color, or national origin, be excluded from participation in, be denied benefits of, or be subject to discrimination under any program or activity receiving federal financial assistance. (National Archives and Records Administration, 2004)

The Kentucky Environmental and Public Protection Cabinet (2004) is the governmental body that oversees the implementation of Title VI by state agencies, requiring them to provide annual compliance reports to the Auditor of Public Accounts. The Cabinet identifies some of the illegal discriminatory practices under Title VI that pertain to language access:

Providing any service or benefit to a person that is different or provided in a different manner from that which is provided to others. Subjecting a person to segregated or separate treatment in any manner related to receipt of service. (Kentucky Environmental and Public Protection Cabinet, 2004, p.2)

The inability of a federally funded institution to provide equal access to health services for those with LEP or who do not speak any English, may provide grounds for filing a discriminatory complaint. As federally funded programs are required to provide language access services under Title VI, many hospitals and larger healthcare facilities that receive federal funding have established programs and departments overseeing language and cultural competence. Other regulatory bodies overseeing the provision of qualified interpreter services in organizations that receive federal funds included The Joint Commission, The Americans with Disabilities Act (ADA) and The National Standards for Culturally and Linguistically Appropriate Services in Health Care (CLAS Standards).

Despite the establishment of institutional policies and Title VI, findings indicated that HLI with LEP continue to face difficulties in accessing linguistically appropriate healthcare services in Louisville. Reasons for these discrepancies were attributed to the lack of fully implementing and upholding legal rights to language access services, because it wasn't a priority in the healthcare setting and providers were unaware of their responsibilities and were not held accountable for inconsistencies in implementing these laws. Findings from a local study based on a series of interviews with community advocates for LEP populations and health providers, revealed four overarching language access barriers in Kentucky:

1. *Healthcare providers realized the importance of language access for their patients, but the extent and scope of the policies they developed varied greatly.*
2. *Language access services lack consistency and often do not follow the provider's stated policy.*
3. *Language access services fall short on quality and breadth*
4. *Information is not readily available to patients to explain the language access services providers are required to offer. (Kentucky Youth Advocates, 2009, p.1)*

The majority of study participants reported that during several healthcare visits they were not provided interpreter services at federally funded health and social institutions, especially in emergency rooms. Only three participants acknowledged their legal rights to have access to interpreter services. However, in general, the Louisville HLI populations were uninformed about policies and their rights to language access, indicating the lack of outreach and advocacy regarding this issue. Additionally, many HLI, especially the undocumented were restricted from filing complaints with the government because of their fears of being identified based on their immigration status. This fear, which was also a recurring theme in shaping sociocultural and economic contexts, further prohibited HLI from having a voice in the community and standing up for their rights. Although language policies were intended to improve language access for HLI, improper implementation and lack of enforcement significantly affected the ability of these policies to facilitate healthcare access for HLI.

Advocacy and Outreach

Facilitators to healthcare access. Factors that shaped the political contexts of facilitators to healthcare access included *Advocacy and Outreach, Empowerment, Civil Rights and Immigration Legal Services*. Advocacy and outreach among local community members and groups through efforts to preserve civil rights for HLI helped empower these groups and facilitated access to health and social services. Private and public organizations affiliated with churches; agricultural, horse racing and other industries; legal services; educational institutions; cultural, civil rights and health organizations; and local community advocates played a central role in promoting equality for HLI members in Louisville and throughout the state. Specific organizations were also listed under outreach and advocacy factors influencing sociocultural contexts.

Among other organizations, the KYCHR was fundamental in providing education and outreach programs to empower immigrants with the knowledge on their rights and responsibilities under Kentucky civil rights laws (KYCHR, 2008). While the commission dealt with several cases of civil rights and discrimination disputes involving HLI, its outreach program that educates foreign-born Kentuckians about

their rights and responsibilities under Kentucky civil rights laws were far more outreaching in the community. The Kentucky Hispanic, Immigrant and Refugee Networking Summit, which is annually hosted by KYCHR, aims to promote cultural awareness and acceptance regarding HLI:

The objective for this program is to foster mutual understanding and increase communication between the federal, state, and local governments with the Hispanic community in Kentucky. Participants get the opportunity to address concerns and strategize to enhance collaboration between all Kentuckians, including people of other national origins and immigrants. (KYCHR, 2007, p.39)

Individual community members were also recognized for their contribution in promoting justice and equality for HLI. In 2012, two members of the HLI community were nominated to the KYCHR's Civil Rights Hall of Fame for being pivotal in promoting access to education and opportunities for immigrants to improve their quality of life. The *Al Día en América* reported:

This year, two outstanding Hispanics and community leaders, Mr. Edgardo Mansilla of Louisville and Mr. Leo Calderon of Covington, were nominated. Both leaders have dedicated their time to improve others' lives. Both have been a voice for many immigrants and refugees in our state and have utilized their time to assure that young immigrants can be successful in their education and achieve their dream. (p.8)

Empowerment through education was identified as an essential component of advocacy and outreach, because of the direct and powerful influence that educational attainment was shown to have on types of employment and levels of income among HLI. Lack of education was also related to lack of awareness regarding health and availability of community resources. Understanding the importance of the strength and need for educational empowerment, a local Catholic Church initiated a program targeting HLI women in Louisville. Father David Sanchez commented on the need for this program saying:

Education is critical for Hispanic women who are learning to cope with life in the United States...First, the women have to be empowered to know the resources they have in the community. (Archdiocese of Louisville, 2012, p.1)

Educational empowerment was also made possible through national policies such as the DREAM Act (SB 1291, 2001) that were pivotal in improving educational and employment opportunities for undocumented immigrants by motivating them to pursue higher education. Local and state-wide programs such as the Annual Latino/Multicultural Student Statewide College Fair, 55,000 Degrees Initiative, Kentucky Dream Coalition, Kentucky Latino Education Alliance, Adelante Hispanic Achievers and the Behold 1500 Latinos have also played a significant role in promoting higher education and increasing the number of HLI with advanced degrees. These programs facilitated young immigrants to pursue their

educational and career dreams by providing them with encouragement and hope to be successful students.

Advocacy and outreach organizations also emphasized the importance of empowering HLI by keeping them informed about their rights, which gave them the power to make their own decisions and take control of their lives. This was a driving force for many advocacy groups that promoted health equity and equal access to healthcare for HLI in Louisville. Dr. Adewale Troutman President-Elect of the American Public Health Association and former Director of Public Health in Louisville stated:

Part of good public health is empowering communities. And I don't think we should shy away from that. And empowering communities, means creating those conditions where people become empowered and make the changes they need to control their lives...Power is a public health issue. It's about human rights. It's about addressing the social determinants of health in order to make a difference. It's about fairness. It's about health equity and social justice. (California Newsreel, 2008, p. 13-14)

This powerful statement by Dr. Troutman is highly indicative of the need for continued advocacy and outreach to help empower underserved populations such as HLI, who continue to suffer from the social determinants of health that stem from inequalities and injustices. The political contexts that helped shape the facilitators to healthcare access were made evident through various advocacy and outreach efforts to promote equal rights and empower HLI in Louisville.

CHAPTER V

DISCUSSION

Introduction

The purpose of this dissertation was to critically explore the perceived barriers and facilitators to primary healthcare access among HLI residing in highly concentrated communities of the southern metropolitan city of Louisville, KY. Guided by the Conceptual Framework for Assessing Access to Health Services (CFAAHS; Peters et al., 2008) framework, postcolonial theoretical perspectives and critical ethnography methodologies, this study asked the following research questions:

1. What are the perceptions of HLI on health, healthcare, and healthcare access?
2. What are the identified barriers to accessing healthcare services for HLI?
3. What are the identified facilitators to accessing healthcare services for HLI?
4. What are the historical, sociocultural, economic, and political contexts that shape the social determinants of healthcare access within this population?

A multidimensional theoretical approach was used to investigate access to healthcare for HLI in the Louisville community within historical, sociocultural, economic and political contexts. Research findings indicated that barriers and facilitators to accessing healthcare services within these various contexts constituted the social determinants of healthcare access. In this chapter, the investigator provides a general discussion of research findings as they relate to existing literature, conceptual frameworks, and pilot study findings followed by a theoretical discussion of findings using postcolonial perspectives. Research findings indicated that postcolonial concepts of race, ethnicity and racialization, hybridity and unhomeliness, Other and the subaltern, and language and power were highly applicable to providing a substantial understanding of the social determinants of healthcare access for HLI in Louisville. These findings prompted further discussion on the implications and recommendations of research findings on

healthcare systems, community, nursing education, practice and research, and policy. Study limitations and areas for future research were also discussed in this chapter.

Discussion of Research Findings

As indicated in the review of literature and supported by the CFAAHS, the major barriers and facilitators to healthcare access in this study pertained to the four dimension of access: availability, accessibility, affordability and acceptability (Peters et al., 2008; see Figure 3). Distinctive barriers and facilitators to healthcare access among HLI in Louisville were related to historical, sociocultural, political and economic factors that shaped both the demand side (individual) and the supply side (organizational and societal) characteristics of access (Cristancho et al., 2008). As individual, organizational and societal factors were often interrelated and overlapping in nature, only barriers and facilitators that were distinctly relevant and significantly contributed to understanding differences in demand and supply of healthcare access were discussed in detail. Research findings that were new and contributed to existing literature were also discussed in further detail.

In general, study findings identified numerous barriers to healthcare access for HLI in Louisville that were supported by existing literature and the CFAAHS. Under the four dimensions, the largest barriers to healthcare access were related to time and availability; healthcare personnel characteristics; patient-provider communication; documentation; financial barriers; discrimination; cultural barriers; health-seeking behaviors; and, the healthcare business idea. As evidenced in the literature, Cubans and Puerto Ricans in Louisville had fewer barriers to healthcare access when compared to Mexicans and immigrants from Central America (Castaneda, et al., 2011; IOM, 2003; Rivers & Patino, 2006). This discrepancy was associated with immigration status, where Cubans and Puerto Rican participants were all U.S. residents or citizens, making them eligible to receive most federally funded programs and resources. Mexican and Central American participants were residing in the U.S. on a work visa or were undocumented, making them ineligible to access vital health and social services.

Similar to the review of literature, relatively fewer sources of data were indicative of the perceived facilitators to healthcare access when compared to barriers. The major facilitators to healthcare access pertained to healthcare personnel; HIV; type of healthcare facility; documentation; government resources; general resources; and, knowledge and awareness. The distal determinants of access as identified by the

CFAAHS were shaped by historical, sociocultural, economic and political contextual factors (see Figure 3). Research findings indicated new perspectives on the influences of the social determinants of healthcare access stemming from these contextual factors that were specific to Louisville. Central historical factors that contributed to healthcare access for HLI in Louisville included the historical accounts of Kentucky Native Americans; European colonization and slavery; racism, discrimination and segregation; civil rights; and, Hispanic Latino immigration. The sociocultural contexts that shaped barriers and facilitators to healthcare access included geographic, societal and cultural factors, immigration, language and outreach and advocacy. Education, employment, federal systems and the notion of healthcare business were central in contributing to the economic contextual factors. Political contexts that shaped healthcare access included immigration, politics and governance, policies, and advocacy and outreach. Analysis of barriers and facilitators within these contexts constituted the social determinants of healthcare access for HLI in Louisville.

Availability and Healthcare Access

Barriers and contextual findings. Participant narratives indicated that the most significant availability barriers to accessing healthcare service in Louisville were predominantly related to organizational factors such as limited time and availability of healthcare providers, limited availability and training of Spanish to English interpreters, lack of patient-provider communication, and lack of language and cultural competency among providers. These findings were consistent with the literature, which indicated that limited office hours, availability of appointments and longer waiting times resulted in delayed access to healthcare (Betancourt, 2006; Derose, Escarce, & Lurie, 2007; Chavez, 2012; Escarce & Kapur, 2006; Peters et al., 2008). Studies also identified lack of cultural and language competency among healthcare providers and delivery of services as significant barriers to healthcare access among HLI (Asanin & Wilson, 2008; Castaneda et al., 2011; Rivers & Patino, 2006). As indicated in the literature, language barriers represented both individual and organizational factors as it was shown to be related to the LEP of HLI patients and the limited availability of interpreters within the healthcare system (Gurman & Becker, 2008; Harari et al., 2008; Perez-Escamilla, Garcia, & Song, 2010). Findings from a qualitative study on barriers to healthcare access among rural HLI indicated that language and communication were the main perceived barriers to access, as the LEP of participants influenced healthcare knowledge and

health-seeking behaviors (Cristancho et al., 2008). Similarly, findings from this study indicated that language served as a significant barrier to healthcare access among HLI in Louisville as a result of their LEP and the unavailability of trained interpreters.

Further promoting language barriers were political contexts shaped by language policies, where inadequate enforcement of Title VI at the organizational level was shown to result in decreased patient-provider communication. These findings were consistent with existing studies that indicated limited enforcement of Title VI in local healthcare facilities in Louisville (Alcalde, 2005; Capps et al., 2006; Coffman et al., 2007; Harari, et al., 2008). Study findings also indicated that limited promotion of diversity, language and cultural competency in healthcare systems affected the ability of HLI to access appropriate services.

Analysis of sociocultural contextual factors indicated that language barriers also shaped the societal influences on healthcare access, along with cultural factors and outreach and advocacy. Findings from interviews, participant observations and document reviews revealed that a major sociocultural difference between HLI cultures and the U.S. culture was that while HLI upheld ideas of *personalismo*¹⁶, *familism* and communalism, the U.S. society was more individualistic and capitalistic. This idea was also expressed in economic contexts through the idea of *Healthcare business*, where participants perceived limited availability of services and contact with doctors as indicative of being treated indifferently by the healthcare system. The individualistic tendencies of U.S. society and culture are driven by the idea of capitalism. In order to become one of the wealthier nations in the world, the economic structures of the U.S. were highly dependent on these capitalist movements. Similarly, the healthcare system has adapted to meet these economic trends, and over the years has become a growing force in the economy because of the perpetual demand for healthcare services (IOM, 2003). From a business perspective, healthcare is viewed as a commodity in the U.S., whereas cultural perspectives of HLI uphold healthcare as a basic human need. This incongruence in cultural factors played a vital role in influencing time and availability barriers to healthcare access and contributed to existing literature on healthcare access for HLI.

Facilitators and contextual findings. Consistent with the literature, the availability of bilingual healthcare personnel (including nurses and medical case managers), trained interpreters, and increased

¹⁶ Operational definition of terms can be found in Appendix D

levels of familiarity, trust and cultural identification with healthcare providers were shown to serve as important facilitators to healthcare access among participants (Cacari-Stone & Balderrama, 2008; Gurman & Becker, 2008; Pares-Avila et al., 2011; Rivers & Patino, 2006). Findings from a study by Keatings et al., (2009) revealed that cultural identification or the level of social connectedness between the healthcare provider and recipient was strongly associated with health-seeking behaviors as HLI were more likely to access health services from providers who they perceived as relatable and sensitive to their cultural and language needs. Similarly, study findings indicated that cultural identification increased levels of trust and familiarity, which served as a significant catalyst to patient-provider communication and health-seeking behaviors. Although the literature identified that the use of ad hoc interpreters, such as family members and non-health related staff occurred as a result of limited availability of interpreters, participants indicated that English-speaking family members facilitated communication and understanding during healthcare encounters, encouraging them to access services when needed (Cristancho et al., 2008). However, this finding must be cautiously interpreted as a facilitator to access due to its breach in ethical and privacy issues, especially when young children are used as interpreters.

While the availability of interpreters and building of familiarity, trust and cultural identification pertained to organizational and individual factors, the availability of community resources that facilitated healthcare access were predominantly shaped by the sociocultural factors of outreach and advocacy, and community and social support. Findings indicated that many HLI in Louisville, especially those who had lower levels of education and income, were uninsured and/or undocumented reported increased access to healthcare through free community health fairs and screenings. Interestingly, it was found that health fairs and screenings were the only source of healthcare for several HLI communities in the city, indicating the essentiality of these community services on improving health outcomes of HLI. In addition, the provision of limited yet essential primary healthcare services through a free community clinic also significantly facilitated healthcare access for uninsured, undocumented, Spanish-speaking HLI in Louisville. Similar to literature findings, this free clinic, which is minimally funded, used strategies of outreach and advocacy to better understand and meet the needs of the population they serve (Derose et al., 2007). Although it is not located in the southern region of Louisville with highly concentrated HLI populations (Figures 13, 15 & 16), the clinic facilitated healthcare access for many HLI and other immigrants because it did not require

any type of documentation (immigration or health insurance) or fee in order to obtain services. Studies have indicated that HLI are more likely to access services from such community clinics that remove these eligibility criteria, especially those pertaining to immigration documentation (Durden & Hummer, 2006; Chavez, 2012). The availability of community resources were also influenced by economic contextual factors such as government funding and support, and political contextual factors such as advocacy, outreach and empowerment. Organizations that advocated for civil rights, social justice and empowerment of HLI and other immigrant groups played a central role in promoting programs that facilitated healthcare access for HLI. Empowerment through education and outreach was identified as a significant facilitator to healthcare access. These findings largely contributed to the limited literature on availability facilitators to healthcare access for HLI, emphasizing the need for promoting outreach and advocacy programs among underserved populations.

Accessibility and Healthcare Access

Barriers and contextual findings. Similar to literature findings, the main accessibility barriers to healthcare access for participants in this study were related to lack of legal immigration documentation (Dang et al., 2012; Durden & Hummer, 2006; Khan et al., 2011; Nandi et al., 2008; Ortega et al., 2007; Quesada et al., 2011). As evidenced in the literature, study findings indicated that undocumented immigrants had lower educational and income levels, and were highly likely to be uninsured when compared to documented immigrants, which influenced their ability to access healthcare services (Passel & Cohn, 2009; Gossey & Volk, 2008; Bustamante et al., 2012; Rodriguez et al., 2009). In a study on undocumented HLI and healthcare access, Chavez (2012) found that being undocumented led to increased stressors, underutilization of medical services and limited health insurance. Similarly, findings from this study revealed that undocumented HLI in Louisville were often scared to access health services due to fears of being identified as being undocumented and being deported to their country of origin.

Although being undocumented was identified as an individual factor, it was often influenced by organizational and societal factors as evidenced by the historical, sociocultural, economic and political contexts that shape this accessibility barrier. Findings indicated that the historical accounts of Hispanic Latino immigration to the U.S and Kentucky, as well as the civil rights issues such as equal employment opportunities for immigrants highly influenced the current socioeconomic positioning and undocumented

status of HLI in Louisville and nation-wide (IOM, 2003; Telles & Ortiz, 2008). Historical factors were shown to impact the types of employment, educational levels and policies that pertained to immigration, welfare and health. These findings contributed to the limited literature on the influence of historical events on understanding the negative effects of being undocumented on healthcare access for HLI.

Participant narratives and other study findings indicated that being undocumented created an identity that was analogous to subordination, fear and feelings of insignificance for HLI as a result of sociocultural contextual factors. These emotions were related to being turned away from accessing healthcare services because undocumented immigrants could not provide a social security number, identity card and health insurance, which were often required to access services at certain clinics. Due to their undocumented immigration status, individuals were limited to working in low-wage, service jobs that often did not provide any health insurance coverage or adequate income to purchase health insurance. Additionally, as indicated in literature findings immigration, welfare and health policies restricted undocumented immigrants from accessing federally funded health and social services (Derose, et al., 2007; Okie, 2007; Sonfield, 2007; California Immigrant Policy Center, 2006). Health policies, such as the PPACA, were found to considerably restrict undocumented immigrants from accessing health insurance and services. These findings contributed to the limited literature on the influence of the PPACA on the health of undocumented immigrants, providing several implications for health policy reform that promotes equitable healthcare access to reduced health expenditures and improve overall community health.

Other significant sociocultural contextual factors affecting accessibility barriers were related to geographic elements, such as environment and physical segregation. Participants themselves did not identify geospatial factors as significant barriers to access, although several participants had to travel an average of thirty-minutes to get to their primary healthcare provider. Consistent with the review of literature, geospatial analysis and community mapping results indicated that geographic location and physical characteristics of the environment have significant effects on healthcare access for HLI in Louisville (Alcalde, 2005; Friedrich, 2009). Midwest and southern regions of the U.S. with relatively newer populations of HLI and other immigrant groups were identified in the literature as having substantially greater geospatial limitations to accessing health services, resulting in physical segregation and feelings of social isolation from mainstream society and resources (Abraido-Lanza et al., 2011; Berdahl et al., 2007;

Coffman et al., 2007; Harari, et al., 2008; Khan et al., 2011). Similarly, the physical segregation of HLI in Louisville was evident in geospatial analysis, which revealed that higher concentration of these populations were found in southern regions of Louisville, which also had lower income, educational and English proficiency levels; access to fewer health resources; longer travel times to healthcare facilities; and, limited bus routes for transportation to provider locations when compared to other regions of the city.

The literature indicated that geographic location serves as a factor for healthcare disparities, especially among populations residing in central states, inner-cities, and rural areas that have the highest need for improved quality and access to healthcare services (AHRQ, 2011). In order to assess variations in healthcare quality and access disparities across States, achievable benchmark methods that recorded the “frequency with which states perform in the top 10% of states and contribute to the achievable benchmark” were examined (AHRQ, 2011, p.10). Data revealed benchmark states were least often found in the East North Central, East South Central, and West South Central regions of the U.S. Kentucky and its surrounding states, which belong to the East South Central division of the U.S, fell in the third, lowest quartile that represented the smallest number of benchmark measures. Within these regions, subdivisions that placed populations at further risk for receiving poorer quality of, and access to healthcare include inner-city and rural areas (AHRQ, 2011). Significant disparities in access to care were found among residents in large inner cities, micropolitan areas, and noncore areas (AHRQ, 2011). Similarly, as an inner-city area in the central state of Kentucky, the geographic location of southern Louisville placed HLI at high risks for experiencing poorer health outcomes related to the social determinants of healthcare access. Consistent with findings from previous studies examining barriers to access among HLI in Louisville, findings from this study indicated that geospatial factors such as long distances and limited transportation were also seminal in shaping barriers to healthcare access for this population (Alcalde, 2005; Capps et al., 2006; Friedrich, 2009). These findings provide additional implications for the healthcare system in Louisville to promote access by expanding the provision of health services in these geographically underserved areas.

Facilitators and contextual findings. Consistent with literature findings, having legal immigration documents such as a visa, green card, social security number and/or citizenship was identified as a facilitator to healthcare access, as it was a prerequisite to accessing most public services (Durden &

Hummer, 2006; Khan et al., 2011; Quesada et al., 2011). However, several distinctive themes emerged from the data on accessibility facilitators that contributed to existing literature pertaining to HIV and the infectious disease clinic.

Among other common chronic health concerns in the HLI population in Louisville, HIV was a growing, yet underrepresented issue. Although limited literature was available on the rates of HIV among HLI in Louisville, the CDC (2011) reported that HLI are disproportionately affected by the disease, representing 20% of new HIV infections in the U.S. in 2009. The majority of participants with HIV stated that they were diagnosed with the condition after immigrating to the U.S. They were often times in the advanced stages of the disease as a result of cultural stigma and lack of awareness, prevention and resources in their home countries. Similarly, in a study examining the determinants of delayed HIV presentation in one Northern California County, it was found that over 78% of the immigrants with HIV were Hispanic and that immigration status was shown to be significantly and independently related with delayed presentation of HIV (Levy, Prentiss, Balmas, Chen, Israelski et al., 2007). Additionally, qualitative findings indicated that reasons for delayed presentation were attributed to lack of knowledge, social stigma and secrecy. Similar trends were indicated among participants in this study and other HLI in the Louisville community. However, participants indicated that being HIV positive and having low-income, facilitated access to affordable medical services and free medications.

A local infectious disease clinic was identified as the primary source of healthcare for participants who were HIV positive, especially due to the provision of culturally and linguistically competent medical case managers and healthcare providers. Similar to literature findings that identified community health workers or *promotoras* as facilitators to healthcare access, medical case managers facilitated access for participants in this study by encouraging healthcare access and utilization through the promotion of HIV screening, testing and education in the community, enhancing patient-provider communication and reducing cultural and language barriers (Pacheco et al., 2012; Perez-Escamilla et al., 2010). Several participants indicated that they received better medical attention, resources and social support for being HIV positive in the U.S. than they did in their home countries. As indicated in the literature, access to better quality health and social services for HIV in the U.S. was a major reason that compelled HLI to remain in

the country, despite undocumented and lower socioeconomic status (Servin, Munoz, Strathdee, Kozo & Zuniga, 2012).

Along with the infectious disease clinic, other types of healthcare facilities that assisted HLI in accessing healthcare services in Louisville were emergency rooms, public health clinics and a primary healthcare clinic offering healthcare services for employees of the local horse racing industry. The increased ability of these organizations to provide affordable healthcare services were largely related to government funding and support, type of employment, and welfare and Medicaid benefits, which shaped the economic contexts of healthcare access. Additionally, political contextual factors pertaining to welfare policies, governance and politics were also influential in facilitating healthcare access at these various facilities. However, it must be noted that HLI had to either be employees of the race track or have legal immigration documents, to be eligible to access services at the public health and primary healthcare clinics. It was also found that most emergency rooms did not ask for proof of legal immigration documents, as they are mandated by the Emergency Medical Treatment and Active Labor Act (EMTALA) to provide services to everyone who presents to the emergency room in critical condition regardless of ability to pay and health insurance coverage (Grimm & Wells, 2009). Findings indicated that despite the high expenses incurred from emergency rooms visits, most participants accessed services from this facility because it provided convenient operating time and did not require proof of documentation. Therefore, it was evident that immigration documentation played a significant role in shaping accessibility barriers and facilitators to healthcare access.

Affordability and Healthcare Access

Barriers and contextual findings. Pertinent individual factors that served as affordability barriers to healthcare access included limited income or financial resources, lack of health insurance coverage and having dependents. These factors were shown to be strongly related to the historical, sociocultural, economic and political contexts that contribute to the current socioeconomic conditions of HLI in Louisville. As indicated in the literature, the financial ability of participants to pay for health services were related to economic factors such as their lower levels of educational attainment, employment in low-wage jobs, and limited income levels, which were also related to historical factors related to unequal educational and employment opportunities, Hispanic Latino immigration and discrimination (Escarce & Kapur, 2006;

Coffman et al., 2007; Passel, 2006). However, sociocultural contextual factors such as being undocumented or being physical segregated also contributed to this discrepancy as these factors were shown to severely restrict access to health services and health insurance coverage regardless of income levels (Bustamante et al., 2009; Durden & Hummer, 2006; Siddiqi et al., 2009). The review of literature identified Mexican immigrants as being highly susceptible to experiencing barriers to healthcare access related to higher rates of poverty, lack of insurance and undocumented status when compared to other HLI (Castaneda, et al., 2011; Rivers & Patino, 2006; Wallace et al., 2008). Findings from this study indicated that Mexicans, along with Guatemalans, Ecuadorians and Hondurans were more likely to face barriers to healthcare access as a result of limited income, lack of health insurance and undocumented status when compared to Cubans and Puerto Ricans. Participants who shared their stories of illegally crossing the border were from Mexico, Guatemala, Ecuador and Honduras. These findings emphasized the centrality the undocumented theme as immigration status was shown to influence all dimensions of barriers to healthcare access.

Lack of health insurance was also a result of unique sociocultural, economic and political factors that influenced the ability of HLI to afford health insurance coverage. Similar to literature findings, the majority of study participants did not have health insurance and stated that it was a result of their limited income, which was directly related to working in low-wage, service industry jobs (Khan et al., 2011; Wilper et al., 2009a; 2009b). Political contextual factors that influenced health insurance coverage were health and welfare policies that restricted immigrants, especially the undocumented from accessing public health and social services. Health policies such as the PPACA exclude undocumented immigrants from buying private health insurance coverage by restricting their participation in state-wide health insurance exchanges (California Immigrant Policy Center, 2006; NILC, 2010). Adding to these limitations is the fact that the majority of HLI work in low-wage service industry jobs that do not provide sufficient compensation for health insurance coverage (Passel, 2006). Therefore, undocumented immigrants, who are already significantly restricted from accessing public services, will face increased barriers to healthcare access in 2014, when the PPACA goes into full effect. These findings indicate the need for collaborative and comprehensive health, welfare and immigration policy reform.

Facilitators and contextual findings. Affordability facilitators to access pertained to government resources, such as welfare benefits and other funding mechanisms that provided access to Medicaid, KTAP

and KADAP for study participants. Most government funded programs were only accessible to documented immigrants, especially to citizens and permanent residents (Fortuny & Chaudry, 2011). Therefore, those who are ineligible to access these services turned to other limited community services and resources. However, many participants had children who were born in the U.S., which made them eligible to receive some government services. The major sociocultural and economic factors that facilitated access to affordable health services were community and social services and government funding and support. Political contexts influencing affordability facilitators to access included welfare policies, governance and advocacy and outreach. Participants identified the need for free socialized healthcare to help increase access to health and social services for underserved, immigrant groups. As many participants came from countries with universal healthcare systems, or healthcare systems partially subsidized by their governments, they were accustomed to receiving affordable health services when needed. Participants from Cuba were especially vocal about the need for universal healthcare in the U.S. because it is the central healthcare system in Cuba. Similarly, in Mexico, the healthcare system provides various options fully or partially subsidized by the government, including public healthcare, the Mexican Social Security Institute, universal healthcare coverage for pregnant women, and life insurance for babies (Lucas & Denham, 2004). Access to these provisions in the Mexican healthcare system, have increased rates of medical tourism, where Americans seek affordable healthcare and medicine south of the border (Peng, 2008; Hawley, 2009).

Existing literature identified universal healthcare coverage as the fundamental mechanism to facilitate healthcare access for immigrants as well as U.S. citizens, which helps reduce health disparities and improve overall community health (Prus et al., 2010). In a study that compared health outcomes of foreign-born and minority populations in the U.S. to Canada, Lasser et al. (2006) found that immigrants and minorities had poorer health outcomes as a result of unmet healthcare needs and were less likely to have a regular source of healthcare when compared to Canadian immigrants. Canada's universal healthcare system provides free, affordable services for its immigrants, which were shown to reduce barriers to access. Similarly, participants in this study verbalized that having access to free healthcare service would eliminate significant barriers to access, especially those related to affordability. These findings provide several implications and recommendations for increasing government funding in current healthcare systems in the U.S. that would decrease costs of services and insurance for HLI.

Acceptability and Healthcare Access

Barriers and contextual findings. Consistent with the literature, findings from this study indicated numerous acceptability barriers pertaining to external factors (societal and organizational factors) and internal factors (or individual factors). Significant affordability barriers identified by participants included external factor such as discrimination and the healthcare business idea, and internal factors such as cultural barriers, health-seeking behaviors and mental health. Similar to existing literature, discrimination based on race, ethnicity, language, health insurance and HIV status within the healthcare setting and the community resulted in emotional barriers that had strong influences on health-seeking behaviors among participants (Cristancho et al., 2008; Gurman & Becker, 2008). Negative emotional stressors associated with discrimination were shown to discourage health-seeking behaviors and result in negative physiological and psychological consequences (Flores et al., 2008; Lauderdale et al., 2006; Prus et al., 2010; Sanchez-Birkhead et al., 2011). Participants in this study verbalized that emotional distress and discomfort caused by experiences of discrimination discouraged access to healthcare services.

Geospatial analysis, document reviews and participant observations indicated that physical segregation and social isolation contributed significantly to external acceptability barriers to healthcare access. Hispanic Latino immigrant communities were predominantly concentrated in southern regions of Louisville, with distinct socioeconomic factors such as higher rates of poverty, linguistic isolation¹⁷ and lower educational and income levels. Similarly, the *Louisville Metro Health Equity Report* (Center for Health Equity, 2011) indicated that southern regions of Louisville, which had the lowest life expectancy rates, also had the highest levels of poverty and crime (see Figure 22). As indicated in the literature, these barriers were shown to stem from historical, sociocultural, economic and political contexts that continue to oppress HLI in Louisville (Derose, et al., 2007; Nandi et al., 2008). These findings provide significant contributions to understanding the geographic, sociocultural and economic factors that influence the physical segregation, isolation and marginalization of HLI in Louisville.

Sociocultural factors including racism and discrimination, social isolation, being undocumented, fear of deportation, and physical segregation, were central in shaping acceptability barriers to access for HLI in Louisville. In a descriptive qualitative study exploring HLI challenges in navigating Utah's

¹⁷ Operational definition of terms can be found in Appendix D.

healthcare system, social isolation was identified as the leading sociocultural barrier to healthcare access (Sanchez-Birkhead et al., 2011). Similarly, findings from this study indicated that social isolation, which was also a product of historical physical segregation and political exclusion of HLI and other minorities, disempowered HLI from equal education and employment opportunities that were pivotal in improving their socioeconomic status. Therefore, social isolation resulted in limited physical access to health and social services, lack of social support, and feelings of discrimination, unfamiliarity and distrust with healthcare providers and the overall healthcare system (Lauderdale et al., 2003; Perez et al., 2008). As identified in the review of literature, immigration, welfare and health policies also contributed to social isolation by excluding and restricting HLI, especially the undocumented from accessing health and social services (Quesada et al., 2011; Gradstein & Schiff, 2006; Canales, 2007). Furthermore, undocumented immigrants were less likely to seek healthcare services due to fears of deportation. Once again, immigration status significantly contributed to barriers to healthcare access as undocumented HLI were restricted from accessing primary healthcare services or health insurance as a result of their immigration status.

Facilitators and contextual findings. The main acceptability facilitators to healthcare access were increased knowledge and awareness and family and social support. Increased knowledge and awareness regarding health issues among participants were shown to encourage health-seeking behaviors and treatment compliance. Family and social support enhanced positive psychological health, and served as vital factors influencing healthy behaviors and the use of preventive healthcare services. These facilitators were predominantly shaped by sociocultural contextual factors of outreach and advocacy, community and social services, and *familism*. Consistent with existing studies, findings indicated that HLI were more likely to be family-oriented and receive higher levels of family support when compared to their U.S.-born counterparts and non-Latino whites (Almeida, Molnar, Kawachi & Subramanian, 2009). One study identified family and social support to have significant effects on improving health for HLI in the U.S. (Landale, Orpresa & Bradatan, 2006). Similarly, study findings indicated that participants associated health with family and social support, which encouraged them to engage in healthy behaviors and promoted healthcare access.

Community and social support was further enhanced through organizations and programs promoting civil rights and social justice for HLI. These programs were central in shaping the political

contextual factors influencing acceptability facilitators to healthcare access. Limited literature was available to support understanding of the direct influences of community and social support on health and healthcare access of HLI (Almeida et al., 2009). Therefore, findings from this study provide implications for continual efforts of local advocacy and outreach programs and social support on improving healthcare access for HLI and overall community wellbeing.

Comparing Provider and Recipient Perspectives on Access

As the second of two studies focused on access to health services for immigrant populations in Louisville, this dissertation revealed numerous barriers and facilitators to healthcare access as perceived by HLI. As indicated in part one of chapter two, this dissertation was preceded by a pilot study, which examined barriers and facilitators to health and social services as perceived by providers in the Louisville community. Community members and providers were also interviewed in this study regarding the historical, sociocultural, economic and political factors that help shape barriers and facilitators to healthcare access for HLI, adding depth to these participant perspectives. These findings fulfilled the additional purpose of this program of research, which was aimed at examining the congruence or incongruence between the actual healthcare needs of the recipients as indicated by participant narratives and the perceived healthcare needs as identified by health and social service providers. Comparative analysis between study findings and pilot study findings revealed that providers and recipients shared similar perspectives on barriers and facilitators to healthcare access for HLI in Louisville (Figure 31).

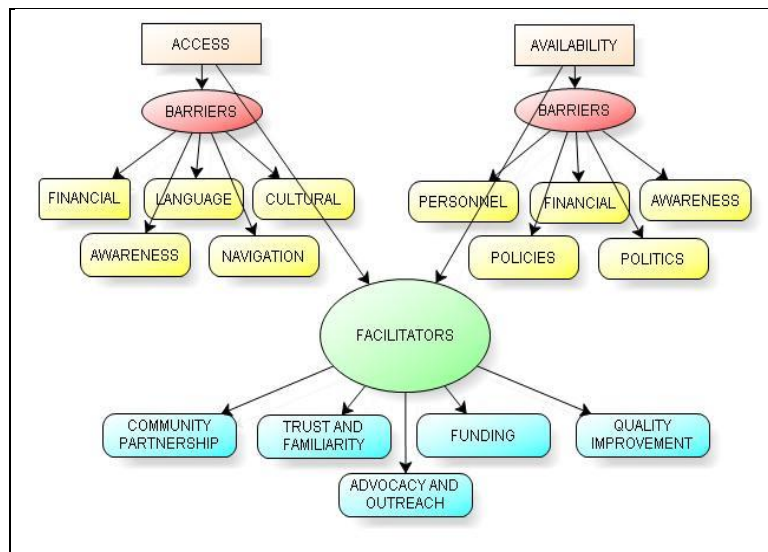


Figure 31. Provider perspectives on barriers and facilitators to barriers to healthcare access.

As indicated in Figure 31, central access barriers for immigrants in Louisville identified by providers were related to financial factors, language and culture, awareness and navigation of the healthcare system. Findings revealed that financial, language and cultural barriers had the largest number of sources and references.¹⁸ The major financial barriers were related to cost of healthcare, lack of health insurance and type of employment. Lack of interpreter services, limited communication with healthcare providers, and LEP of immigrants were identified as language barriers. Cultural barriers were influenced by the use of traditional medicine practices and differences in the cultural perceptions of health and healthcare among immigrants. Frequently cited availability barriers pertained to healthcare personnel, financial factors and policies and politics. Lack of culturally and linguistically competent healthcare personnel as a result of limited training and education on immigrant health was identified as a significant barrier to accessing health and social services. These findings were reflective of participant perspectives on barriers to healthcare access, which were represented under the dimensions of availability, accessibility, affordability and acceptability using the CFAAHS.

Pilot study findings combined access and availability facilitators to access, representing relatively fewer references to access facilitators when compared to barriers. Significant facilitators to accessing health and social services include community outreach, partnership and advocacy, funding, and building trust and familiarity. Providers made several recommendations for improving healthcare access and eliminating health disparities that were focused on immigration and health policy reform, improved community collaboration, outreach and advocacy, and increased access to public and private financial funding. These findings resonated with participant perspectives on healthcare access facilitators shaped by sociocultural and political contextual factors pertaining to policies, outreach and advocacy, and resources. Therefore, it was evident that health and social service providers were cognizant of the health and social needs of HLI and other immigrants in Louisville. Providers were also aware that several structural barriers shaped by historical, sociocultural, economic and political contexts continue to restrict equitable access to healthcare services for this population.

Despite these similarities, research findings revealed an inadequate degree of fit between the needs of HLI as the health service recipients (demand) and the ability of the healthcare system to meet those

¹⁸ See Appendix C for Nvivo Functions

needs (supply). Discrepancies between the provision of healthcare services and the utilization of those services were highly influenced by the barriers that constituted the social determinants of healthcare access. These variations have resulted in increased disparities in healthcare access and health outcomes within HLI and other immigrant communities in Louisville (Alcalde, 2005; Capp et al., 2006; Center for Health Equity, 2011; Freidrich, 2009). Therefore, in comparing pilot study findings and dissertation findings, it is evident that the social determinants of healthcare access continue to play a central role in determining equitable access to health services for HLI in Louisville. Challenges in addressing the social determinants of healthcare access for this population are related to the integral historical structures of power and dominance that continue to shape the current sociocultural, economic and political contexts of healthcare access in Louisville. Further examination of healthcare access disparities for HLI within these contexts is supported using postcolonial theoretical perspectives.

Understanding Findings from a Postcolonial Perspective

Research findings indicated numerous barriers and facilitators to healthcare access for HLI in Louisville that stemmed from unique historical, sociocultural, economic and political contexts shaping the everyday experiences of HLI in this community. Findings indicated that the barriers to healthcare access far surpassed facilitators as they stemmed from historically rooted issues of colonialism, racial and ethnic segregation, socioeconomic positioning and other external determinants that have left a permanent mark in current society (IOM, 2003; Perea et al., 2007). Hispanic Latino immigrants continue to suffer from historically embedded and socially constructed identities of race, ethnicity, power and oppression. These elements have retained the marginalized positions of HLI and other minority groups in U.S. society, continuing to exclude them in social, economic and political arenas (Kirkham & Anderson, 2002; Mohammed, 2006). The colonial histories and conquest of Hispanic and Latino populations are often underrepresented or erased in current historical accounts (Turner & Guerrero, 2003). However, the coloniality of these groups was central in understanding the continued oppression of HLI throughout history and the current social positioning, inequities and injustices experienced by HLI in the U.S. (Acuna, 2005; Delgado, 2007; Delgado & Stefancic, 2007). Perea et al., (2000) attributed these discrepancies to the limited acknowledgement of coloniality in the legal histories of Hispanics and Latinos:

Perhaps historians and textbook writers unconsciously need to forget that the United States engaged in aggressive military conquest of Mexico, and later the military invasion and subsequent

annexation of Puerto Rico. Perhaps the facts of these conquests, and ensuing developments, were too inconsistent with the image of a peaceful, benevolent United States spreading freedom throughout the world. (p.248)

Historians emphasize the need to understand how the colonial histories of Spanish, British and Anglo American conquest, slavery and other imperial forces continues to shape contemporary issues pertaining to sociocultural, economic and political inequities for HLI (Boehmer, 1995; Childs & Williams, 1997; Perea et al., 2007). Racially segregated healthcare systems were shown to originate during slavery, where plantation health services were the earliest systems comparable to managed healthcare plans in current systems (IOM, 2003). Segregated healthcare systems were maintained throughout U.S. history with events such as the passing of Jim Crow laws and civil rights legislations on Medicare and Medicaid. As a result of these inequities, HLI continue to be subjected to the social determinants that serve as barriers to healthcare access in current society.

Therefore, the application of postcolonial theory to research findings helped critically reframe the construction of meanings of health and the social determinants of healthcare access for HLI in Louisville. This analysis was accomplished by examining the underlying structures of colonial power and dominance that manifests through discourses of race, ethnicity and racialization, Other and the subaltern, hybridity and unhomeliness, and language and power. Table 22 provides a summary of all barriers to healthcare access within their historical, sociocultural, economic and political contexts and the influence of postcolonial theoretical constructs in the deconstruction of these social determinants of healthcare access within a critical lens. As these postcolonial constructs were shown to predominantly influence the barriers to healthcare access, they are discussed in further detail to bring subjugated knowledges of the Other, or in this case HLI into the current context of health (Anderson, 2000a; Foucault, 1972; Kirkham & Anderson, 2002, 2010). Furthermore, discussion of research findings within a postcolonial frame allowed for an in-depth understanding of the root causes of inequalities in health and healthcare access among HLI and identification of solutions to alleviate health disparities through social justice and empowerment.

The Racialization and Ethnicization of Healthcare Access

...it is clear that what divides this world is first and foremost what species, what race one belongs to. In the colonies the economic infra-structure is also a superstructure. The cause is effect: You are rich because you are white; you are white because you are rich. (Fanon, 2004, p.5)

Table 22

Applying Postcolonial Concepts to Contextualized Healthcare Access Barriers

Access Dimensions	Barriers	Historical Contexts	Sociocultural Contexts	Economic Contexts	Political Contexts	Postcolonial Concepts
Availability	Time and Availability		Cultural factors	Healthcare business		
	Healthcare Personnel Characteristics		Language Outreach and Advocacy		Language policies	Language and Power
	Patient-Provider Communication Navigating the Healthcare System		Language Outreach and Advocacy	Education	Language policies	Language and Power Language and Power
Accessibility	Documentation	Hispanic Latino Immigration; Civil rights	Immigration	Employment; Education; Federal system	Policies; Immigration	Race, ethnicity and racialization; Hybridity and unhomeliness; Other and subaltern
	Emergency Room		Cultural factors	Healthcare business	Governance; Language policies	Language and Power
	Type of Healthcare Facility		Geographic		Policies	
Affordability	Financial Barriers	Hispanic Latino Immigration; Civil rights	Immigration	Healthcare business; Employment; Education; Federal system	Policies	Race, ethnicity and racialization; Other and subaltern
	Knowledge and Awareness		Outreach and Advocacy	Federal system		Language and Power; Other and subaltern
	Resources	Racism, discrimination and segregation	Societal factors; Geographic		Politics and Governance	Race, ethnicity and racialization; Other and subaltern
Acceptability	Discrimination	Kentucky Native	Societal factors;		Language policies	Race, ethnicity and

	Americans; European colonization and slavery; Racism, discrimination and segregation	Immigration; Geographic			racialization; Hybridity and unhomeliness; Other and subaltern; Language and Power
Cultural Barriers		Cultural factors			Hybridity and unhomeliness
Health-seeking behaviors	Civil rights	Cultural factors	Employment	Immigration	Hybridity and unhomeliness
Mental health	Racism, discrimination and segregation	Immigration; Societal factors		Immigration; Policies	Race, ethnicity and racialization
Healthcare Business	Racism, discrimination and segregation	Cultural factors; Outreach and Advocacy	Healthcare business	Immigration; Policies	Race, ethnicity and racialization

The racialization and ethnicization¹⁹ of HLI in the U.S. have been products of the colonial histories of the Americas, which laid the foundation for slavery, oppression, segregation and discrimination. First coined by the anti-colonial revolutionary and philosopher Frantz Fanon, racialization refers to the historical, socioeconomic and political processes that maintain boundaries between groups based on race (Fanon, 1967; Woodward, 2004). As a historical process, racialization is not only affiliated with racial groups, but also applies racial identities to ethnic groups, such as Hispanics and Latinos, creating stereotypical images that guide levels of social interaction within different ethnic and racial groups (Telles & Ortiz, 2008). The inaccuracies in defining the socially constructed concepts of ‘race’ and ‘ethnicity’ have been debated over the centuries and have been of significant concern among Hispanics and Latinos whose multifaceted identities are often narrowed down or lessened to these restrictive definitions of ethnicity. Therefore, racialization provided a basis for social positioning of groups resulting from the hierarchical colonial systems of power and dominance. According to Rodriguez (2002, p.7), “as populations compete for land, status and resources they build hierarchies based on clusters or phenotypical biological factors which are then assumed to represent archetypes for members of a particular racial group.” This provides the basis for the historically embedded process of racialization, which defines the hierarchical positioning of HLI as an ethnic group through various social institutions, such as economy, education and healthcare.

Findings from this study indicated that HLI in Louisville faced significant perceived barriers to healthcare access as a result of being racialized or ethnicized by the healthcare system and other societal structures. This was evidenced by the intersectionality of ethnicity, undocumented immigration status, LEP, lack of education, low income and lack of health insurance, which constituted the social determinants that served as barriers to healthcare access. Historical contexts indicated the struggle of other racialized groups such as Native Americans and African Americans in Kentucky and the U.S., who as a result of their ‘race’ fought for civil rights and social justice throughout centuries of domination and oppression (Aguirre-Molina, Molina & Zambrana, 2001; Perea et al., 2007). The health experiences of these groups, beginning with the Native Americans serves as the foundation for understanding the historical contexts of racial and ethnic health in the U.S. (IOM, 2003). Study findings suggested the racialization of current sociocultural,

¹⁹ Operational definitions of terms can be found in Appendix D.

economic and political factors shaped the barriers to healthcare access for HLI especially in relation to discrimination.

Orientation to a specific race or ethnicity was essential in defining the identity of HLI in Louisville, especially within the healthcare system as admission paperwork to health facilities usually required demographic information pertaining to racial and ethnic background. Interestingly, when asked about their ethnicity, many participants did not identify themselves as Hispanic or Latino, and were hesitant or unsure about the meaning of ‘ethnicity’ as they asked the investigator for further explanation of the term. However, the majority of participants identified their ‘race’ as Hispanic or Latino and only three identified their ‘race’ as *blanco* or white. This provides evidence for the discrepancies among HLI themselves regarding their socially constructed identities in the U.S. that results from their lack of affiliation with these racialized and ethnicized groups in their home countries. The categorization of Hispanics and Latinos as an individual from Cuba, Mexico, Puerto Rico, South or Central America, or other Spanish culture or origin, is very limiting as these countries represent varying subgroups, cultures and languages (Ennis, Rios-Vargas, Albert, 2011; Passel & Taylor, 2009; Soltero, 2006). Additionally, while admission paperwork at healthcare facilities may provide ‘Hispanic’ or ‘Latino’ as an option for ethnicity, the choices for racial background are often limited to white, black or African American, American Indian or Alaska Native, or Asian, and does not account for the mixed races and ethnic groups such as Mexicanos, *chicanos* and *mestizos*, which are commonly represented in Hispanic Latino groups (Rinderle, 2005).

As identified in the literature, the racial and ethnic heterogeneity of HLI was a direct consequence of colonialism, where economic and political forces increased rates of migration and resettlement of various groups (Ashcroft, Griffiths, & Tiffin, 2006; Clifford, 2006). Spanish conquest of the Americas resulted in racially varied groups, identified today as Hispanic or Latino, through intermarriage, as well as rape between Spaniards, Native Americans, and black slaves (Perea et al., 2007). The diasporic identities of HLI created by colonialism are depicted in the statement, “There are no Latinos, only diverse peoples struggling to remain who they are while becoming someone else” (Shorris, 1992). As a diasporic community, HLI in Louisville were also subjected to a sense of hybridity and unhomeliness²⁰ that influenced their cultural identity and ability to integrate to U.S. society (Bhabha, 1994; Tyson, 2006). This

²⁰ Operational definition of terms can be found in Appendix D.

sense of hybridity and unhomeliness was also depicted through the physical segregation, social isolation and marginalization of HLI that influenced availability, accessibility, affordability and acceptability barriers to healthcare access.

Physical segregation and social isolation of HLI in Louisville are comparable to the neocolonial idea of internal colonization, which analogized Latinos to an internal colony of the U.S., where these groups are dominated and ruled by imperial forces, treating them, in effect, as a colony (Acuna, 2005; Barrera, Mufioz, & Ornelas, 1971; Delgado, 2007; Thomas, 2000). The literal manifestation of these internal colonies can be seen through the *colonias* or shantytowns that line the Texas border, where neglected HLI communities live in deplorable, substandard housing conditions (Larson, 1995). Surrounding counties have limited resources to provide adequate services or employment for Mexican Americans living in these *colonias*. Over the years, other areas with large Latino concentrations have emerged across Midwestern and Southern regions of the US, where HLI have moved in search of jobs and affordable housing. Hispanic Latino immigrants living in southern states such as Kentucky, live in marginalized locations with limited resources, comparable to the shantytowns or *colonias* lining the Texas borders (Delgado & Stefancic, 2008; Bowdler, 2005). Study findings indicated that these geographic and social demarcations were applicable to HLI in Louisville, who predominantly resided in southern regions of the city on the outskirts of downtown (Urban Mapping, 2011; Migration Policy Institute, 2007). These southern regions were also shown to have significantly lower levels of income, education, and English language proficiency when compared to the more affluent, predominantly Caucasian, eastern regions of the city (Capps et al., 2006). Essentially, south Louisville can be viewed as an internal colony of HLI, due to its clear demarcation from mainstream society as evidenced by physical segregation and social isolation that are products of racial colonial discourses. The sense of hybridity and unhomeliness is perpetuated by the consequences of colonialism, where boundaries and borders were not only created to geographically divide lands, but also racial and ethnic groups.

As the principle of colonialism, the conquest of the Americas produced barriers for intermingling between colonized and once-colonized regions and peoples, essentially separating Hispanics and Latinos from North American regions (Acuna, 2005; Delgado, 2007; Delgado & Stefancic, 2008). As a result, borders were established as a means of physically and social segregation between racial and ethnic groups.

The U.S.-Mexico border has been a longstanding example of these barriers, which represent modern or neocolonial remnants of American colonization. Several study participants indicated the struggles of crossing the U.S.-Mexico border, leaving behind their families, possessions and culture to a new land where despite better economic opportunities; they continue to live in fear and dependency. The foundation of colonialism was the use of power and domination to create a system of fear, deprivation and dependency, which is also evident in current oppressive systems affecting social justice for HLI. Economic, political and cultural manipulation of these groups within the U.S. and in the countries they come from is evident through neocolonial discourses or imperial forces of the U.S. that continue to place HLI in subordinate, segregated positions (Loomba, 2005; McLeod, 2000). Study findings indicated that HLI in Louisville continue to be dependent on the system because they are often deprived of the basic human needs, such as healthcare. Furthermore, the fear of deportation, which was a central sociocultural theme that was identified as a direct barrier to healthcare access, was highly related to the level of economic dependency of HLI on the U.S. This is indicative of the consequences of colonialism that continue to economically manipulate Hispanic Latino peoples and their countries (Perea et al., 2007). Therefore, it is evident that this cycle of fear, deprivation and dependency, which is related to the postcolonial discourses of racialization, hybridity and unhomeliness, continue to place HLI in subjugated positions within Louisville. Postcolonial interpretation allowed for the critical analysis of SDH and social determinants of healthcare access as racialized and ethnicized products of socioeconomic inequalities and social injustices.

Studies have indicated that the most significant variances in health outcomes and healthcare access characteristics were seen among racial and ethnic groups in Louisville (Office of Policy Planning and Evaluation, 2012; Alcalde, 2005; Capps et al., 2006; Fredrich, 2009). Findings from this study also indicated that race and ethnicity played a significant role in the ability of HLI to access healthcare services because these socially constructed identities were associated with being undocumented, uninsured or poor, subjecting them to racism and discrimination within healthcare settings. The latest *Louisville Metro Health Status Report* (Office of Policy Planning and Evaluation, 2012) identified differences in health outcomes among ‘whites’, ‘blacks’, and ‘Hispanics’, equivocating the ethnicized term ‘Hispanic’ to the racialized terms of ‘white’ and ‘black’. Inconsistencies in the use of these socially constructed terms also contribute to the sense of hybridity and unhomeliness that creates confusion and a lack of identity among HLI in the

U.S. This leads to misunderstanding, stereotyping and generalizing of the groups, as was seen predominantly in the case of African Americans and their history in the U.S. The powerful, racialized term of 'black', was a direct product of colonialism that continues to serve as a fundamental basis for segregation in current society (Fanon, 1967). Hispanics and Latinos, however, do not fit precisely into the black-white binary of American society because of their mixed racial and ethnic backgrounds (Soltero, 2006; Skerry, 1993). Adding to this dilemma of identity are the effects of the changing nature of immigration on the notions of race and ethnicity, which has produced a new wave of racial stereotypes and stigma stemming from sociocultural and economic characteristics of HLI (Telles & Ortiz, 2008). The powerlessness of this socially defined ethnic group to establish itself in the mainstream U.S. society currently and throughout history, has led to the inequities in basic human rights and social injustices for HLI. So powerful are the ideas of race and ethnicity that clear socioeconomic demarcations can be seen in physical and geographic segregation of racialized groups, and through the societal mechanisms that keep them socially isolated from mainstream society.

As a central societal institution, healthcare was not immune to the colonial effects of racialization, where discourses of race and ethnicity have been shown to constantly shape the social determinants of healthcare access for HLI. The unique histories of southern U.S. regions were shown to influence the distinct racialization processes affecting new HLI populations. Smith & Furuseth (2006) discuss these unique racialized structures affecting HLI in the South:

In a region where social status, economic relations, and public consciousness have been framed by the bi-racial constructs of 'White' and 'Black', the arrival of a growing number of culturally different and linguistically alien immigrants has had far reaching effects. Cultural conventions and social institutions have been challenged. Commercial and residential landscapes have been transformed. New Latino migrants are cautiously viewed as 'assets' and/or more boldly as 'problems'. In a region that continues to grapple with long held traditions of privilege, belonging, and 'race', the growing presence of Latinos complicates the traditional mythology of southernness and gives rise to yet another iteration of the so called 'New South'. (p. 2)

Study findings indicated that over the years the drastic influx of HLI to southern U.S regions like Louisville and Kentucky has brought a significant strain on the local health and social service infrastructures that are unable to adequately meet the needs of this population, resulting in significant health and healthcare access disparities (Capps et al., 2006 Migration Policy Institute, 2007). The influences of racialization and ethnicization that continue to marginalize HLI in Louisville were represented in geospatial segregation and other sociocultural, economic and political factors that served as

barriers in accessing healthcare services. The intersectionality of race with other social factors such as socioeconomic and immigration status, influenced inequitable access to healthcare for HLI. Furthermore, racialization shaped the interaction between HLI and the healthcare system, where experiences of discrimination discouraged health-seeking behaviors of many participants. These social determinants of health have been shown to further impede access to healthcare among this population, increasing the inequities that segregate HLI from other groups (Alcalde, 2005; Friedrich, 2009). The influences of colonialism and neocolonialism are evident in the current conditions of HLI in Louisville, KY and allowed for critical interpretations of barriers to healthcare access.

Language and Power

Every time the question of language surfaces, in one way or another, it means that a series of other problems are coming to the fore: the formation and enlargement of the governing class, the need to establish more intimate and secure relationships between the governing groups and the national-popular mass, in other words to re-organize the cultural hegemony. (Gramsci, 1985, p.183-4)

Language, in postcolonial terms, doesn't simply refer to a means of communication, but represents a symbol of power that when deconstructed reveals the political undercurrents of domination and oppression (Derrida, 1994; Gramsci, 1985, 1971). Influenced by Marxist philosophy, Italian revolutionary Antonio Gramsci's theories on the subaltern²¹ as a product of the hegemonic structures of colonialism provided the foundation for postcolonial constructs of language and power, and Other and the subaltern (Bhabha, 1994; Gramsci, 1971; Said, 1978, 1994; Spivak, 1993, 1994). Although the definition of the subaltern as a creation of colonial oppression is greatly influenced by racial and ethnic discourses, language was identified as a powerful factor in developing the identity of the Other, which contributed to the binary social relation of 'Us' and 'Them' (Said, 1978). Colonization of the Americas was achieved through the isolation of groups on the basis of race, ethnicity and culture, but also on the basis of language. By subordinating Hispanics and Latinos on the basis of language, the colonizer was able to dissolve their sense of identity and deprive them of the resources for empowerment (Dominguez, 2005; Gonzalez, 2000). Therefore, the postcolonial discourses of power and language allowed for the understanding of how speaking Spanish or not being able to speak English served as a barrier for social equity, especially in relation to accessing healthcare services for HLI. The power of language on understanding the influences

²¹ Operational definition of terms can be found in Appendix D.

of oppression on current conditions of HLI was evident in the study findings, necessitating an independent discussion of these postcolonial concepts in understanding the barriers to healthcare access.

Study findings indicated that language and power were central concepts in shaping availability, accessibility, acceptability and affordability barriers to healthcare access and were influenced by the lack of interpreters and bilingual healthcare providers, discrimination based on language, limited enforcement of language policies such as Title VI and limited knowledge and awareness. Language barriers were shown to not only limit direct access to healthcare services, but also disempowered HLI from gaining knowledge and awareness regarding their health and legal rights to accessing appropriate language services. The lack of outreach and advocacy through Spanish media and other communicating methods limited the awareness of HLI regarding their legal rights to obtain interpreters and other language resources. Numerous barriers to language access served as a method of disempowering HLI from having an equal voice or presence in society. Therefore, as indicated in postcolonial discourses language was identified as a political issue that shaped policy, education and everyday communication, but also served as a mechanism to help analyze the political circumstances that influenced culture and social relations (Gramsci, 1985; Ives, 2004; Volosinov, 1973). Language was particularly influential in determining socioeconomic positioning of HLI through employment characteristics and level of income, and also through social interactions and levels of acceptance through communication and discrimination.

Although the U.S does not have an official national language, English is viewed and accepted in mainstream society as the most commonly spoken language, despite growing changes in demographic and language profile (USA.gov, 2013). Telles and Ortiz (2008) stated that “Those that do not speak English with near native fluency are excluded not only from sharing in communication with the mainstream but also from institutions that determine success, including primary labor markets and higher education” (p.186). As indicated in study findings and existing literature, language served as a barrier to healthcare access by delimiting social boundaries that influence economic growth and social positioning of HLI in U.S. society (AHRQ, 2008; Coffman et al., 2007; Passel, 2006). Geospatial analysis of study findings indicated linguistic isolation²² of HLI in Louisville in areas that have higher levels of poverty and poorer health outcomes. Lower socioeconomic positioning of HLI as a result of working for low-skilled, low-wage

²² Operational definition of terms can be found in Appendix D

service industries was shown to be related to their LEP (Kaiser Commission on Medicaid and the Uninsured; 2003). Therefore, language was indicated as a source of disempowerment for HLI, where economic deprivation and dependency as a result of LEP limited equitable access to healthcare services among other vital resources.

While language served as a significant barrier to healthcare access by limiting income necessary to afford healthcare services and health insurance for HLI, it also served as a means for discrimination from mainstream society and institutions that facilitated healthcare access. As indicated in earlier discussions, racialization and ethnicization of healthcare access occurred as a result of the clear demarcations in access based on socially determined boundaries of race and ethnicity (Fanon, 1967; Woodward, 2004). However, languages, which were used to identify a certain group of people, were also stratified in U.S. society as evidenced by language based discrimination (Telles & Ortiz, 2008). Study findings indicated that participants experienced discrimination based on their inability to speak English or LEP, but also based on their Spanish accents. Some participants indicated that racialized physical appearances also served as a basis for judgment on LEP by health and social service providers. Inferior and subordinate treatment based on language both in and out of the healthcare setting was a common experience for HLI, indicating the power of language in influencing the hierarchical social structures that continue to place HLI in subordinate positions.

Although discrimination based on language in federally funded health and social institutions is illegal, “narrow and formal construction of anti-discrimination laws can render them virtually meaningless in protecting relatively politically powerless groups” (Soltero, 2006, p. 3). The disempowerment of HLI in Louisville and in the U.S was made evident through study findings and literature that indicated the effects of race, ethnicity, language and immigration status in perpetuating the powerlessness of these groups throughout history (IOM, 2003; Telles & Ortiz, 2008). Study findings indicated that the lack of enforcement of Title VI of the Civil Rights Act of 1964 served as a barrier to healthcare access mainly because interpreters and other Spanish resources were not available for HLI in Louisville. Over the years, state and local level efforts have continued to challenge provisions of Title VI, mandating English to be an official language of different institutions within the U.S. These efforts in seeking to mandate English were shown to have discriminatory effects on HLI, which includes deprivation of and exclusion from federal

benefits and programs (Soltero, 2006). Bender (1997) uses the term “language vigilantes” to refer to institutions, such as schools or places of employment that impose the conventional use of English on individuals who speak other languages. Despite the growing diversity of U.S. society, in racial, ethnic and language backgrounds, HLI continue to be excluded from mainstream society through policies and legal forces as seen through the attempts to mandate the English language. The hegemonic influences of language on the oppression of HLI are further discussed in the postcolonial discussions of the subaltern.

Critical interpretation of research findings within the postcolonial discourses of language and power revealed that language served as a significant social determinant of healthcare access as a result of its effects on hegemonic historical, sociocultural, economic and political structures that influence the social positioning of HLI in U.S. society (Gramsci, 1985, 1971; Soltero, 2006; Telles & Ortiz, 2008). The inability of HLI to communicate effectively in English was associated with lower socioeconomic status, physical segregation, social isolation and political exclusion, indicating the power of language in promoting oppressive colonial structures that maintain HLI in subordinate positions. Findings indicated that the disempowerment of HLI in advocating for equal rights to healthcare access was significantly affected by language barriers. Language, along with postcolonial discourses of race and ethnicity, was shown to play a vital role in creating the cycle of oppression for HLI.

Muting the Voice of the Subaltern

To surmount the situation of oppression, men must first critically recognize its causes, so that through transforming action they can create a new situation, one which makes possible the pursuit of a fuller humanity. But the struggle to be more fully human has already begun in the authentic struggle to transform the situation. (Freire, 1973, p. 31)

The identity of the subaltern as a subjugated entity is created in postcolonial discourses through the weaving of the structures of power, dominance, oppression, race, ethnicity and language (Gramsci, Hoare & Smith, 1978; Bhabha, 1996; Spivak, 1993, 1994). The discourses of colonial power and oppression situates the colonized in inferior positions and frames them as the ‘Other’ or the subaltern in order to set them apart from the colonizer (Said, 1978; Said, 1994; Slemon, 1995; Smith, 1999). This central feature of colonialism was a powerful force that changed the histories of various racial and ethnic groups in the U.S., from Native Americans and African Americans to HLI. As indicated in previous discussions of racialization, the cycle of fear, dependency and deprivation was central to creating the subalternity of HLI, where underlying structures of power and oppression continue to suppress their voices

and keep them in subordinate positions (Spivak, 1993, 1994). In order to give voice to and empower the experiences of subjugated HLI, it is essential to include their perspectives and experiences in current contexts of knowing. Gandhi (1998) defines a subaltern study as “as an attempt to allow the ‘people’ finally to speak within the jealous pages of elitist historiography and, in so doing, to speak for, or to sound the muted voices of, the truly oppressed” (p. 2). Guided by postcolonial theory and critical ethnography, this study also aimed to accurately represent the voice of the Other by illuminating the subaltern voices of HLI that are muted or lost in translation in the dialogical process of healthcare access (Ashcroft, Griffiths, & Tiffin, 2006; Said, 1978).

Using a critical ethnographic research process, the subaltern narratives of HLI were expressed in their own words and were contextually interpreted by the investigator (McLeod, 2000). The deliberate decentering of dominant ideologies and culture that consequently gives voice to marginalized knowledges of the subaltern is another essential feature of the postcolonial research method (Kirkham & Anderson, 2002). Incorporating the perspectives and experiences of marginalized HLI into the foundation of research and science was essential in understanding the social determinants of healthcare access. This study addressed these features of postcolonial methods by utilizing purposeful sampling techniques to recruit non-English speaking, or limited English speaking (LEP) participants. To ensure that subaltern voices were not muted or lost in translation, the study utilized certified Spanish interpreters to assist in the data collection process. A central feature of postcolonial scholarship positions the socially constructed nature of meanings and practices in a larger historical, sociocultural, economic, and political context (Kirkham & Anderson, 2002, p.10). The proposed study explored social constructed meanings of health and healthcare access among HLI, by giving voice to participants within these different contexts (Stevens, 1989). Socially constructed experiences and meanings derived from everyday world experiences and pertaining to healthcare access were expressed through participant perspectives, allowing the investigator to identify influences of postcolonial discourses. Additionally, understanding barriers to healthcare access as perceived by HLI themselves, further acknowledged the multiple perspectives of the Other or the subaltern. Examining these alternative ways of knowing was accomplished through prolonged immersion in the field, participant observations, focus groups, and individual interviews.

While maintaining the critical integrity of the research methods was a simple process, applying postcolonial theoretical constructs to interpret research findings was far more complex due to the intersectionality of race, ethnicity and racialization, hybridity and unhomeliness, Other and the subaltern and language and power. Postcolonial scholarship emphasizes the need to understand these critical discourses independently and in conjunction with each other (Kirkham & Anderson, 2002). This feature accounts for a more in-depth, complex analysis of data where the interconnectedness or intersectionality of different mechanisms of oppression, such as racism and classism, are revealed (Mohammed, 2006). The experiences of HLI in the context of historical colonialism and contemporary neocolonialism were reflective of this intersectionality in the analyses of oppression. Additionally, the variability of the roles of the Anglo, Hispanic, and Latino cultures from oppressed to oppressor, and the multiple levels of oppression (related to race, ethnicity, and class) are indicative of the co-existence of multiple identities. In this study, the analysis of oppression of HLI was further explicated by examining the intersectionality of race, ethnicity, language, and immigration, socioeconomic and HIV status that created the subalternity of participants.

The socially constructed identities of race and ethnicity categorized groups into racial hierarchies, which further established racialization and the subalternity of these groups (Dominguez, 2005). Research findings on historical contexts of colonization, slavery, civil rights and Hispanic Latino immigration in Kentucky, provided evidence for the continual oppression of different racial and ethnic groups, predominantly Native Americans, African Americans and HLI (IOM, 2003; Perea et al., 2000). Oppression started with the first wave of European colonization, which resulted in the wiping out of many indigenous peoples as a result of war, famine, and diseases introduced by the colonizers. The end of European colonization gave birth to neocolonial forces that established the U.S. as an imperial power that continued conquest of land and people (Boehmer, 1995; Childs & Williams, 1997; Sage, 2010). Using its newly found hegemonic power, which was ironically a byproduct of gaining independence from its own colonizer, the U.S. continue to dominate and oppress Native American populations pushing them Westward and eventually into reservations. The oppression of racial and ethnic groups continued well after colonization with the introduction of slavery, where slaves were considered to be subhuman and consequently treated in brutal, inhumane conditions in the U.S. These historical accounts, among others,

provide evidence for how the idea of colonizer and the colonized is embedded in the societal structures of the U.S., shaping the contemporary issues affecting HLI.

Similar to the colonial and imperial global forces that conquered indigenous peoples and their lands based on racialization and economic and political mechanisms, racialized hierarchies of power continue to be embedded in U.S. society as a means of controlling the subalterns, or in this case the HLI (Dominguez, 2005). By creating this sense of Other, which was initially used to differentiate the colonized from the colonizer began with its basis in race and ethnicity, but was constantly redefined throughout history to evolve into class, language and other socially constructed identities (Said, 1978, 1994). The unrelenting oppression of HLI and other racial and ethnic groups in the U.S. is primarily related to sociocultural, economic and political issues, which were shown to shape issues of civil rights and social justice for HLI in Louisville. Study findings indicated that the social determinants of race, ethnicity and language independently and in conjunction with other socioeconomic factors played a significant role in restricting healthcare access for HLI in Louisville. Literature supports the establishment of race, ethnicity and language as determinants of socioeconomic position as it influenced educational levels, type of employment and levels of poverty and income, which were essential in determining ability to access healthcare services (Derose et al., 2009; Passel, 2006; Rivers & Patino, 2006).

As indicated in previous discussions, language was a central and powerful discourse in creating the sense of Other by disempowering HLI and placing them in marginalized or subordinate positions (Gramsci, 1985, 1971; Said, 1978; Freire, 1970). Study findings identified language as a notable method of oppression that disabled HLI from having their health concerns addressed in a community with English as the dominant language and limited access to Spanish interpreters and resources. Similar to race, language has the power to define hierarchical positioning of subaltern groups as indicated in Gramsci's (1971) reflections on hegemony, language and the subaltern. The inability of HLI to communicate in English continues to define their subaltern positions in current society, as it was shown to serve as a significant barrier to equitable healthcare access and other social services. Although it is beyond the scope of this dissertation, analysis of postcolonial discourses of language, in and of itself reveals various hegemonic structures of dominance and oppression. However, the basic analysis of language in this study revealed the underrepresentation or muting of voices and experiences of HLI in healthcare as a result of their inability to

communicate in the dominant English language. Therefore, findings revealed that race, ethnicity and language continue to define HLI as a subaltern group that struggles to gain equality in healthcare access as a result of their subordinate positions.

Although race, ethnicity and language continue to be central in shaping the current condition of HLI in U.S. society, issues of globalization and immigration have further complicated these postcolonial discourses (Dirlik, 1994, 2006; Gikandi, 2006; Robertson, 2006). Like colonialism, immigration is fueled by economic and political processes that define immigrants as the Other or the subaltern through laws and policies restricting them from having equal access to health and social services in the U.S. Although various immigration statuses were indicated in study findings to influence the degree of healthcare access, being undocumented was identified as a significant accessibility, affordability and acceptability barrier to healthcare access. The term undocumented was often replaced with anti-immigration discourses such as “illegal” or “illegal alien”, which identify undocumented immigrants as being an outsider both in the legal system and in the community (Chavez, 1991). Furthermore, as indicated in study findings and the literature, being undocumented was associated with discrimination and a constant sense of fear among undocumented immigrants, perpetuating the cycle of fear, dependency and deprivation for this population (Chavez, 2012; Lauderdale et al., 2003; Perez et al., 2008). The fear of deportation made it impossible for undocumented HLI to have an equal voice in society and limited their ability to advocate for their rights in accessing equitable healthcare services. These characteristics contributed to the identity of Otherness and subalternity of undocumented HLI in Louisville, which excluded them from being equal members of the community.

Being undocumented also contributed to the subalternity of HLI in Louisville by influencing their ability to seek high-wage employment, educational attainment or other methods to improve their economic conditions. As a result, HLI were found to be in lower socioeconomic positions which served as significant affordability barriers to healthcare access. Postcolonial discourses highlight race, ethnicity, and language, as well as socioeconomic status as a determinant of class in hierarchical social structures (Freire, 1970; Gramsci, 1985, 1971). Throughout history, power and dominance have been manifested through the preservation of capitalism and socioeconomic class, which helped the bourgeoisie maintain powerful positions in society (Morana, Dussel & Jauregui, 2008). The idea of bourgeoisie was first introduced in Karl Marx’s *The Communist Manifesto* (1930) to delineate the reigning class of capitalist society.

Postcolonial discourses identify the subaltern to be products of class, race and ethnic struggles, which promoted imperial dominance on political, economic and social levels. The discussion of class struggles is necessary in understanding the social positioning of HLI and other oppressed groups within the capitalistic U.S. society.

The capitalistic tendencies of the U.S. have been engrained in its social, economic and political structures, making it one of the foremost imperial global powers throughout history and in current times (Boehmer, 1995; Judd, 1996; McLeod, 2000). Hispanic Latino Immigrants, even the undocumented, have made significant contributions to the economic development and growth of the U.S. as indicated in the literature (Immigration Policy Center, 2009; National Research Council, 1997; Passel, 2006). Despite these trends, HLI continue to work in low-wage service industries, with limited income as a result of their undocumented immigration status, lower educational levels and LEP. Hispanic Latino immigrants struggle to maintain their cost of living while working in subpar working conditions with minimal wages that also determined their ability to access healthcare services. Therefore, this vicious cycle of oppression manifested through immigration and socioeconomic status is central in shaping the social determinants of healthcare access for HLI in Louisville.

Study findings also denoted HIV status as a contemporary factor contributing to the subalternity of HLI in Louisville. Negative cultural stigma, discrimination and delayed representation of HIV among HLI in Louisville were indicative of the ability of HIV status to influence social positioning. Although study findings indicated that HIV was a growing problem among HLI Louisville, statistics on HIV rates among HLI in Louisville and Kentucky were limited. Furthermore, cultural factors were shown to influence the ability of these communities to obtain access to culturally competent preventive care and education (Levy et al., 2007; Servin et al., 2012). Individuals with HIV were ashamed to be open about their condition for fear of being judged by family and community members. They also experienced discrimination as a result of their positive HIV status, which further discouraged them from verbalizing their experiences and concerns. As a result, there was limited knowledge among providers and community members on the issue of HIV among HLI in Louisville and it had not gained the attention that is required to help eradicate or reduce disease rates. Therefore, HLI who didn't speak English and were poor, undocumented, less

educated, and HIV positive were essentially at the very bottom of the hierarchical social structure, where these factors collectively determined their subaltern identities.

In summary, muting the voice of the subaltern was accomplished through the oppression of HLI as evidenced by various historical, sociocultural, economic and political mechanisms. Findings indicated that HLI were unable to function as equal members of the community as a result of their subaltern identities defined by race, ethnicity, language, and undocumented immigration, lower socioeconomic and positive HIV statuses. Each of these determinants of subalternity also served as social determinants of healthcare access, indicating the influence of hierarchical social positioning of HLI on their ability to access equitable healthcare services.

Conclusion

Discussion of research findings within postcolonial theoretical perspectives provided evidence for the disparities or inequalities in health and healthcare access among HLI in Louisville, which were attributed to the colonial discourses of race, ethnicity, power and oppression that continue to shape social inequities and injustices for this population. Postcolonial discourses of race, ethnicity and racialization, and language and power were central in shaping critical understanding of the effects of colonialism on current social positioning of HLI and their ability to access healthcare services. Furthermore, the subalternity of HLI in Louisville was constructed by race, ethnicity, language, and immigration, socioeconomic and HIV statuses that were manifested through physical segregation, social isolation and political exclusion through various societal institutions. These factors served as the social determinants of healthcare access, limiting the ability of HLI to be viewed as equal members of the community and impeding healthcare access.

Despite being the largest growing immigrant population in Louisville, many HLI believed that ‘no one is listening’ to their story, which was attributed to the lack of government initiatives that promote change and enhance progression for equal rights and social justices for HLI. Narratives from this study represent the plight of many other HLI throughout the nation, questioning reasons for the limited level of attention given to meet the needs of this growing population. Perea et al., (2000) partially attribute this discrepancy to the diversity of the HLI population stating, “Notwithstanding the uniform label, *latinas/os* speak in many different voices. In fact, although the generic term “*latina/o*” is used to designate a class...the term really classifies an “outsider” ethnic group that is far from homogenous” (p.249). Limited

attention is given to the needs of these groups as a result of the diverse representation of HLI experiences and the complexities involved in addressing issues that dissect historical, sociocultural, economic, political realms. As a result, the voices of these oppressed groups remain unheard and unanswered in the larger contexts of health and social justice.

Informed by the epistemological assumptions of both CE and postcolonial theory, this study aimed to represent the subjugated voices and experiences of these oppressed HLI groups as a means of emancipating these groups from social injustices and unfairness, especially those pertaining to inequitable healthcare access (Freire, 1970; Gandhi, 1998; Hammersley & Atkinson, 1995; Loomba, 2005; Spivak, 1994). A crucial feature of a postcolonial research method is praxis-oriented research that challenges the status quo, illuminates inequities in the distribution of power and resources, and is committed to building a just society through social change (Kirkham & Anderson, 2002). The role of postcolonial scholarship within an emancipatory research paradigm requires a commitment to critical inquiry that moves beyond describing what 'is' to what 'ought to be' (Thomas, 1993). According to Lather (2001), critical perspectives in social and health research necessitates the use of "empowering approaches where both researcher and researched become the changer and the changed" (p.56). In this study, the emancipator role of the investigator was manifested through the illumination of structural barriers to healthcare access for HLI stemming from colonial domination and neocolonial imperial powers. Through accurate representation of the HLI experience, the investigator aims for empowerment through increased awareness of the social determinants of healthcare access, while simultaneously engaging in the critical reflexivity process that reflects on the investigator's positionality. In doing so, this study aimed to fulfill an overarching goal of promoting social justice and healthcare equity for HLI. Discussion of research findings within a postcolonial lens provided insight into the structure of power and dominance that were central in shaping the social determinants of healthcare access for HLI in Louisville. This discussion provided several implications and recommendations for current healthcare systems, community programs, nursing and policies in promoting methods to eliminate healthcare access disparities in the community.

Implications and Recommendations

Research findings revealed that contextually based barriers and facilitators to access also identified as the social determinants of healthcare access have several implications for public health and must be

addressed in relation to organizational, community, individual and policy levels. These findings provided several implications and recommendations for healthcare systems, community programs, nursing education, practice and research, and policy. Participant recommendations for the community and government were integrated into this discussion, to ensure that participant voices and needs were aptly represented. Findings help inform health service providers, recipients and policymakers by identifying the subjective and socially constructed barriers to healthcare access and promoting development of programs and policies to reduce health disparities and improve access to healthcare for HLI.

Healthcare Systems

Research findings provided several implications for modifications in the healthcare system in Louisville that promotes equitable access to healthcare services for HLI. As indicated through geospatial analysis of data, few healthcare facilities and health related services were available in southern regions of Louisville with higher concentrations of HLI. Geospatial factors such as distance and transportation served as barriers to healthcare access indicating the need for increased presence of healthcare facilities within these underserved regions. The NCLR (2011) recommends the expansion of Federally Qualified Health Centers or public health centers, free and affordable health clinics, and hospital services through charity care and other community benefits. These programs are especially recommended in geographically underserved areas. Expanding healthcare services in these areas requires the equal distribution of healthcare providers who have the ability serve disadvantaged HLI in culturally appropriate ways.

It is imperative to increase the presence of healthcare providers, especially nurse practitioners, through private offices, clinics and other healthcare facilities. Over the years, research has indicated that expanding the role of nurse practitioners has established them as a significant source of primary healthcare in community health clinics and nurse-managed health clinics across the U.S., serving over 20 million patients yearly (Kaiser Commission on Medicaid and the Uninsured, 2011). Nurse practitioners also work in diverse healthcare settings such as physician practices, managed care facilities, retail or convenient care clinics, providing them with the ability to expand healthcare services in underserved areas. Research indicated that nurse practitioners are more likely to practice in underserved, lower income areas and predominantly serve minorities and uninsured patients, which is indicative of their ability to promote healthcare access for disadvantaged immigrant groups such as HLI (Stange & Sampson, 2010; Grumbach

et al., 2003; Hansen-Turson et al., 2004; Office of Technology Assessment, 1986). Therefore, it is recommended that healthcare systems and other social systems work in collaboration to increase the presence of such clinics in southern Louisville, to improve access to vital primary healthcare services for this disadvantaged population.

Participants and providers indicated the lack of workforce diversity in healthcare professions, which impacts cultural identification and competency levels, served as a barrier to healthcare access for HLI in Louisville. Similar to existing literature, study findings revealed that the ability of providers to identify with the culture of their patients (or cultural identification) significantly enhanced the patient-provider relationship by promoting communication and trust (Cacari-Stone & Balderrama, 2008; Gurman & Becker, 2008; Keatings et al., 2009; Pares-Avila et al., 2011; Rivers & Patino, 2006). Therefore, measures must be taken by the healthcare system to enhance diversity in the workforce to include representation of nurses, doctors and other healthcare professionals including administrative staff from various racial and ethnic backgrounds. Promoting workforce diversity encourages health-seeking behaviors of HLI and other patients who feel accepted and understood by providers who are cognizant of their cultural needs. Additionally, increasing workforce diversity better equips healthcare facilities with the personnel and knowledge to guarantee the provision of culturally competent care.

Another central factor in shaping HLI health-seeking behaviors and patient-provider relationships was the lack of cultural and language competence of healthcare facilities and providers. The limited provision of Spanish interpreters and other language services was shown to significantly restrict access to care for HLI (Gurman & Becker, 2008; Harari et al., 2008; Perez-Escamilla et al., 2010). Study participants with LEP expressed the need for increased interpreter services or the establishment of language service departments within healthcare facilities to promote communication and understanding of health needs. Therefore, it is essential to enhance the provision of culturally and linguistically competent care through the establishment of consistent language services, use of bilingual healthcare providers, and continual training of providers (Bell, 2004). Using critically based approaches to train providers advances understanding of cultural competence. This is accomplished by increasing awareness among providers of how their own positionality and biases influences how they treat patients of racial and ethnic backgrounds different from their own (Kirkham & Anderson, 2002). By cultivating critical perspectives in the way they care for their

patients, healthcare providers can be better equipped to provide culturally competent care to a diverse patient-base. Therefore, increased cultural competency training is essential and must be conducted frequently with healthcare providers, especially in Louisville where community demographics continue to change on a daily basis. As HLI and other immigrant groups continue to grow exponentially in Louisville, it is essential for healthcare facilities to modify their cultural competency models. The healthcare system in Louisville may benefit from modeling their cultural competency models to those used in states such as New York and California who are more familiar with and knowledgeable on providing culturally and linguistically appropriate healthcare services for diverse populations. Increased cultural and language competency measure must be adopted in Louisville's healthcare system in order to promote healthcare access for HLI and eliminate health disparities within the community.

Community Programs

Findings indicated that community outreach and advocacy efforts that promoted civil rights, social justice and empowerment of HLI played a central role in directly and indirectly facilitating healthcare access. These findings provide implications for continual efforts of local advocacy and outreach programs and social support on improving healthcare access for HLI and overall community wellbeing. Although the local government and community organizations took efforts to promote equitable access to health and social services for HLI, there was a lack of collaboration between these various institutions. The lack of collaboration resulted in the duplication of programs geared towards HLI, increased costs and ineffectiveness of programs, and a negative sense of competition between providers that influenced the availability and accessibility of healthcare services. According to the National Policy Consensus Center (NPCC, 2004) collaborative involvement is essential in eradicating health and healthcare access disparities in the community. The involvement of community members, health and social service providers, advocates, government officials and other stakeholders is essential in developing collaborative approaches to improving healthcare access for HLI. Therefore, it is essential for community outreach and advocacy programs in Louisville to continually provide support to HLI through collaborative efforts by expanding programs, influencing policies and implementing research on outcomes and effectiveness of programs (NPCC, 2004). Community-based collaborative programs should focus on empowering individuals with the knowledge and resources that encourage healthy behaviors and facilitate access to primary healthcare

services. According to the Pew Hispanic Center and Robert Wood Johnson Foundation's research report on *Hispanics and Health Care in the U.S.* (Livingston, Minushkin, & Cohn, 2008), media outlets were identified as significant sources of health information, demonstrating the "power and potential of these alternative outlets to disseminate health information to the disparate segments of the Latino population" (p.5). Therefore, it is essential to utilize existing media outlets and expand media sources within the Louisville community to disseminate culturally and linguistically appropriate health information to HLI.

Although outreach and advocacy were integral facilitators to healthcare access for HLI, these measures were often scarce and inconsistent. As a result, many HLI groups in Louisville expressed feelings of being underrepresented and abandoned by organizations and institutions, especially those that were government affiliated. Limited data on HLI population in Louisville and their health outcomes also indicate the lack of initiative and outreach in representing the needs of this growing yet underrepresented community. Therefore, it is recommended that local government organizations affiliated with promoting equitable access to health and social services among racially and ethnically diverse groups take additional efforts to reach out to HLI in Louisville. In order to represent the health needs of HLI and develop appropriate health and social services, state and local level sociodemographic census data must be collected on this growing immigrant community (Riffe, Turner & Rojas-Guyler, 2008). Data on HLI populations that are difficult to attain due to physical segregation or social isolation, such as the undocumented, must be reached through alternative methods. These methods involve employing community outreach workers and liaisons to connect with underrepresented groups and provide an outlet for their concerns through narrative inquiry methods (Pacheco et al., 2012). Reaching out to these communities to understand their perspectives on health and healthcare needs is empowering and provides mechanisms to incorporate the voices of oppressed groups in research and interventions aimed at improving healthcare access for HLI.

Nursing

Findings from this study provide several implications for community and public health nursing in areas of education, practice and research. Critical perspectives such as postcolonial theory and critical ethnography provided a basis for understanding healthcare access disparities and inequities within a critical paradigm of social injustice. With the ethical responsibility of advocating for their patients wellbeing, nurses are in a unique position to promote the ideals of social justice by promoting changes in the societal

structures that underline the social determinants of healthcare access inequities for HLI (Kagan, Smith, Cowling & Chinn, 2009). As a centrally established work focused on activism and social justice in nursing discourse, the *Nursing Manifesto* promotes the emancipatory perspectives of nursing research, practice and education (Cowling, Chinn & Hagedorn, 2000). These critical perspectives will be used as a guide to discuss implications and recommendations of research findings on advancing the emancipatory role of nurses.

Education.

We advocate for a critical formulation of the educational enterprise of nursing that places a greater emphasis on personal and professional sovereignty and that nurtures the development of action generated from reflection, contemplation, and recognition of values. We believe that it is time to attend to inherent wholeness and natural healing tendencies that are often educated out of nurses as students. (Cowling et al., 2000)

As the initial and sometimes only form of healthcare contact for HLI and other underserved groups, it is essential for nurses to establish trusting patient-provider relationships through the provision of linguistic and culturally competent care. Research findings indicated that participants were more likely to have increased contact with nurses than physicians during their healthcare visits. Nurses were also identified as key individuals in providing health education and counseling for patients regarding their conditions and treatment regimens. However, participants also faced language and cultural barriers when receiving care from nurses and other healthcare providers. Providing culturally competent care begins with the foundations of nursing education that are built on the metaparadigm of wholeness, where the interconnected entities of the individual and the universe create the idea of health (Newman, Smith, Dexheimer-Pharris & Jones, 2008; Rogers, 1970). Critical ethnography and postcolonial theoretical perspectives are also supported by this fundamental paradigm of nursing, and should be incorporated in educational programs to promote understanding of inequities in healthcare access for HLI (Cowling et al., 2000). Educating nurses using holistic health perspectives enhances understanding of the social determinants of health and healthcare access, illuminating issues of social injustice and inequities among HLI and other underserved groups (Kagan et al., 2009; Pauly, MacKinnon, Varcoe, 2009). As indicated in study findings, health is not merely a product of illness or disease, but is related to the social determinants of healthcare access shaped within historical, sociocultural, political and economic contexts. Incorporating

critical perspectives in the nursing curricula is crucial for nurses to have a thorough, holistic and contextual understanding of health.

With increased globalization and diversification of communities, it is essential to continually promote cultural competence in nursing education. Although educating nurses on different cultures, practices and beliefs that influence the health of individuals from diverse backgrounds is an essential feature of cultural competence, educating students on how to be critical and self-reflective of their own biases and prejudices when providing care is imperative and enduring (Cowling et al., 2000; Kirkham & Anderson, 2002; Tang & Browne, 2008). As a core component of CE and postcolonial theory, reflexivity emphasizes the need for nurses to engage in a continual process of self-examination, especially when providing care for individuals whose linguistic and cultural background are different from their own (Freire, 1970; Blackford, 2003). Critical self-reflection is a powerful skill that equips nurses with the ability to provide culturally competent care in all healthcare settings, despite differences in language and culture. By promoting respect and understanding for their patient's cultural and individual differences, nurses build a foundation for a healthy, trusting patient-provider relationship, which has been shown to enhance health-seeking behaviors and promote healthcare access for HLI (Cowling et al., 2000). Nurses are in important positions to promote health and healthcare access for underserved groups and must be equipped with the knowledge to practice in critical self-reflection that enhances the provision of culturally competent care.

Practice.

We believe that nurses are particularly attuned to the needs for social justice throughout the world, given their connection to humans in times of personal change and challenge. It is because we cannot practice the art of nursing that we act. While we may have grown silent, our patients believe in us. We must listen. We must speak. (Cowling et al., 2000)

Promoting the emancipatory role of nursing practice is dependent upon the adoption of a praxis-oriented philosophy that challenges the status quo, illuminates inequities in the distribution of power and resources such as healthcare, and functions as a foundation for building a just society through social change (Freire, 1970; Cowling et al., 2000; Creswell, 2007; Kagan et al., 2009; Kirkham & Anderson, 2002). Nurses are at the forefront of providing primary healthcare services to underserved immigrant populations, indicating their centrality in eliminating the social determinants that serve as barriers to healthcare access for HLI (International Council of Nurses, 2011). According to Reutter & Kushner (2010), nurses are essentially mandated to ensure access to healthcare by providing culturally competent, empowering care to

the underserved by promoting changes in societal structure that perpetuate social injustices and health inequities. As indicated in study findings, health and health-seeking behaviors of HLI were significantly influenced by unique immigration factors, which make them increasingly susceptible to psychological and physiological stressors. These findings indicate the need for nursing interventions aimed at facilitating healthy integration of immigrants by empowering immigrants with the knowledge and resources needed to improve their health and quality of life. Listening to and representing the voice of HLI during these stressful transitional times is an essential component of providing culturally competent and empowering care (Cowling et al., 2000). Empowerment through outreach and advocacy was shown to be an effective facilitator to healthcare access for HLI in Louisville, and must be a central feature of nursing practice aimed at reducing health disparities.

Expanding nursing practice to address social determinants of health and healthcare access is essential and requires an emphasis on policy analysis as a form of advocating for health equity for HLI and other disadvantaged groups (Rains Warner, 2003; Reutter & Kushner, 2010). As indicated in study findings, policies play a central role in shaping political contexts that serve as barriers to healthcare access. Therefore, in order to address these disparities, nurses must go beyond their traditional praxis roles by adopting an active critical voice and politicized stance (Browne & Tarlier, 2008). Nurses must continue to expand their roles, not only in health practice and research, but also in the policy world as lobbyists, policy analysts and implementers (Reutter & Kushner, 2010). With the power to represent the voice of those who are unable to be heard, especially undocumented immigrants, nurses are in a unique position to influence policy changes that improve healthcare access for HLI.

Research.

These emancipatory research methods are founded on the beliefs that humans long for wholeness; wholeness requires connection; connection demands participation; participation leads to empathy; empathy implies responsibility; and humans cannot experience wholeness or freedom without responsibility. (Cowling et al., 2000)

Research findings provided several implications for the use of critical ethnography and postcolonial theory in nursing research to effect change in addressing healthcare access disparities for HLI (Baumbusch, 2010). Findings indicated that critical perspectives such as postcolonialism provide an emancipatory framework to examine health experiences of HLI and other underserved groups whose voices

are often muted or not represented in larger contexts of health (Cowling et al., 2000; Kirkham & Anderson, 2002). Perspectives of immigrants, especially the undocumented are not adequately represented in healthcare services research, resulting in substantial gaps in literature. Critical, emancipatory research methods provide a framework where participants become active components of the research process and become engaged in providing meaningful insight into the SDH (Lather, 2001; Thomas, 1993). The use of critical ethnography and postcolonial theoretical constructs in this study provided an in-depth, contextually-based analysis of the barriers and facilitators to healthcare access for HLI from their own perspective. Furthermore, including the voice of participants enhances political empowerment, which is imperative to understanding SDH. Enhanced nursing research using participatory action and community-based research approaches are warranted to enhance understanding of the social determinants of healthcare access for HLI from a social justice perspective (Pauly et al., 2009).

The WHO's CSDH (2008) calls for an enhanced focus on SDH in public health research in order to aptly address ways to reduce disparities in healthcare access and health outcomes. Findings from this study helped identify healthcare access as a vital SDH, but also provided insight into the contextually based barriers and facilitators to access that served as social determinants of healthcare access (CDC, 2011; IOM, 1993). Using the CFAAHS helped identify that access was influenced by social determinants stemming from historical, sociocultural, economic and political contexts that were unique to influencing healthcare access inequities among HLI. This provided implications for healthcare systems to focus on accommodating to the dynamic elements of the process of healthcare access rather than individual parts (Ricketts & Goldsmith, 2005). The ability of access frameworks to stimulate changes in the provision of health services is contingent upon the adaptability of the healthcare system. As the Louisville community continues to change with its growing HLI population, the healthcare system must be able to adapt to the needs of this diverse group by providing equitable access to health services. The CFAAHS provides a dynamic framework to measure healthcare access in changing societies and must be incorporated in nursing research to develop appropriate interventions to address healthcare access inequities.

Advancing nursing research using emancipatory methods of inquiry should be encouraged as it contributes to the CSDH's goal of enhancing focus on the SDH in order to aptly address ways to eliminate health disparities (CSDH, 2008; Cowling et al., 2000; Kirkham & Anderson, 2002). Additionally, as

findings signified the strength and intersectional nature of immigration, welfare, social, economic and health policies, nurses must also engage in policy analysis research to understand the effectiveness of policies on reducing health inequities for HLI and other underserved groups (Bryant, 2011; Duncan & Reutter, 2006; Reutter & Kushner, 2010). Effective policy analysis research will help make a case for comprehensive policy reform and the implementation of innovative and cost-effective strategies to improve healthcare access and eliminate health disparities. Further implications and recommendations for policy reform are discussed in the following sections.

Policy

Study findings indicated that barriers and facilitators to healthcare access for HLI especially the undocumented, were significantly impeded by immigration, welfare and health policies. The intersectional nature of immigration and healthcare reform indicates the need for future policies that focus on improving access to care for undocumented HLI. Health economics and public health perspective support the need for health policy reform that provides equal access to healthcare services and insurance coverage for all (Nandi et al., 2009). Providing better access and quality of care for immigrants benefits the community as a whole by improving public health outcomes and reducing healthcare expenditures. This signifies the need for collaboration of policymakers from different public sectors, including healthcare, immigration, social and economic sectors. In analyzing the effects of past, current, and future immigrant health policy changes and its implications for access, quality and cost of care for HLI, findings from this study make a case for comprehensive policy reform that expands access to healthcare immigrants. However, findings indicated that health policies such as the PPACA (Pub. Law No. 111-148., 2010) impose considerable barriers to accessing health insurance and healthcare for HLI, especially the undocumented. The establishment of the PPACA has resulted in growing concerns among policymakers and advocates regarding the exclusion of undocumented immigrants from purchasing health insurance through state exchange programs (American College of Physicians, 2011). The rippling effects of these restrictions can be seen throughout the healthcare system, but has been shown to have significant implications for the healthcare expenditures, public health and the role of healthcare providers.

Healthcare expenditures. By excluding undocumented immigrants from purchasing healthcare insurance, the PPACA serves as a barrier to healthcare access, which also results in increased healthcare expenditures (NILC, 2010, 2009). As indicated in the study findings and existing literature, HLI and other

immigrants are less likely to access primary healthcare services, resulting in significantly fewer dollars per capita for healthcare (Mohanty et al., 2005). However, immigrants who were undocumented, uninsured and did not have a usual source of healthcare sought services from hospital emergency rooms. Although undocumented immigrants account for only 1.5% of total U.S. medical costs, most of these costs were incurred from emergency room visits (Okie, 2007; DuBard & Massing, 2007). Under EMTALA, hospitals are mandated to provide medical treatment to everyone who presents with an emergent condition regardless of their ability to pay, health insurance coverage or immigration status (Grimm & Wells, 2009). Due to insufficient health insurance coverage and inadequate income, HLI are unable to cover their healthcare expenses, resulting in increased government spending and strain on taxpayers. Costs incurred from unpaid emergency room bills usually becomes the responsibility of hospitals and state and local governments, increasing overall healthcare system costs and expenditures (Footracer, 2009; Galewitz, 2013).

The Immigration Policy Center (2009) argues that the greater the number of people who pay into the healthcare system, the more costs are distributed, eventually reducing overall expenses for all. Excluding undocumented immigrants from purchasing health insurance from state exchanges established by the PPACA and barring them from subsidies can be detrimental to others who are paying into the system. Exchanges will be more expensive due to the lack of distribution among all those utilizing the healthcare system (NILC, 2009). Others (Ross, 2007; Majority Staff Committee on Oversight and Government Reform, 2007) argue that taxpayer dollars should not be wasted on immigration status verification systems and other documentation schemes that further burden the system and create barriers for those who need healthcare. Instead, suggestions have been made to change focus from enforcing immigration laws to finding ways to include immigrants in the system to address the impending issue of disparities in healthcare access.

Public health. Findings indicated that as a result of barriers to healthcare access, the focus of health among HLI has changed from preventive care to immediate or emergent care, which prevents early detection and treatment of illnesses and diseases. Study findings and existing literature indicated that HLI, like other immigrants, are less likely to have a primary healthcare provider or other regular sources of healthcare, which resulted in delayed health-seeking behaviors for more than one year (Lasser et al., 2006; Guendelman, Schauffler, & Pearl, 2001). Furthermore, immigrants are less likely to access or utilize

preventive services, especially in areas of cancer screening, STD testing, vaccinations, and pediatric and prenatal preventive care (Echeverria & Carrasquillo, 2006; Goel et al., 2003; Lees et al., 2005; Cohen & Christakis, 2006). Delayed presentation of HIV was also of particular concern among HLI, due to lack of screening and preventive measures (Levy et al., 2007; Servin et al., 2012). As seen among participants in this study, advances in the stages of the disease process that are left undetected can pose serious threats to the health and wellbeing of the community as a whole, while consequently increasing healthcare expenditures. Studies have indicated that access to preventive healthcare services improves the overall public health and minimizes healthcare expenditure (Cohen & Christakis, 2006; Cosman, 2005; Carrasquillo et al., 2000). Therefore, promoting preventive healthcare measure among HLI, which includes having regular visits to a primary healthcare provider, can help prevent delayed health-seeking behaviors and disease presentation and spread of communicable diseases.

Role of healthcare providers. Healthcare providers are obliged to follow their respective codes of ethics that generally address justice, nondiscrimination, and confidentiality in the provision of healthcare for all people (Mappes & Degrazia, 2006). The implementation of the PPACA and the exclusion of undocumented immigrants from equitable access to healthcare has significant implications for healthcare providers and their ethical conducts of practice (ACP, 2011). As a result, several professional organizations, such as the ACP, American Medical Association (AMA) and the American Nurses Association (ANA) oppose legislation that restricts provision of healthcare to undocumented immigrants or require providers to report the “illegal” status of immigrants (Footrace, 2009). As indicated in study findings and existing literature, being undocumented was a significant barrier to healthcare access for HLI due to fears of being detected and deported based on their immigration status. According to the American Association of Registered Nurses (2012), once the PPACA is fully implemented, this fear will be worsened as undocumented immigrants will be easier to identify being the only group restricted from participating in this program. Essentially, nurses and other healthcare providers will be faced with the dilemma of choosing between abiding to their ethical principles of practice or implementing immigration law by turning away patients in need of healthcare services based on their immigration status.

The ANA (2001) code of ethics states that nurses are required to practice with “compassion and respect for the inherent dignity, worth, and uniqueness of every individual, unrestricted by considerations

of social or economic status, personal attributes, or the nature of health problems” (p. 1). In adhering to the ethical principles of non-maleficence, beneficence, and confidentiality, nurses are often times faced with ethical dilemmas when treating undocumented immigrants, due to legal issues associated with providing care. As patient advocates, nurses and other healthcare providers are obligated to provide care to all those in need, regardless of immigration status (Grimm & Wells, 2009). The primary goal of healthcare providers is to promote overall health and wellbeing of the community. This can be achieved by providing equal access to healthcare and health insurance coverage for HLI and other immigrants through active health policy reform.

Recommendations for comprehensive policy reform. It is evident that restricting HLI from receiving equal access to care can have several negative repercussions on healthcare costs, community health and healthcare disciplines (ACP, 2011; NILC, 2009). Policymakers have a short window of opportunity to act before the PPACA takes its full effect in 2014. During this time, healthcare providers and other community members are urged to take action by supporting policies aimed at improving healthcare access and insurance coverage for immigrants, especially the undocumented. Advocacy organizations such as the NCLR (2011) recommend enhanced measures to expand healthcare coverage and access for HLI through policy reform. Similarly, professional health organizations such as the ACP have emphasized the need for comprehensive immigration and health policy reform. The ACP (2011) calls for a national immigration policy that addresses expansion of healthcare for immigrants in the U.S. Therefore, it is recommended that other health professionals, especially nurses, support the implementation of policies that focus on improving access to healthcare for HLI and other immigrant groups.

Over the years, nurses have become increasingly active in health policymaking and implementation that focuses on eliminating health disparities and providing equal access to care for immigrants. In the U.S., nurses are in a unique position to serve as lobbyists, policymakers, and in other leadership roles that enable them to make effective changes in improving the future of community and public health. Nurses should focus on policies that aim to reduce the vulnerability of undocumented immigrants by expanding health insurance coverage and safety-net infrastructures, decreasing barriers to accessing care, and revising the current provisions of the policies such as PRWORA and the PPACA (ACP, 2011; Derose et al., 2007). Policies such as the PRWORA and the PPACA that restrict access to vital health

and social services for HLI must be addressed in order to promote equitable access to resources, especially for the undocumented. According to Derose et al. (2007) policies such as PRWORA that were put into place to curb the rate of immigration in the U.S. should be reconsidered in light of growing access disparities for this population. Study findings and existing literature indicated that restricting immigrants from Medicaid, but allowing them to access emergency services, were shown to have a significant impact on primary prevention practices of immigrants, eventually leading to the overburden of the healthcare system and jeopardizing the health of the broader community (Galewitz, 2013).

These findings provide implications for policy reform on local and state levels in order to expand access to health and related social services for HLI. Future policies should focus on increasing funding for public programs, community health centers, and organizations that provide free or subsidized care to HLI and other immigrants (NCLR, 2011). Research suggests modifications and revision of federal, state, and local level policies that restrict healthcare access for HLI, especially the undocumented, enhances availability of and access to healthcare (Cacari-Stone & Balderrama, 2008). Policies that expand healthcare insurance coverage at the state level can help advance healthcare access for HLI and the uninsured population at large. Additionally, policies should be aimed at increasing employer-provided health insurance in immigrant labor sectors, in order to expand health coverage and encourage health-seeking behaviors (Buchmueller, Lo Sasso, Lurie & Dolfin, 2007). According to Bell (2004), employer-provided health insurance can be promoted through the provision of benefits such as state-sponsored benefit packages. Similarly, increasing funding to expand publicly funded health programs can also increase healthcare coverage and access for immigrants.

In order to eliminate language barriers to healthcare access, policy changes must be implemented in hospitals and other health facilities and measures must be established to enforce Title VI and provide culturally and linguistically competent healthcare services (Kentucky Youth Advocates, 2009). The provision of interpreter services in hospitals and primary care centers are federally mandated and should be enforced in healthcare facilities. Establishing Title VI, along with the expansion of educational programs for bilingual staff members, can help reduce language barriers among HLI and healthcare providers (Bell, 2004). As indicated in study findings, increased communication builds trust and familiarity, which was shown to enhance the patient-provider relationship and promote health-seeking behaviors among HLI.

Modifications to current policies can be effectively designed based on lessons learned from healthcare system models of other developed nations. Although the U.S. has a diverse immigrant population similar to other nations, the U.S. is incomparable to other westernized countries such as Canada in respect to providing access to care for immigrants (Zuberi, 2006). Findings from a cross-national comparative study suggests that a more comprehensive approach to healthcare and provision of health insurance, such as the one utilized in Canada, would significantly improve immigrants' access to care in the U.S. (Siddiqi et al., 2009). Participants from countries with universal healthcare coverage, such as Cuba, also indicated that better access to healthcare through a universal healthcare system promoted health-seeking behaviors. Using Canada and European countries as an example, the U.S. is urged to make immediate policy changes to the current healthcare reform system to ensure the health and wellbeing of the nation. Policies that aim to advance access to healthcare and coverage for immigrants are shown to be effective in reducing overall healthcare costs and improving health outcomes in other developed nations (Lasser et al., 2006; Prus et al., 2010). Implementing a successful and comprehensive healthcare system can be achieved by shaping policies through lessons learned from other nations.

Research findings provided several implications and recommendations for health and social policies, indicating that effective health policy reform is imperative in order to overcome barriers to healthcare access for HLI and undocumented immigrants. Findings from this study also provided a contextual basis of understanding the social determinants of healthcare access that occur as a result of inequitable health and social policies. Understanding the forces that have shaped policy implementation over the years is essential for policymakers who aim to implement comprehensive health, social and immigration policies that address current and future needs of HLI, immigrants and the community as a whole. The future of the health and wellbeing of immigrants and the nation as a whole lies in the hands of policymakers whose influential roles can establish health policy reform to improve access to healthcare for all.

Limitations

There are several limitations to this study that must be acknowledged. As this project used qualitative methodologies and critical perspectives, it introduced several sources of bias into the research process and findings (Carspecken, 1996). The investigator made numerous efforts to minimize the effects

of these biases on influencing the integrity of this study by addressing issues of positionality, otherness and critical reflexivity (Hammersley & Atkinson, 1995; Madison, 2005; Merriam, 1988). Ethical considerations taken in this study (see chapter three), help clarify the sources of investigator bias and provide readers with an understanding of the investigator's positionality or assumptions that may have influenced the research process. Eliminating bias altogether is essentially impossible in critical ethnography due to its value-laden, political nature (Carspecken, 1996). Therefore, while efforts were taken to minimize sources of bias, readers must acknowledge the critical stance of this study, especially when interpreting research findings.

Clarifying researcher positionality and bias through critical reflexivity also helped distinguish the influences of power on the relationship between the researcher and the researched (Carspecken, 1996; Thomas, 1993). Power relations in the ethnographic research process, where the researcher is viewed to be in a more powerful position than the researched, is influenced by the intersectionality of various aspects, such as language, education, social status and gender (Fine, 1994; Chen, 2011). As this study was guided by postcolonial theory, built on the constructs of power and domination, the investigator took several measures to minimize researcher-researched power dynamics, namely through the use of culturally and linguistically appropriate critical ethnographic methods. However, power relations between the investigator and the participants may have influenced the integrity of participant narratives in this study. This is a limitation of the study, because it is not feasible to confirm the verity of information provided by participants by removing the effects of these power relations. Therefore, findings must be understood within the context of power relations in the research process.

As purposeful sampling methods were used in this study to target a specific HLI population within a distinct geographic location of southern Louisville, findings from this study are not generalizable to other populations and settings. However, as generalizability is not of ultimate importance in naturalistic methods of inquiry, this study used transferability techniques to maintain trustworthiness of study findings (Glesne & Peshkin, 1992; Lincoln & Guba, 1985). In doing so, the investigator provided the reader with sufficient knowledge to determine transferability of data based on purposeful sampling strategies and thick descriptions. Additionally, a sample size of 20 participants may be deemed as a limitation of this study. However, qualitative methodologies determine sample size adequacy through the use of data saturation, valuing the quality of the sample over the quantity (Patton, 2002, Denzin & Lincoln, 2005; Sandelowski,

1995). Therefore, sample size in this study was determined by the ability of the research findings to provide an in-depth, varied understanding of HLI health experiences in Louisville.

Although efforts were taken to provide a diverse representation of HLI subgroups in Louisville, this study did not adequately account for immigrants from South American countries. Findings indicated that the total HLI population in Louisville was predominantly represented by Mexicans, Cubans, Puerto Ricans and immigrants from other Central American countries such as Guatemala and Ecuador. These subgroups were also identified to be at a lower socioeconomic level relative to other South American HLI. However, incorporating the perspectives of other HLI subgroups could have provided depth to understanding barriers to healthcare access, especially in relation to varying cultural and socioeconomic backgrounds of HLI.

Another limitation of this study is the representation of varying subgroups of HLI as one cohesive cultural group. Hispanic Latino immigrants represent different races, nationalities, socioeconomic backgrounds and cultures. As the intent of this study was not to generalize all Hispanic Latino subgroups as one cohesive group, the investigator took several measures to adequately represent variations among HLI subgroups on perceptions of health and healthcare access when necessary. Nevertheless, findings must be interpreted cautiously, as they are not generalizable to all members and/or groups of the HLI community in Louisville.

Future Research

Research findings indicated that despite the growing rates of HLI and their major contributions to U.S. society, they continue to experience health inequities as a result of the unique SDH that serve as barriers to healthcare access. These disparities can be addressed through enhanced future research on the social determinants of healthcare access relative to varying sociocultural, economic, political, and historical contexts (CSDH, 2008). This study serves as a basis for future research examining the impact of SDH on healthcare access among other HLI subgroups and immigrant populations, highlighting the need to further explore these phenomena on regional and national levels. As findings from this study are not generalizable to HLI groups in other geographic locations, continued research on perceived barriers and facilitators to healthcare access among HLI subgroups in different settings is warranted. This will provide insight into

ways to address contextually based social determinants of healthcare access in order to appropriately inform and enhance interventions and policies aimed at reducing health inequities among HLI groups.

Findings also provide significant implications and recommendations for future interdisciplinary and collaborative research in nursing, health services research, social work and other related disciplines focused on further examining ways to eliminate health disparities. Future studies must focus on establishing effective, collaborative methods to tackle healthcare access inequities in a comprehensive manner. This can be accomplished through the enhanced policy analysis research in nursing and other health disciplines. Reutter & Kushner (2010) emphasize the need for policy analysis research in nursing to address the SDH and promote health equity by understanding the process, contexts and content of policies. Policy analysis research is imperative to inform advocacy efforts of nurses to bring changes in current policies that restrict healthcare access for HLI and other immigrants. Through enhanced research, nurses can inform policies to establish changes in areas of immigration, health and social policy reform to aptly address health disparities.

Similar to this study, qualitative research using postcolonial theory and other critical perspectives to understand the health experiences of immigrants, the underserved and those who do not have a voice in mainstream U.S. society are necessary (Kagan et al., 2009; Kirkham & Anderson, 2002; Mohammad, 2006). These studies can provide insight into the reasons for health and healthcare access disparities that stem from underlying social, economic and political structures of power and oppression that continue to influence the current inequities that oppress HLI and other immigrant groups. Critical perspectives must be embraced in nursing education, practice and research, especially in areas of policy advocacy to appropriately inform community efforts to promote health equity and social justice for the oppressed and underserved. Giving voice to these groups through the use of critical research methods helps empower individuals to fight for their rights to healthcare as equal members of society.

Based on findings from this dissertation, developing interventions through community programs and policy advocacy to eliminate healthcare access inequities among HLI in Louisville must be taken as the next logical step of this research program. The effectiveness of these interventions in improving healthcare access for HLI can be efficiently examined through enhanced participatory action and community-based nursing research approaches (Pauly et al., 2009). Future research focused on examining effective methods

to establish equitable healthcare access, reduce health disparities and improve overall community health outcomes is warranted. Findings from this study serve as a basis for future research on the impact of SDH on healthcare access among immigrants and other underserved groups, highlighting the need to further explore these phenomena on a national and international level.

Conclusion

Findings from this dissertation have the potential to help promote social justice and healthcare equity for HLI in Louisville by critically examining the barriers and facilitators to healthcare access. Based on critical perspectives of postcolonial theory and critical ethnography, the social determinants of healthcare access were identified in several areas of access pertaining to availability, accessibility, affordability and acceptability. Although several studies have been conducted in health and social service areas to understand the needs of HLI in Louisville, this study is the first of its kind to take the voice and narratives of HLI and understand barriers and facilitators to healthcare access within a postcolonial, critical framework. Critical perspectives allowed for an in-depth contextual analysis that revealed numerous factors that were unique to the history and culture of Louisville and the social economic and political structures that influenced the current condition of HLI in this region.

This new approach to inquiry illuminated the need to address healthcare access disparities using both a top down approach, by advocating for policy reform, and a bottom-up approach through the empowerment of HLI in order to meet in at the core of social justice and equality. Findings indicate that systemic problems were integral to shaping the social determinants of healthcare access for HLI. However, historical, sociocultural, economic and political factors were shown to affect individuals, community and systems simultaneously and therefore, must be addressed concurrently. Findings provide several implications and recommendations for changes in healthcare systems, community programs, nursing and policy to reduce healthcare access disparities among HLI. Although not generalizable to HLI groups in other geographic locations, findings from this study provide significant insight for health and social service providers, researchers and policy makers to tailor healthcare services to meet the needs of this underserved growing population. Addressing the social determinants of healthcare access for HLI reduces health disparities within the community and promotes social justice and equality for all.

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APPENDIX A

Informed Consent Forms in English and Spanish

Informed Consent

UNIVERSITY OF LOUISVILLE
INSTITUTIONAL REVIEW BOARD
Date Approved 11/29/2012 Valid Thru 11/28/2013

Understanding Social Determinants of Healthcare Access from the Perspective of Hispanic Latino Immigrants in Louisville, KY

Investigator(s) name & address: Vicki Hines-Martin, PhD, RN, FAAN & Jean Edward, RN, BSN, PhD Student, University of Louisville, School of Nursing, 555 South Floyd Street, Louisville, KY 40292

Site(s) where study is to be conducted: Multiple Locations in Louisville, Kentucky

Phone number for subjects to call for questions: Vicki Hines-Martin- 502 852 8511; Jean Edward 502 852 5129

Introduction and Background Information

You are invited to participate in a research study. The study is being conducted by Vicki Hines-Martin and Jean Edward from the University of Louisville, School of Nursing. The study will take place at multiple locations. Approximately 20 people will be invited to participate.

Purpose

The purpose of this study is to explore your thoughts about healthcare access for Hispanic Latino immigrants in Louisville, KY.

Procedures

In this study you are being asked to share your experiences about going to a doctor or a nurse to take care of your health. During this interview you will be asked about your experiences finding and using healthcare services. You will be interviewed in a private place using questions from a short survey and an interview guide. The interview will take approximately 60 minutes to complete. All interviews will be audiotaped to make sure the information you provide is accurately recorded and notes will be taken by the investigator.

Potential Risks

There are minimal risks associated with participating in this program. There may be unforeseen risks.

Benefits

There are no direct benefits to you from your participation of this study, although the information learned in this study may be helpful to others.

Compensation

You will receive a \$10 gift card to Kroger for your time, after completing the interview in this study.

Confidentiality

The investigators will protect the information you provide during and after your interview. However, total privacy cannot be guaranteed. Your privacy will be protected to the extent permitted by law. If the results from this study are published, your name will not be made public. While unlikely, the following people may look at the study records:

The University of Louisville Institutional Review Board, Human Subjects Protection Program Office, and Privacy Office

People who are responsible for research and HIPAA oversight at the institutions where the study is conducted

Office for Human Research Protections (OHRP),

Information you disclose to the research team will be kept in password protected files and/or locked file cabinets within a secure research office that are available only to the study investigators.

Conflict of Interest

This study does not involve a conflict of interest because neither the institution nor the investigators will be compensated (paid) for your participation.

Voluntary Participation

Taking part in this study is voluntary. You may choose not to take part at all. If you decide to be in this study you may stop taking part at any time. If you decide not to be in this study or if you stop taking part at any time, you will not lose any benefits for which you may qualify. You will be told about any changes that may affect your decision to continue in the study.

Research Subject’s Rights, Questions, Concerns, and Complaints

- If you have any concerns or complaints about the study or the study staff, you have three options.
- You may contact the principal investigator Vicki Hines-Martin at 502 852 8511.
 - If you have any questions about your rights as a study subject, questions, concerns or complaints, you may call the Human Subjects Protection Program Office (HSPPO) (502) 852-5188. You may discuss any questions about your rights as a subject, in secret, with a member of the Institutional Review Board (IRB) or the HSPPO staff. The IRB is an independent committee composed of members of the University community, staff of the institutions, as well as lay members of the community not connected with these institutions. The IRB has reviewed this study.
 - If you want to speak to a person outside the University, you may call 1-877-852-1167. You will be given the chance to talk about any questions, concerns or complaints in secret. This is a 24 hour hot line answered by people who do not work at the University of Louisville.

This paper tells you what will happen during the study if you choose to take part. Your signature means that this study has been discussed with you, that your questions have been answered, and that you will take part in the study. This informed consent document is not a contract. You are not giving up any legal rights by signing this informed consent document. You will be given a signed copy of this paper to keep for your records.

_____ Signature of Subject/Legal Representative	_____ Date Signed
_____ Signature of Person Explaining the Consent Form (if other than the Investigator)	_____ Date Signed
_____ Signature of Investigator	_____ Date Signed

LIST OF INVESTIGATORS/PHONE NUMBERS
Vicki Hines-Martin 502 852 8511
Jean Edward 502 852-5129

UNIVERSITY OF LOUISVILLE INSTITUTIONAL REVIEW BOARD Date Approved <u>11/29/2012</u> Valid Thru <u>11/28/2013</u>
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Documento de consentimiento informado para el sujeto de investigación

Reconocimiento de los determinantes del acceso a atención médica desde la perspectiva de los inmigrantes hispanos en Louisville, KY

Datos del equipo de investigación: Vicki Hines-Martin, PhD, RN, FAAN y Jean Edward, RN, BSN, estudiante de doctorado, Facultad de Enfermería, University of Louisville, 555 S Floyd ST, Louisville, KY 40292

Sitio(s) en donde se efectuará la investigación: Varias localidades en Louisville, KY.

Números de teléfono si los sujetos tienen preguntas: Vicki Hines-Martin 502 852 8511; Jean Edward 502 852 5129

Introducción e información preliminar

Está invitado/a a participar en un estudio investigativo. Vicki Hines-Martin y Jean Edward de la Facultad de Enfermería de la University of Louisville dirigirán la investigación. La investigación se realizará en varias localidades. Se invitarán a participar a aproximadamente 20 sujetos.

Objetivo

El propósito de esta investigación es explorar sus pensamientos acerca del acceso a atención médica para los inmigrantes hispanos en Louisville, KY.

Procedimientos

En esta investigación pedimos que usted comparta sus experiencias al ser atendido/a por un/a médico/a o un/a enfermero/a para cuidar de su salud. Durante esta entrevista le preguntaremos acerca de su búsqueda y su uso de servicios de salud. La entrevista se llevará a cabo en una localidad privada, y se utilizarán una breve encuesta junto con un guión con preguntas. La entrevista durará aproximadamente 60 minutos para completar. Se grabarán todas las entrevistas y la investigadora sacará apuntes para asegurar la precisión de la información recopilada.

Potenciales riesgos

Existen muy pocos riesgos asociados con la participación en este programa. No obstante, puede haber riesgos imprevisibles.

Beneficios

No habrá beneficios directos, aunque la información recopilada de esta investigación pueda ser beneficiosa para otros.

Compensación

Usted recibirá una tarjeta de Kroger con el valor de \$10 por su tiempo después de la entrevista.

Confidencialidad

No se puede garantizar privacidad completa. Sin embargo, su privacidad será protegida con todo el peso de la ley. Si se publican los resultados de esta investigación su nombre no aparecerá en la publicación.

Aunque no sea probable, las organizaciones en la lista a continuación pueden revisar los documentos de la investigación:

The University of Louisville Institutional Review Board (el Consejo de Revisión Institucional de la Universidad de Louisville), Human Subjects Protection Program Office (la Oficina del Programa de Protección para Sujetos Humanos) y Privacy Office (la Oficina de la Privacidad)

El personal responsable por la supervisión de investigaciones e HIPAA en las instituciones en donde se realizan la investigación

Office for Human Research Protections (OHRP) (la Oficina de Protección para Investigaciones de Seres Humanos)

Información compartida con el equipo se mantendrá en archivos cerrados con contraseña y/o en archiveros cerrados con llave.

Conflictos de interés

Esta investigación no presenta ningún conflicto de interés porque ni la institución ni la investigadora recibirán compensación por la participación de los sujetos.

Participación voluntaria

Participar en la investigación es voluntaria y usted puede escoger no asociarse de ninguna manera. Si usted decide ser parte de la investigación puede dejar de hacerlo a la hora que quiera. Si usted decide no colaborar en la investigación o si deja de participar a cualquier hora, no perderá ningún beneficio para el cual se califique. Se le notará a usted cualquier cambio que pueda afectar su decisión para continuar en la investigación.

Derechos, preguntas, preocupaciones y quejas del sujeto de la investigación

Si tiene preocupaciones o quejas acerca de la investigación o del equipo investigativo, hay tres opciones.

-Se puede contactar con la investigadora principal, Vicki Hines-Martin, 502 852 8511.

-Si tiene cualquier pregunta, preocupación o queja con respecto a sus derechos como sujeto de investigación, se puede llamar la Oficina del Programa de Protección para Sujetos Humanos (HSPPO) 502 852 5188. Se puede tratar preguntas acerca de sus derechos como sujeto, en confidencia, con personal del Consejo de Revisión Institucional (IRB) o de la HSPPO. El IRB es un comité independiente que se consta de miembros de la comunidad de la universidad (de Louisville), personal de las instituciones, y también de miembros de la comunidad sin vínculos a estas instituciones. El IRB ha revisado esta investigación.

-Si prefiere hablar con alguien fuera de la universidad, se puede marcar 1-877-852-1167. Tendrá la oportunidad de hacer preguntas y/o hablar de preocupaciones o quejas en confidencia. Ésta es una línea abierta 24 horas al día y contestada por personal que no trabaja en la University of Louisville.

Este documento le informa acerca de lo que sucederá durante la investigación si usted escoge colaborar. Su firma implica que se ha tratado la investigación con usted, que ha recibido respuestas a sus preguntas y que si usted participará en el estudio investigativo. Este consentimiento informado no es contrato. Usted no renuncia ningún derecho civil por firmar este consentimiento informado. Recibirá una copia de este documento para su propia información.

Firma del participante o del guardián

Fecha

Firma de la persona que le explica el documento
(si no es la investigadora)

Fecha

Firma de la investigadora

Fecha

LISTA DE INVESTIGADORAS/ TELÉFONOS

Vicki Hines-Martin 502 852 8511

Jean Edward 502 852 5129

UNIVERSITY OF LOUISVILLE
INSTITUTIONAL REVIEW BOARD
Date Approved 11/29/2012 Valid Thru 11/28/2013

APPENDIX B

Descriptive Survey Forms and a Semi-structured Interview Guide in English and Spanish

Descriptive Survey Form

1. Age (how old are you?) _____
2. Gender - Female _____ Male _____
3. Country of origin/birth (that you come from) _____
4. Race _____
5. Ethnicity _____
6. How many years have you lived in the US? _____
7. How easy is it for you to speak English? ___Not at all ___Somewhat ___Very
8. Occupation (Where do you work?) _____
9. How much money do you make weekly? _____ \$0- 124
_____ \$125-249
_____ \$250-374
_____ >\$375
10. What was the last year of school that you completed? _____ grades 1-8
_____ Some high school
_____ High school diploma
_____ Some College
_____ 2-year College degree
_____ 4-year College degree
11. Do you have health insurance? ___Yes ___No
- If yes- Do you receive your health insurance through: ___ Your job
_____ From the (U.S. or state) government?
_____ Medicaid
_____ Medicare
_____ Pay for yourself
_____ Other (identify) _____
12. Do you have a doctor or nurse you go to see most of the time when you are sick in the U.S.?
___ Yes ___No

If Yes- What is the address/zipcode of the office location? _____

How do you get there? Walk

Bus

Your own car

Taxi

Get a ride from someone

How long does it take you to get there? _____

What zipcode do you live in? _____

13. Did you have a doctor or nurse you go to see when you were sick in your home country?

Yes No

If no- Who did you go to when you were sick in your home country?

Encuesta descriptiva

1. Edad (¿Cuántos años tiene?)_____
2. Sexo – mujer _____ hombre_____
3. País de origen/natal (de donde viene) _____
4. Raza_____
5. Etnicidad_____
6. ¿Hace cuántos años que vive en los EE.UU.? _____
7. ¿Cuán fácil es para usted hablar el inglés? ___Nada ___un poco ___muy fácil
8. Ocupación (¿En dónde trabaja?)_____
9. ¿Cuánto dinero se gana cada semana? _____ \$0- 124
_____ \$125-249
_____ \$250-374
_____ > (más de) \$375
10. ¿Cuál fue el último año que complete en la escuela? _____ grados 1-8 (escuela primaria)
_____ unos años de la secundaria
_____ título de la secundaria
_____ unos años de la universidad
_____ título universitario de 2 años
_____ título universitario de 4 años
11. ¿Tiene seguro médico? ___Sí ___No
 ¿Recibe su seguro medico por: _____ su trabajo?
 _____ del gobierno estatal o federal (EE.UU.)?
 _____ Medicaid?
 _____ Medicare?
 _____ pagarlo usted mismo/a?
 _____ Otra opción?(identifique)_____
12. ¿Hay un/a medico/a o enfermero/a que lo/la atienda la mayoría de las veces cuando se pone enfermo en los EE.UU.?

___ Sí ___No

¿Cuál es la dirección/el código postal del consultorio o de la clínica?_____

¿Cómo llega allí? ___ a pie

___ en autobus

___ en carro propio

___ de taxi

___ alguien me lleva

¿Cuánto se demora en llegar? _____

¿Qué es el código postal de su domicilio?_____

13. ¿Había un/a medico/a o enfermero/a que lo/la atendiera cuando se ponía enfermo/a en su país de origen?

___ Sí ___No

Si la respuesta es no, ¿quién lo/la atendía cuando se ponía enfermo/a en su país natal?

HLI Access Interview Guide

Research Questions	Core Questions	Probes
<p>RQ1: What are the perceptions of HLI on health, healthcare, and healthcare access?</p>	<p>a. What does being healthy mean to you? (SC)</p> <p>b. What are the biggest differences between getting help for when you are sick (need some help with your health) in your home country and the US? (SC/E)</p> <p>c. Who is most important when you need help when you are sick in the US? (SC/E)</p>	<p>a. How does a person know that they are healthy (what types of things can they do to be healthy?) How do you think your culture influences your understanding of health? What areas of your health are you most concerned about?</p> <p>b. What did you do/would you do in your home country if you got sick? (for example, did you go to see a doctor/nurse/ or someone else?). What were the reasons you would go to visit this healthcare provider? How is the healthcare system in your home country different from the healthcare system in the US (i.e. is it socialized? Do you pay for healthcare/need health insurance coverage?)</p> <p>c. Where do you usually get your health services? Do you go somewhere to get help as soon as you feel sick or do you wait- How do you make your decision about this? What types of health services would you like to receive more of?</p>
<p>RQ2: What are the identified barriers to accessing healthcare services for HLI?</p> <p>(Availability)</p> <p>(Accessibility)</p>	<p>a. Tell me about the last time you were sick and how you got help to feel better.</p> <p>b. Tell me about a time you went to get help for your sickness that did not turn out as you expected it to (or it did not help you)?</p> <p>c. How easy is it to speak with a doctor or a nurse about your health?</p> <p>d. Have you ever used an interpreter (by phone or in person) when going to get help for your sickness? If</p>	<p>a. How often do you go to get healthcare? What was the reason for your last visit to a healthcare provider? What did you think about that experience?</p> <p>b. Did you go back to this place to get services again- Why or why not? How did your past experiences affect your decision to go to this place again? Where else do you go to get your healthcare when you are sick (ER, free clinic, pvt. doctor/nurse, healer, other)?</p> <p>c. How do you feel you and your (use the term identified by the participant for healthcare provider) communicate with each other? How easy is it to understand what is being said about your health?</p> <p>d. Who interprets for you if there is no interpreter when you go to the healthcare provider? What happens if</p>

	yes how did using this person work for you? (P)	there is no interpreter available? What would be the difference for you if the person giving you healthcare could speak in Spanish to you?
(Affordability- insurance/policies/free clinics)	e. How important is to you to be able to pay for health services?	e. What are some things that are more important to you than paying for healthcare? How many people do you support with the money you earn?
	f. How do you usually pay for your health services? (E)	f. If someone you know was sick and needed healthcare but cannot pay, how might they handle this situation? How important is having money to pay for healthcare services?
(Acceptability-discrimination)	g. Tell me about a time when you felt like you were being treated in a different way than others when you get help with your health	g. How do you feel healthcare providers understand you, your culture, and your health needs? How does this affect how you follow advice you are given about your health? How satisfied are you with your relationship with your healthcare provider?
(summary questions on barriers)	h. Based on your experiences, what are the difficulties you face when trying to take care of your health/when you are sick in Louisville? (SC/E/P)	h. What are some things/problems/barriers that make it hard for you to get help with your health?
	i. What do you think causes these difficulties? (H/P)	i. How do you think these difficulties are related to policies/laws/ and other legal things? How do you think these difficulties are related to the way other people look at your race, ethnicity, and culture?
RQ4. Accessibility-immigration status	j. What are some legal things that keep you from accessing care (related to the country you come from)? (P)	j. What type of documentation do you have to show to get healthcare services? How does showing these documents affect (or make it easier or difficult) for you to see a healthcare provider? How do you feel the U.S. government views and treats you as a HLI? (Do you feel that HLI get enough support from the government?)

<p>RQ3: What are the identified facilitators to accessing healthcare services for HLI?</p>	<p>a. Based on your experience, what things make it easier to get your health needs met/to take care of your health?</p> <p>b. What other things (steps, ideas) could you share with your community, the city or the government, to make things better in the future to (improve or) make it easier to take care of your health? (SC/E/P/H)</p>	<p>a. What makes it easier to visit a healthcare provider when you are sick? What are some other ways that you take care of your health in the community (s.a.community screenings, health fairs)?</p> <p>b. How do you think the community can improve healthcare access for HLI? What could your healthcare provider do differently to make it easier to take care of your health?</p>
<p>RQ4: What are the historical, sociocultural, economic, and political contexts that shape the social determinants of healthcare access within this population?</p> <p>(Acceptability)</p> <p>(Acceptability)</p>	<p>a. Tell me about your experiences of coming to the US and Louisville, KY. (H/SC)</p> <p>b. What concerns do you have about living in Louisville? (SC/E)</p> <p>c. How do you feel about how HLI are viewed and treated in the community? (SC/H/P)</p> <p>d. Tell me about a time when you felt like you were being treated differently because of your race/ethnicity, the language you speak, or something else? (H/P/SC/E)</p> <p>e. Tell me about where your family comes from (about your family history)? (H)</p>	<p>a. How easy has it been to get settled into the community and get along with other community members?</p> <p>b. How do you feel about safety; economic situation; government (rules/laws); culture; and immigration in Louisville?</p> <p>c. How do you think the local community views the HLI culture? How do you feel about interacting and communicating with people in Louisville? In what ways do you feel HLI are treated the same as/or different from everyone else?</p> <p>d. If you are treated differently, who are the types of people who do that (you do not have to use names): people in the community, health care providers, police officers, etc?</p> <p>e. Tell me about your family's connection to the U.S. - if any? You say your family comes from _____, how do you think this background made your life better or worse here in the U.S.? Would you identify in what ways or if it had any effect at all?</p>

Note: H= Historical; SC= Sociocultural; E= Economic; P= Political

Guion para la entrevista

Research Questions	Preguntas principales	Indagaciones
<p>RQ1: What are the perceptions of HLI on health, healthcare, and healthcare access?</p>	<p>a. ¿Qué significa ser saludable/sano/a para usted? (SC)</p> <p>b. ¿Cuál es la mayor diferencia entre buscar ayuda cuando está enfermo/a (necesita ayuda con su salud) en su país natal y en los EE.UU.? (SC/E)</p> <p>c. ¿Quién es el más importante cuando usted necesita ayuda al enfermarse en los EE.UU.? (SC/E)</p>	<p>a. ¿Cómo sabe una persona si es saludable (qué tipo de cosas puede hacer)? ¿Cómo cree que su cultura influye en su entendimiento de la salud? ¿Cuáles aspectos de su salud le preocupa más?</p> <p>b. ¿Qué hacía en su país natal cuando se enfermaba? (Por ejemplo, ¿visitaba a un/a médico/a o a un/a enfermero/a o alguien más?). ¿Cuáles eran las razones por que visitaba a ese proveedor de atención médica? ¿Cuál es la diferencia entre el sistema de salud en su país de origen y el de los EE.UU.? (i.e. ¿Es socializado o universal? ¿Usted paga la atención médica/necesita tener seguro médico?)</p> <p>c. ¿A dónde suele ir para recibir atención médica? ¿Usted va a una clínica o a un consultorio tan pronto como se pone enfermo/a o espera hasta que se empeora? ¿Cómo toma la decisión acerca de eso? ¿Qué tipos de servicios de salud le gustaría recibir más?</p>
<p>RQ2: What are the identified barriers to accessing healthcare services for HLI?</p> <p>(Availability)</p> <p>(Accessibility)</p>	<p>d. Cuénteme acerca de la última vez en que se puso enfermo/a y cómo buscó ayuda para que se sintiera mejor.</p> <p>e. ¿Cuénteme acerca de alguna vez cuando fue a recibir atención médica para alguna enfermedad y su problema no se resolvió cómo se esperaba (o no lo/la ayudó)?</p> <p>f. ¿Cuán fácil es hablar con un/a médico/a o con un/a enfermero/a acerca de su salud?</p>	<p>d. ¿Con qué frecuencia recibe atención médica? ¿Cuál fue la razón de su última visita con un proveedor de atención médica? ¿Qué pensó acerca de la experiencia?</p> <p>e. ¿Volvió a ese lugar para recibir atención médica otra vez? ¿Por qué sí o no? ¿Cómo afectaron sus experiencias pasadas su decisión de volver a ese lugar otra vez? ¿A cuáles otros lugares va usted a enfermarse (sala de emergencia, clínica gratuita, médico/a o enfermero/a particular, curandero/a, sanador/a, otro)?</p> <p>f. ¿Cómo se siente acerca de la comunicación entre usted y su médico/a (o el término usado por el/la</p>

		entrevistado/a)? ¿Cuán fácil es entender lo que se dice acerca de su salud?
	g. ¿Jamás ha usado a un traductor/a (o en persona o por teléfono) durante una consulta médica? ¿Cómo le sirvió el uso del/a traductor/a? (P)	g. ¿Quién traduce para usted si no hay traductor/a cuando tiene consultas médicas? ¿Qué ocurre si no hay traductor/a disponible? ¿Qué diferencia habría si las personas que le proveen atención médica hablaran español con usted?
(Affordability-insurance/policies/free clinics)	h. Lo importante es que usted sea capaz de pagar por los servicios de salud?	h. ¿Cuáles son algunas cosas que son más importantes para usted que pagar por el cuidado de la salud? ¿Cuántas personas apoyas con el dinero que haces?
(Acceptability-discrimination)	i. Por lo general, ¿cómo pagan los servicios médicos? (E)	i. Si alguien que usted conoce está enfermo y necesita atención médica pero no tiene cómo pagar, ¿cómo lidiaría con la situación? ¿Cuán importante es tener dinero para pagar servicios de salud?
(summary questions on barriers)	j. Cuénteme acerca de alguna vez cuando sentía como se lo/la trataba diferente de los otros al visitar una clínica o un consultorio.	j. ¿Piensa que su médico/a, enfermero/a lo/la entienda y que entienda su cultura y sus necesidades médicas? ¿Cómo eso afecta su manera de seguir los consejos que el/la médico/a o el/la enfermero/a le da? ¿Cuán satisfecho/a está con su relación con su proveedor de atención médica?
	k. Según sus experiencias, ¿cuáles son algunas dificultades que usted encara al cuidar de su salud o cuando está enfermo/a en Louisville? (SC/E/P)	k. ¿Cuáles son algunos problemas/barreras/otras cosas que dificulten su acceso a atención médica?
	l. ¿Cuál es la causa de estas dificultades? (H/P)	l. ¿(Cómo) cree que estas dificultades tengan que ver con políticas, leyes y otros asuntos legales? ¿(Cómo) cree que estas dificultades tengan que ver con la percepción de otras personas acerca de su raza, etnicidad y cultura?
RQ4- Acceptability-immigration status (political)	m. ¿Cuáles son algunos asuntos legales que impidan su acceso a atención médica (relacionados con su país de origen)? (P)	m. ¿Qué tipo de documentos tiene que mostrar para que reciba atención médica? ¿Cómo se afecta su acceso a atención médica (lo facilita o lo dificulta) el hecho de mostrar tales documentos? ¿Cómo cree que el gobierno estadounidense lo/la ve y trata como inmigrante hispano? (¿Piensa que recibe apoyo suficiente del gobierno?)

RQ3: What are the identified facilitators to accessing healthcare services for HLI?	<p>n. De acuerdo con su experiencia, ¿cuáles cosas facilitan la realización del cuidado de su salud ?</p> <p>o. ¿Cuáles otras cosas (pasos, ideas) puede compartir con su comunidad, su ciudad o con el gobierno para mejorar las cosas en el futuro a fin de facilitar el cuidado de su salud? (SC/E/P/H)</p>	<p>n. ¿Cuáles cosas facilitan su visita con su proveedor de atención médica cuando está enfermo/a? ¿Existen otras maneras de cuidar de su salud en la comunidad (por ejemplo, exámenes en la comunidad, ferias de salud)?</p> <p>o. ¿(Cómo) cree que la comunidad pueda mejorar el acceso a atención médica para inmigrantes hispanos? ¿Qué podría hacer diferente su proveedor de atención médica para facilitar el cuidado de su salud?</p>
RQ4: What are the historical, sociocultural, economic, and political contexts that shape the social determinants of healthcare access within this population?	<p>p. Cuénteme acerca de sus experiencias cuando vino a los EE.UU. y a Louisville? (SC/E)</p> <p>q. ¿Cuáles preocupaciones tiene con respecto al vivir en Louisville?</p> <p>r. ¿Qué opina en cuanto a cómo se ven y cómo se tratan a los inmigrantes hispanos en la comunidad? (SC/H/P)</p> <p>s. Cuénteme de alguna vez cuando se sentía como se le trataría diferente a causa de su raza, etnicidad, del idioma que habla o por otra razón. (H/P/SC/E)</p> <p>t. Cuénteme de donde viene su familia (sobre la historia de su familia). (H)</p>	<p>p. ¿Cuán fácil ha sido integrarse en la comunidad y llevarse bien con otros miembros de la comunidad?</p> <p>q. ¿Cómo se siente con respecto a la seguridad (pública); la situación económica; el gobierno (las leyes y reglas); la cultura; y la inmigración en Louisville?</p> <p>r. ¿Cómo piensa que la comunidad ve a la cultura de los inmigrantes hispanos (o sea, la cultura hispana)? ¿Cómo se siente acerca de interactuar y comunicarse con la gente en Louisville? ¿De qué modo piensa que se tratan a los inmigrantes hispanos de la misma manera o diferente del resto del mundo?</p> <p>s. Si se le trata de modo diferente, ¿qué tipo de gente hace eso (no tiene que identificarlos por nombre): gente en la comunidad, proveedores de atención médica, policías, etc.?</p> <p>t. Cuénteme sobre los vínculos de su familia con los EE.UU., si existen algunos. Ha dicho que su familia es de _____. ¿Cómo cree que esa herencia ha mejorado o empeorado su vida en los EE.UU.? ¿Puede identificar en qué maneras (se ha mejorado o no) o si ha tenido siquiera afecto alguno?</p>

Note: H= Historical; SC= Sociocultural; E= Economic; P= Political

APPENDIX C

Nvivo Functions

Cluster Analysis

Cluster analysis is an exploratory technique that helps visualize patterns by grouping nodes that share similarities in words by sources or coding by nodes. Therefore, cluster analyses can help visualize similarities or differences across sources or nodes. “Cluster analysis diagrams provide a graphical representation of sources or nodes to make it easy to see similarities and differences. Sources or nodes in the cluster analysis diagram that appear close together are more similar than those that are far apart” (QSR International, 2012).

NCapture

The NCapture function visually captures information from website and other internet sources and directly imports it into Nvivo as a PDF file for coding purposes. This function helps preserve the integrity of the document being reviewed, representing texts and pictorial data used during analysis (QSR International, 2012).

Queries

“Queries provide a flexible way to gather and explore subsets of your data” (QSR International, 2012). Queries were used in this study to find and analyze words and phrases in sources to look for specific words and find patterns based on coding.

References

References refer to the data or items that are coded under a specific theme or node (QSR International, 2012).

Sources

“In NVivo, 'sources' is the collective term for your research materials—anything from 'primary' materials such as documents, videos or survey results, to memos that record your ideas and insights” (QSR International, 2012)

Text Search

Text search is a type of query that finds all occurrences of words and phrases in data (QSR International, 2012).

Word Frequency

Word frequency is a type of query that finds the most frequently occurring words or concepts in data (QSR International, 2012).

APPENDIX D

Definition of Terms

Critical ethnography

Critical ethnography is an ethnographic method of research with the purpose of uncovering social injustices and inequities afflicting the oppressed (Bransford, 2006; Carspecken, 1996; Madison, 2005; Thomas, 1993).

Critical Reflexivity

Critical reflexivity refers to the ethnographer's ability to reflect on how their understanding of the Self and culture affects the research process by focusing on the dialectic relationship between the researcher and the Other, which is shaped by a researcher's historical, sociocultural, economic, and political positions (Aamodt, 1991; Anderson, 1989; Davies, 1999).

Ethnicization

"The dynamic processes that construct people as belonging to a particular 'ethnic' group on the basis of assumptions about culture, national origin, or language" (Woodward, p. 125).

Excess death

"The notion of excess death says that you should be able to predict in any one time frame how many people in a population will die. And if the number that actually die is higher than that, that differential is excess death; premature death; death that should not have happened" (California Newsreel, 2008, p. 2).

Health Disparities

The CDC (2011, p.1) defines health disparities as "differences in health outcomes between groups that reflect social inequalities."

Hispanic or Latino

“Hispanic or Latino refers to a person of Cuban, Mexican, Puerto Rican, South or Central American, or other Spanish culture or origin regardless of race” (U.S. Census Bureau , 2012). The term Hispanic Latino immigrants (HLI) is used in this proposal to identify Hispanics or Latinos who were born outside of the U.S.

Hybridity

Homi Bhabha considers hybridity to be a “discursive, enunciatory, cultural, subjective process having to do with the struggle around authority, authorization, deauthorization, and the revision of authority” (Olson & Worsham, 1999). Hybridity refers to the ambivalence associated with colonial identities that creates a sense of ‘unhomeliness’(Bhabha, 1994). Globalization or the global culture produces new perspectives of knowledge related to its heterogeneity of race, ethnicity, culture, identity, and subjectivities, also referred to as hybridity.

Immigrant

According to the Immigration and Nationality Act (INA), an immigrant is broadly defined as “any alien in the United States, except one legally admitted under specific nonimmigrant categories” (U.S. Citizenship and Immigration Services, 2010). The term immigrant includes foreign nationals who are admitted as immigrants and gain lawful permanent residency and/or citizenship (US Department of Homeland Security [USDHS]; 2012). Refugees and those seeking asylum, also fall under the immigrant category. Foreign nationals who enter the United States on a temporary basis for a specific purpose (e.g. tourists, students, or workers) do not fall under the legal definition identified as “immigrant’. The terms “immigrant” and “foreign-born” are used interchangeably in this dissertation, to identify immigrants of Hispanic or Latino origin.

Linguistic Isolation

“Linguistic isolation is a measure of English-speaking ability in a household. A linguistically isolated household is one in which no person age 14 or over speaks English at least "very well." That is, no person age 14 or over speaks only English at home, or speaks another language at home and speaks English "very well." A linguistically isolated person is anyone living in a linguistically isolated household” (U.S. Census Bureau, 2012).

Other (ness)

Derived from the term *Orientalism*, coined by postcolonial theorist Edward Said (1978), ‘otherness’ represents the marginalization of indigenous populations under colonial rule. The marginalization of the indigenous centered the colonizer and created a sense of ‘otherness’, where the colonized were considered to be inferior or less than human (Said, 1994).

Personalismo

Personalismo, “refers to the preference in Latino cultures for developing personal relationships as a prelude to personal disclosure” (Aguirre-Molina et al., 2001, p.450).

Positionality

Positionality refers to the ability of the ethnographer to self-reflect on his or her own power, privilege, and biases that may influence the intentions, methods, and findings of the research process (Carspecken, 1996; Madison, 2005).

Postcolonialism

Postcolonialism refers to theoretical and empirical works that focus on the issues of colonialism and their aftermath stating that subjectivities or the identities of the colonized are determined through the discourses of colonial power, which situate the colonized in inferior positions and frames them as the ‘Other’²³ in order to set them apart from the colonizer (Ashcroft, Griffiths, & Tiffin, 2006; McLeod, 2000; Slemon, 1995; Smith, 1999).

Racialization

“A process that ‘assumes that ‘race’ is the primary, natural, and neutral means of categorization, and that the groups are distinct also in behavioral characteristics, which result from their race” (Ahmad 1993, p. 18). Although it is generally used to refer to ways of thinking regarding race, it also refers to institutional processes-cultural, political, and historical- that manifest forms of ethno-racial categorization (Murji & Solomos, 2005).

Subaltern

“The general attribute of subordination..., whether this is expressed in terms of class, caste, age, gender and office or in any other way” (Guha, 1988, p.35). Subaltern refers can be used as a noun to refer to the oppressed or as an adjective to describe something or someone that is oppressed, marginalized, or

²³ Conceptual definition of terms can be found in Appendix D.

viewed as being subordinate to the dominant culture. Spivak (1994) purports that subaltern voices or the voices of the oppressed are muted, or lost in the transaction between the speakers and the listeners.

Subjugated knowledge

Subjugated knowledge refers to knowledge or ways of knowing that are ignored or opposed by the mainstream, dominant culture (Foucault, 1972).

Unhomeliness

Occurring as a result of hybridity, unhomeliness refers to the feeling of being caught or trapped between two cultures (Bhabha, 1994). The sense of being unhomed, or not feeling at home even in one's own home, is resonant of a cultural identity crisis that serves as both a physiological and psychological sense of entrapment (Tyson, 2006).

APPENDIX E

List of Abbreviations

ACP- American College of Physicians

AHRQ- Agency for Healthcare Research and Quality

ANA- American Nurses Association

CDC- Centers for Disease Control

CE- Critical Ethnography

CFAAHS- Conceptual Framework for Assessing Access to Health Services

CSDH- Commission on Social Disparities of Health

DREAM- Development, Relief, and Education for Alien Minors Act

EMTALA- Emergency Medical Treatment and Active Labor Act

GIS- Geographic Information Systems

HLI- Hispanic Latino Immigrants

ICE- Immigration and Customs Enforcement

IOM- Institute of Medicine

LEP- Limited English Proficiency

KADAP- Kentucky Aids Drug Assistance Program

KHCCP- Kentucky HIV/AIDS Care Coordinator Program

KYCHR- Kentucky Commission on Human Rights-

NCLR- National Council of La Raza

NHDR- National Health Disparities Report

NILC- National Immigration Law Center

PPACA- Patient Protection and Affordable Care Act

PRWORA- Personal Responsibility and Work Opportunity Reconciliation Act

SDH- Social Determinants of Health

USDHHS- United States Department of Health and Human Services

WHO- World Health Organization

APPENDIX F

Brief Kentucky History Timeline

1792	1838	1848	1863	1865	1866-1966	1904	1954	1954-1966
Kentucky Admitted to Union	Indian removal Act	Mexican-American war	Emancipation proclamation signed, but not in KY because it was in the Union	Slavery ends nationwide after states ratify 13 th amendment. Kentucky did not ratify amendment until 1976.	Period of racial segregation and integration	Day Law – racial segregation in public and private schools across KY	Brown vs. Board abolishes segregated public schools	Civil Rights Movements
1966	1976	1970	1980's	1986	1990's			
Kentucky Civil Rights Act passed prohibiting discrimination	General assembly ratifies 13 th , 14 th , 15 th amendments to U.S. constitution in KY, which was ratified by the majority of the nation in 1865.	Migrant workers from Latin American countries are employed in agricultural industries	Migrant workers seek other employment in labor industries as the use of technology advances in agricultural industries required less manual labor.	Immigration Reform and Control Act	Increasing number of immigrants arriving to Southeast and Midwestern cities including Louisville, KY			

CURRICULUM VITAE

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Education

05/2009 to 04/2013	PhD	University of Louisville
08/2010 to 05/2012	Certificate in Health Professions Education	University of Louisville
01/2005 to 05/2008	BSN	Bellarmino University

Other Employment

08/2009 to 5/2013	Research Assistant , School of Nursing, University of Louisville, Louisville, KY
01/2010 to present	Research Assistant , Sports and Spine Rehab Clinical Research Foundation, Fort Washington, MD
06/2008-06/2009	Registered Nurse, Intensive Care Unit , Jewish Hospital and St. Mary's Health care, Louisville, KY
05/2007-05/2008	Nurse Extern, Operating Room , Jewish Hospital and St. Mary's Health care, Louisville, KY
08/2005-05/2008	Resident Assistant , Bellarmine University, Louisville, KY

National Board Certification(s) and state RN Licensure(s)

06/2008	Commonwealth of Kentucky Registered Nurse # 1117597
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Professional Memberships and Activities

2008 to present	Leadership Succession Chair, Delegate, and Member, Sigma Theta Tau International, Lambda Psi Chapter (2008-2010); Iota Zeta Chapter (2011-present)
2010 - 2011	Member, Council for the Advancement of Nursing Science
2011-present	Member, Southern Nursing Research Society
2009-2012	Representative, Graduate Student Council, University of Louisville, KY

Honors and Awards

2013	Graduate Dean's Citation Award , University of Louisville, KY
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2012	Doctoral Fellowship- Dissertation Completion Award , School of Interdisciplinary and Graduate Studies, University of Louisville, KY
2012	Kentucky Nurses Association Research Grant Recipient . Kentucky Nurses Foundation. (\$1909)
2012	2nd place poster winner , Minority Research Interest Group, SNRS conference, New Orleans, LA, February 22 nd -25 th , 2012
2011	1st place poster winner for School of Nursing, Research! Louisville conference, October 11 th , 2011, Louisville, KY. (\$500)
2011	Graduate Student Award Recipient , Honor Society of Nursing, Sigma Theta Tau International, Iota Zeta Chapter, School of Nursing, University of Louisville, Louisville, KY. (\$500)
2011	Graduate Student Diversity Grant Recipient Commission on Diversity and Racial Equality (CODRE), Office of the Executive Vice President of Research Grant Opportunities, University of Louisville, Louisville, KY. (\$750)
2010	Dr. M. Celeste Nichols Award Recipient , Women's Center, University of Louisville, Louisville, KY. (\$500)
2010	Women in Leadership Conference Speaker , Bellarmine University, Louisville, KY
2005-2008	Jewish Hospital Nursing Scholar , Jewish Hospital and St. Mary's Health Care Donna & Allan Lansing School of Nursing, Louisville, KY
2005-2008	BecVar Nursing Endowed Scholarship , Bellarmine University Donna & Allan Lansing School of Nursing, Louisville, KY
2006-2007	Presidential Scholarship , Bellarmine University, Donna & Allan Lansing School of Nursing, Louisville, KY
2006-2007	Louisville Rotary Scholarship , Louisville Rotary Club, Louisville, KY

Committee Service

2009-2011	Vice President, Association of Graduate Nursing Students (AGNS) University of Louisville, School of Nursing, Louisville, KY
2009- 2011	Alumni Representative, Multicultural Advisory Board Bellarmine University, Louisville, KY
2010- present	Alumni Career Consultant for the Donna Alan Lansing School of Nursing , Bellarmine University, Louisville, KY
2010- 2011	Graduate Student Representative, Graduate Academic Committee , University of Louisville, School of Nursing, Louisville, KY
2010- 2011	Graduate Student Representative, Graduate Program Committee , University of Louisville, School of Nursing, Louisville, KY
2011-2012	Graduate Student Council Representative , University of Louisville, School of Nursing, Louisville, KY
2009-present	Member, Greater Louisville International Professionals (GLIP) , Louisville, KY
2011-2012	State of Kentucky, Student Representative, Southern Nursing Research Society (SNRS)
2011-present	Leadership Succession Committee Chair, Sigma Theta Tau International , Iota Zeta Chapter, University of Louisville, School of Nursing, Louisville, KY
2011-present	Chapter Delegate, Sigma Theta Tau International , Iota Zeta Chapter, University of Louisville, School of Nursing, Louisville, KY

2012 **Program Committee**, Wesley House Community Center, Louisville, KY

Community Service

2009 Medical Team RN Volunteer, Iron Man, Louisville, KY
2009 Medical Team RN Volunteer, Southeast Christian Church, Louisville, KY
2009 Volunteer, Haiti Medical Relief, Supplies Over Seas, Louisville, KY
2010 Volunteer, Harambee Nursing Center Annual Health Fair, Louisville, KY
2011 Community Health Outreach Worker/Lay Health Navigator, Kentucky African Americans Against Cancer (KAAAC), Louisville, KY
2011 Volunteer, Kentucky Cancer Program (KCP), Louisville, KY
2012 RN Volunteer, Family Community Clinic, St. Joe's Parish, Louisville, KY
2012 Volunteer, Program Committee, Wesley House Community Center

Journal Editorial Boards, Advisory Councils, Peer Reviewer of Manuscripts

05/2012 to present **Reviewer**, Qualitative Health Research Journal (QHR)

Board Memberships

2009- 2011 **Multicultural Advisory Board**, Alumni Representative, Bellarmine University, Louisville, KY
2011-present **Sigma Theta Tau International, Iota Zeta Chapter** Leadership Succession Committee Chair & member. University of Louisville, School of Nursing, Louisville, KY

Teaching

10/2012-4/2013 **Instructor**. Undergraduate Research Practicum, Research Scholar Program.
3/2013 **Guest Lecturer**. NURS 374 Nursing Research for Evidence-based Practice
09/2012 **Guest Lecturer**. NURS 466, Global Healthcare Issues, Systems and Policies.
05/2007-12/2007 **Teaching Assistant**, Multicultural Interdisciplinary Course, Bellarmine University, Louisville KY
05/2006-12/2007 **Nursing Tutor**, Academic Resource Center, Bellarmine University, Louisville, KY

Abstracts and Presentations

09/2012 Schreiber, J. & **Edward, J.** *Image of God, Religion, Spirituality, and Life Changes in Breast Cancer Survivors: A Qualitative Approach*. Research Louisville, Louisville, KY.

- 03/2012 Hines-Martin, V. Bowland, S., **Edward, J.**, & Myers, J. *The Social Determinants of Depression in a Low-Income Public Housing Community*. International Society of Psychiatric-Mental Health Nurses Psychopharmacology Institute and Annual Conference, Atlanta, GA.
- 02/2012 Hines-Martin, V., **Edward, J.** & Bowland, S. *Understanding Environment and Health - The Dosker Manor Study*. Southern Nursing Research Society Annual Meeting, New Orleans, LA.
- 01/2012 Bowland, S. & Hines-Martin, V., **Edward, J.** & Myers, J. *Needs Assessment in a Public Housing Community with Health and Aging Concerns*. Poster presented at the Society for Social Work and Research Annual Meeting, Washington, D.C.
- 2011-2012 **Edward, J.**, Hines-Martin, V., Bowland, S. *Social Determinants and Disparities in Health Status - The Availability of Dietary Needs in a low income, inner city, public housing community*. Presented at Research! Louisville conference, October, 2011, Louisville, KY and at Southern Nursing Research Society 26th annual conference, New Orleans, LA, February, 2012.
1st place winner for Research!Louisville and 2nd place winner for Minority Research Interest Group, SNRS.
- 11/2012 Shawler, C., Meyers, J., **Edward, J.**, Ling, J., Calloway, A., Stinson, K., Rayens, M.K. *Older Mother-Daughter Dyads: How to Improve Hypertension Management to Increase Lifespan*. Gerontological Society of America, 64th Annual Scientific Meeting
- 11/2011 Bowland, S., Hines-Martin, V., **Edward, J.S.**, & Myers, J. *Needs of Aging Urban Adults Living in Public Housing*. Poster presented at Gerontological Society of America 64th Annual Scientific Meeting. Boston, MA.
- 02/2011 **Edward, J.S.** and Shawler, C.M. *Understanding the Effects of Inner Strength on Health Outcomes in Relation to Race* Southern Nursing Research Society for the 2011 25th annual SNRS conference, Jacksonville, FL.
- 02/2011 Hines-Martin, V. and **Edward, J.S.** *Developing a Health Disparities Agenda at a Metropolitan University*. Southern Nursing Research Society for the 2011 25th annual SNRS conference, Jacksonville, FL.
- 9/2010 Topp, R., Ridner, S.L., Jacks, D.E., **Edward, J.S.**, Conte, K.P., *Fit Into College: A Program to Improve Physical Activity and Dietary Intake Lifestyles Among College Students*. Council for the Advancement of Nursing Science Program Committee for the 2010 State of the Science Congress on Nursing Research, Washington, DC.
- 10/2010 El-Mallakh, P., Evans, B.N, Myers, J., and **Edward, J.S.** *Diabetes Knowledge and Caregiving Experiences among Family Members of People with Schizophrenia and Diabetes Mellitus*. First place winner for research poster at the American Psychiatric Nurses Association (APNA) annual conference held in Louisville, KY.

Publications and Manuscripts

- Schreiber, J. & **Edward, J.** (2012). Image of God and psychological well-being and distress: A qualitative approach. *Psycho-oncology*. (In review)
- Greenstein, J.S., Bishop, B.N., **Edward, J.S.**, Huffman, A., Davis, D., Topp, R. (2012). Sleep characteristics in patients with whiplash-associated disorders- A descriptive study. *Topics in Integrative Health Care: an International Journal*, 3(4), 1-11.
- Greenstein, J.S., Bishop, B.N., **Edward, J.S.**, Huffman, A., Davis, D., Topp, R. (2012). The Effect of the Tri-Core® Cervical Pillow on Sleep Outcomes among Whiplash Associated Disorder (WAD) Patients. *Topics in Integrative Health Care: an International Journal*, 3(3).
- Hines-Martin, V.P., Bowland, S., **Edward, J.**, Haleem, A.(2012). Effects of a Community-Based Research Project on Interdisciplinary Student Learning. *Journal of Higher Education, Outreach, & Engagement* (In review).
- Shawler, C., **Edward, J.S.**, Ling, J., Wang, X., Stinson, K., Calloway, A., & Myers, J. (2012). Older Mothers with Hypertension and Adult Daughters: Health Related Quality of Life and Quality of Relationship. *Journal of Family Nursing* (In review)
- Greenstein, J.S., Bishop, B.N., **Edward, J.S.**, Topp, R. (2011). The Effects of a Closed-Chain, Eccentric Training Program on Hamstring Injuries of a Professional Football Cheerleading Team. *Journal of Manipulative and Physiological Therapeutics*, 34(3), 195-200.
- Topp, R., **Edward, J.S.**, Ridner, S.L., Jacks, D.E., Newton, K., Kieffner, P., Woodall, D., & Conte, K. (2010) Fit Into College: A Program to Improve Physical Activity and Dietary Intake Lifestyles Among College Students. *Recreational Sports Journal*, 35(2), 69-78.

Independent Funded Research

Edward (PI) 2012-2013

Funding: Kentucky Nurses Association

Amount Awarded: \$1909

Title: Understanding the Social Determinants of Healthcare access for Hispanic Latino Immigrants in Louisville, KY.

Purpose: Dissertation research to understand healthcare access disparities among Hispanic Latino immigrants.

Edward (PI) 2011-2012

Funding: Graduate Student Award, Sigma Theta Tau International, Iota Zeta Chapter, School of Nursing and the Graduate Student Diversity Grant, Commission on Diversity and Racial Equality (CODRE), Office of the Executive Vice President of Research Grant Opportunities, University of Louisville, KY.

Amount Awarded: \$1254

Title: PILOT STUDY 1: Exploring the Providers Perspective of the Availability of Health and Social Services for Immigrant and Refugee Populations in Louisville, KY

Purpose: Pilot study in preparation for dissertation research examining the availability of health and social services for general immigrant and refugee populations in Louisville, KY.

Edward (PI) 2012

Funding: Graduate Student Award, Sigma Theta Tau International, Iota Zeta Chapter, School of Nursing and the Graduate Student Diversity Grant, Commission on Diversity and Racial Equality (CODRE), Office of the Executive Vice President of Research Grant Opportunities, University of Louisville, KY.

Amount Awarded: \$1254

Title: PILOT STUDY 2: Exploring the Providers Perspective of the Availability of Health and Social Services for Hispanic Latino Immigrants populations in Louisville, KY

Purpose: Pilot study in preparation for dissertation research examining the availability of health and social services for Hispanic Latino immigrants in Louisville, KY.

Other Funded Research and Research Support

Nash (PI) 2013

Funding: U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA)

Amount Awarded: \$1.1 million

Title: Enhancing Interprofessional Collaborative Practice between Nursing and Dental Students Via a Technology Enhanced Interprofessional Education (IPE) Model Focused on the Oral Systemic Health Connection.

Role: Research Assistant- Grant proposal development and submission, IRB submission.

Logsdon (PI) 2012-2013

Title: Ideas About Ads for Health Websites

Purpose: Determine motivators to use internet sites to obtain health information. Testing recruitment ads for an internet based social marketing intervention with pregnant adolescents and adolescent mothers. This preliminary step is necessary before we can measure the extent to which a social media ad campaign is effective as a recruitment strategy for an internet based social marketing intervention.

Role: Research Assistant- Data collection, focus group interviews, data analysis

Hines-Martin (PI) 2010-2011

Funding: Office of Community Engagement, University of Louisville

Amount Awarded: \$8800

Title: Dosker Manor Assessment Research Project.

Purpose: Pilot study focused on factors associated with quality of life within a low-income, inner city public housing community using quantitative and qualitative measures.

Role: Research Assistant- IRB submission, data collection and analysis, manuscript preparation.

Topp (PI) 2010-2011

Funding: Sports and Spine Rehab Foundation

Title: The Effects of a Closed-Chain, Eccentric Training Program on Hamstring Injuries of a Professional Football Cheerleading Team

Purpose: To identify the effectiveness of an eccentric, closed chain hamstring exercise intervention on hamstring injury associated pain over the course of the football season among professional football cheerleaders.

Role: Research Assistant- IRB submission, data collection and analysis, manuscript preparation and submission.

Ridner (PI) 2011-2012

Funding: Sports and Spine Rehab Foundation and Core Products International.

Title: The Effectiveness of the Tri-Core® Cervical Pillow in Improving Posture and Sleep Quality, and Reducing Pain and Disability in the Whiplash Associated Disorder (WAD) Patient – A Randomized Controlled Trial

Purpose: To determine if a semi—customized orthopaedic cervical pillow can improve clinical outcomes and reduce the cost of conservative care by speeding the rate of recovery as compared to a generic pillow in people who suffer from cervical pain as a result of a motor vehicle accident.

Role: Research Assistant- Data collection and analysis, manuscript preparation and submission

Shawler (PI) 2008 - 2011

Funding: NIH/NINR Grant Number 1K01NR010239-01A1

Amount Awarded: \$261,905

Title: Older Mothers and Adult Daughters: High Blood Pressure Self-Management Behaviors

Purpose: The purpose of this study was to investigate if a difference exists between older mothers and their adult daughters on the concepts of health-related quality of life and quality of relationship.

Role: Research Assistant- Data collection and analysis, manuscript preparation and submission, presentation of findings.

King (PI) 2010-2011

Title: Fit into College: Fitness Interns' Perspectives of using Critical Thinking Skills during Internship

Purpose: To examine the exercise and dietary behaviors fitness Interns (students who were enrolled in HSS 492: internship) and to determine how they infuse critical thinking skills into promoting health and fitness promotion among students?

Role: Research Assistant- IRB submission, data analysis

Topp (PI) 2010-2011

Funding: Internally Funded by University of Louisville

Title: Fit Into College II

Purpose: To determine if an interdisciplinary, theoretically based 14-week intervention can impact the risk factors for weight gain including dietary intake, physical activity physical fitness and decisional balance (benefits and barriers) of increasing dietary intake of fresh fruits and vegetables and participating in physical activity among college students.

Role: Research Assistant- IRB submission, data collection and analysis, manuscript development and submission

Topp (PI) 2009-2010