ONE GOAL, DIFFERENT PATHS: CULTURAL MODELS, HIV/AIDS, AND MINORITY HEALTH OUTCOMES IN URBAN AMERICA

By

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To the Faculty of Washington State University:

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HIV, since its emergence in the 1980s, has affected millions of people across the globe. Although the U.S. has seen three decades of research that has increased our knowledge of the virus, created medications to suppress its replication, and improved upon prevention techniques, minority populations continue to be disproportionally affected. The goal of the research reported here is to elucidate the barriers that minority populations encounter while seeking care, and to examine this population’s strategies for healthcare navigation. The construction of cultural models presented here that are based on healthcare decisions of minority persons living with HIV/AIDS will further illuminate the context of healthcare navigation and use, as well as promote understanding of barriers that may impede healthy behaviors. Cultural models theory is a useful tool to establish knowledge that is shared among a group (Strauss and Quinn 1977). In this study I use narratives to investigate two cultural models surrounding the domains of healthcare from a minority group located in Las Vegas, Nevada. Participant observation and in-
depth interviews were conducted with twelve providers and forty-seven African-American and Hispanic men and women living with HIV or AIDS during 13-months of fieldwork in 2012-2013. Two specific cultural models that directly affect strategies of tertiary prevention opportunities emerged among people living with HIV/AIDS, 1) the African-American self-advocacy model and 2) the Hispanic ethnic provider model. The former relies on the construction of informal relationships within one’s social network to disseminate information and barriers to healthcare. The latter is reliant upon top-down modes of information dissemination that is delivered within a culturally relevant atmosphere. The investigation of cultural models as a tool to understand local populations has the potential to be part of the elimination of HIV worldwide by providing policy makers, research centers and local programs with important culturally relevant information.
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DEDICATION

To all the Cliffs in the world. May your run be long and your candle burn bright.

and

To Mary “The Brave.”
List of Acronyms:

AFAN- AID for AIDS of Nevada
AIDS- Acquired Immunodeficiency Syndrome
ART- Anti-retroviral Therapy
ASO- AIDS Service Organization
CDC- Centers for Disease Control and Prevention
DHAP- Department of HIV/AIDS Prevention
HAART- Highly Active Anti-retroviral Therapy
HHS- Health and Human Services
HIV- Human Immunodeficiency Virus
IDU- Injection Drug Use
MMWR- Morbidity and Mortality Weekly Report
MSM- Men who have sex with Men
PCP- Pneumocystis pneumonia
PLWHA- People living with HIV/AIDS
TasP- Treatment-as-Prevention
CHAPTER ONE

Introduction

Beginnings

December 1\textsuperscript{st}, 2012, 7PM. The 24\textsuperscript{th} annual World AIDS Day was coming to a close across the globe and I found myself in front of the performing arts center on the campus of the University of Nevada, Las Vegas, my alma mater. I assisted Heather, the development coordinator from Aid for AIDS of Nevada (AFAN), one of the most well known AIDS Service Organizations (ASO) in Southern Nevada, with setting up a small table covered with a red table cloth and on top placing AFAN pamphlets, a donation box, a small propane canister, coffee and of course, cupcakes. Heather was the cupcake queen. Every fundraising event involved an assortment of gourmet cupcakes. They welcomed volunteers at the door of every event, big or small. Tonight there were only eight in the tiny box and I eyed my favorite, carrot cake. Many of the fine foods enjoyed by ASO employees and clients alike are donated. Over several months of fieldwork I would come to know many of the clients who rely on the generosity of donated food and also partake in this food myself.

On this day I volunteered alongside Heather to lead the candlelight vigil in remembrance of those who have been affected by HIV/AIDS and, as a secondary goal, advertise the Fallen Guardian Angels play that began afterward. The vigil was to take place at the AIDS memorial garden, located on the campus grounds. As a student for several years at UNLV I had had no
idea there was such a garden. Apparently, a UNLV Alumnus constructed it in 1999 and the first
time I have heard of it was six years after I had graduated (Figure 1.1).

Figure 1.1. AIDS Memorial Garden, University of Nevada, Las Vegas.

The turnout was small, approximately fifteen people, and included members from AFAN’s board
of directors, employees and other volunteers. Heather passed out candles and after the first
candle was lit with the propane flame, we each lit our candle using our neighbor’s flame. We
then proceeded through campus to the memorial garden. On our way I met Cliff, and we began
to walk and talk. He was a runner and looked forward to the half marathon that began the next
day. He had just moved back to Las Vegas after living in Los Angeles for five years. He told me
about his family and growing up in Las Vegas. He said that he interviewed with 24-hour Fitness
for a job and hoped they would call back. He had never been to a vigil before and asked if I would take a photo with him. I asked if he was going to the play after the vigil and he said that he would like to, but did not have 15 dollars to spend on it.

We arrived at the memorial garden. It is a rock covered, shrub area that is not easy to see by any passerby. You have to be looking for it in order to see it and enter. We gathered around in a circle and a representative from AFAN turned on a portable speaker system with a microphone. He thanked everyone for coming and wanted to pass the microphone around the circle to give everyone a chance to say something. A few people shared their stories about how HIV/AIDS has affected them, including Cliff. Cliff was diagnosed as HIV positive in 2007. Two months later his friend died of AIDS. He runs half marathons and marathons for those he has loved and who have died of this disease. He runs because he can, and his friends and others cannot. He has never been this healthy in his life, he said, even before he was diagnosed with the virus.

After a moment of silence Heather asked me to pass out fliers advertising the Fallen Angels play. The mood was somber, emotional. Tears were present on most faces. I wanted to be silent and not push people to spend money on a play after memorializing their loved ones. She grabbed the fliers from my hands and passed them out herself. A news crew was filming the vigil and many AFAN affiliated members were being interviewed. Cliff hugged me and said he needed to catch his bus home. He had a long day tomorrow. Slowly the crowd dispersed from the garden, and all that was left was a square-shaped rock with a dateless plaque glowing in the moonlight.
Before starting my fieldwork I had never directly worked with people who were living with HIV/AIDS. My first exposure to the HIV/AIDS field was at a summer fellowship at the Centers for Disease Control and Prevention (CDC) in 2009. I conducted an epidemiological investigation with about 15,000 women who had perinatally exposed their children to HIV across the US and Puerto Rico from 1988 to 2007. I did not actually meet these women; rather, I got to know their health care behaviors through the manipulation of a very large database that consisted of categorical variables. These women did not have names; the data that I worked with had ID codes, race, ethnicity, parity, and place of birth. I did not know anything about their lives, how they perceived their relationships, their access to healthcare, and other important humanistic information that brings understanding about human beings- the “thick description” (Geertz, 1973).

After working on the epidemiological project of these 15,000 women, I set out to conduct anthropological research to enrich the data currently known about minority populations, to improve the lives of those most vulnerable and give voice to those who are often ignored in studies of the HIV/AIDS epidemic. During thirteen months of fieldwork I have met many people like Cliff, searching for the meaning of death and doing as much as possible to avoid it themselves. I have also met people who are nothing like Cliff. Health evolves for many people living with the virus, and the strategies that are used to cope with it are varied. I have met enthusiastic and determined providers like Heather, who left corporate America to give back to her community. I use Las Vegas, Nevada as an ethnographic field site to understand the environments of racial and ethnic disparities among those who live with HIV/AIDS so that we
may find solutions to eliminate the disproportionate burden these populations face in the United States.

*The HIV/AIDS Situation*

The HIV virus, since its emergence in the 1980s, has affected millions of people across the globe. As simultaneously one of the most feared and fascinating viruses among scientists and laymen alike, it has severely impacted disadvantaged populations and has been called “a disease of poverty”. As a result, practically every country in the world has attempted to combat the virus via social policies, social medial and universal healthcare and the availability of life saving antiretroviral therapies (ART). Three decades and several initiatives later, however, many countries, including the United States (US), continue to grapple with the effects of HIV and AIDS.

In the United States, despite providing people living with HIV/AIDS (PLWH) universal access to infectious disease physicians and antiretroviral therapy (ART) to improve the body’s immune system and block replication of HIV\(^1\), people are not receiving treatment and are dying from the disease’s opportunistic infections. In 2011, although 86% of people living with HIV were diagnosed, only 40% were actively engaged in healthcare. While 37% of this population was prescribed ART, only 30% were virally suppressed with less than 75 copies of HIV per milliliter of blood (CDC 2011). High viral loads, coupled with risky behaviors, such as unprotected sex and sharing needles, increases the chance of transmitting the virus to sexual and drug-using populations.

\(^1\) These programs are federal, state, and county programs. Ryan White for example, is a federally funded program that provides physician visits, medication and other support services as a payer of last resort.
partners. This is why the Treatment as Prevention (TasP) initiative has recently gained ground among infectious disease specialists; if we can suppress the virus in seropositive people, we can prevent the spread to seronegatives.

In 1993, President Bill Clinton, in an effort to establish a joint force in combating HIV/AIDS, developed the White House Office of National AIDS Policy (PBS 2015). This office exclusively focuses on the National HIV/AIDS strategy to reduce new HIV infections and lower the burden of disease in the United States. Three decades of research among people living with HIV have greatly improved the medications that suppress the replication of the virus, increased our knowledge of how HIV and medications affect women, and improved upon HIV prevention techniques. Despite these advances, minority populations have been disproportionately affected by the epidemic. Because of this the major focus of the National AIDS Strategy over the last two decades has included a specific focus on minority populations (National HIV/AIDS Strategy 2015:38-39).

Minority populations in the United States (US) have been disproportionately diagnosed with HIV/AIDS since the beginning of the epidemic. In 2010, the estimated rate of new HIV cases for Black/African-American men and women were 103.6 and 38.1 per 100,000, respectively, as compared to Caucasian men and women, 15.8 and 1.9, respectively. The realities of the disproportionate burden are evident when comparing the proportion of the entire US racial and ethnic composition to the HIV-infected population. For example, in 2011, although Black/African-Americans made up 12% of the entire US population, they totaled 47% of HIV diagnoses. In a similar vein, that same year, Hispanics made up 17% of the entire US population,
and totaled 21% of HIV diagnoses. These minorities are also dying from HIV more than any other racial/ethnic group. In 2013, for example, HIV was the fourth leading cause of death for African-American males aged 45-49 and females aged 35-39 years old (National Vital Statistics System, 2015).

Barriers to HIV prevention and treatment continue to plague minority populations in the United States. However, what are the barriers that prevent minority populations in the US from accessing care and achieving viral suppression? And how can we overcome them? The research presented in this dissertation focuses on elucidating these barriers and documenting the strategies that minority populations use to access and remain in healthcare. Although many prevention and treatment methods have been adopted and assessed by health services research, such as the health belief model and the theory of planned behavior, with varied success, I believe that understanding the sociocultural environments of people and how they interpret these environments will create a major and as yet not well researched contribution to un/successful healthcare. We must understand the diversity of the HIV/AIDS minority population in order to avoid one-size-fits all approaches to tertiary prevention; understanding culture is one avenue of exploration.

The strategies that minority populations employ are linked to certain cultural domains that surround their illness, society’s perception of their illness, service organizations and their employees, and the clinic. Constructing cultural models that are based on these domains further illuminate the context of healthcare navigation and use, as well as provide understandings of barriers that may impede healthy behaviors. The investigation of cultural models as a tool to
understand local populations has the potential to be part of strategies in other U.S. communities
to assist with tertiary prevention. The goal is to improve healthcare for all people living with
HIV/AIDS by using culturally specific care to reduce economic, racial and ethnic disparities.
These culturally specific strategies have the potential to be part of the elimination of HIV
worldwide by providing policy makers, research centers and local programs with important
culturally relevant information.

Layout of the dissertation

The second chapter of this dissertation provides historical and current information about the
location of the study, Las Vegas, Nevada. The location, as well as the economy of the area, has
aggravated individuals’ response to HIV/AIDS and affects individual access and engagement in
the healthcare system. The third chapter details the history of HIV/AIDS in the U.S. with a focus
on health disparities among minority populations. The fourth chapter discusses the challenges of
preventing and treating HIV/AIDS in the U.S. due to socioeconomics and stigma. The fifth
chapter focuses on cultural modeling, as a technique for health practitioners to narrow the health
inequity gap among minority populations who are living with HIV/AIDS. The sixth chapter
outlines the methods used in this study to obtain data from a minority population located in Las
Vegas, Nevada. The seventh chapter reports on the in-depth interviews with providers. The
eighth chapter reports on in-depth narratives with PLWHA, freelists and Health Related Quality
of Life (HRQL) scores among participants. Participant results are categorized based on self-
reported racial/ethnic identities, as well as sex. Finally, the ninth chapter interprets the results of
the previous chapter and makes suggestions on future policy implications among minority
populations in the U.S.
CHAPTER TWO

The Research Site

Las Vegas, Nevada

“Las Vegas is sort of like how God would do it if he had money.” Steve Wynn, CEO of Wynn Resorts Limited (Grimes 2013).

“[Las Vegas] where easy divorce, open prostitution, licensed gambling and legalized cockfighting are only the more luridly publicized manifestations of a free and easy, individualist spirit deriving straight from the mining camp and cattle ranch.” – The One Sound State campaign, 1937 [in Schwartz 2009].

Las Vegas is a well-known vacation destination that attracts millions of tourists from all over the world. According to the Las Vegas Convention and Visitors’ Authority, over 39 million people visited the city in 2013. Las Vegas’ attractions include the ever-evolving Las Vegas Boulevard, popularly known as ‘the Strip,’ with sky-high, world famous hotels and casinos. Las Vegas, however, is much more than a vacation destination. It is home to millions of individuals seeking to maintain their current lives, or to build them anew. The city has grown tremendously since its early days due to seemingly limitless opportunities for individuals and businesses, with the former to improve their lives through better employment and the latter to cater to tourists. This boom and bust city is a sort of spectacle for many tourists and prospective residents alike.
This chapter outlines the historic, geographic, socio-demographic and economic factors that have shaped the Las Vegas and the everyday lives of its residents. As will be demonstrated in this chapter, the combination of these factors reveals that populations in Clark County are especially vulnerable to a poor quality of life. Las Vegas’ promise of well paying, low-skilled jobs that were plentiful in the 1990s are currently no longer available. As casinos tighten their budgets, they are also fattening their wallets by decreasing the workforce needed to perform satisfactorily. Individuals who immigrated to Las Vegas, often without their families, have no familial network on which to rely, further prompting assistance from local agencies when times get difficult. Generally, the city has a low priority for health and has frequently received low scores on measures of healthy environments. For example, Clark County, where Las Vegas is located, was ranked 15th out of 16 counties within Nevada for physical surroundings that contributed to quality of life and 12th in health factors, such as access to and the availability of quality healthcare and health behaviors, such as alcohol and drug use. These issues further complicate medical navigation and health decision-making for individuals, including those living with HIV/AIDS.

Las Vegas: A Short History

Life in the Desert

Archaeologists and early ethnographers have identified sixteen Southern Paiute bands or tribes who have occupied a broad strip of territory extending from Southeastern Utah, Southern Nevada and following the Colorado River into California (Kelly and Fowler 1986). The Las Vegas Paiute tribe resided in what we now know to be the Las Vegas valley during the winter and sheltered themselves from the extreme summer heat in the Spring Mountains. Although the
neighboring Utes and Navajo were in close proximity to the 16th century Spanish entrada, the Southern Paiutes were indirectly impacted. Spanish priests Francisco T.H. Garces, Francisco Atanasio Dominguez and Silvestre Velez de Escalante documented the first direct contact with the Southern Paiutes in 1776. They noted little evidence of foreign presence and described largely aboriginal conditions (Kelly and Fowler 1986).

By the early nineteenth century the Spanish entrada was heavily felt in the Las Vegas area. In 1829 Rafael Rivera, a scout for a New Mexico merchant, established Las Vegas as the northern branch of the Old Spanish Trail, a trade route between New Mexico and Southern California (Moehring and Green 2005). The area became a route for slaving activities in the 1830s where “‘Piutes’ were hunted in the spring of the year, when weak and helpless, by a certain class of men, and when taken, are fattened, carried to Santa Fe and sold as slaves” (Kelly and Fowler 1986:386). In 1844 Las Vegas was officially recorded on a government map by Captain John C. Fremont, a mapmaker from the U.S. Army Topographical Corps (Moehring and Green 2005). Fremont’s exploration of the West, and his report of the Western territory fueled America’s interest in acquiring the area and promoted Westward expansion. By the mid-1850s slave raids had subsided with the migration of Mormons who established communities and missions in the Las Vegas area. However, the Mormons eventually turned back to Utah.

After the arrival and departure of the Mormons, the area continued to receive new migrants who mostly lived on cattle ranches and farms. On October 31st, 1864 Nevada was admitted as the 36th state in the Union. Western expansion prompted the establishment of reservations for the Southern Paiute, who still occupies treaty lands today (Kelly and Fowler 1986:386-387). In
1902 William Andrews Clark, a Montana copper baron, acquired a large portion of the Las Vegas valley from ranch owner, Helen Stewart, to construct a railroad (Moehring and Green 2005). By May 1905 the Los Angeles and Salt Lake railroad (LA&SL) was routed between Salt Lake City, Utah, and San Pedro, California. The division point between the railroad track that ran from newly established gold mines in Goldfield, NV and the LA&SL was located in Southern Nevada. The establishment of the LA&SL gave birth to a railroad town that would eventually transform into a tourist attraction.

Touristic Beginnings
The city began its official steps toward tourism when President Calvin Coolidge signed the Boulder Canyon Project Act into law on December 21, 1928. The decision to construct the biggest dam ever to be built started a frenzy in the little town of Las Vegas; land began to sell for a higher cost, Highway 91 (between Los Angeles and Salt Lake City) was widened and improved, and the railroad began to plan its expansion into Boulder City, the site of the future dam. The construction of the dam, which took five years, brought not only new residents and jobs into the city, but tourists as well. Between 1933 and 1934, over half a million people visited the city to see the construction of the new dam. Las Vegas’ residential population doubled between 1931 and 1935. The population boom was a boon to the development of the city’s infrastructure, prompting sewage construction, housing and school construction, paved roads and the establishment of several hotels and casinos. The dam provided much needed water and electricity for Las Vegas’ future development (Moehring and Green 2005).
Although gambling was legalized in 1869, pressure from churches, education leaders, women’s groups and reformists forced the state to outlaw it in 1910 (Koch 2008). The pastime was then practiced illegally until 1931, when the “Wide Open Gambling Bill of 1931” passed the Assembly and the Senate. Soon after the passage of the bill casinos began to be built. The first casino was the Meadows in May 1931 and later that year the Railroad Pass Casino opened outside of Boulder City. The legalized gambling, and soon after the legalization of alcohol in 1933, prompted Las Vegas to become a tourist attraction, and the city promoted itself as the “last frontier of the West”. After the construction of the Boulder (now Hoover) Dam, Las Vegas needed a new draw and began to host several events that publicized the town as a tourist center: Helldorado Rodeo and an Elks Club Parade (Moehring and Green 2005:91). Although these small endeavors slightly improved the city’s economy, it wasn’t until the 1940s that Las Vegas succeeded in significantly promoting tourism.

World War II expanded Las Vegas’ opportunities in the 1940s and solidified the city’s main industry: gaming-tourism. The city expanded with the development of a magnesium plant (Basic Magnesium, Inc.), a US military gunnery school, which would later become Nellis Air Force Base, and a marine camp. If it were not for influential city officials who brought the Gunnery school to Las Vegas, “[the city] would have died after Boulder Dam was completed (Moehring and Green 2005:142).” Soldiers and defense workers flocked to the gambling halls and clubs in the center of the city. As tourist structures began to impose on the city center’s residential neighborhoods, displaced residents began to occupy areas further from the city center, which encouraged suburban development. Throughout the war construction on Las Vegas Boulevard contributed to a constantly growing resort center (Moehring and Green 2005:108). Although the
heat remained a huge obstacle for many, by 1945 the improvement of air conditioners and swamp coolers encouraged comfortable living in the semi-arid desert. By the late 1940s these cooling systems were in every hotel, casino establishment and home in Las Vegas (Moehring and Green 2005:107).

Concerns about a possible post-war recession led city officials to invest heavily in promoting Las Vegas’ “tourist” image. The combination of advertising and continued outside investment in resort style hotel and casinos resulted in Las Vegas becoming a well-known tourist center by the 1950s (Kaufman 1974). The famous “Las Vegas Strip” began to form during this time, with the valley’s first high-rise, the Riviera, opening its doors in 1955. Several major casinos in the city center and on the Strip offered unique services. For example, the Showboat offered bowling, a popular sport in the 1950s, and hosted state and regional championships from across the nation. The Hacienda catered to large families by offering multiple swimming pools and a quarter-midget racetrack for children (Moehring and Green 2005). By 1955 nearly eight million people visited Las Vegas every year.

Minorities in Las Vegas

Despite most of Las Vegas’ early prosperity, the city’s African-American/black population struggled to experience these opportunities until the late 1960s (Moehring and Green 2005). African-Americans fought to work at the Dam, frequent local establishments, and live alongside their Caucasian counterparts (Kauffman 1974). Although no official segregation laws were implemented, and in any case were ruled unconstitutional in 1954, Las Vegas’ Caucasian

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2 Quarter midget racing is a type of automobile racing where the automobiles are approximately ¼ size of a full automobile.
residents, many of whom had migrated from the South, brought with them a segregationist mentality. In the late 1930s due to housing covenants that excluded blacks from moving into specific sections of the city, most African-Americans moved into an area known as the “Westside,” where rent was relatively low. The Westside did not have the infrastructural improvements, such as paved roads, sanitary improvements or public facilities, that other areas of the city experienced until the late 1950s, despite black community leaders’ protests (Moehring and Green 2005; Kauffman 1974). The building of the Basic Magnesium, Inc. plant in 1941 by the Anaconda Copper Company brought the first mass migration of African-Americans to Las Vegas, most of them coming from Louisiana, Arkansas and Mississippi. The Westside did not have houses to accommodate the mass influx of people, and as a result the community became a tent and shack city (Kauffman 1974:341).

African-Americans came to Las Vegas because of employment opportunities; however, many found the racism worse than that they had experienced in the South. The “back doors” that existed in the South were nonexistent in Las Vegas, and African-Americans were advised to stay out of local “white only” establishments (Kauffman 1974:350). Although, while blacks were able to work as janitors, housekeepers and dishwashers (“back of the house” jobs) in the casinos and hotels, many could not patronize them. The creation of several organizations to address human rights issues, including the Westside Chamber of Commerce, worked together with the National Association for the Advancement of Colored People (NAACP) to fight City officials on infrastructural and sanitary development and discrimination issues, such as the enactment of the Civil Rights ordinance. However, racism was prominent among both state and city authorities, who did not take action to eliminate racist practices. Black entertainers, such as Sammy Davis,
Jr. and Lena Horne could not stay at the hotels where they performed. The City Commission, upon refusal to adopt the Civil Rights ordinance in 1954, led the NAACP to call Las Vegas, the “Mississippi of the West” (Kauffman 1974:366).

Housing development did not come to the Westside until city officials realized that the area had become a slum, an insight that coincided with the availability of federal urban renewal money to cities in the late 1950s (Kauffman 1974). Project Madison, the title of the Westside urban renewal project, was conceptualized in 1957 and realized in 1960 with the assistance of both federal and city funds. Slum houses were demolished, and “decent, safe and sanitary” housing was constructed. However, in the four years that it took to finance, plan, survey and construct the program more people moved into the Westside than the new housing units could accommodate. Recommendations to build housing in locations other than on the Westside were ignored. Prominent black leaders indicated that the urban renewal program was a method used to “keep blacks in the ghetto” (Kauffman 1974:378).

The year 1960 brought more than failed dreams to the Westside; it also brought hope. NAACP leader Dr. James MacMillan and others proposed a strategy to eliminate racial segregation in the city by encouraging city and county officials along with hotel and casino executives to end Jim Crow practices in public and private facilities (Kauffman 1974). They reasoned that if hotels and casinos on the Strip and downtown ended racial discrimination, the city would follow suit. If talks would not successfully sway the minds of officials and casino executives, Dr. MacMillan suggested that peaceful demonstrations and marches would ensue. A few months after initiating talks, Mayor Gragson, Governor Sawyer and other officials announced that they had received
“assurances from the majority of downtown and Strip businesses that the policy of racial discrimination has ended” (Kaufman 1974: 395). Although integration led blacks to patronize hotels, casinos and businesses beyond the Westside, many still encountered job discrimination and continued to occupy “back of the house” positions. After 1960 many families chose to remain on the Westside despite integration, perhaps due to economic constraints coupled with continued housing discrimination (Kauffman 1974). While the accomplishments of this period were major turning points in Las Vegas history, even in the 20th century remnants of discrimination are present. Makenta’s late 1990s ethnography about the Westside illuminates current race issues, when a participant stressed, “You can’t quote me. This is a very racist town. I gotta live. I gotta work in this town (Makenta 1999).

Tourism, Inc.

Gottdiener, Collins and Dickens (1999) identify three phases in Las Vegas history that changed the city from an emerging tourist destination, to a world-class tourist’s dream. The first phase, between 1954 and 1969, solidified Las Vegas’ rise in the gaming industry with continued construction of resort hotels and big-name entertainment. The Rat Pack (Frank Sinatra, Dean Martin, Sammy Davis Jr., Joey Bishop and Peter Lawford), Wayne Newton, and the Beatles all performed during the 1960s. Hollywood also visited the city as a film-making destination with Elvis Presley, who later hosted his own show on the Strip for several weeks a year (Las Vegas Sun 2014) The second phase, between 1969 and 1987, addressed Mob influence and ownership of casinos, hotels, and other establishments. The passage of the Corporate Gaming Act in 1969, gave permission to public corporations to own casinos for the first time in history. The act also removed gaming license background checks previously required of all shareholders (PBS 2005).

The ‘megaresort’ era began with the opening of the Mirage on the central Strip in 1989. It was twice as large as the MGM Grand, which for 20 years, from 1969-1989, was considered the largest resort on the Strip. The Mirage ushered in much needed tourism for the city; the 1976 legalization of gambling in Atlantic City, New Jersey, provided intense competition for Las Vegas. The Mirage set the stage for the next three decades of building themed resort-style casinos that catered to every individual imaginable (PBS 2005). Today, over 30 million people each year visit the former sleepy, whistle-stop town known as Las Vegas and thousands of people relocate there every month. Tony Hsieh, CEO of Zappos, puts it very clearly, “Las Vegas has been and always will be the City of Possibilities” (Spirit 2013).

Characteristics of Las Vegas and its Population

*Geography*

Nevada is the 7th largest state in the nation, with over a quarter of its population living in Southern Nevada (U.S. Census 2010). The Las Vegas valley is comprised of approximately 600 square miles and is bordered by several mountain ranges. The Sheep Range Mountains border the valley to the north, the Black Mountains to the south, the Spring Mountains to the west, and several smaller ranges, such as the Muddy Mountains and Eldorado Range, are situated in the
east. Mount Charleston, located in the Spring Mountains, is the region’s highest peak at 11,018 feet.

The city of Las Vegas is situated in Clark County, located in the southern tip of Nevada (Figure 2.1). Clark County is comprised of the following cities and municipalities: Las Vegas, Henderson, Summerlin, North Las Vegas, Mesquite, Laughlin, Searchlight, Moapa Valley, Charleston, and Boulder City. Figure 2.2 details the Las Vegas metropolitan area as well as common neighborhood titles.

Figure 2.1. Nevada’s county territories, with Clark County in the Southern most corner of the state.
Climate

The Las Vegas valley displays classic southwest desert characteristics (Figure 2.3). Summer temperatures typically exceed 100 degrees Fahrenheit with mild 70-degree lows. The summer heat is coupled with extremely low humidity. Air conditioning is a necessity to survive comfortably in temperatures that exceed 100 degrees. Prior to air conditioning, many business owners who had settled in the 1905 whistle-stop town returned their business licenses and headed back to Southern California, noting not only the economic climate, but also the summer heat (Moehring and Green 2005:13). Early residents “just suffered,” and attempted anything for daytime relief, from hanging wet sheets in doorways to cool the air inside homes to sleeping on porches (Goldman 2010). Although the invention of air-conditioning has allowed urban centers
to thrive in the harshest environments, electric bills are typically high during the summer months, which may become a significant burden for low-income individuals. The city and county have addressed this situation with establishing cooling stations at various locations throughout the valley.

The Southern Nevada Regional Planning Coalition’s Inclement Weather Shelter Program was established as a seasonal response to provide relief to seniors, low-income and homeless populations (Wingert 2012). Heat has killed more people in the U.S. than floods, lightening, tornados or hurricanes over the last ten years (National Weather Service 2014). Excessive heat exacerbates health complications and claims the lives of Las Vegans every year (Associated Press 2013). Cooling stations are located throughout the Las Vegas valley, predominantly in community centers and non-profit organizations. Cooling stations are in operation between May 1st and September 30th between 11AM and 7PM. These stations provide water, air-conditioning and information on free or low cost fans, air conditioners and financial assistance and grants for summer energy bills (Hara and Johnson 2012).

During the cold winter months “warming stations” are also located throughout the valley, providing shelter throughout the night. Winter warming stations typically operate between November 15th and the last week of March. Winter shelters provide nighttime relief from the cold between 7PM and 9AM. Motel vouchers are available for families who are not able to relocate to the stations. On average, warming stations are able to accommodate 310 individuals.

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3 A technological, social and economic history on air-conditioning in the United States can be found in Gail Cooper’s (1998) book, Air-Conditioning America: Engineers and the Controlled Environment.
per night with an average of 564 motel vouchers per winter season (Hara and Johnson 2012). These services provide much needed relief for vulnerable populations throughout the valley and contribute to the social betterment of the city as a whole.

![Monthly Climate Normals (1981–2010) – Las Vegas Area, NV (ThreadEx)](image)

**Figure 2.3.** Monthly climate and precipitation averages in the Las Vegas valley. Graph created with the National Weather Service Forecast Office interactive website (http://www.wrh.noaa.gov/vef/).

*Water*

Las Vegas’ original source of ground water was three springs located in the center of the city, which is now a nature preserve called Springs Preserve. The springs were over-pumped for several decades, and are now totally dry. The city has relied on the Colorado River for its main
source of water since 1944. The Colorado River Compact agreement divided water rights to the river among seven states and Mexico, and with the construction of Hoover Dam, 85% of Las Vegas’ water now comes from the Colorado River (Figure 2.4). Although Nevada can legally sequester 300,000 acre-feet annually from the river, the Southern Nevada Water Reclamation District can exceed this amount due to an arrangement called “return-flow credits,” which is swapping wastewater for fresh water. In 1996, Las Vegas returned 131,000 acre-feet of treated wastewater into Lake Mead and pumped an additional 56,000 acre-feet of fresh water from the Colorado River (Ward 1999).

Figure 2.4. Colorado River drainage system. Note Lake Mead’s location to Las Vegas. Photo courtesy of Scripps Institution of Oceanography, UC San Diego.

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4 A historical account of water availability and water rights in Las Vegas can be found in Florence Jones and John Cahlan’s (1975) book, Water: A History of Las Vegas.  
5 Seven states include: Colorado, Wyoming, New Mexico, Utah, Arizona, Nevada and California. The full text for the original Colorado River Compact and its revisions can be accessed through the U.S. Department of the Interior’s website at: http://www.usbr.gov/lc/region/g1000/lawofrvr.html
Although many residents claim that most of Southern Nevada’s water is used by millions of tourists, the Southern Nevada Water Authority (SNWA) documents that resorts use a small fraction of the water supply, approximately 7% annually (Cooley et al. 2007). Meanwhile, single-family and multi-family residential households demand more than 50% of Nevada’s water annually (Cooley et al. 2007). Indoor water use is on par with other Western states with arid climates; however, Southern Nevada residents have the highest outdoor water demands (Figure 2.5). The SNWA has largely focused on outdoor water conservation education since outdoor water is absorbed and cannot be used as return-flow credits (SWA 2004). The city has adopted ordinances to limit grass areas to no more than 50% and 40% in single- and multi-family residential homes, respectively (Cooley et al. 2007). In addition, from May until October it is illegal to water lawns and gardens between the hours of noon and 7pm (Ward 1999). The high use of water in Southern Nevada may be contributed to its uncommonly low cost. The Las Vegas Valley Water District has a four-tier system, where usage of 0-5,000 gallons is $1.16 per 1,000 gallons, 5,001-10,000 gallons is $2.08 per 1,000, 10,001-20,000 gallons is $3.09 per 1,000 gallons and anything over 20,001 gallons is $4.58 per 1,000 gallons (LVVWD 2014). These rates are one of the lowest in the Southwest region (Table 2.1).

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6 The SNWA seeks multiple avenues to reduce water consumption. The Pacific Institute and Western Resource Advocates have compiled recommendations on improving the efficiency in existing homes and businesses, ensuring that new housing units are highly efficient, developing educational programs, and considering alternative, local and cost-effective water sources (Cooley et al. 2007).
Figure 2.5. 2004-2005 per capita water demand in Southern Nevada; Southern California; Irvine, California; Tucson, Arizona; and Albuquerque, New Mexico. Graph courtesy of Cooley, Hutchins-Cabibi, Cohen, Gleick and Heberger (2007).

Table 2.1. Comparison of water rates across the Southwest. Courtesy of the Las Vegas Valley Water District.
Socio-demographics

Clark County is one of the fastest growing metropolitan areas in the nation. According to the United States Census, the population residing within the Las Vegas metropolitan area has increased from approximately 273,000 people in 1970 to over 2 million in 2010 (U.S. Census 2013) (Table 2.2). The average number of people per square mile in 2010 was 247.3 in Clark County compared to 24.6 for the state of Nevada (U.S. Census 2013).

<table>
<thead>
<tr>
<th>Year</th>
<th>Population #</th>
<th>% Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1970</td>
<td>273,288</td>
<td>---</td>
</tr>
<tr>
<td>1980</td>
<td>461,861</td>
<td>69%</td>
</tr>
<tr>
<td>1990</td>
<td>770,280</td>
<td>67%</td>
</tr>
<tr>
<td>2000</td>
<td>1,425,723</td>
<td>85%</td>
</tr>
<tr>
<td>2010</td>
<td>2,036,358</td>
<td>43%</td>
</tr>
<tr>
<td>2013</td>
<td>2,062,254</td>
<td>13%</td>
</tr>
</tbody>
</table>

Table 2.2. Population trends of the Las Vegas metropolitan area that include: Boulder City, Henderson, Las Vegas, Mesquite, and North Las Vegas, 1970-2013. Census taken from the U.S. Census Beaur, Nevada State Demographer (U.S. Census 2013).

Approximately 60% of the Clark County population identified as White/Caucasian in 2012 (Table 2.3). However, within the last decade, Clark County has boasted a relatively large Hispanic/Latino population of 29.1%, with 21% of the entire Clark County population claiming Mexican ethnic heritage. The growth of Clark County’s Hispanic/Latino population mirror other Western and Southwestern states, such as Los Angeles County, California (48.2%), and Pima
Disaggregating Las Vegas’ metropolitan population by zip code illuminates the racial and ethnic distribution of neighborhoods (Figure 2.6). Hispanics are concentrated in the central and eastern areas of the valley. The African-American/black population historically occupied North Las Vegas, historically called the “Westside,” due, as noted earlier, to organizations barring the population from renting or buying housing elsewhere in the valley (Makenta 1999). Although segregated housing practices are more regulated, the Westside remains heavily populated by
African-Americans/blacks today (American Community Survey 2010). The negative effects of segregation on minority populations are well documented. For example, political isolation (Massey and Denton 1993), cultural and linguistic isolation (Kotlowitz 1999; Massey and Denton 1993), concentration of poverty and violent crime (Kotlowitz 1999), decreased economic strength, and limited housing options (Massey and Denton 2013) impact social environments and quality of life outcomes.

Figure 2.6. The racial and ethnic distribution of households in the Las Vegas metropolitan area, 2010. Image created with the New York Times American Community Survey web tool.

Education

High school graduation estimates are calculated by the National Center for Education Statistics as the percentage of incoming ninth graders who will graduate within four years and are considered regular graduates\(^7\). The relationship between education and health has been well documented, where better-educated individuals have more positive health outcomes, such as

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\(^7\) The rate is the number of graduates divided by the estimated count of freshmen four years earlier. The estimated count of freshmen is the sum of the number of 8\(^{th}\) graders five years earlier, the number of 9\(^{th}\) graders 4 years earlier and the number of 10\(^{th}\) graders three years earlier, divided by three.
fewer sick days, and normal Body Mass Index (Cutler and Lleras-Muney 2007). According to 2013\textsuperscript{8} estimates, Nevada ranks 50\textsuperscript{th} for high school graduation rates with 58\% of the state’s youth graduating with a high school diploma. This estimate is very low when the national graduation average for 2013 is 78.2\%. Clark County has similar graduation rates that closely align with the state’s average, as well as its racial/ethnic diversity (Figure 2.7 and 2.8).

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure2.7.png}
\caption{Nevada and Clark County High School graduation rates, 2011-2014. Data compiled using Nevada Report Card (nevadareportcard.com).}
\end{figure}

\textsuperscript{8} Due to item non-response, data for Nevada was imputed for 2008-2009.
Economy

Southern Nevada’s dominant industry is casino gambling. As Moehring and Green (2005:17) emphasize, “this is the industry Las Vegas depends on for its survival.” In 2011, the U.S. Census on State and County Business Patterns reported a total of 107 casino hotels in Nevada. Forty-six of these establishments employ over 1,000 total employees, 29 establishments employ 500-999 employees, 10 establishments employ 250-499 employees and 9 employ 100-249 employees. The 2008 economic downturn had a particularly negative impact on Nevada’s service sector. Although unemployment rates for Clark County were well above the national average between 2008 and 2013 (Figure 2.9), historically racial and ethnic minority populations were disproportionately affected (Table 2.4).
While the 2008 economic downturn generated high unemployment levels across the country, Las Vegas’ home construction and hospitality industry were particularly affected. Nevada’s lack of diversity in the economy coupled with the unavailability of federal employment training programs hindered Nevada’s recovery from the recession. The majority of individuals involved in these industries are from specific racial and ethnic populations, particularly Hispanic and black/African American (Tuman et al. 2013). As a result, the recession has disproportionately affected minority populations in Las Vegas. Between 2003 and 2006 approximately 24 percent of Hispanics were employed in construction. As residential construction came to a near halt, by 2012 only 7.6 percent were employed in this industry (Tuman et al. 2013). Figure 2.10 breaks down occupations among Foreign-born Hispanic individuals in Las Vegas.

![Figure 2.9. Unemployment rate for the U.S. and Clark County, 2003-2013. Source: Nevada Workforce Informer: Data Analysis tool.](image)
<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>% Rate (1990)</th>
<th>% Rate (2000)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Clark County Population</td>
<td>6.7%</td>
<td>6.6%</td>
</tr>
<tr>
<td>White Alone not Hispanic</td>
<td>6.1%</td>
<td>5.3%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>7.6%</td>
<td>8.8%</td>
</tr>
<tr>
<td>Black Alone not Hispanic</td>
<td>11.5%</td>
<td>11.5%</td>
</tr>
<tr>
<td>Asian Alone not Hispanic</td>
<td>5.0%</td>
<td>5.7%</td>
</tr>
<tr>
<td>American Indian Alone not Hispanic</td>
<td>9.5%</td>
<td>11.0%</td>
</tr>
</tbody>
</table>

Table 2.4. Clark County, Nevada Unemployment rate by race/ethnicity, 1990 and 2000. 2010 data unavailable. Source: Nevada Workforce Informer.

<table>
<thead>
<tr>
<th>Sector</th>
<th>Mexico</th>
<th>Other Central America</th>
</tr>
</thead>
<tbody>
<tr>
<td>Agriculture, Forestry, Fishing, Hunting, Mining</td>
<td>2.5%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Construction</td>
<td>13.1%</td>
<td>5.5%</td>
</tr>
<tr>
<td>Manufacturing</td>
<td>7.3%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Wholesale Trade</td>
<td>2.1%</td>
<td>1.0%</td>
</tr>
<tr>
<td>Retail Trade</td>
<td>6.5%</td>
<td>9.9%</td>
</tr>
<tr>
<td>Transportation, Warehousing, Utilities</td>
<td>3.0%</td>
<td>2.5%</td>
</tr>
<tr>
<td>Information</td>
<td>0.7%</td>
<td>0.9%</td>
</tr>
<tr>
<td>Finance, Insurance, Real Estate, Rental, Leasing</td>
<td>3.4%</td>
<td>0.8%</td>
</tr>
<tr>
<td>Professional, Scientific, Management, Administrative, Waste</td>
<td>11.3%</td>
<td>8.2%</td>
</tr>
<tr>
<td>Educational Services, Health Care, Social Assistance</td>
<td>5.2%</td>
<td>6.2%</td>
</tr>
<tr>
<td>Arts, Entertainment, Recreation, Accommodation, Food Services</td>
<td>37.2%</td>
<td>52.1%</td>
</tr>
<tr>
<td>Other Services (Except Public Administration)</td>
<td>7.1%</td>
<td>4.8%</td>
</tr>
<tr>
<td>Public Administration</td>
<td>0.6%</td>
<td>3.4%</td>
</tr>
</tbody>
</table>

Note: Data from the 2011 American Community Survey

Figure 2.10. Occupation of Nevada Latinos born in Mexico and Latin America. Data obtained from the 2011 American Community Survey. Adopted from Tuman, Damore and Agreda 2013.
Hospitality sector jobs, such as hotels and casinos, changed their hiring practices as the city’s tourism industry plunged. While I was moonlighting at various temporary agencies during my fieldwork, my co-workers complained about the economy and difficulty of finding full-time employment. One afternoon Han Lee, while occupying a nearby seat in Quick Staffing Company’s lobby, related to me that he had an on-call position at Bellagio Hotel and Casino, but they had not called him to work in over 6-months. To support his wife and new baby boy he signed up at various temporary agencies to earn a somewhat steady paycheck. Terry, a longtime culinary union member and casino employee, witnessed a drastic shift in her housekeeping department’s hiring practices; between 2009 and 2013 many newly hired housekeepers and other service personnel are on-call, part-time employees. These positions offer low wages, no benefits and irregular work hours. Getting into the local culinary union is like striking gold. Mark Zartarian, a room service waiter explains why,

Once we were in, it was so worth it. The wages and benefits were beyond anything I’d ever imagined. I had worked in states where the dining room waiter would make the subminimum of $2.25 an hour plus tips with no benefits at all, not even a meal. Here they were paying $7.50 an hour plus full health, paid vacation, guaranteed break, two meals a day, can’t be fired unless you’re really screwing up. We were gonna stay for six months at the outside. That was over seven years ago (Miller 2002).
Although employees revere the union, casino owners despise it. Every year Terry’s culinary workers union experiences stalled contract negotiations with the casino, and every year the Union threatens a strike due to casino noncompliance (Figure 2.11). The last union negotiation in April 2013 resulted in her losing two-weeks of paid vacation. She explains “it was either a strike, where we get paid $300 a week, who could live on that? Or cuts in our benefits. I’m working overtime now to make up for it.” After working toward four-weeks of paid vacation for over 15 years, she had lost half of it during her 20th anniversary year with the union. Despite Terry’s loss of vacation time, unionization, generally, provides stability for service workers and the economy, and when individuals are paid a livable wage they reinvest into the local economy (McQuarrie 2013). Many individuals struggle for years to get into the union or into a full-time position at casinos via on-call or part-time positions. However, despite high under employment and unemployment rates, Nevada’s casinos continue to prosper, with $11 billion in gaming revenue reported during 2013 (Stutz 2014). This is a decrease from 2012 revenue reports from Clark County casinos (Figure 2.12).

Figure 2.11. Culinary Union members and supporters protest in front of the Cosmopolitan, June 14th 2013. Courtesy of the Las Vegas Review Journal.
HIV/AIDS participants in my research are not immune to these economic issues and must also navigate a very slim job market while maintaining their health. Hispanic, undocumented males, who comprise approximately 7.2% of the Nevada population (Passel and Cohen, 2011), are particularly affected by the economy because they do not qualify for many state and federally funded social programs and must work ‘under the table’ to avoid immigration detection. Rudy came to Las Vegas from Mexico at age 16 with just the clothes on his back and shoes on his feet. He sold items door-to-door, graduated to restaurant work and finally secured a position as a catering assistant for an independently owned catering company. After 16 years in this country, he was finally able to pay off his truck— one of his most prized possessions. The onset of the recession coupled with the catering company owner’s own health issues brought on hardship for the catering company. Rudy finally lost his position after 12 years with the company. During the fieldwork year I met Rudy about 1 year into his unemployment period. He was washing dishes irregularly for 5 dollars an hour at a Chinese restaurant, looking for a roommate to share his two-bedroom duplex and scraping up anti-retroviral therapy pills to get by for the month. He took advantage of St. Therese food pantry and noted all the different varieties of cereal boxes

**Figure 2.12.** Gaming revenue for Clark County Casinos (152), 2012. Courtesy of UNLV Center for Gaming Research.
displayed on his refrigerator. He explained, “At this point, I would not be able to eat without them [the food pantry].”

Ariel, another participant in my research, had worked at a well-known hotel and casino for 12 years before quitting due to workplace conflicts. Five years later Ariel struggles to locate employment, pay his rent and feed his two pets. I met him at a participant’s home, waiting for a ride to the health department to obtain his health card. Casino employment in Las Vegas typically requires at least three types of work cards: a Sherriff’s card, food handling cards, and a Techniques of Alcohol Management (TAM) card. Many temporary agencies require these cards for casino employment. Each card has education requirements and a fee of around $100. Ariel was able to secure money from local service agencies for this certification to become eligible for food service-related jobs through temporary agencies. Ariel’s situation is in stark contrast to Rudy’s due to his current citizenship status: Ariel is a permanent resident. He is able to obtain work cards and verify his eligibility for temporary casino work, whereas Rudy is subject to under the table, below minimum wage pay washing dishes at a Chinese restaurant due to his undocumented status. Although both men were affected by the recession, in Las Vegas even irregular casino/hotel positions via temporary employment operations provide greater opportunities for documented individuals. Rudy’s success and then downfall due to the economic climate illustrates the fragility of individual’s lives, especially undocumented individuals, in the U.S. economy.
America’s Health Rankings (AHR) is a partnership between the United Health Foundation, the American Public Health Association and Partnership for Prevention. Since 1997, AHR has analyzed comprehensive data sets of behaviors, public and health policies, community and environmental conditions and clinical care data to provide a holistic understanding of population health across all 50 states. Rankings are based on a model of population health that emphasizes policies and programs, and health factors that influence health outcomes (Figure 2.13). The purpose of AHR is to prompt action by individuals, elected officials, health care professionals, public health professionals, educators and employers to improve the health of the U.S. population (AHR 2014).

![Figure 2.13. America’s Health Rankings’ model of population health outcomes. Adapted from AHR 2014.](image)

The state of Nevada’s and Clark County’s health ratings in AHR are poor compared with other states and counties across the nation. Clark County was ranked 6th (out of 16 counties) for mortality, 10th for morbidity, 7th for clinical care, 12th for social and economic factors and 15th
for physical environment. Overall, Clark County is ranked 8th in health outcomes and 12th in health factors. Compared to 2010 national averages, Nevada ranked 1st out of all the states in the percentage of children not covered by health insurance (17.5% Nevada vs. 9.8% national average) and 4th in the percentage of the population not covered by health insurance (20% Nevada vs. 15.8% national average). The state has one of the highest teen pregnancy rates in the nation with 84 pregnancies per 1,000 teen girls aged 15-19 (thenationalcampaign.org). These figures are alarming when coupled with Nevada’s child poverty rate (24% Nevada) that has risen by one-third in just five years (Green 2013). These rankings reflect not only poor social and economic factors, but also illustrates inadequate prevention and intervention efforts among public health stakeholders and the community at large.

**Women’s Health**

Women’s health is unique, in that many chronic diseases are gender-specific or gender-related. The Nevada State Health Division compiles information from a series of databases to provide a snapshot of women’s health in Nevada. The report identifies leading causes of mortality and morbidity, as well as behavioral risk factors and access to preventative screenings. Nevada uses the Healthy People (HP) 2020 initiative as a marker for improving the health of women. In 2012 Nevada has achieved all HP 2020 goals with the exception of adults over 18 years of age who have their blood cholesterol checked within the preceding 5 years. However, 19% of the female  

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9 Health outcomes represent the length of life and quality of life. It is measured using the following proxy items: premature death, poor or fair health, poor physical health, poor mental health, low birth weight.

10 Health factors represents what influences the health of a county. There are four types of health factors: 1) Health Behaviors (alcohol and drug use, diet and exercise, sexual activity, tobacco use); 2) Clinical care (access to care, quality of care); 3) Social and Economic Factors (community Safety, education, employment, family and social support, income); and 4) Physical Environment (air and water quality, housing and transit).
population aged 18 and over is without health insurance. This is similar to rates in the American population as a whole and may change due to healthcare reform as Nevada has elected to expand Medicaid and created their own health plan coverage called the Silver State Health Insurance Exchange.

Minority Health

The Nevada Office of Minority Health (NOMH), established in 2005, seeks to address policy, program and system needs to narrow the gap in health disparities across the state. The NOMH’s mission is to educate and improve the quality, and access to healthcare services for minority populations. The U.S. Department of Health and Human Services awarded NOMH a grant to focus on the impact of diabetes in Nevada’s minority populations. According to Nevada’s 2004-2009 Behavioral Risk Factor Surveillance System (BRFSS)\textsuperscript{11} data, African-American/black non-Hispanics had the highest estimated prevalence (11.4%) of diabetes of all racial/ethnic groups. Although Hispanics have a lower prevalence (5.9%), they are typically diagnosed at a later stage due to cultural and linguistic barriers, and limited access to healthcare due to being uninsured (Nevada Office of Minority Health 2012). This grant has focused on urban and rural outreach education to improve the incidence of diabetes in Nevada’s minority populations.

Although Clark County has a relatively large Hispanic population, identifying and addressing the health needs of this population has been largely overlooked. The cost, followed by distrust in the

\textsuperscript{11} The Behavioral Risk Factor Surveillance System (BRFSS) is the world’s largest on-going telephone health survey system. The Centers for Disease Control established BRFSS in 1984 to obtain state specific data on behavioral health risks that are associated with premature morbidity and mortality. For more information, please visit the BFRSS at the CDC’s website: http://www.cdc.gov/brfss/about/about_brfss.htm.
biomedical healthcare system has led to indigenous treatment clinics and naturalistas to open across the valley (Palchikoff 2011). Chino et al. (2008) solicited over 1,000 Hispanic participants at school fairs and community centers to understand health disparities and access to care among this population. Over sixty percent of respondents were female, an unconventional percentage considering that urban areas usually have a larger concentration of Hispanic men than women. The sample identified a high concentration (47%) of households that were linguistically isolated, where members aged 14 and over speak English less than ‘very well.’ Among this group 28% rated their English skills as ‘poor.’ Forty-eight percent did not have health insurance and identified the use of naturalistas as common practice. Interestingly, when rating health status, Hispanic men were more likely (79%) than women (67%) to rate their health as good or excellent (Chino et al. 2008). These important demographic statistics, and emic notions of health and health care practices are invaluable to inform and guide policy and program decision-making for this population in the state.

Las Vegas HIV/AIDS Statistics

HIV Transmission, diagnosis and prevalence rates of the most affected populations in Clark County mirror that of the nation. HIV/AIDS disproportionately affects men who have sex with men (MSM), especially young, African-American/black MSM (CDC 2014). African-Americans in Clark County have the highest rate of new HIV diagnoses between 2006-2012 (Figure 2.14) and the highest rate of living with HIV/AIDS in Clark County (Figure 13). Note that the rate of new HIV infections among Hispanics is higher than in the White, non-Hispanic population in Clark County (Figure 2.15). Nationally, recent research suggests that between 2006-2009 infection rates for Hispanics were in decline; however, rates differ according to place of birth.
(Espinoza et al. 2012). For example, between 2003 and 2006 HIV diagnoses among Mexican and Central American males increased (Espinoza et al. 2008). Interestingly, between 2006 and 2009 diagnosis rates for Puerto Rican and Mexican males decreased, while rates for Central American males continued to be among the highest (Espinoza et al. 2012). Specific rates for Clark County are unknown due to the absence of country of birth data for this population.

Figure 2.14. Rate of new HIV infections by race/ethnicity in Clark County, NV, 2006-2012. *Rates per 100,000 population were calculated using 2006-2010 population estimates and 2011-2012 population projections from the Nevada State Demographer 2011 data. Data provided by Nevada State Health Division of HIV/AIDS Surveillance.
Figure 2.15. Rate of persons living with HIV in Clark County by race/ethnicity, NV, 2006-2012.
*Rates per 100,000 population were calculated using 2006-2010 population estimates and
2011-2012 population projections from the Nevada State Demographer 2011 data.
Data provided by Nevada State Health Division of HIV/AIDS Surveillance.

The CDC reports that in 2011, 29% of newly diagnosed individuals in Nevada were late in the
disease, which puts these individuals at increased risk for disease progression, death and
transmission of HIV to others (CDC 2013). Between 2006 and 2012 African-Americans in Clark
County had the highest rates of new AIDS diagnoses compared to their Caucasian and Hispanic
counterparts (Figure 2.16). Nationally, survival after an AIDS diagnosis is lower for African-
Americans/Blacks than any other race/ethnicity (CDC 2013). Although the reasons for these
differences are debated, there is an association between race/ethnicity and differences in HIV
testing practices, prescribed HIV treatment regimens and adherence (Ichonivics et al. 2001).
Nevada has the highest rate of new HIV and AIDS diagnosis among adult and adolescent females in the Western states, 6.8 per 100,000 and 4.1 per 100,000, respectively (CDC 2010). Although males have contributed to the majority of new HIV diagnoses since HIV was identified in the 1980s, gender inequalities coupled with racial and ethnic disparities are recognized drivers of the HIV epidemic among minority females in the United States (Meditz et al. 2011). Throughout the six years, from 2006 to 2012, African-American/black females in Clark County were diagnosed with HIV at a considerably higher rate than their Caucasian and Hispanic counterparts, up to 34.2 per 100,000 vs. 4.6 and 5.9 per 100,000, respectively (Figure 2.17). The rate of African-American/black females living with HIV/AIDS in Clark County is also disproportionate, and continues to increase during the six-year period from 2006-2012 (Figure 2.18).
Although race and ethnicity is a prominent epidemiological perspective for examining disease within populations, other socio-demographic characteristics are also important when considering disease distribution. For example, HIV/AIDS surveillance indicates that African-American/black women have disproportionately higher rates of living with HIV/AIDS in Clark County; however, it has been speculated that mother-to-child HIV transmission (MTCT) may be more likely to occur due to demographic variables other than race, such as income ratio, marital status and education (Yang et al. 2009). Yang et al. (2009) suggest that by controlling for race, the overrepresentation of African-American/black mothers in HIV transmission may be attributed to socio-demographic considerations rather than race/ethnicity, specifically.

![Figure 2.17](image_url)  
**Figure 2.17.** Rate of new HIV infections among females by race/ethnicity, 2006-2012. Data provided by Nevada State Health Division of HIV/AIDS Surveillance.
Each year the Nevada Ryan White Transitional Grant Area (TGA) program\textsuperscript{12}, locally managed by Clark County Social Services, collects data from their consumers on perceptions of program performance related to the accessibility of HIV/AIDS medical and ancillary services. The primary purpose of the annual survey is to identify gaps or shortcomings in services and to make improvements were necessary. Secondarily, the data is used to prioritize annual resource allocation. The program serves three counties: Clark and Nye counties in Nevada, and Mojave county in Arizona. Ryan White funds numerous medical and ancillary service organizations in these three counties. A list of these funded service providers appears in the results section (Chapter 7).

\textsuperscript{12} The national Ryan White HIV/AIDS Program is named after Ryan White, who was diagnosed with AIDS at the age of 13. Ryan and his mother fought AIDS-related discrimination in the United States by educating the public. Congress passed the Ryan White CARE (Comprehensive AIDS Resources Emergency) Act months before he died in April 1990. The Ryan White CARE Act provides primary medical care coverage and essential support services for individuals living with HIV/AIDS. Please visit Health Resources and Services Administration’s website for more information: http://hab.hrsa.gov/abouthab/aboutprogram.html.
The most recent Ryan White report (2012) included 121 participants who completed surveys between January and February 2012 (Ryan White 2012). Previous customer satisfaction surveys that were conducted offered a stipend, usually a gift card, for the participant. However, during the 2012 survey, no stipend was offered and participation number dropped from 600-700 participants in previous years to just over 100. The racial and ethnic distribution of 2012 participants includes: Caucasian (30%); Hispanic (25.6%); Black or African-American (28.1%); American Indian/Alaskan Native (3.3%) and Asian (.8%). The 2012 survey focused on why minority populations have lower access rates to services compared to their Caucasian counterparts. The information obtained assisted with the development of local strategies to increase accessibility for this population.

The most important services that were needed and used in 2011 by consumers included (in order): 1) doctor’s visits (79%); 2) medications (69%); 3) dental care/oral health (65%); 4) food bank/food vouchers (60%); and 5) emergency assistance (50%). Barriers to care included an increase in the percentage of consumers who had difficulty accessing services due to lack of knowledge, attitude/stigma, access/cost and system issues (Table 2.5). Although, the majority of African-American/Black and Hispanic populations reported not being aware of existing HIV/AIDS services, Hispanics also reported not knowing what services are needed to deal with HIV/ AIDS. By contrast, the top barriers for Caucasians included stigma and not qualifying for services. Case managers are on the frontlines of care; assisting individuals navigate the healthcare and social service systems in a timely manner. It is surprising that only 69% of clients affirmed that their case managers assisted them with obtaining needed services “always” or “most of the time.” Case managers are critical resources for individuals in the Las Vegas
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<th>Barrier</th>
<th>Percent (%)</th>
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<tbody>
<tr>
<td><strong>Knowledge</strong></td>
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<tr>
<td>Not knowing HIV/AIDS services were available to me</td>
<td>37%</td>
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<tr>
<td>Not knowing the locations of the organizations providing HIV/AIDS services</td>
<td>37%</td>
</tr>
<tr>
<td>Not knowing what services I needed to deal with HIV/AIDS</td>
<td>35%</td>
</tr>
<tr>
<td>Not knowing HIV/AIDS services existed</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Attitude/Stigma</strong></td>
<td></td>
</tr>
<tr>
<td>I was worried about other people finding out I have HIV/AIDS</td>
<td>36%</td>
</tr>
<tr>
<td>I was afraid of how I would be treated</td>
<td>32%</td>
</tr>
<tr>
<td><strong>Access/Cost</strong></td>
<td></td>
</tr>
<tr>
<td>I had to wait too long to get an appointment</td>
<td>33%</td>
</tr>
<tr>
<td>Services aren’t located near my home</td>
<td>30%</td>
</tr>
<tr>
<td><strong>System Issues</strong></td>
<td></td>
</tr>
<tr>
<td>The system of care was too hard to navigate</td>
<td>39%</td>
</tr>
<tr>
<td>They told me I didn’t qualify for services</td>
<td>32%</td>
</tr>
<tr>
<td>I couldn’t get referrals for the services I needed</td>
<td>30%</td>
</tr>
<tr>
<td>The service I needed was not available</td>
<td>30%</td>
</tr>
</tbody>
</table>

Table 2.5. Major barriers to accessing medical and ancillary services in Clark County and Nye County, N = 121.


community, a community that has multiple services with different locations around the city. The scattered locations of these services, coupled with other knowledge barriers, attitudes, and system issues attribute to the majority of accessibility barriers for this population (Ryan White 2012).

Conclusion

Las Vegas, Nevada, as demonstrated in this chapter, is not a conventional city. Its unconventional history and economic reliance on gaming and tourism coupled with poor social and economic factors provide a unique backdrop to every day realities in the valley. Although social programs, such as cooling stations and Ryan White, are in place to provide relief, most are
intermittent and the security of establishing a consistent quality of life is otherwise a precarious gamble for the most vulnerable populations, especially those living with HIV/AIDS. As will be demonstrated in the subsequent chapters, socio-economic inequalities are a catalyst for health inequity among vulnerable populations. In the chapter that follows I focus on a brief history of HIV/AIDS in the United States and how minority populations have been disproportionately affected by HIV/AIDS.
CHAPTER THREE

The Birth and Treatment of HIV/AIDS

The Birth of HIV/AIDS in America: A Brief History

The Centers for Disease Control’s *Morbidity and Mortality Weekly Report*\(^\text{13}\) (MMWR) published on June 5\(^{\text{th}}\), 1981 was the first report of a cluster of patients diagnosed with Pneumocystis pneumonia (PCP) in Los Angeles. These patients garnered interest among physicians and immunologists due to the rarity of young, otherwise healthy individuals succumbing an infection that is almost exclusively limited to severely immunosuppressed populations, such as cancer patients under chemotherapy. The report highlighted the fact that all five patients were homosexual and that there might be an association between “the homosexual lifestyle” and the disease (CDC 1981a). The following month a second report (CDC 1981b) identified both PCP and Kaposi’s Sarcoma, among other associated infections, in a cluster of homosexual men in New York City and California. Kaposi’s sarcoma, an uncommon skin cancer characterized by dark, purple lesions, usually seen among older African and Israeli men, is uncommon in the United States, especially among young, Euro-Americans. Most patients were also diagnosed with Oropharyngeal/Esophageal Candidiasis or “thrush,” a yeast infection found on the mouth and throat, which is, again, uncommon among healthy adults.

The combination of these rare and uncommon diseases suffered by relatively healthy young men prompted the CDC to form the Kaposi’s Sarcoma and Opportunistic Infections (KSOI) task force

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\(^{13}\) CDC’s Morbidity and Mortality Weekly Report (MMWR) is a weekly international publication that contains data on specific diseases reported by state, territorial and international health departments. Reports must contain the most recent data. Investigations that are currently in progress or recently completed have the highest priority for publication.
to begin surveillance and conduct epidemiological investigations (Curran and Jaffe 2011). The KSOI task force initiated a case-control study, which found case-patients\(^{14}\) were much more sexually active than controls and more likely to have sexually transmitted infections, such as Herpes Simplex virus (Jaffe et al. 1983 and Rogers et al. 1983). The task force suspected that the mode of transmission, although not definitely identified, was sexual. The virus itself, the Human Immune-deficiency Virus (HIV), had not been identified at this point in time; however, the cluster of immunodeficiency related symptoms began to be identified according to the population it seemed to target: Gay-Related Immune Deficiency, or GRID (Shilts 1988:121).

Within the next several months the combination of immunodeficiency related symptoms spread into other populations. The MMWR began to publish articles related to “unexplained immunodeficiency” among infants (CDC 1982a) and Pneumocystis carini pneumonia among persons with hemophilia and/or who had recently received blood transfusions (CDC 1982b). Heterosexual females who have had sexual contact with males diagnosed with AIDS and injection drug users were also identified with immunodeficiency symptoms (CDC 1983a; Shilts 1988). Although the first cases of immunodeficiency symptoms emerged in the homosexual population, it was now identified among a broader population. The acronym GRID no longer classified the disease and in July 1982 CDC scientists coined the sexually neutral acronym AIDS, or Acquired Immune Deficiency Syndrome (Shilts 1988:171).

\(^{14}\) A case-control study obtains individuals who are infected with a particular disease and matches them with healthy individuals who have similar variables (sex, age, weight, etc). Differences between the two populations on a variety of measures are examined.
These additional cases provided strong evidence that AIDS was caused by an infectious agent, which was transmitted through sexual contact, blood and breast milk. In November 1982 the CDC issued safety guidelines to protect clinicians working with patients and laboratory workers managing their biological specimens against the spread of AIDS, which were based on previous recommendations to protect against hepatitis B infection (Curran and Jaffe 2011). Several months later, in March 1983, the CDC, the Food and Drug Administration (FDA) and the National Institutes of Health (NIH) issued recommendations for the public to guard against AIDS that were based on previous epidemiologic data (Table 3.1).

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<tbody>
<tr>
<td>1.</td>
<td>Sexual contact should be avoided with persons known or suspected to have AIDS. Members of high-risk groups should be aware that multiple sexual partners increase the probability of developing AIDS.</td>
</tr>
<tr>
<td>2.</td>
<td>As a temporary measure, members of groups at increased risk for AIDS should refrain from donating plasma and/or blood. This recommendation includes all individuals belonging to such groups, even though many individuals are at little risk of AIDS. Centers collecting plasma and/or blood should inform potential donors of this recommendation. The Food and Drug Administration (FDA) is preparing new recommendations for manufacturers of plasma derivatives and for establishments collecting plasma or blood. This is an interim measure to protect recipients of blood products and blood until specific laboratory tests are available.</td>
</tr>
<tr>
<td>3.</td>
<td>Studies should be conducted to evaluate screening procedures for their effectiveness in identifying and excluding plasma and blood with a high probability of transmitting AIDS. These procedures should include specific laboratory tests as well as careful histories and physical examinations.</td>
</tr>
<tr>
<td>4.</td>
<td>Physicians should adhere strictly to medical indications for transfusions, and autologous blood transfusions are encouraged.</td>
</tr>
<tr>
<td>5.</td>
<td>Work should continue toward development of safer blood products for use by hemophilia patients.</td>
</tr>
</tbody>
</table>

**Table 3.1.** Recommendations for prevention of acquired immune deficiency syndrome (AIDS), March 1983 (CDC 1983b).
The infectious agent, a retrovirus\textsuperscript{15} called Human Immunodeficiency Virus (HIV), was identified in May 1983 by French researchers, Drs. Francois Barre-Sinoussi and Luc Montagnier\textsuperscript{16}, from the Pasteur Institute. The following year Dr. Robert Gallo and colleagues from the National Cancer Institute at NIH provided additional proof of its causality in AIDS and sustained viral growth in vitro (Curran and Jaffe 2011). By the time of the virus’s discovery, the CDC reported 1,641 cases of AIDS in the United States with 644 deaths (NIH 2014). The discovery of the virus was essential to understand the biology of the disease and the subsequent development of screening kits and antiretroviral treatment. Scientists developed the first enzyme linked immunosorbent assay (ELISA) test kit to screen for HIV antibodies, which the FDA approved in 1985. ELISA enabled public health officials to identify HIV-infected individuals in the early stages of the disease so that they could be treated and counseled to avoid spreading the disease to others. The ability to screen the population for this virus provided scientists with the opportunity to study the immune system at various stages of HIV duress. Anthony Fauci, director of the National Institute of Allergy and Infectious Disease (NIAID), recalls the stressful years in the early 1980s prior to the development of ELISA:

The difficulty at the time was that the only patients that we had who had AIDS were patients dramatically and drastically ill. We had no way of screening patients, bringing them in early, and studying them the way we do now. In order to become recognized as having the syndrome, a

\textsuperscript{15} A retrovirus is a virus that replicates itself by converting RNA into DNA by using an enzyme called reverse transcriptase. Most cells replicate itself in the opposite fashion, by converting DNA into RNA. Hepatitis B is also classified as a retrovirus (Blumberg 1986, July 3\textsuperscript{rd}, http://history.nih.gov/NIHInOwnWords/docs/page_10.html).

\textsuperscript{16} Dr. Francois Barre-Sinoussi and Dr. Luc Montagnier were awarded the 2008 Nobel Prize in medicine for their discovery of HIV.
person had to have been sick. Once a person got AIDS—since very little could be done for them—the clinical course of the disease was usually virulent (Office of NIH History 2015).

Scientists discovered that the virus entered cells through the CD4 molecule on T4 helper lymphocytes. The identification of the genetic sequences of the virus led to the development of the first antiretroviral treatments, Zidovudine or AZT, which were FDA approved and made available in 1987. The Health Resources and Services Administration (HRSA) assisted with the first AZT drug reimbursement program that provided treatment to individuals who did not have the financial means or insurance to afford treatment.

ART medications

In the era of Highly Active Anti-retroviral Therapy (HAART) there are twenty ART drugs divided into six classes that interfere with the stages of HIV replication within a CD4 cell (Figure 3.1). The six classes include the nucleoside/nucleotide reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs), protease inhibitors (PIs), fusion inhibitors (FIs), a CCR5 antagonist, and integrase strand transfer inhibitors (INSTIs). Optimal initial ART treatments consist of two NRTIs in combination with one from the following classes: NNRTI, PI boosted with ritonavir (RTV) or INSTI. Regiments may differ and change among patients over the course of their lives, which depend on a variety of factors: results of HIV genotypic drug resistance testing, adverse drug effects, drug interactions with other medications, pregnancy, and adherence.
Individuals who are identified as having virologic failure, the inability to achieve or maintain suppression of viral replication to an HIV RNA level of <200 copies/mL, often have developed resistance mutations to certain inhibitors (HHS 2014). Individuals who are non-adherent to medication are at greatest risk for virologic failure due to HIV’s rapid random replication.

![Figure 3.1. Antiretroviral medications that inhibit HIV from successful replication at six different stages.](http://i-base.info/ttfa/section-3/35-how-hiv-drugs-work-main-types-of-drugs/)

rate and its inability to correct replication “mistakes.” The virus’s high mutation rate is evolutionarily advantageous because these mutations can block the effectiveness of ARVs against enzymes they are designed to target. A continuously non-adherent individual is at heightened risk for developing HIV mutations that resist most or all of the six classes of ARV drugs. Medication adherence is extremely important for those who begin treatment due to the
limited classes of ARV drugs available and high potential of associated HIV mutations for resistance against these drugs.

*Treating HIV/AIDS*

HIV cannot be cured, but it is treatable. HIV diagnosis begins a life-long routine of healthcare monitoring, particularly focusing on the CD4 cells that HIV uses to replicate itself. Federal, state and local agencies typically use the HIV care continuum, or the HIV treatment cascade, to respond to and treat individuals diagnosed with HIV (McNairy and Ei-Sadr 2012). The continuum is identified as a series of progressive stages: HIV diagnosis, linkage to care, retention to care, obtaining anti-retroviral therapy (ART) and maintaining a low HIV viral load (viral suppression). The HIV care continuum is theoretically beneficial for patients; however, evidence suggests that only 1 in 4 PLWHA is virally suppressed. Figure 1 identifies the declining percentage of individuals who are engaged in each stage of care.
According to the “Guide to Primary care among HIV/AIDS individuals” (Bartlett et al. 2004), patients who are confirmed HIV seropositive begin routine HIV primary care (also identify as chronic care) called “HIV staging” to document disease trends, such as monitoring viral load progression and immune status. Typically, individuals have their blood work completed before seeing the physician and at the scheduled appointment the physician evaluates the results. HIV staging includes blood work with a Complete Blood Count (CBC), CD4 count and HIV viral load count repeated every 3-6 months. It is recommended that individuals with early-stage disease and those at the start of anti-retro viral therapy (ART) follow-up more frequently, usually every three months.
The recommended guidelines for HIV treatment were revised by the Health and Human Services (HHS) panel on Antiretroviral Guidelines for Adults and Adolescents\textsuperscript{17} in May 2014 to include a series of changes that considered cost containment that do not compromise treatment effectiveness. CD4 cell count is considered the best way to monitor immune status among HIV positive individuals before and after ART initiation; however, viral load is the best measure of response to ART. Evaluation of HIV viral loads serves as a prognostic indicator and is used in conjunction with CD4 counts to assist physicians with making informed decisions on beginning ART, monitoring ART and changing ART medications. The monitoring of lymphocytes other than CD4, such as CD8 or CD19, is not clinically useful, adds to costs and is not routinely recommended. If patients do not initiate ART, viral load monitoring is not recommended during routine care. When patients initiate ART monitoring of viral load levels, as well as CD4 counts, continue every 3-6 months during the first two years of ART. If after two years, viral loads are consistently suppressed and CD4 counts are consistently within 300-500 cells/mm\textsuperscript{3} viral load monitoring is extended to every six months and CD4 monitoring every twelve months. Patients with CD4 counts consistently over 500 cells/mm\textsuperscript{3} may have optional CD4 count monitoring.

Recommendations for initiating ART has changed significantly over the past few years as evidence for the positive effects of beginning ART immediately after diagnosis, irrespective of CD4 levels or viral load, is growing. In the past when CD4 counts drop below a normal range (>200 cells/mm\textsuperscript{3}) physicians have often recommended beginning ART. The potential positive effects of Treatment as Prevention, also called the TasP model of HIV treatment and prevention (Cohen et al. 2010), include treating HIV disease early to maintain high CD4 counts and viral

\textsuperscript{17} The panel is a working group of the Office of AIDS Research Advisory Council (OARC) within Health and Human Services.
suppression in order to prevent disease progression and opportunistic infections. This also lowers incidence of HIV in the general population by reducing the transmissibility of the virus by suppressing the viral load of carriers. TasP, when introduced, was an untested hypothesis with strong evidence from mathematical models predicting its effects on HIV incidence (Eaton et al. 2012; Granach et al. 2009; and Holteletz et al. 2012; Barnighausen et al. 2014). Although the clinical benefit of beginning treatment at high CD4 cell counts are not conclusive, evidence suggesting higher rates of CD4 cell recovery (27) and reduction in the outcome of disease progression from HIV to AIDS (Lodwick et al. 2010; Sterne et al. 2009; Phillips et al. 2007; and Grabar et al. 2009). This new model of treating and preventing HIV disease has been incorporated into clinical HIV treatment guidelines in the U.S. and is currently being practiced across the country (HHS 2014).

The clinical manifestations of PLWHA are not homogeneous, and differ from one individual to another. Although the virus’ trajectory, at a biologic level, generally disrupts the immune system in humans, 5% of infected individuals are known as long-term survivors or persons with long-term non-progressive infection (Sheppard et al. 1993). There are two classifications of persons with long-term non-progressive infection: 1) category 1, “non-progressors”: individuals diagnosed with HIV, but who are completely asymptomatic after several years; and 2) category 2, “slow-progressors”: individuals diagnosed with HIV, who show some HIV disease progression despite several years. Non-progressors and slow-progressors may not have been recommended medications in the past, but new guidelines encourage immediate ART initiation.
As demonstrated above, monitoring HIV progression demands routine care immediately after diagnosis for the rest of an individual’s life. Multiple sectors of the health care system are utilized to maintain the health of PLWHA. For example, infectious disease and primary care clinics, phlebotomists and laboratories (blood lab), and pharmacies are utilized to monitor and control the progression of illness. However, organizations that provide psycho-social support in order to maintain individuals in the HIV care continuum may include: psychiatrists, counselors, medical case-managers, food pantries, rental and housing assistance programs, public medical insurance programs, and peer advocates. The literature has noted several barriers for client medication adherence, for example, medication side effects, depression, anxiety and lack of knowledge about medical regimen (Shelton et al. 2006). In particular, social challenges to successful HIV treatment will be discussed in the subsequent section (Chapter 4).
CHAPTER FOUR

Biomedical and Social Challenges:

The Epidemiology of HIV/AIDS in the United States

The United States has been at the forefront of the development and implementation of HIV medications, HIV treatment and the establishment of an HIV specific care system from the beginning of the epidemic. The US has established a public health workforce that includes doctors, nurses, case managers, epidemiologists, public health advisors and others at the federal, state and local levels to monitor nationwide HIV surveillance systems and successfully treat diagnosed individuals in order to contain the epidemic and respond to increased rates of the virus in the population. The workforce also creates new tools for the prevention of HIV, such as educational campaigns to combat stigma, the development of at-home HIV test kits, and community support programs for PLWHA. However, despite these advancements, the U.S. faces several challenges that significantly impact advances in promoting the nation’s health, such as barriers to care, racial and ethnic disparities, social and economic factors, and persistent social stigma. These challenges have disproportionately affected specific populations in the US. Understanding and addressing these challenges through culture specific care is key to combating the epidemic.
Epidemiology and Public Health

Epidemiology is the study of the distribution and determinants of disease or health outcomes within populations (Merrill 2010:2). The application of epidemiology to control health problems is the discipline’s primary tie with public health (258). Public health is a multi-disciplinary field that promotes the health of populations through organized community efforts. Public health uses epidemiology in two ways: prevention and evaluation. There are three tiers of prevention efforts in public health, primary, secondary and tertiary (Merrill 2010:15), which target different segments of the population. Primary prevention may alter the prevalence, risk or rate of a health outcome within a general population. An example would be HIV/AIDS education to prevent individuals from contracting the virus. Secondary prevention aims to find and treat disease early in those at risk, which can prevent late stage diagnosis. The promotion of frequent HIV testing and incorporating routine testing in emergency rooms for early detection are examples of this tier. Finally, tertiary prevention aims to prevent or minimize damage and pain from disease by slowing down progression and preventing further complications. Adherence to medication and healthcare retention are examples of successful tertiary prevention within HIV/AIDS care. The combination of these prevention efforts is what makes epidemiology and public health an effective tool in health promotion.

Although research presented in this dissertation is focused on the tertiary prevention of HIV/AIDS health outcomes, in recent years the concept of ‘Treatment as Prevention,’ or TasP, has aligned tertiary prevention with its primary counterpart. Cohen et al. 2011 demonstrated that HIV-infected persons who are on ART significantly reduced their risk of transmitting the virus to an uninfected partner by 96%. The reduction in risk has contributed to the continuous
suppression of HIV’s viral load in the blood and genital fluids. Providing treatment to PLWHA becomes a strategy not only for tertiary prevention, but also aids in primary prevention efforts. Longitudinal studies of communities with high concentrations of injection drug users (IDU) and men who have sex with men (MSN) have documented that once ART is increased within these communities, communal viral loads and new HIV diagnosis rates decline (Sturmer et al. 2008).

The Practice of HIV/AIDS Epidemiology and Public Health

In the United States, the nation’s primary source of information on HIV/AIDS is the CDC. As of 2011, the CDC has collected, analyzed and disseminated HIV/AIDS surveillance data throughout the fifty states, the District of Columbia and five dependencies: American Samoa, Guam, Northern Mariana Islands, Puerto Rico, Republic of Palau, and the U.S. Virgin Islands. The CDC began coordinating with health departments in each state and dependency to obtain up-to-date information on the epidemic. The annual HIV surveillance report, published by the Division of HIV/AIDS Prevention (DHAP), summarizes information on the disease and is used by a variety of agencies including federal, state, local and non-profit organizations to inform prevention and treatment strategies throughout the country. Four key demographic and behavioral features primarily disaggregate HIV/AIDS epidemiology: race and ethnicity, sex/gender, age and transmission category. Transmission category is a term that summarizes the

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18 Prior to 2008, not all U.S. states and dependencies implemented confidential name-based HIV infection reporting, a specific type of reporting that allows providers to report cases directly from name-based medical records and facilitates the elimination of duplicate case reports (UNAIDS 2000). Confidential name-based reporting assists the collection of accurate and timely epidemiological data while maintaining strict standards of confidentiality. In 2005, the CDC recommended fourteen state and local health departments to switch from code-based or name-to-code methods to the CDC’s standard reporting method (Letter recommending 2005). The CDC offered technical assistance to all departments transitioning to prevent minimal reporting disruptions. A history of this transition is found in UNAIDS (2000).
risk factors that a person may have that most likely resulted in HIV transmission. The most common HIV transmission categories in the U.S. include: Male-to-Male sexual contact (MSM), Heterosexual contact, Injection drug use (IDU), and Male-to-male sexual contact and injection drug use (combination). Less common transmissions include: blood transfusions/blood products, mother-to-child transmission, and needle sticks (primarily among healthcare workers). Demographic, behavioral, and transmission information assist researchers to identify and assess risk factors and how diseases may differ among populations.

Demographic, behavioral and transmission knowledge furthers public health efforts to target key programs and individuals within a region or community. For example, when disaggregating Hispanics according to mode of transmission, Hispanics born in Puerto Rico are more likely to contract HIV as a result of injection drug use (IDU) than any other mode (e.g. MSM and high risk heterosexual sex) (CDC 2005). Mino et al. (2012) observed further differences among IDU Puerto Rican males in their 1996-2004 longitudinal study among Puerto Ricans in two locations: Bayamon, Puerto Rico and East Harlem, New York. Injection drug users in Puerto Rico became infected with HIV at almost four times the rate of their New York counterparts and died at a rate that was more than three times as high. Although the aforementioned demographic and behavioral features are important to identify high-risk groups, the recent nationwide unification of HIV data in the HIV/AIDS Reporting System (HARS) also contributes epidemiologic information about the regional spread of the disease. In a recent example, seven of the ten states with the highest HIV diagnosis rates per 100,000 population in 2011 were in the Southern U.S.
(HARS 2011). The Southern U.S.\textsuperscript{19} has received particular attention from Health and Human services over the last several years due to increases in new HIV diagnosis rates and HIV-related mortality and morbidity. These data prompted several local health departments and the Health and Human Services to initiate specific intervention programs for this region.\textsuperscript{20}

Three types of epidemiologic data are additionally useful for tracking the progression of HIV infection: 1) estimated diagnoses of HIV infection, 2) AIDS diagnoses and 3) death data. Disparities between populations from the time of HIV diagnoses to AIDS diagnoses to time of death reflect inequities in accessing HIV prevention services and healthcare. These data are necessary for tertiary prevention of HIV/AIDS progression and are used to help direct resource allocation. The timely importance of tracking HIV/AIDS progression is historically demonstrated in the Black/African-American female population. The response to the HIV/AIDS epidemic among black women in the U.S. did not receive adequate attention as the epidemic began to spread out of the white, gay male population (Cohen 1999). The effect of this slow response may explain why, in 2004, HIV/AIDS was the leading cause of death for black women aged 25-34 in the United States (Centers for Disease Control and Prevention 2004).

The validation of TasP, coupled with current prevalence of HIV/AIDS among minority populations increases the importance of developing culturally relevant strategies for PLWHA to access and be retained in healthcare. To understand the importance of this issue, we need to understand the current epidemiology of HIV/AIDS in the U.S.

\textsuperscript{19} Southern States include: Alabama, Florida, Georgia, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee and East Texas.

\textsuperscript{20} More information on these initiatives can be found at: the Southern AIDS Coalition, the Southern HIV/AIDS Strategy initiative, and Southern Reach.
The Changing Epidemiology of the Epidemic

Epidemiological analysis of HIV/AIDS in the U.S. reveals that it is not distributed evenly across the country. The disease tends to cluster around urban areas where the population is greater than 500,000. Figure 4.1 shows a range of HIV infection rates across the United States.

![Figure 4.1](image)

**Figure 4.1.** Rates of Persons Aged 18-64 Years Living with a Diagnosis of HIV Infection, Year-End 2008- United States. (from CDC, June 2012, HIV and AIDS in the United States by Geographic Distribution).

HIV/AIDS epidemiology has changed significantly since the virus was first identified in the early 1980s. Federal and state health agencies have developed surveillance strategies, as reviewed above, to identify and track the virus in order to make informed public health decisions. Although when first reported, HIV/AIDS was diagnosed predominantly among Caucasian male homosexuals, over the decades the epidemic has increasingly affected racial and
ethnic minorities and females. Recent HIV/AIDS surveillance data reveal the disproportionate burden of HIV/AIDS disease on specific racial/ethnic groups and risk-behaviors in the U.S., such as: 1) Black/African-American males (MSM and heterosexual), 2) Black/African-American females, 3) Hispanic females, and 4) Hispanic males (MSM). These populations are also disproportionately affected at the tertiary prevention level, with minority populations having lower engagement at each stage HIV care continuum stage than their Caucasian counterparts (Figure 4.2).

Figure 4.2. Percent of PLWHA by race/ethnicity who are engaged in each stage of the HIV continuum of care (HIV Treatment cascade). Adopted from AIDS.gov (http://aids.gov/federal-resources/policies/care-continuum/)

Black/African-American

The proportion of new HIV cases among Caucasians in the U.S. dropped from 60% in 1981 to 28% in 2001 (Osmond 2003). However, the proportion of new cases among African-Americans increased from 25% in 1981 to 50% in 2001. HIV/AIDS continues to disproportionately affect
specific racial and ethnic groups in the U.S. Surveillance data from 2010 indicate that African-Americans are the most affected racial/ethnic group; although they totaled 12% of the US population in 2010, they made up 44% of all new HIV infections for the same year (Figure 4.3). Black/African Americans have the highest burden of new infections rates of all racial/ethnic groups in the U.S. (Figure 4.4).

**Figure 4.3.** New HIV Infections by Race/Ethnicity, 2010 (n=47,500). African Americans are disproportionately affected by new HIV diagnosis. Adopted from Centers for Disease Control and Prevention, HIV/AIDS Surveillance.

**Figure 4.4.** Estimated rate of new HIV infections, 2010. African Americans are disproportionately affected by new HIV infections. Adopted from Centers for Disease Control and Prevention, CDC report, Estimated HIV incidence among adults and adolescents in the United States, 2007-2010.
Hispanics/Latinos

Hispanics/Latinos, like African American/Blacks, are also affected disproportionately by HIV/AIDS. Although in 2010 Hispanics/Latinos represented 16% of the total U.S. population, they accounted for 21% of new HIV infections (Figure 5). The rate of new infections for Hispanic/Latino males was 2.9 times that for white males and for Hispanic/Latina females it was 4.2 times that for white females (Figure 2). Rising incidence of HIV among Hispanics is pressing when considering their 43% growth in the U.S. over the last decade (Passel, D’Vera, and Lopez 2011). To obtain more nuanced data among this population, HIV/AIDS surveillance tracks country of birth among all individuals who report Hispanic/Latino ethnicity. Espinoza et al. 2008 found that between 2003-2006 over half (61%) of HIV infected Hispanics in 33 states who reported place of birth were born outside of the US (Espinoza, Hall, Selik, and Hu 2008).

The HIV Care Continuum Initiative, part of the goals of the National HIV/AIDS Strategy, seeks to improve levels of care and viral suppression among all Americans by 2015. Goals for the initiative for Hispanics include a) 85% of Hispanics/Latinos diagnosed with HIV to be linked to care, b) 80% to be retained in care, and c) a 20% increase in viral load suppression. A recent analysis of 2010 data reveals that although 80% were linked to care, only 54% were retained in care21 (Gant et al. 2014). Furthermore, although 44% were prescribed ART, only 36% had achieved viral suppression (< 200 copies/mL). Hispanic females with transmission of HIV through injection drug use had the lowest percentage of viral suppression (23%) compared with

21 Data from this study are from 19 jurisdictions: California (Los Angeles County and San Francisco only), Delaware, District of Columbia, Georgia, Hawaii, Illinois, Indiana, Iowa, Louisiana, Michigan, Minnesota, Missouri, Nebraska, New Hampshire, New York, North Dakota, South Carolina, West Virginia, and Wyoming.
females who with heterosexual transmission (42%). Hispanics with a history of injection drug use typically had lower levels within each level on the HIV care continuum.

![Diagrams](Image.png)

**Figure 4.5.** Diagnoses of HIV Infection and Population by Race/Ethnicity, 2011—United States. Adopted from CDC Slide Sets, HIV surveillance.

*Men Who Have Sex with Men (MSM)*

Anal sex is the riskiest type of sex for contracting or transmitting the HIV virus. Among all men who have sex with men (MSM), African American men are the most affected by HIV. In 2011 African American MSM accounted for the largest estimated percentage of diagnosis of HIV infection (39%) compared to their white (34%) and Hispanic (23%) counterparts (CDC 2014). Furthermore, data from 2010 reveal that young African American MSM have twice as many estimated new infections than their white or Hispanic counterparts (Figure 4.6). When we consider that the African-American population makes up approximately 12% of the total U.S. population these figures demonstrate a particular burden of HIV/AIDS among this group (US Census, 2014).
HIV has been labeled a “disease of poverty,” (Gillies et al. 1996) where social and economic environments play a primary role in transmission. Poverty, homelessness, drug use, high crime rates and mass incarceration that plague African-American communities across the US lead to an absence of health seeking behavior (Adimora and Schoenbach 2005; and Kim et al. 2012). These particular environments have seen the most HIV/AIDS diagnoses within the last three decades and it is a focus for primary prevention efforts in numerous vulnerable communities.

![Figure 4.6. Estimated Incidence of HIV Infection Among MSM, by Race/Ethnicity and Age at infection, 2010-United States. Adopted from CDC, 2012k.](image)

**Females**

In 2011, African American females made up 12% of the U.S. population, but accounted for 64% of diagnoses of HIV infection among females (Figure 4.7). As mentioned above, the slow response to prevention and treatment efforts among African American females may have resulted in HIV/AIDS as the leading cause of death for black women aged 25-34 in 2004 and aged 35-44 in 2011 (Centers for Disease Control and Prevention 2004 and 2011).
Nevada, along with California, has one of the highest rates of individuals living with HIV in the Western United States. When disaggregated by sex, Nevada has the highest rate of females living with HIV in the Western United States (Figure 4.8). This does not necessarily mean, however, that individuals contracted HIV or were diagnosed with HIV in the state of Nevada. Nevada, especially Las Vegas, is a transient city; according to census research, Las Vegas had hundreds of thousands of people relocating to Las Vegas in 2010. Las Vegas’ lure of people from out of state has caused considerable turmoil in how the city is categorized for HIV federal funding.
Federal HIV funding, Ryan White, is allocated based on the number of new diagnosis for each state. As a result, despite the fact that Nevada has one of the highest rates of persons living with HIV in the West, it does not receive money for most of the individuals residing there. Instead, HIV funding stays where these individuals were diagnosed - money does not move with the individual. In a 2013 survey among Ryan White recipients in Las Vegas, 40% indicated that they were diagnosed in a state other than Nevada (Ryan White 2014).
“While the number of Americans living with HIV has always been going up, American deaths from AIDS have always been going down.” – Beloit College’s mindset list for the class of 2018, #39.

“The United States will become a place where new HIV infections are rare and when they do occur, every person, regardless of age, gender, race/ethnicity, sexual orientation, gender identity or socio-economic circumstance, will have unfettered access to high quality, life-extending care, free from stigma and discrimination.” – Vision for the National HIV-AIDS Strategy, July 2010

**HIV/AIDS Health Care in America**

The most recent National AIDS Strategy focuses on 1) Increasing access to care and improving health outcomes for people living with HIV; and 2) Reducing HIV-related disparities and Health inequities (National AIDS Strategy 2010). The document identifies that there are social and structural challenges that prevent the success of combating the epidemic at all three prevention levels (primary, secondary and tertiary). Most notably, at the tertiary level, these challenges include stigma, barriers to care and falling out of care.

**Stigma**

“The future of prevention and care for HIV means standing up to two societal foes, scarcity and discrimination, as much as the biologic challenge of the virus itself... successful efforts for prevention must also include sustained and visible efforts to combat stigma and prevent discrimination.” – Curran and Jaffe, 2011.

Stigma is a social phenomenon that involves the complex interaction of economic and psychosocial factors within an environment that negatively affects an individual (Ogden and Nyblade 2005). Goffman (1963) describes stigma as “an attribute that is significantly discrediting” that
reduces the carrier “from a whole and usual person to a tainted, discounted one.” HIV-related stigma refers to the prejudice directed at people living with HIV/AIDS. Three main types of stigma are primarily identified in the HIV literature: perceived stigma, internalization of stigma and experienced stigma (Nyblade 2006). These types are not mutually exclusive, and can negatively affect each other. For example, perceived stigma can become internalized and lead to a negative self-image of oneself (Lee et al. 2002). Discrimination is the negative result of stigma that serves to devalue individuals with unjust and prejudicial treatment. Stigma and discrimination serve as a barrier to accessing prevention, care and treatment services.

HIV/AIDS stigma is similar to other diseases and disorders that have a history of stigma and discrimination, such as leprosy, mental illness and alcoholism. These stigma-related diseases typically have the following characteristics:

- The person with the disease is seen as responsible for contracting it
- The disease is progressive and incurable
- The disease is not well understood by the public
- The symptoms cannot be concealed

One cannot discuss HIV without including an account of stigma and discrimination. These negative human actions seem to go hand in hand with an emotional-neutral virus that is spread though blood, vaginal fluids, semen and breast milk. Early reporting of the disease in America focused on one behavioral risk factor, homosexuality- a highly stigmatized topic during the 1980s. The early uncertainty of modes of HIV transmission coupled with the dramatic affects of the progression of the disease, instilled fear in the general public. Since HIV was not well
understood for many years in the beginning of the epidemic, and the first population associated
with it was seen as “immoral” in the eyes of mainstream America and faith based organizations,
the public’s fear of the untreatable disease increased. The presence of homosexual men seemed
to discourage media reporting and delay public health and research funding for AIDS in the early
years of the epidemic (Shilts 1988).

The stigma and discrimination continued as new populations contracted the virus. The (false)
consensus was that all who contracted the disease were on the margins of society; women were
prostitutes and men were drug addicts, homosexuals, or both. As the public continued to
misconstrue information about the disease, particularly where it originated from and how it had
spread into the United States, even identifying as Haitian became synonymous with AIDS
(Farmer 2006:211). The only groups that seemed to avoid shame, blame and negative labeling
were hemophiliacs and newborns. However, most individuals were given little sympathy due to
society’s dismissal of the “taboo” behaviors (homosexuality, drug-use and poverty) associated
with the disease during its discovery (Farmer 2006:212-213 in Panem 1988). The beginning of
the AIDS epidemic saw many opportunistic infections in early patients, such as PCP, Kaposi
Sarcoma, and wasting syndrome\(^\text{22}\). These visible symptoms, such as coughing, skin lesions and
dramatic weight-loss, contributed to the common association with AIDS diagnosis. These
characteristics, similar to other historical diseases, placed HIV/AIDS on an early trajectory for
stigma and discrimination.

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\(^{22}\) Wasting syndrome is characterized by an individual losing at least ten percent of his/her body
weight and has at least thirty days of diarrhea and/or weakness and fever. Severe loss of weight
and muscle, or lean body mass, leads to muscle weakness and organ failure (Office of Women’s
Health 2014).
The causes, forms, and consequences of stigma and discrimination may occur on a micro (psychological) or macro (institutional) level within a given context. Stigma prevents people from accessing and retaining HIV prevention and treatment, such as HIV testing (Chesney and Smith 1999; Herek et al. 2003), disclosing HIV status (Rao et al. 2007), delayed receipt or adherence of antiretroviral therapy (Carr and Gramling 2004; Castro and Farmer 2005; Rao et al. 2007; Taylor et al. 2014; Vanable et al 2006; Wolitski et al. 2009), and staying in care (Kinsler et al. 2007; Taylor et al. 2014). The emotional effects of stigma, isolation, depression and anxiety, contribute to decreased use of prevention, treatment and care services. Lowther’s et al. (2014) international comparison on stigma across a wide range of populations found that the prevalence of depression and anxiety is associated with the high prevalence of HIV-related stigma. Internationally, approximately 42-83% of people living with HIV in the era of HAART have experienced some type of stigma. These micro and macro contexts are situated within unique psycho-social environments that may cause heightened sensitivity to stigma and being identified as HIV positive that create barriers to accessing adequate healthcare.

Parker and Aggleton (2004) argue that stigma is deeply rooted in power and domination within sociocultural structures, which repeatedly produce and reproduce power and control. Stigma thus becomes an outcome of social inequality that seeks to categorize individuals based on difference. Women, for example, tend to feel more oppression and stigma simply because they are women and have the ability to infect children through mother-to-child transmission (Sandelowski et al. 2004). Early public health posters have spread this image of the immoral mother through their, “She has her father’s eyes and mother’s AIDS” series (Figure 4.9), laying fault of a perinatal HIV diagnosis on mothers alone.
Parker and Aggleton’s (2004) socio-cognitive models of stigma are not typically included in interventions to reduce perceived, internalized and experienced stigma. Instead, much research has been devoted to addressing stigma through education in the general population to reduce experienced stigma (Perry et al. 1991). Although many stigma reduction interventions are limited (Manajan et al. 2008), the most successful programs include a skills building component that is coupled with education (Brown et al. 2003). The generalizability and long-term success of these studies, however, remain in question with many utilizing a pre- and post-test experimental design among convenience samples of university students (Perry et al. 1991 and Manajan et al. 2008).

Furthermore, a deeper problem with understanding stigma is that measures are rarely standardized and, in many cases are hypothetical questions. For example, the question, “will you be willing to share food with a person who has HIV/AIDS?” is an ambiguous measure of
perceived stigma (Nyblade 2006). Effective HIV/AIDS prevention and treatment programming depends on standardized and relevant measures of stigma to inform successful interventions.

PLWHA have coped with stigma in a variety of ways since the beginning of the epidemic. MSM have reacted by presenting themselves with a less stigmatizing illness (other chronic disease) or mode of transmission (blood transfusion), or not disclosing their HIV status (Siegel et al. 1998) to one of proactive advocacy in community education (Shilts 1988). Women have coped by normalizing HIV as any other illness, engaging in HIV education, creating a social community of HIV positive women and limiting disclosure (Sandelowski et al. 2004). Self-management of HIV education courses have had a positive effect on psychosocial coping techniques that correlate with increased quality of life in addition to medication adherence and healthy living (Millard et al. 2013).

**Barriers to Care**

The United States offers three insurance options, which are dependent on an individual’s circumstances, to obtain chronic healthcare for HIV. Options may include the following:

- Private insurance
- Public insurance (Medicaid and Medicare)
- Federal Insurance (Ryan White)

Ryan White Part B is administered by the U.S. Department of Health and Human Services (HHS), Health Resources and Services Administration (HRSA), HIV/AIDS Bureau (HAB) and the Nevada Division of Health. It is described as a “payer of last resort,” meaning the program
will pay for medical costs after other forms of insurance have paid, or for those who have no
other source of coverage. Federal funds are awarded to each state with local agencies being
appointed to deliver care to eligible individuals. Many programs also function at the state, county
or local level. For example, Clark County Social Services in Nevada, issues a temporary medical
card that is renewable every three months through a program called Access to Healthcare
Network.

As mentioned earlier, adherence to antiretroviral therapy reduces disease progression, improves
health outcomes and reduces the risk of viral transmission (Cohen et al 2011; Attia et al. 2009).
In order to realize the National AIDS strategy is it pertinent to provide tertiary prevention to
PLWHA. Programs in the U.S. such as Ryan White and ADAP were created in order to assist
individuals with accessing routine medical care and prescription medications. These programs
are found in all fifty–states and are federally funded. Although these programs are available,
structural barriers to accessing benefits create challenges for PLWHA. Difficultly with policies
and implementation includes patient transportation, ADAP medication refill schedules and
procedures, mailing of medications and the recertification process (Olson et al. 2014) reflect
barriers to service utilization, and retention in care.

In a recent survey of the SPNS program, a demonstration project in 10 states, which was
implemented in conjunction with multiple community partners to link PLWHA into care, found
that agency competition for patients resulted in non-referrals (Garcia et al. 2014). Non-referrals
typically involve non-disclosure of available services to clients who are in need of those services.
Non-referrals may typically result in care gaps, or falling out of care since the relationship
between retention to care is often highly associated with access to ancillary services (Garcia et al. 2014). Chase (2011) also documents this type of referral reluctance, practiced primarily for sustained funding reasons, among Puerto Rican women in New York City. Implementation of access and retention programs among organizations must balance a socio-ecological framework that anticipates multi-level challenges at the program, team, agency, and partnership level (Garcia et al. 2014).

Access to treatment is an important biomedical intervention to treating HIV/AIDS and reducing the spread of infection, however, social and environmental factors assist with the effectiveness of biomedical interventions. Andersen et al. (2000) for example, reported that certain populations, namely women and African-Americans, did not have early access to HAART, a standard HRT regimen, due to “predisposing and enabling variables”. Basic needs, such as housing stability and food security, are generally positively associated with timely health care utilization (Kushel et al. 2005). Food security not only affects the well-being of individuals, but also the efficiency and adherence of antiretroviral medications. Well-nourished individuals are more likely to withstand the effects of HIV disease and delay AIDS progression (Thomas and Mkandawire 2006). As Sallie, in NPR’s news article reports, “my medicine doesn’t work if I’m not eating right” (Figure 4.10). In a systematic review, Singer et al. (2014) found that food insecurity in both developed and developing nations is a significant barrier to ART adherence. When ART adherence is widespread, however, food insecurity can strain social solidarity and perpetuate mistrust among members in a community (Kalofonos 2010). To provide holistic services to clients and reduce the disease’s burden on low-income populations, Ryan White funds nutritional services (e.g.
dieticians) and the Department of Housing and Urban Development (HUD) funds housing options (HOPWA).

Drug abuse, however, is a challenge to overcome, even if one is involved with ASOs. O’Daniel (2011) through documenting the challenges of poverty and local conditions found that chemical dependency frequently placed low-income African-American women into what she describes as “vulnerable women” and “temporarily (un)stable women.” These women, who had difficulty meeting their basic needs, even through ASOs, could not achieve a healthy lifestyle, which included medication adherence and an absence of opportunistic infections, without the assistance of non-ASOs. Many chemically dependent women fluctuated between vulnerable and temporarily (un)stable depending on the frequency of drug use. Drug-use also has implications

Figure 4.10. The association of food security and ART effectiveness. Photo taken by author.
for increasing the risk of mother-to-child transmission of HIV. Among pregnant Hispanic women who exposed their children to HIV, drug-using women were less likely to have prenatal care, even though they were knowledgeable of their HIV status (Artstein-McNassar et al. 2012). This report is disconcerting when mother-to-child HIV transmission is reduced significantly, from 25% to less than 2%, if perinatal HIV treatment opportunities are utilized.

**Falling Out of Care**

Within the HIV continuum of care, patient retention involves routine physician visits and medication adherence. Patient retention to routine primary care has shown to improve HIV-related outcomes, and reduce emergency room visits and opportunistic infections (Hortsmann 2010). Retention to care is correlated with viral suppression (Rowan et al. 2014). Surveillance data from New York City (2005-2010) found that the longer one is retained in care, the higher the probability of viral suppression. In a recent US study, Blacks were least likely to have viral suppression and a u-shaped relationship between viral suppression and age occurred, with 20-29 year olds having the least viral suppression (Torian et al. 2014).

When an individual does not attend medical care appointments to monitor viral load and immune status for a particular amount of time, usually within 12-months, s/he may be labeled as “falling out of care,” “lost to follow-up,” “lost to care” “failure to engage in care,” or “failure to be retained in care” (Garcia et al. 2014). Falling out of care predicts poor survival (Giordano et al. 2007), and loss of life-years among PLWHA (Losina et al. 2009). Although patient retention is critical, the measurement is not standardized in health services research. Hortsmann’s et al. (2010) and Mugavero’s et al (2010) review of the literature identifies that it is typically measured
in a variety of ways: 1) appointments missed; 2) medical visits at regularly defined intervals; 3) appointment adherence; 4) gaps in care; 6) two visits within a 12-month period (HRSA HIV/AIDS Bureau performance measure for retention in HIV care); or 5) a combination of these methods.

The identification of populations most at risk of falling out of care is important for targeted interventions (Horstmann et al. 2012). Specific demographic variables that are associated with falling out of care include African-American race, young age (Torian and Weiwel 2011), less education, lack of health insurance, drug use (Torian and Weiwel 2011) and early-stage diagnosis (Torian and Weiwel 2011). In contrast, older individuals have higher adherence to medication and health care (Hinkin et al. 2004; Barclay et al. 2007). Individuals who are diagnosed via routine testing procedures, such as at an emergency room or a doctor’s visit, may not “follow” the treatment cascade for obtaining and remaining in care and this is where linkage to care services are most important (Christopoulos et al. 2013). Health officials, who have attempted to engage or reengage individuals in care, often use surveillance procedures, which tend to fail (Bertolli et al. 2013).

Community level interventions, however, are frequently successful. Community interventions typically are culturally sensitive to the population being served. Multiple studies conclude that social support, for example, facilitates retention to care (Waldrop-Valverde et al. 2014). The use of peer advocates has also shown to significantly increase clients’ contact with ancillary and medical services by frequently initiating contact (Cabrel et al. 2007). Social factors, such as disclosing HIV status to friends and family and reducing community-wide MSM stigma are also
positively correlated with retention to care (Whorl et al. 2011). Additionally, regular participation in ancillary services has been shown to retain clients in primary medical care (Sherer et al. 2002; Ashman 2002; Lo et al. 2002). Addressing healthcare and social barriers provides valuable assistance to PLWHA so that they do not fall out of care. However, identifying, addressing and incorporating cultural beliefs about HIV/AIDS and into treatment practices is an important step to combat increased HIV risk and barriers to care.

Culture as a Remedy

Centers for Disease Control and Prevention has funded demonstration projects in seven states to address HIV and AIDS-related morbidity and mortality among racial and ethnic minorities in the United States. These projects, collectively named the Care and Prevention in the United States (CAPUS) Demonstration Project, directly supports the National HIV/AIDS Strategy goals among racial and ethnic minorities by reducing new infections, increasing access and retention to care, reducing HIV-related disparities and health inequities and better coordinate care among local, state and federal agencies. Seven states were selected to take part: Illinois, Missouri, Tennessee, Virginia, North Carolina, Georgia, Louisiana and Mississippi. Evident in each state’s executive work plan summaries is the need for more agencies who provide longitudinal, one-to-one assistance for PLWHA. There simply need to be more people on the ground assisting with navigation of a complex system. Many of these plans include community based organizations and peer support groups that lean on community experts to recruit community members for HIV testing and treatment. These “cultural experts,” such as promotores de salud\(^2\), have a stake in the community and have been effective in many health programs with Latino populations in the

\(^2\) Promotores de salud translates as “promoters of health” and are community health workers that conduct outreach activities within their own communities.
United States and abroad (Nino 2011). Findings from the CAPUS study, however, suggest that there is a lack of capacity for CBOs to provide case management services due to limited trained staff and program structures (GEARS 2015).

Patient-provider interactions are considered to be a key determinant in medication adherence and retention to care (Bakken et al., 2000; Heyer & Ogunbanjo, 2006; Wagner, Justice, Chesney, Sinclair, Weissman, & Rodriguez-Barradas, 2001). Many of the states’ executive work plans address cultural competency training for providers in order to address populations of focus, such as African-American MSM, women, and Hispanic populations. The Be Safe cultural competency system focuses on provider training through various techniques such as the BATHE (background, affect, trouble, handling and empathy; Stuart and Lieberman 1993), LEARN (listen, explain, acknowledge, recommend and negotiate; Berlin and Fowkes 1983) and anthropologist Author Kleinman’s (1980) Explanatory Model (EM). Each of these techniques focus on providers eliciting a conversation that brings forth the clients’ perception of one’s illness and treatment options. These tools gather culturally sensitive information that the provider can contextualize and act on according to the treatment plan.

Culture is an important worldview from which individuals operate and is a driving force of behavior. In the past public health officials have attempted to control culture in order to prevent the spread of disease, particularly HIV/AIDS (Taylor 2000). The use of the aforementioned techniques (BATHE, LEARN, and EM), however, provides cultural information that health professionals take into consideration in order to understand emic perspectives of health and illness. This information, in turn, influences culturally sensitive realistic treatment interventions.
and goals. Equally, anthropologists attempt to understand norms and practices in order to modify HIV/AIDS interventions, treatment and outreach efforts. Although understanding each individual patient’s EM is an important step to understanding norms and perspectives in the clinic, obtaining cultural consensus on specific cultural domains associated with HIV/AIDS and health behaviors is an essential element to retain individuals in care using cultural specific care models.
Cultural Models

The final goal of ethnography is ‘to grasp the native’s point of view, his relation to life, to realize his vision of his world.’

[Bronislaw Malinowski (1922:22)]

Cultural models are useful theoretical tools to establish knowledge that is shared among a group, to explore how it is shared, and to establish how knowledge is used to drive behavior. Cultural models are loose, interpretive frameworks. Essentially, they are the unconscious assumptions and understandings that a society or group of people shares about an object, a relationship, an experience, or an event. They mediate an individual’s understanding of the world and help direct behavior. Mageo (2011) interprets cultural models as “a master plan for how to live in a particular culture” (5). These models, however, are not fixed, but malleable; a person’s accumulated experience of the world may reinforce or change models (Simova, Robertson and Beasley 2015).

Cultural models rely on experience. When multiple elements of experience, such as emotions, muscle movements, language, and cognition, occur and reoccur together, the brain develops neural associations. A clustering of these neural associations is called a cognitive schema (Quinn 2009). When people have similar experiences, they will form similar associations. When these similar experiences, “are patterned… people in the group will end up sharing schemata” (Quinn 2009).
People share schemas from having similar learned experiences “created by everyday practices and artifacts.” These schemas, which are mental structures or frameworks, which represent the world and help individuals interact with the environment around them (Strauss and Quinn 1997). Anthropologists (Strauss and Quinn 1997; Dressler et al. 2007; D’Andrade 1995; Garro 2000) focus on how schemata may represent the knowledge individuals hold about a specific cultural domain, or an area of focus, such as kinship, religion, marriage or illness.

Methodologies

Cognitive anthropological methods are used to develop a framework for understanding how individuals and groups interpret cultural domains, such as illness and disease (Garro 1999; Garro 1994; Farmer 1994; Young and Garro 1981). Similar to an explanatory model (Kleinman 1980), a cultural model of illness includes an individual’s own perception of that illness or disease. Cultural models, however, are distinct from explanatory models in that cultural models may not specifically focus on etiology, time and onset of illness, pathophysiology, course of the illness and treatment (Kleinman 1980). Instead, depending on the specific cultural domain being examined, a cultural model of illness explores how an individual’s discourse identifies salient information pertaining to his or her illness. Kleinman and Benson (2006) promote this extended view of the explanatory model that transcends illness to identify practical barriers to healthcare, such as socioeconomic factors, which focus on structural violence. Dunn’s framework (1985) is also a useful way to understand socio-political factors influencing healthcare and health seeking behavior. It considers both intra (emic) and external (etic) factors that promote or assuage health
and disease within communities\textsuperscript{24}.

Cultural models were investigated in the 1950s using an ethnoscience, or new ethnographic, approach \textsuperscript{25} that consisted of linguistic methods (Simova et al. 2015). The underlying assumption of understanding a native’s perception of cultural reality was to understand one’s mental models by using language as a key to unlock one’s schemata (McGee and Wars 2008:360). Thus, the structure of language, such as studying phonologies, and linguistic determinism, such as the Sapir-Whorf hypothesis, became the primary methods which to “view the world in the same way as native speakers of that language” (McGee and Wars 2008:361). The approach of cognitive anthropology in the 1960s and 1970s, which developed out of ethnoscience, differed in that culture was seen as more of a dynamic process between humans and the physical world, and was not able to be accessed verbally or elicited through questioning (McGee and Wars 2008:3623).

Since the development of cognitive anthropology, in order to understand such schemata, information has been elicited primarily through cultural consensus (Weller and Romney 1988) and cultural consonance (Dressler and Bindon 2000 and Dressler et al. 2007), or through discourse (or “talk” as Quinn titles her 2005 edited volume, Finding Culture in Talk). Each method aims to collect the frequently held knowledge and beliefs about a specific cultural domain among individuals, which can then be considered important aspects of the group’s culture- or subculture (D’Andrade 1995). Cultural consensus theory, however, in contrast to

\begin{itemize}
  \item Dunn’s framework focuses on four areas of disease control: 1) intra community factors that enhance health, 2) intra community factors that lower health, 3) outside factors that enhance health, and 4) outside factors that lower health (Hewlett and Hewlett 2008).
  \item Ethnoscience was concerned with items and their relationships with indigenous cultures. See D’Andrade (1995) for a history on this specific area of cognitive anthropology.
\end{itemize}
cultural models theory, uses categorical response data, such as true-false, multiple-choice, and fill-in the blank to determine culture, instead of narrative.

Recent methods for investigating cultural models involve an explicit system for constructing and mapping shared knowledge that is quantifiable, typically using a factor analysis (Weller 2007). Specifically, cultural consensus is “a collection of analytical techniques and models that can be used to estimate cultural beliefs and the degree to which individuals know or report those beliefs” (Weller 2007:339). It aims to construct “a principal components analysis of a correlation matrix of respondents” (Dressler 2012:392) based on a specific domain. Cultural consensus theory has two analytical approaches. First, individual knowledge is estimated among a group of people. Then, the “culturally correct answers are estimated by weighting the responses of each person by their competency [or knowledge] and aggregating responses across people” (Weller 2007:340).

Copeland (2011) investigated immigrants’ cultural models of maintaining health and wellness while living with HIV/AIDS after a rural to urban migration in Nairobi, Kenya. The author found a shared cultural model of self-managing HIV/AIDS among the women whose lives she explored, despite economic hardship and a shortage of ART. The cultural model does not follow the suggested care routes that clinicians, churches and NGOs offer these women. Instead, the women learn, over time, that maintaining access to basic needs, such as food, and that support from formal entities, such as churches and NGOs, instead of family, is key to maintaining health. Copeland (2011) found that women who have lived longer in Nairobi were more likely to construct this cultural model of health, as opposed to newly arrived migrants who faced multiple
barriers to maintain wellbeing.

Cultural consensus and consonance can both be used to identify salient shared cultural models within a population. Cultural consonance theory uses cultural consensus to assess the degree to which individuals are in line with their cultural model. It “identifies the contradictions that can arise between shared cultural models and individual attempts to apply those models in their own lives” (Dressler, 2012:390). Cultural consonance theory then tests an individual’s outcome behavior (such as depression, happiness, or diabetes) against adherence to the established cultural model. When cultural models are inconsistent with individual lifestyles it can be psychologically stressful, impacting the health of individuals, and presumably, whole cultural populations.

Dressler’s (2007, 2012) research among African-Americans in the United States and in Brazil, for example, documents this inconsistent pattern to understand the link between culture and health. Dressler and Bindon (2000) sought to identify whether lifestyle and social support correlate with the presence or absence of high blood pressure in an African American population in the Southern US. The authors identified culturally salient models of social support and lifestyle based on cultural consensus theory. They found that individuals who relate most closely to what he identifies as an “African-American” lifestyle, characterized by close familial social support, had an absence of high blood pressure. However, those identified as not living an African-American lifestyle (low familial social support) had a hyperbolic interaction with high blood pressure. As family support increased, blood pressure was reduced to a point.
Strauss and Quinn’s (1997) relying on their discourse-based method of eliciting cultural models, believe that there is no set point at when a set of understandings constitutes a cultural model; it is, really, a matter of “taste” established by the anthropologist. The difference, however, between researcher’s constructing a cultural model through discourse, as opposed to cultural consensus, is that it provides no explicit grounds for determining the extent to which a cultural domain is shared. The construction of cultural models may, in this sense, be constructed and controlled by an ethnographer (an outsider), which is one of the grievances that early ethnoscientists had of ethnographers in the 1950s. Quinn (2005) uses a technique called “minnowing,” where metaphors are identified and classified throughout semi-structured, in-depth narratives. As Quinn (2005) explains,

> when one is able to reconstruct the same structure from the talk of different people, then this is evidence that they share the understandings embodied in that structure- that these understandings are cultural. When these speakers repeatedly, in different linguistic forms, express these shared understandings, this argues for their relative centrality and stability” (p.47).

Quinn’s (2005) examination of cultural understandings of marriage among a group of educated, Caucasian American men and women, describes how she identified and classified metaphors through talk. In order to obtain a corpus of narrative data to analyze metaphors, Quinn conducted approximately 11-28 interviews per person. From these interviews, Quinn’s minnowing located metaphors of similarity, which were classified and coded. Quinn (2005:51) provides an example of a typical narrative passage:

> I think that we were so different, and we had such complementary differences that our weaknesses- that both our weaknesses were such that
the other person could fill in. And that quickly became apparent to us, that if we wanted to not deride the other person for their weaknesses, we would instead get their strengths in return. And that’s what I think has been the asset—these are the assets that have been very good for us. And I suppose what that means is that we have both looked into the other person and found their best parts and used those parts to make the relationship gel, and make the relationship complete.

Quinn identifies three categories of metaphors in the previous passage: compatibility (“could fill in,” and “finding and using “parts,”” “gels”), mutual benefit (“get their strengths in return”), and lastingness (“their best parts,” “the relationship gel”). Overall participants’ talk about marriage fell into eight categories: lastingness, sharedness, (mutual) benefit, compatibility, difficulty, effort, success (or failure), and risk (Quinn 2005).

Although cultural consensus is a widely accepted quantifiable method to determine cultural knowledge, it may not fully capture how individuals interpret cultural information. In other words, cultural consensus will identify what types of knowledge are shared among a population, but it will not explain how this information is used to make decisions. Such nuanced information may only be elicited through narrative. Garro (2000) explored the use of cultural consensus theory versus cultural models theory within understandings of diabetes among an Ojibwa population in the U.S. She found that understanding the etiology of diabetes in this population is not about how much cultural information one knows, but how individuals interpret cultural information. Compared to younger Ojibwa individuals, the majority of older Ojibwa, for example, agreed that diabetes was not present before the arrival of Europeans, that diabetes did not run in families, and that poisons caused diabetes. Although younger Ojibwa were knowledgeable about the older group’s understandings of “white man’s sickness” they did not adhere to it. As a result, it may not be the underlying cultural models of these individuals that
differ, but rather their interpretations of these cultural shared frameworks (Struass and Quinn 1997). What one knows about diabetes is tied to how one knows it. In this case, history is the primary driving force of constructing a cultural model of diabetes. Garro’s (2000) findings have applied importance in that the understanding of diabetes may inhibit older Ojibwa from following practitioner diet and medical guidelines. Similarly, among PLWHA, what one knows about accessing HIV/AIDS services is tied to how one knows it.

Culture- Its Remedies and Contagions

Cultural model theories have been criticized because they focus on “what is in the minds of community members rather than what is on their backs” (Scheper-Hughes 1993). Cultural models assume that people behave because of traditional beliefs rather than political economic circumstances. However, the process of developing cultural models may stem from shared experiences that include a history of political economic circumstances, as explained previously with Garro’s (2000) research on diabetes among the Ojibwa. The Social Determinants of Health recognize that social, economic and physical environments influence behavior and affect a wide range of health-related conditions, such as quality of life outcomes, risks, and functioning. Examples of social determinants may include access to education, healthcare services, transportation, social support, economic stability and exposure to crime and violence (Healthy People 2020). These social determinants of everyday life are an important part of how individuals create meaning, which ultimately affect the construction of culture.

Similarly, Farmer’s (1994) extensive, longitudinal fieldwork as a medical doctor in Do Kay, Haiti, for example, traces the evolution of Haitian cultural models of HIV/AIDS between 1983
and 1988 through the use of narrative. He demonstrates how the HIV/AIDS cultural model among impoverished populations in Do Kay evokes associations drawn from the larger political-economic context of North American imperialism, coupled with a lack of class solidarity among the poor and corruption from the ruling elite. These political-economic associations play a central role in illness narratives and the emergence of cultural models about the disease.

Culture, as Taylor (2006) points out, is something that can be controlled, and since culture is a driving factor for behavior, public health officials have attempted to control it in order to prevent the spread of disease. Hewlett and Hewlett (2008:78-79) provide an excellent Congolese example of how public health officials have attempted, much to the detriment of family members, to control traditional funerary practices that are considered to spread disease when a family member dies of Ebola. Burials teams, for example, replaced family members, who would wash bodies while grieving. The deceased’s possessions were burned, as opposed to laid on top of the grave. In order to retain cultural sanctity and decrease the spread of the disease, medical anthropologists suggested modifications to these public health procedures. These modified practices were to remain culturally appropriate in order to strengthen trust between families and burial teams. For example, instead burning possessions, the burial of them with the may enhance trust. In addition, communally washing with bleach spray by both family members and burial teams alike would further solidify bonds by engaging in local funerary practices and grieving.

There are also social and environmental conditions that shape cultural practices, which lead to behaviors that may place certain populations at greater risk for HIV/STDS. The substance abuse, violence and AIDS (SAVA) syndemic (Singer 1994), for example, brings an emotional disease
(substance abuse), physical suffering (violence) and an infectious disease together under a particular set of social conditions that impose a disproportionate burden of disease on women in the United States. Women are vulnerable to this particular syndemic not only because of their increased vulnerability to domestic violence and poor health outcomes because of substance abuse, but also because of larger economic and political inequity. The term syndemic refers to “a set of intertwined and mutually enhancing epidemics involving disease interactions at the biological level that develop and are sustained in a community because of harmful social conditions and injurious social connections” (Singer and Clair 2003). In the case of SAVA, when two social determinants of health interact (substance abuse and violence), women are placed at greater risk for HIV/AIDS. It is important to identify and understand these social and environmental conditions so that HIV/AIDS prevention programs are efficient and effective.

In another example, Singer et al. (2006), focus on inner city minority youth in Boston, Massachusetts and highlights the social conditions that influence a “cultural logic” of sexual decision making, which makes them more vulnerable to STD risk. This cultural logic is informed by a series of events such as living in poverty, coming from a broken home, experiencing domestic violence, having limited expectations and lack of hope about the future, having limited positive relationships and role models, not expecting a long life, low expectation of depending on others and fear of intimacy due to vulnerability. Singer et al. (2006) indicate that these impending uncertainties influence lack of relationship trust, patterns of condom use and fear of attachment. Youth tended to be cautious with their relationships and were more likely to have multiple sexual partners and relationships. These beliefs and behaviors are a result of youths’ complex living environment that Singer et al. (2006) identify as “life experiences of injustice and
social suffering.” Illuminating and understanding these lived realities offer the beginnings of social and public health policy implications that may provide new and innovative solutions to efficient and successful HIV/AIDS and STD prevention programs.

The work of Singer et al. (2006) highlights the vulnerabilities of impoverished populations, but vulnerabilities can also be found in middle to upper class populations, as well. Niehaus (1990) establishes class as an organizer of the illness experience and observed that professional gay and bisexual PLWHA in New York City, rely on informal networks of family and friends for care and support. This reliance inevitably presents not only an emotional and social cost of support, but also may further alienate the professional class from HIV/AIDS specific support, such as medication adherence assistance provided by medical case managers.

Watkins-Hayes (2013:95) offered a similar argument where the use of AISD Service Organizations (ASOs) were underutilized by middle-income women due to status diminishing effects and violations of privacy:

One of the major shocks to the system for anybody who comes from a middle-class or upper middle-class background is that [service providers] are going to feel free to ask you these questions and think nothing of it, and more than one person. Because nobody with HIV, once you’ve had it for a while, has only one case manager. So you have to repeat the same soul-crushing, degrading stories to multiple people. You have no privacy, your whole life- you have to discuss the most private and intimate parts of your life with someone who’s basically a stranger, to get services. You’re no longer seen as a human being; “you’re a client.” Client does not equal human.
Middle class women are able to draw on pastors, therapists and private doctors to assist with managing illness, but reported fewer networks of providers and people with whom they could rely for HIV-related information and social support. A significant drawback to this is a small HIV-related network, where resources and timely information about HIV-related issues are absent.

These examples of various types of culture, established by class, suggest that cultural adaptations of survival strategies influence nuanced sexual practices and healthcare seeking. Identifying and understanding socio-cultural environments of the nation’s most vulnerable populations can provide necessary information that improves health in the US by providing the knowledge necessary to develop useful tools to combat the biomedical and social challenges that emerge in these populations. As such, the use of cultural modeling may assist researchers to bridge this gap by understanding how select groups establish knowledge and how it is used to drive behavior. In the following chapters I present a sample population of minority men and women living in Las Vegas while managing chronic disease(s) and highlight socio-cultural environments of health and strategies used to maintain their health and well-being.
CHAPTER SIX
Research Methods

“Ethnographers are their own obstacles in the field and we need to overcome ourselves in order to obtain good data and good rapport. We need to believe in ourselves and in the words of Russell Bernard, “Be Brave!” We may be our biggest obstacle.” –Melissa Artstein-McNassar, Dissertation Diary, October 8th 2013

Introduction to the fieldwork

One of my participants, Xiomara26, played with a paper flower as she revealed how separated she felt from her husband. “I don’t care if he sleeps with other women,” she went on in Spanish, “I just want him to be happy. And since we can’t sleep together the way we used to [before I was diagnosed], I want him to be satisfied.” It had been nine months since Xiomara was diagnosed with HIV, arrested for prostitution and jailed for illegal immigration- a triple blow to her and her ‘husband’ just a few months after moving to Las Vegas, Nevada from Phoenix, Arizona. We were sitting in the dining/living room area of her one bedroom apartment. Her marido27 had arrived just a few moments earlier and slipped inside their bedroom, closing the door to give us some privacy. I asked if she felt comfortable continuing the interview with him present. She switched to Spanish after his arrival, and assured me that he did not speak sufficient Spanish to understand us. “I am not going back to Mexico,” she continued on the topic of her immigration case, “people aren’t tolerant of gays and transgenders there. It’s been over ten years [since I’ve been to Mexico] but the discrimination against me for being HIV positive and transgender would be unbearable. I’ll just walk right back into the U.S. like I did years ago if I have to.”

26 For the confidentiality of all participants pseudonyms are used throughout this dissertation.
27 Spanish for husband or boyfriend.
The unfolding of events in Xiomara’s narrative is typical of most interviews I conducted with participants living with HIV/AIDS. Over the last year, I have documented lives filled with violence, drug addiction, financial hardship, mental illness, and homelessness among minority men and women living with HIV/AIDS. And yet, kindness, hope, friendship, love, and laughter always seem to permeate their darkness. Xiomara’s story of bureaucratic and relational hardship was being told while she held a paper flower that she had made to participate in the annual Dia de los Muertos event she facilitated with a local counseling center. Despite her hardship, all her happiness and hope were revitalized due to this center along with other organizations within the HIV community. Throughout my experiences as a social worker in community and county organizations, I have witnessed the power of human resilience to overcome barriers. My witness to the experiences of people like Xiomara has influenced me to study human behavior through an anthropological lens, and most importantly, to work to ameliorate conditions that enable individuals to live to their fullest potential.

Two groups participated in the research for this dissertation: individuals living with HIV/AIDS and ancillary HIV/AIDS organizations or AIDS support services (ASO). All Las Vegas HIV/AIDS organizations and other community agencies responded positively to my study. I spoke with at least one provider from nearly every agency that served the Las Vegas area. During the fieldwork year, I learned that three organizations were committed to a focus on understanding the needs of women, particularly minority women. One agency concentrated on outreach activities, another focused on developing women-only support groups and the final agency collected surveys on satisfaction of services. Although, this yearly survey was being conducted within the community, no other qualitative research was concurrently conducted with
this dissertation. All provider participants thought it important to conduct qualitative research on the barriers to the healthcare system and did not recall any qualitative research having ever been conducted.

Jim, a provider at an ASO indicated that for his graduate degree he had the option of doing research, but that he could never do what I was doing: interviewing people and collecting data. Instead, he related to me that he opted for a literature review thesis. This discussion with Jim prompted me to ask, why are people reluctant to gather qualitative data? The following excerpt from my dissertation diary is a response to Jim’s comment and succinctly sums up 12 months of participant-observation:

I am in the trenches! I am doing it day-by-day, person-by-person, word-by-word. I am rubbing elbows and waiting for participants at 7-11s on the corner of Las Vegas blvd and Charleston while watching people dig in the trash for half eaten bags of chips. I am witnessing drug deals across the street in the parking lot of a weekly as obvious tourists staying at nearby hostels walk toward the strip with excitement and maybe a little bit of fear. I am conducting interviews at McDonald’s where it takes 20 minutes to get two cups of coffee and three cookies because everyone is asking for extras, especially the homeless people. Some employees don’t speak Spanish and interactions take 3 times longer; I help translate, “He says he paid for an orange juice, and he doesn’t want ranch dressing.” I put entire bikes in the trunk of my car so that someone doesn’t have to peddle an hour and a half to get home late at night after a peer support group meeting. I help organizations sort out the rotten, half rotten and “good enough to be edible” food so that it can be taken home as rations for the week. I then help people put bags and bags of half rotten and “good enough to be edible” food into their car. Or if they don’t have a car, into their little rolling suitcases that they can wheel onto one bus, and then another, and if they live far, onto another. They do this week in and week out because it is the only affordable type of food they can consume. And now, I am bringing lunch to an informant in a part of town that is reputable for a variety of non-glorified human activities so that I can understand life from people who are vulnerable, stigmatized and lonely. I love it, but I also fear it.
The fear that I mention is primarily the typical concern of a lone female researcher conducting fieldwork in a large, urban environment. Although I have experience working with a variety of populations as a single female, each research opportunity was undertaken with caution. I frequently met informants in their own homes located in various areas of the city that some would consider “unfavorable.” Some informants, interested in how I conducted research, chastised me, saying that I shouldn’t visit strangers, especially males, alone. I typically carried mace in my right pocket and a high-powered flashlight in my purse. These defense weapons coupled with my hyper-awareness of my surroundings provided me with ample confidence about my safety during each ethnographic encounter.

Although I took all the aforementioned precautions, there was one incident where I did feel momentarily unsafe. However, from this incident I learned a lot more about my own ethnocentric perspective on issues related to identity and sexuality. One afternoon I met Clyde, a male informant, at his weekly rental apartment. He had returned home from the food pantry earlier in the day and offered me a variety of cookies and snacks during our interview. He had arrived from California just a few months prior and continued to have trouble obtaining his prescription medications. He told me, “I can feel it. I can feel me getting sicker. I haven’t been off medications in so long and now just after a few months I can feel my body changing.” His one-bedroom apartment had the typical weekly rental furnishings: an orange couch, a T.V. situated between the living room and bedroom that swiveled to accommodate bed-time and day-time entertainment, a below the window air-conditioning unit, a kitchen table with two chairs, a refrigerator, microwave, and an oven with a stove-top range. The only personal décor found throughout the apartment appeared on the wall over the kitchen table: a neatly arranged collage.
of photographs. Clyde explained to me that these photographs were taken a few years earlier during the opening of his club in Los Angeles. He walked me through each photo and relived the night through his narrative. He indicated that this monument gave him motivation to continue what he initially came to Las Vegas to do: open up a nightclub. However, in order to fulfill his dreams he first needed to access the healthcare system and obtain his HIV medications in Las Vegas.

Clyde was the first male informant to express his loneliness to me and explain how the virus not only causes a sickness in the body, but also sickness in the heart. His last girlfriend of eight years left him once he was diagnosed with HIV. Since then, his relationships have been unsteady with various women. He longed for companionship, and his faith in finding it was strong. Once finished with his open-ended interview and during the process of completing two questionnaires for the study, I asked if I could use his bathroom. Once inside the bathroom I noticed a large, oblong object inside the bathtub that was next to the toilet: a dildo. My body immediately fell into the fight or flight response. My heart pounded; the hairs on my arms lifted; and I felt the bathroom close in on me. The only question in my mind was why would a heterosexual man have a dildo? I felt as though I was in danger due to the presence of this sexual object and the mismatch between the object and this man’s sexual orientation. After I used the restroom, Clyde must have remembered the object in the bathtub and looked to see if everything was “in-order” for me. He came out, apologized and began an extensive monologue about his loneliness.

As I drove away from his apartment, I realized that I had received a lesson in ethnocentrism. Sensing danger, I immediately reverted to my own beliefs about sexuality. I assumed that
because Clyde disclosed himself as a heterosexual male that he must sexually perform like a heterosexual male in our Western culture: as the penetrator, not the penetrated. The dildo in the bathtub led me to think either 1) he is the penetrated, or 2) I was going to be the penetrated. Through my own temporary state of ethnocentrism and his heterosexual disclosure, I could not classify him as the former; I felt in danger. As an anthropologist I know that sexuality is to a great extent culturally constructed rather than exclusively biologically determined. Furthermore, there are diverse sexual preferences within cultures, as well. This situation illuminates the fine line between anthropological training and practice while immersed in the field. Although Clyde taught me much about my own ethnocentrisms, I did not discover further details about Clyde’s sexuality.

**Methodology**

*My work that I am conducting right now, in Las Vegas; a vast city of 2 million plus people frightens me. I don’t necessarily have a specific “field site”- my field site is broadly located within “Las Vegas”- a city overflowing with people. But as an anthropologist I need to narrow my “field site” down- I need some honing in. But what if I don’t have a “place” to do fieldwork? What if, I only am looking for a specific type of person, people with a specific disease that is so stigmatized that having a designated “place” is shunned even in the most tolerant circles? Can a group of individuals replace the cozy, comforting space of ‘place’ that anthropologists are so attached to? – Melissa Artstein-McNassar: Dissertation Diary, September 23rd, 2012*

As a field researcher studying a population with a long history of stigma, I was aware of the sensitivity of my field research. I was also aware that I did not want to attach myself to one ‘place.’ By doing so I might bias my sample population. Although I had doubts about securing a ‘place’ to conduct fieldwork, I knew that culture resides within the minds of individuals. The
physicality of fieldwork is often represented in a specific place, but I reminded myself that culture is in the minds of individuals (Scheper-Hughes 1993) and that culture, not place, will successfully complete this project. Preliminary research began by talking with directors and supervisors at social service organizations and clinics about the study’s research objectives. Although place is not the focus of this research, the support I obtained from numerous ASOs and participants was paramount in the success of this project.

Research Design

The research took place in Las Vegas, Nevada between August 2012 and August 2013, with two more short visits in September 2013 and February 2014. A particular strength of this research design is the participation of multiple actors in the health care system (patients, clinicians and social services personnel) in contributing to an understanding of healthcare utilization gaps among urban minority populations living with HIV/AIDS. I initially recruited a few select providers by directly soliciting them via face-to-face appointments and phone calls. After these initial contacts I recruited many more providers through word-of-mouth. PLWHA were initially recruited using flyers and referrals from providers; however, after a few interviews, word-of-mouth referrals from PLWA increased. In-depth interviews were conducted with providers and PLWHA. Providers were interviewed once during the fieldwork period. PLWHA were interviewed on two occasions: once at baseline and again after 6 months. These longitudinal interviews not only provided follow-up data, but also established an in-depth understanding of the social conditions present that affect healthcare decision-making.

28 Washington State University’s Institutional Review Board approved this human subjects research project prior to data collection. IRB# 12887-001.
During the first several months of the study participant-observation and semi-structured interviews were conducted with providers and clinicians working at ancillary organizations in Las Vegas. Participant-observation involved volunteering at local organizations to assist with food organization and distribution, fundraising events and meetings. These volunteer opportunities provided great insight into the organizational structure of healthcare and ancillary services, the individuals who seek care and the individuals who provide care. These organizations not only assist individuals by offering services, but also offer employment opportunities. For example, the traditional pathway to a paying position at the food pantry is to volunteer for a few weeks. Once management notices your hard work and dedication to the pantry, employment may be offered.

During the research period, twelve clinicians and social service personnel were interviewed from seven different ASOs in the Las Vegas area. Each interview was conducted in the participant’s work place and was audio recorded. Participants were asked semi-structured questions on their experiences working with PLWHA including barriers to care and race/ethnic/gender differences, several aspects of their duties and service needs in the community. Each interview lasted approximately 1 hour.

Forty-seven minority men and women were recruited from the following racial/ethnic and sex categories: nineteen African-American men, eleven African-American women, eleven Hispanic men and four Hispanic women (Table 6.1). One individual identified as a Hispanic transgender woman and one man identified as an Asian/Pacific-Islander. Interviews were conducted in English and/or Spanish. Before the beginning of each interview, participants read and signed the
consent form in their preferred language (English or Spanish). Each participant was orally asked for permission to have the interview audio recorded. Although most participants agreed, some refused to be recorded. Each interview lasted approximately 1.5 hours.

Each interview began with a request to free-list the following: 1) support service agencies/clinics utilized; 2) individuals and informal social groups whom they solicit to help with everyday activities; and 3) recurrent hardships. Then, participants were asked open-ended semi-structured interview questions about their access to care, satisfaction with healthcare and support services, barriers to healthcare, and environmental questions. Finally, each participant answered a quality of life questionnaire, the Functional Assessment of HIV/AIDS Infection (FAHI) and the Medical Outcomes Study- HIV (MOS-HIV).
Table 6.1. Racial/Ethnic and sex distribution, in addition to other demographic characteristics of PLWHA participants.

The FAHI (Spanish and English version), is a psychometrically sound, illness-specific measure of health related quality-of-life (Viala-Danten et al. 2010). It evaluates physical well-being,
functional and global well-being, emotional well-being/living with HIV, social well-being and cognitive functioning. It was used in conjunction with the MOS-HIV to identify a greater depth and breadth (O’Brien et al. 2010) in psychological barriers to care and health outcomes. This questionnaire took approximately 5-8 minutes to complete. Participants who did not feel comfortable reading and completing the surveys on their own had both surveys (MOS-HIV and FAHI) read to them by the interviewer.

Follow-up interviews provide additional information on healthcare decision-making, which enhances the investigation of cultural models for these populations, as well as follows individuals’ health outcomes and quality of life measures. Forty-three percent (20 out of 47) of PLWHA participated in follow-up interviews 6 months after their initial interviews. Participation in the follow-up sample consisted of convenience sampling, with individuals who expressed interest in the follow-up interview contacting me within 6 months of their baseline interview. After their permission, I also personally contacted individuals who expressed interest in the follow-up portion of the study. The following racial/ethnic and sex categories for all follow-up interviews include: seven African-American men, eight African-American women, one Hispanic male, and three Hispanic women.

Recruitment and Sampling

The Internet guided the first few weeks of fieldwork in Las Vegas. A list of organizations and clinics that provide direct assistance to individuals living with HIV/AIDS was identified. I initially contacted the directors and managers of these nine organizations to discuss my research objectives, timeline and participant confidentiality. The reasons for contacting these
organizations were twofold: 1) the recruitment of providers and 2) the recruitment of individuals living with HIV/AIDS. These purposive sampling methods were necessary to recruit individuals living with this specific disease and those who are employed to assist this specific population.

Once directors and managerial staff granted me access to recruit from the agencies I invited case managers, counselors, education specialists, outreach workers and clinical staff to participate in in-depth interviews. Twelve individuals from seven different agencies agreed to participate in the support services/clinician portion of this study. All audio-recorded interviews took place at the participant’s place of employment between the months of Jan 2013 and May 2013. At the end of each interview participants were given a $25 VISA gift-card to compensate them for their time. Participants were also given the study’s recruitment flyer to distribute to their clients. This flyer displayed eligibility information to participate in the study: 1) over 18 years of age; 2) of Hispanic/Latino and/or African-American/black race/ethnicity; and 3) diagnosed with HIV/AIDS.29

Fliers about the study and contact information were posted on bulletin boards of facilities that provide direct assistance, prevention, case management, or treatment services to solicit eligible HIV/AIDS participants. In addition, clinicians, counselors and case managers also personally informed their clients during appointments. Interested individuals contacted me through my cell

29 Two organizations that participated in this study did not exclusively serve HIV/AIDS clients; as a result flyers indicated that the study focuses on individuals living with HIV/AIDS. Additionally, due to HIPPA and IRB regulations I was not able to directly ask individuals their HIV status once they contacted me. However, this specific regulation had no ill effect on the recruitment of individuals for this study. All individuals who responded to the advertisement were living with HIV/AIDS.
phone and were given more details about the objectives of the study and the interview process. Individuals who were interested in scheduling an appointment were asked where they felt most comfortable meeting for the interview. I offered to come to their homes to conduct a private interview, to meet in a public place or in a private meeting room at the local library\(^\text{30}\). I offered transportation if the participants did not have their own vehicles or a convenient mode of transportation. Over half of the participants agreed to meet at their own homes. I also met and picked up individuals at gas stations, casinos, McDonald’s restaurants, public libraries, clinics and social service organizations. Interviews typically lasted approximately 2 hours. All participants were compensated with a $25 VISA gift card.

My initial recruitment plan was to offer respondent driven sampling (RDS) as the primary recruitment method among individuals living with HIV/AIDS. RDS is a useful way to locate and enroll study participants by working through the power of referral (Chase 2011). Participants who have completed an interview are offered an additional cash incentive for referring individuals who meet the study criteria (HIV-diagnosis and African-American and/or Hispanic/Latino). Participants are given a referral card that is complete with my contact information and a specific number that corresponds to the participant. This number is different from numbers given to participants to maintain confidentiality. When referred individuals contact the researcher and meet for an interview, the card is retrieved and the referrer is contacted for payment. This technique is especially useful for working with hard-to-reach and stigmatized populations (Chase 2011 and Scott 2008).

\(^{30}\) There are over ten library locations throughout the Las Vegas valley. I identified five libraries that offered private meeting rooms at no cost.
I initiated RDS for the first participant as a preliminary experiment. I explained that if he referred two other individuals interested in participating in this study and they completed interviews he would receive $10 per person. I emphasized the importance of referees giving me the referral cards so that I could trace the referral back to him. However, after a few weeks I did not receive any of the participants’ referral cards. Instead, case managers referred many individuals to the study, or individuals read the flyer on bulletin boards and called to schedule appointments. A few months later my first experimental RDS participant asked if anyone had ever turned in his referral cards. I indicated to him that no one had given me a card. As a result of this initial experiment, and the success of the fliers and provider referral, I did not find the RDS method useful for this study.

Individuals who were interested in follow-up interviews solicited me 6 months after their initial interviews. Many individuals who agreed to participate in the follow-up interviews during our initial meeting gave me permission to call them around the 6-month mark. There were some individuals who changed their numbers during this period, and some individuals who were not interested in further participation. Twenty out of forty-seven individuals participated in the follow-up interviews. All participants were compensated with a $50 gift card after completing the final interview.

The combination of in-depth interviews, participant observation, and questionnaires, often called mixed methods, contributed to a nuanced understanding of how people understood and

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31 Insight on the multiple definitions of mixed methods and its paradigmatic history can be found in Johnson et al. 2007. For this study’s purposes, mixed methods is the combination of both quantitative and qualitative methodology used for data collection.
responded to their illness, the relationships that people developed with the healthcare system and the decision making process. Halfway into my fieldwork the Social Services Council, the county organization appointed to distribute Ryan White funds, hired a research company located at the University of Nevada, Las Vegas (UNLV) to conduct a survey on the satisfaction with services in the Las Vegas community. One of my informants was eager to fill out the survey and obtain the compensatory $10 gift card. She indicated that she fills out these surveys every year, but that they were boring. She showed me the five-page survey. One of the questions read, “On a scale of one to seven indicate how satisfied you are with: counseling services, transportation services, medication refills, support groups.” She later indicated to me that she liked my “surveys” much better. She was referring to the health outcome (MOS-HIV) and quality of life (FAHI) surveys that asked reflective, personal questions, such as “I am satisfied with how I am coping with my illness” (FAHI) and “Were you afraid because of your health (MOS-HIV)?” The combination of these questions and in-depth narratives reveals the important contribution of these methods to describing and understanding individuals living with this disease.

The recruitment of Hispanic females was especially difficult during the study. HIV stigma, prevalent among the Hispanic population, and the combination of machismo, limited the number of Hispanic females who came forth to interview. A total of four females, two undocumented and two citizens, were the result of intense recruitment over 13-months. Zelaya (2014) documents extreme difficulty in recruiting undocumented day laborers in Las Vegas, Nevada. She writes that they were suspect about answering any questions about themselves and even were reluctant to be paid in gift cards, which they speculated that they may need documentation in order to use them or be accused of stealing them. Despite my association with popular
Hispanic case managers and appearances at a variety of Hispanic focused events, females were especially difficult to recruit.

*Analysis*

Initial data analysis involved creating a profile data matrix in SPSS (Bernard 2006:454) of socio-demographics and variables from the project’s research questions to document mode of transmission, year of diagnosis, number of social service agencies participant utilizes, HAART medication adherence, quality of life measures, health outcomes measures, marital status, and number of children. Support services/clinics free-listed data has been analyzed for frequency and proportion among the entire sample population, as well as rank order for racial/ethnic categories. Individuals and informal social groups whom they solicit to help with everyday activities and recurrent hardships were analyzed using thematic analysis. All narrative data has been inputted into a qualitative data analysis program, Atlas.ti, in order to permit an analysis of relationships among health outcomes, socio-cultural environments, and decision-making codes identified from narratives.

All audio-recorded interviews were transcribed into Microsoft Word documents using Express Scribe Pro audio player. The transcribed narratives were then exported into a qualitative analysis program, Atlas.ti, for coding of themes. I read each narrative as a whole and coded words and phrases. Coding was primarily based on content analysis, using deductive coding (Bernard 2006:510). A codebook was created to assist in readily identifying themes and subthemes within each participant’s narratives. Once in Atlas.ti, all documents were assigned a family. A family is a group of narratives that have similar characteristics. The following families were created to
examine race, ethnicity and sex differences: 1) AIDS Support Services (ASO); 2) African-American Black Women; 3) African-American/Black Men; 4) Hispanic/Latino Women; and 5) Hispanic/Latino Males. The following families were created to examine sexuality differences: 1) African-American/Black MSM; 2) African American/Black Heterosexual Males; 3) Hispanic/Latino MSM; and 4) Hispanic/Latino Heterosexual males.

Each narrative’s themes were coded in Atlas.ti using grounded theory. Atlast.ti is constructed on 1) groundedness: the number of data segments (quotations) associated with a specific code; and 2) density: the number of associations between codes or group of codes (families). Families were created from codes that have similar themes. For example, the family, case manager techniques, was created due to the various skills case managers utilized with clients. The case manager techniques family is comprised of the following codes: Importance, Education, Coaching/Triage, Similarity, and Trust. The code, Importance, refers to case managers making their clients feel important. An example of this found in ASO narratives is “I make sure I call my clients and personally invite them to support group meetings.” Another code, Similarity, refers to case managers identifying with their clients’ disease, for example, “I let them know, I am no different than you. I go to the same clinics, I go to the same food pantries, I have the same transportation issues like you do.” These codes are similar in theme (case management), but different in context (different techniques) to form an Atlas.ti code family. Using density, we identify the associations between families (themes) and where they are located in a coding network. Networks are graphic views of codes within a project. The purpose of developing a network is to analytically realize the relationships among codes in order to make sense of data.
This information was cross-listed with the profile data matrix to determine patterns among participant families. Narratives were used to identify multiple and persistent themes and sub-themes in the lives of the sample population, most notably 1) barriers to care, 2) cultural and socio-economic contributions to a health outcomes, and 3) cultural models of health-care navigation. FAHI questionnaire data was analyzed and cross-listed with the profile data matrix. The MOS-HIV questionnaire data was not reported for the analysis of this study. The following chapters (chapters 7 and 8) reviews the results of this study’s analysis, focusing on one case manager family and two racial/ethnic families: African-American women and men and Hispanic women and men.
CHAPTER SEVEN

Results

Part I: Providers

The multi-faceted population and design of this project has produced multi-faceted results, which are presented in this chapter. This first chapter will report on providers and their perspectives of general and specific barriers to health care retention. Narratives reveal that providers use varied techniques in order to obtain rapport and assist PLWHA. In some cases, these methods are successful in overcoming certain barriers, such as language, and stigma; however, structural barriers within agencies themselves remain large obstacles of access for both providers and PLWHA.

*AIDS Service Organizations*

The first step in this study was to identify agencies that provided assistance to PLWHA via public sources. Many of these organizations are non-profit or public government entities and are listed in telephone books, social service resource lists, and maintain websites on the Internet. These agencies served as the foundation for beginning fieldwork in Las Vegas to establish contacts, both providers and PLWHA, within the HIV/AIDS community. All agencies contacted were receptive to this project and disseminated recruitment information to both interagency providers and clients. Individuals willing to participate contacted me via telephone or in-person during visits to the agency.
I conducted interviews and participant observation with various providers during the first half of fieldwork from October 2013 to March 2014. Providers were identified as employed or volunteered persons who assist PLWHA. Providers in this category include: case managers, medical case managers, nurses, nutritionists, community educators, mental health counselors, and peer advocates. All one-on-one audio taped interviews were conducted at each provider’s workplace in a private office or unoccupied break room, or in a private area of their personal home. Informal conversations were held at food pantries, community outreach events, fundraising events and other organization specific events, such as agency lectures for employees.

Providers were a diverse set of individuals with varied histories and roles within the community. Some providers had professional education with college degrees, such as mental health counselors, nurses and nutritionists, while others gained experience by working with various social service agencies. Peer advocates were primarily experienced individuals within the medical system and volunteered their time to help fellow PLWHA. All providers played a pivotal role within the lives of PLWHA and served as gatekeepers to health system navigation, from information about available services and support groups to accessing medications and disability benefits. PLWHA frequently mentioned certain providers that have had a lasting and continued impact on their lives, especially those who worked with them when first diagnosed and during times of particular hardship. Peer advocates were overwhelmingly popular and respected in the community, as one participant’s affectionate response reflects, “they inspire you and make you want to come around.”
This section introduces the agencies that assist PLWHA and providers’ perspectives of the HIV/AIDS community in Las Vegas. Agencies are listed in Table 1 and categorized by funding type and the services they provide. Image 6 provides a geographical map of organization location in Las Vegas. Providers’ knowledge of PLWHA and community issues were elicited with narratives, analyzed using qualitative software and grouped into cognitive concepts based on similarity. Please refer to the methods chapter for a complete step-by-step process of the narrative analysis used in this research study.

**HIV/AIDS Organizations in Las Vegas**

The Ryan White HIV/AIDS Program funds the majority of agencies who serve the HIV/AIDS population; however, there are many organizations that are non-profits and/or self-funded. Ryan White has two classifications of grants available: Emerging Metropolitan (EM) and Transitional Grant Areas (TGA). To be eligible for these grants, an area must have at least a population of 50,0000 and have reported at least 2,000 (EM) or 1,000 to 1,9999 (TGA) AIDS cases, respectively, in the last five years. EMAs and TGAs are calculated using the U.S. Census designation of a Metropolitan Statistical Area. Las Vegas is considered a TGA (HRSA 2013).

All Ryan White grants are categorized into four parts, A, B, C, and D. Part A funds are used to provide core medical and support services for PLWHA, which includes outpatient and ambulatory\(^32\) medical care, AIDS drug assistance program, AIDS pharmaceutical assistance, oral health, health insurance premium and cost-sharing assistance for low-income individuals, medical nutrition therapy, case management and mental health services. Part B includes the

\(^{32}\) Ambulatory care is a treatment or intervention that uses procedures delivered on an outpatient basis. For example, day surgery or x-rays.
AIDS Drug Assistance Program (ADAP). Part C supports outpatient HIV early intervention services and ambulatory care. Unlike Parts A and B, Part C grants are awarded directly to service providers and not to local and state governments that contract with organizations to deliver services. Finally, Part D provides grants for comprehensive family-centered care to children, youth, women and their families to improve access to clinical trials and research (HRSA 2013).

Table 7.1 lists agencies that provide HIV/AIDS services in Las Vegas, Nevada, with those agencies that receive Ryan White funds according to each specific part. Figure 7.1 displays their locations in the city.

<table>
<thead>
<tr>
<th>Organization</th>
<th>Part A</th>
<th>Part B</th>
<th>Part C</th>
<th>Part D</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aid For AIDS of Nevada (AFAN)*</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Counseling Center</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Outreach Medical Center</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Golden Rainbow*</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Southern Nevada Health District</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
</tr>
<tr>
<td>UMC Wellness Center</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>UNLV School of Dental Medicine</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Access to Healthcare Network</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Rebuilding All Goals Efficiently, INC. (RAGE)</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Catalyst RX – Pharmacy Benefits Manager</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Nevada Disability Advocacy and Law Center</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
</tr>
<tr>
<td>Nevada Care Program (Program is carried out by University of Nevada, School of Medicine)</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Sin City Sisters of Perpetual Indulgence*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Action Red*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>St. Theresa Food Pantry*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HELP of Southern Nevada (HOPWA food vouchers)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 7.1. HIV/AIDS service agencies in Las Vegas, Nevada, Ryan White and non-Ryan White Funded. *Organizations exclusively provide HIV/AIDS services.
Figure 7.1. Locations of HIV/AIDS organizations/clinics. Not mapped: St. Theresa (located in Henderson, NV).

Agencies have their own unique services that clients are able to access depending on eligibility requirements. The most well known HIV agency that is also the largest is Aid For AIDS of Nevada (AFAN). AFAN is a comprehensive service agency and employs social workers, case managers, a nutritionist, community educator, and development coordinators under their organization. The agency oversees an HIV/AIDS specific community living space called, Casa de Esperanza, funded by the Housing Opportunities for Persons with AIDS (HOPWA) program, the only federal funding program available to house PLWHA. Children affected by HIV/AIDS are also included in agency events, from receiving back to school gear to a weeklong kids summer camp. AFAN is well known among clients for organizing educational seminars on HIV, medications, medication adherence, and coping with the disease. These seminars build community and support among clients and provide necessary medical information to empower them to become involved in their healthcare. Another agency, Action Red, a new Las Vegas non-
profit, HIV/AIDS organization, also focus on client-centered education. Lists of classes that they offer are identified in their flyer posted on Facebook in the Fall of 2013 (Figure 7.2). Provider seminars are also held, where fellow providers and pharmaceutical outreach representatives give educational lectures to keep personnel in the field up-to-date on medications and other aspects of HIV care and research.

![Figure 7.2. A social media post on Facebook advertising a list of courses designed for PLWHA in the Las Vegas area. Photo taken from the author’s phone.](image)

Other agencies, although not as comprehensive as AFAN, focus on essential services for PLWHA. For example, Golden Rainbow focuses on housing needs and provides direct emergency short-term financial assistance to maintain an adequate living environment. The organization also runs an affordable housing program with a number of apartments and homes
available for an affordable rate. The Sin City Sisters of Perpetual Indulgence raise money for their Sisters AIDS Drug Assistance Program (SADAP) who assists clients that have short-term barriers to pay for medications. Generally, larger organizations, such as AFAN, refer clients to these smaller agencies when in need. Ideally, these agencies, large and small, combine their expertise and services in order to assists clients with a variety of medical, psycho-social and practical needs.

The racial/ethnic make-up of the employees at these agencies is varied. Since 2013 there have been an increase in Hispanic case managers and providers available to PLWHA. For example, in 2015 AFAN has four female Hispanic employees who work case management, social work and the front office, as well as two female African-American/black case managers. COMC employs all Hispanic case managers, including two Hispanic males who identify as MSM. Although the number of diverse case managers and providers are plentiful, the case manager to PLWHA ratio is significantly imbalanced. There were approximately 7,589 PLWHA in the 2011 Las Vegas Ryan White Transitional Grant Area, which includes Clark County, Nevada, Nye County, Nevada and Mohave County, Arizona. The 2009 prevalence of HIV/AIDS cases in Mohave County is approximately 200. If we count social workers and case managers at AFAN (6) and COMC (4), the ratio is approximately 7,389:10 in both Clark and Nye County. If we include four early intervention case managers at the Southern Nevada Public Health District who only case manage individuals up to 6 months after they are initially diagnosed, the ratio is 7,389:14.
Provider Narratives

In-depth, semi-structured interviews with 12 providers (case managers, counselors, and peer advocates) identified a series of prominent themes surrounding the PLWHA in Las Vegas, as seen in Figure 7.3. These themes focus on the collective knowledge that providers have of their clients’ life ways and hardships, the current climate of HIV primary and secondary care and prevention, and community needs.

![Figure 7.3. Las Vegas Provider Narrative Themes.](image)

Providers, especially those who are peer advocates, have specific knowledge of client health concerning physical and emotional well-being, medications (including side effects) and medical care. Knowledge of client social experiences, for example, financial situations, violence, drugs/alcohol, and crime are also an important repository for successfully understanding clients’ lives to either assist or refer. Although knowledge of one’s clientele is beneficial, being familiar with different types of support services and funding options is equally important as a provider.
The combination of these knowledge bases identified specific provider techniques for client retention.

*Provider Techniques for Retention*

During fieldwork two types of case managers who assist clients emerged from this research: medical and non-medical case managers. These two types of case managers are similar, but with one important difference, medical case managers have intensive, more frequent contact with their clients. Medical case managers specifically work with clients on medication adherence and the maintenance of regular healthcare practices, such as laboratory blood work and doctor’s visits. However, many non-medical case managers, such as counselors and peer advocates also assist PLWHA with medical management. For example, a nonprofit organization offers free 8-week medication adherence classes in both English and Spanish. Each participant enrolls in the program, which consists of weekly meetings with informational presentations from providers within the community that focus on best practices on medication adherence, healthy living and other HIV/AIDS wellness topics. Additionally, participants have the option of submitting information on personal medication adherence for the week, as well as lab tests. Peer advocates meet weekly with each participant who elects to participate on medication/lab work monitoring.

As will be demonstrated, the complicated medical system relies on case managers and others in the community to assist clients with medical navigation. Interviews with providers elicited ninety-five codes that encompassed the “case manager techniques” code family, which was subdivided by the author into six different cognitive categories that providers utilize to retain clients into medical case management and social service case management. These six techniques,
including 1) education, 2) importance, 3) similarity, 4) trust, 5) coaching and 6) experiences (Figure 7.4 and Table 7.2), are especially implemented among hard to reach and sensitive populations, such as minority men and women. These six cognitive categories were not overtly recognized by providers themselves, but were identified through narratives during data analysis by the author. These techniques form an important communication system that retains clients to healthcare services.

![Figure 7.4. HIV/AIDS Provider Retention Techniques for clients.](image)

<table>
<thead>
<tr>
<th>Provider Techniques</th>
<th>Ranking (Total % of code family)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>1 (27%)</td>
</tr>
<tr>
<td>Coaching</td>
<td>2 (17%)</td>
</tr>
<tr>
<td>Similarity</td>
<td>3* (16%)</td>
</tr>
<tr>
<td>Experiences</td>
<td>3* (16%)</td>
</tr>
<tr>
<td>Importance</td>
<td>4 (14%)</td>
</tr>
<tr>
<td>Trust</td>
<td>5 (10%)</td>
</tr>
</tbody>
</table>

Table 7.2. Rank order of techniques used by providers to assist clients with medical and non-medical needs.

* Similarity and Experiences have similar percentages per code and rank equally.
Case managers “educate” their clients on two important aspects of HIV and AIDS for two reasons: 1) in order to ease fear of the chronic disease, and 2) to disseminate information on HIV-specific organizations in the community. These two important areas of education go hand in hand so that clients are not naïve about their disease and have the knowledge and autonomy to seek services in the community. One case manager specifically outlines her reasoning for educating clients early on:

I want them to take ownership of this process. They need to know every single step of the way. If something falters, if they don’t know these steps, then they will drop. But if you have in front of them...okay this is what we are going to do, you design a case or care plan. “What do you think about this? These are the steps, what do you think about this step?” I do this gradually with them because they see it. They take ownership and once they take ownership they are able to thrive. If they don’t take ownership from the beginning, if we include them in step five instead of at the beginning, forget it, you lost them, because they need to see the whole thing and we are going to work on this stuff. [I ask them] “How do you feel about this? Is there something else we can do to add to this process?” So I want them to take ownership...it’s important to me.

Many providers, especially those who work with Hispanics in the community, recognize the need for Hispanics to “take ownership” in the medical navigation process. One peer advocate describes this as “advocating for oneself.” To be diligent in seeking and securing services that are available in the community is an important quality to posses, but it is difficult for the most vulnerable, particularly those who are undocumented.

“Coaching” involves not only educating clients on medical care navigation, but also assisting and supporting them to overcome barriers to care and obtain services. When PLWHA need specialized assistance with navigating the system, case managers are usually on the front lines, advocating and paving the way for clients to obtain services and care. Coaching may also involve
emotional support and guidance during navigation. A case manager, for example, stresses the importance of taking care of oneself in addition to family:

I think about a friend that’s got AIDS, and she’s got three kids. And she said my kids come first because they are little. I said, I understand that, but you got to put yourself in that priority too. Well, they are first and then me. And I said are you making room for [yourself]?

Sharing “similarity” with clients is a key way to earn trust. When clients can identify with case managers, whether it is by disease, language, sexuality, or ethnicity, clients feel a sense of comfort and guidance (see Hispanic participants results section). In particular, case managers and peer advocates who disclose that they are living with a similar disease, and utilizes the same services that clients do, promotes understanding that leads to solidarity. Geraldo explains,

I access all the organizations like anybody else [who is HIV positive]. Rental assistance? Oh my God, I can’t pay my rent, what am I going to do? I call the agencies; can you help me? You see my life is nothing different from my clients. That is why I connect very well because I live through it. It’s helped me a lot in my job. It helps me connect. Because I am no different from anybody.

Making clients feel that they are “important,” and not just another number in the system is beneficial for client retention. Some providers make time for their clients by seeing them during flexible hours. For example, one case manager asks clients to stop by between 9 and 11am, or if a client happens to walk in without an appointment, they make time. Case managers from smaller organizations are able to accommodate their clients’ schedules in this manner. However, larger organizations, bound by policy and procedure, rarely provide clients with this type of flexibility. Appointments in these larger offices may be scheduled two or three weeks in advance.
“Importance” also encompasses a heightened level of contact with clients. For example, one case manager specifically calls his clients several times to remind them of classes or support group meetings taking place that week. He also gives out his personal cell phone number to his clients. These types of behaviors develop rapport and strengthen clients’ ties not only to the case manager, but also the institution. One Hispanic case manager explains,

I call [my clients] sons, a lot of them. I know it’s not very ethical. But again, between Hispanics we tend to be more friendly, you know, less stiff, less case manager/client. We tend to be more, you know, friends. Yeah, they call me. They call me for not only health related problems; sometimes they call me for other things in their lives. And it’s not only me, it’s all of us [Hispanic case managers]. I have a good relation with my clients [and] I think it is important to have them keep coming back and to stay in the system.

**Barriers to Care**

Case managers were asked about current barriers to the accessibility and retention to health care among the HIV community as a whole. A total of one hundred and thirty-four codes encompassed the “Barriers to Care” code family and were further subdivided into 12 specific categories. Each category was coded and ranked based on case managers’ frequency of mention (Table 7.3).

All case managers identified the structure of the medical system itself and the policies under which the system operates as a major barrier for all clients. Providers, especially case managers, must understand this structure to successfully assist clients with proper navigation; however, most providers acknowledge that it is a complex system, fraught with multiple barriers. Providers must assist clients with navigating this system and overcoming barriers that may lead individuals to fall out of care. Although the system’s complexity is identified by almost all who
work within the system itself, progress toward change is slow. Despite multiple attempts by agencies in the Las Vegas area to network and communicate, the system has yet to be improved for clients. As one case manager points out, “we should be working together.” A peer advocate offered a poignant example of how agencies do not work together, a situation that may place clients’ lives at risk:

A client told me [that] they couldn’t help [him at one agency] and they said to go to [another agency]. And I asked him, where [is the other agency]? And he says, “well I don’t know.” You can look [up] their phone number in the [directory] list. So I call the number, this is me pressing, he was telling me this. [I found out that] well that is so wrong because they are literally 50 feet away [from the referral agency], from the front door to front door. [I said] let’s call [the referral agency]. So we call the agency [that referred the client] and sure enough the receptionist or whoever answered the phone and said, “oh yeah we can’t help you with these drugs, but this agency can. But you have to find [out] where they are.” Well where are they? “Oh, well we don’t have the address, we don’t know.” And it is literally in the same parking lot… I was dumbfounded.

The most commonly reported structural hardship is the lack of service “integration.” Many organizations offer a variety of medical and non-medical services; however, qualifying for certain services that are low-cost or free, such as infectious disease doctor’s visits, blood laboratory work, and medications under public insurance policies (either Ryan White or Access to Healthcare Network) require “verification” from an outside agency. One new case manager began to familiarize himself with the variety of services each agency offers and associated eligibility requirements and found that it took several months of persistent calls and meetings to understand the basic services of each agency in the Las Vegas area:
[I called agencies and was like] I just want to know what you do so that if someone calls me I know… I was like lost for the first two months to the point of where, I just didn’t want to stay with [case management]. I graduated valedictorian in high school, I got a full ride [to college], I am not an uneducated dummy. I felt so stupid…

Another case manager pointed out that without a “really high mental function” clients are not able to understand that they need to “go to these three different places to get to this.” Many federally funded agencies are contingent on grant funding that identifies the policies and procedures for each service they are able to provide. Almost all agencies require a large amount of paperwork, multiple appointments, and specific documentation to receive services. Even then, however, services may not be provided.

<table>
<thead>
<tr>
<th>Barriers to Care</th>
<th>Rank #</th>
<th>(Total % of code family)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical System Structure and Policy</td>
<td>1</td>
<td>(36%)</td>
</tr>
<tr>
<td>Language Barriers (non-English speaking)</td>
<td>2</td>
<td>(12%)</td>
</tr>
<tr>
<td>Transportation</td>
<td>3</td>
<td>(10%)</td>
</tr>
<tr>
<td>Stigma</td>
<td>4</td>
<td>(8%)</td>
</tr>
<tr>
<td>Family Responsibilities</td>
<td>5</td>
<td>(7%)</td>
</tr>
<tr>
<td>Unemployment</td>
<td>6</td>
<td>(6%)</td>
</tr>
<tr>
<td>Lack of Support Groups</td>
<td>7</td>
<td>(5%)</td>
</tr>
<tr>
<td>Competition Among Agencies</td>
<td>8*</td>
<td>(4%)</td>
</tr>
<tr>
<td>Client to case manager ratio</td>
<td>8*</td>
<td>(4%)</td>
</tr>
<tr>
<td>Homelessness</td>
<td>8*</td>
<td>(4%)</td>
</tr>
<tr>
<td>Feeling Healthy</td>
<td>9*</td>
<td>(3%)</td>
</tr>
<tr>
<td>Homelessness</td>
<td>8*</td>
<td>(4%)</td>
</tr>
<tr>
<td>Domestic Violence</td>
<td>9*</td>
<td>(3%)</td>
</tr>
</tbody>
</table>

* These codes have similar percentages in their respective categories and are ranked equally.

Table 7.3. Barriers to Care Identified by Providers.

A specific example of how the medical system is inherently disintegrated, specifically after a policy change, follows,

With Access to Healthcare, which is Ryan White part B, the program that covers, that pays for medication, [has had] some changes…[let’s say a client] has a prescription, or they know they have a refill [for that prescription], but no one fills [it]. One pharmacy says no, we don’t [get] put on the ticket for
Ryan White any more. You go to Walgreen’s; Walgreen’s [says no I need two cards, one mailed to the clients, the other one to the… it’s really confusing.

A peer advocate who works specifically with the Hispanic community succinctly stated that, “the bottom line is, if you don’t know who to ask, what to ask, and how to ask it, then you are going to get nothing. And chances are you will fall out of care.” The “who, what and how” to obtain services within this community is the art of successful medical navigation; however, not all PLWHA are familiar with or practice it. Traditionally, case managers, situated at the frontlines of system navigation, are charged with the responsibility of assisting clients with navigating the HIV organizational system that may include medical and non-medical support. However, in Las Vegas, the health district is also a hub of service management, utilizing the FAST: find, assess, stabilize and treat method for newly diagnosed HIV individuals. There are also referral centers that exclusively refer clients to specific organizations without case management services, depending on eligibility. However, in order to initially utilize these services, it is important to know these services exist.

The multiple system barriers were not initially evident when one education specialist, who identifies the system as a “cascade of services,” walked me through how one would navigate the system from entry (HIV testing) to establishing routine HIV chronic care (HIV treatment). This scenario, I have learned through other case managers, providers and peer advocates, is the ideal secondary prevention cascade, but it does not consider organizational policies, procedures, and other barriers as indicated in Table 1. I have numbered each step below to ease understanding of the navigation scenario.

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33 Social capital is the best way to initially utilize these services and is examined in each subsequent results chapter.
So you are going to test for HIV; you can go to the gay and lesbian center [either on] Mondays and Thursdays, [or the] Richard Steels Tuesdays and Wednesday from like 11 to 6 pm [for] free testing, free std scan…(2) If you do end up positive, they will refer you back to the health district, and they run the western blot, you get results back from 1 to 2 weeks. (3) Come back in [and] they say you are positive. (4) They will send you through to the std nurses and they will then do an assessment….the nurse case managers who are in the HIV side, they have a program…basically what they do is they will take you in, and the nurse is going to go over your [blood] labs…The health district is kind of like the hub where it all begins. (5) They [nurses] are going to refer out to…Ryan White or at least get the eligibility done. (6) They [clients] are going to the wellness center so they can talk to one of the doctors and get that going and (7) get started on meds. (8) They [nurses] might even refer them over to the ADAP program so that they can actually pay for their drugs. (9) They [clients] need to go to community counseling center they have a refer to get them set up and get that done. b/c dealing with it they are gonna need to talk to someone. so every[one] starts to help them and then they branch out and you know, you just, you go to where you need to go. (10) You call up AFAN. (11) You need to come in and do an appointment. (12) You call wellness center.

This path is a skeleton of procedures; a cascade that should ideally occur among newly diagnosed PLWHA. The road to successful navigation may not be so straightforward, since each level may be thwarted depending on the specific barriers clients face, as providers have identified in Table 1. Do I possess the documents needed to qualify? Do I understand the requirements of the program? Am I physically able to get to a specific agency for an appointment? Each of these steps places the client at risk for “falling out of care” or “failure to engage in care.”

34 ADAP is an acronym for AIDS Drug Assistance Program
Services Needed

Providers identified a variety of services and community needs that were primarily based on the provider’s clientele, or area of expertise. For example, female providers who frequently came into contact with females identified childcare or a female “buddy\textsuperscript{35}” program as a service most needed in the community. During the fieldwork year, no agencies offered child care services, even during support group meetings or counseling sessions. Hispanic providers who primarily worked with undocumented individuals identified services that were not related to medical care (ancillary services), such as Latino/Latina-specific treatment education programs, food assistance programs, and rental assistance services. Program coordinators focused on sex education in secondary schools and placing condom dispensers in major clubs, not only homosexual clubs. Although medical and ancillary services exist in Las Vegas, the services are broad, with no particular agency specializing in “population specific” programming. Transportation is the one service that multiple providers identified as being a major service need. The list below, in no particular order, presents the services providers feel are most needed within the community.

- Female Physicians
- Buddy Program
- Increase in case managers
- Socialization initiatives for homosexual Latinos
- Mental Health services for Hispanics
- Asian population outreach
- HIV/AIDS community education
- Childcare
- Ancillary services for undocumented Hispanics
- Latinas support group
- Condoms in major Las Vegas clubs

\textsuperscript{35} The Buddy program was a specific program within one HIV/AIDS organization that would send volunteers to clients’ homes for companionship and/or light household work. Due to confidentiality issues and problems in the past, the program was shut down approximately two years before fieldwork began.
Secondary school sex education (comprehensive)
- Transportation services
- Female Latina counselors

Transportation

The majority of providers indicated that transportation services are needed more than any other type of service. Transportation is needed to get to medical appointments, blood laboratories, pharmacies, mental health appointments, medical card appointments, food pantries, employment, education classes and other important activities related or unrelated to HIV/AIDS. Service organizations are located all over the city, including in the suburbs and often clients take two or three busses in order to obtain services. Currently, one HIV/AIDS organization provides daily bus passes to clients, gas cards and taxi rides.

The majority of clients interviewed predominantly use or have used the organization’s bus pass program; however, no one indicated receiving gas cards or taxi rides. Gas cards and taxi rides are used for clients who have vehicles and are employed, or have medical appointment and are physically not able to take the bus. Clients must provide documentation that satisfies proof of employment or disability in order to receive these services. The gas cards and taxi rides are grant funded from the transportation program of the City of Las Vegas to reduce the number of people who use the bus due to overcrowded conditions. On average, the agency gives out eighty gas cards ($20 value per card) and thirty taxi vouchers per month.

Hundreds of bus passes are given throughout the month, with approximately 70% of the organization’s clients being enrolled in the bus pass program. However, usage depends on the weather; Las Vegas’ hot summer season and cold winter months keep people indoors rather than
outside. A few years ago, the agency went from giving out thirty-day (unlimited ride) bus passes to twelve daily bus passes per month per client. The change occurred after the funding agency requested regulations on the distribution of passes (why is one client getting a thirty-day pass and another a daily pass?), coupled with the knowledge that some clients were selling bus-passes for cash. As a result, current clients are given twelve daily bus passes each month and must return the used passes and obtain signatures from each (approved) organization they visit in order to receive another month’s worth of passes. The agency feels that obtaining required signatures and used passes promote “accountability;” however, among clients it often leads to frustration and confusion. During fieldwork I met frustrated participants who withdrew from the bus pass program, or sought a non-HIV/AIDS organization’s assistance with a thirty-day unlimited pass, which required no signatures.

Male and Female PLWHA

All providers agree that males who live with the disease are the most prevalent in the community, but that there has been an increase among females since the beginning of the epidemic. Providers noted differences in the lives and health seeking behavior among males and females in the community. Women are more sensitive to HIV related stigma, which prevents them from accessing services. The stigma that is most commonly identified is an internal stigma from a perceived “negative morality,” such as contracting the disease because of immoral behavior (e.g. promiscuity, prostitution, drugs, etc). In addition, most providers stated that women have traditionally been the caretakers and that they place the needs of others before their own. It may be because of these two factors that women often feel more isolated. Hispanic

36 Participants who were clients of the county mental health system were given thirty-day unlimited bus passes every month.
females feel a triple burden, with many providers pointing out that Latinas have no cultural support or “voice” within the community to be “all they can be.” Hispanic women, even after migration to the U.S. are bound by gendered cultural norms and traditions as they navigate host communities. These boundaries significantly prevent access to medical and ancillary care.

**Hispanic Services**

Providers point out that serving the undocumented community with medical and ancillary services runs up against a huge barrier. Although undocumented individuals may have access to basic medical care related to their HIV/AIDS, other primary medical services or ancillary services such as physical therapy, food stamps and food assistance are not covered. Undocumented clients are hesitant to seek assistance from formal organizations for fear of deportation. The assistance is minimal and “very hidden,” where only providers who exclusively work with undocumented individuals are able to refer clients to “safe” programs or assist with obtaining medical services. For example, a peer advocate will advise undocumented individuals to use all zeros for social security numbers or leave questions blank when filling out certain applications. All applications, will generally “go through,” however, some agencies require additional paperwork, and one must know where to “watch out.” In fact, most Hispanic clients must work, albeit “under the table,” in order to survive, due to the limited assistance programs.

Providers who work exclusively with Hispanics run into cultural barriers with clients seeking services. If services are requested, or an application filled out and the result is a refusal of assistance, many Hispanics, especially undocumented individuals, are inclined to withdraw from seeking further assistance. As one peer advocate explains:
This one client of mine, he no longer lives here, he went back to Mexico. But he is one of the ones when once somebody says “no,” he goes, “let me fight my fight like I would with my family. I am going to sit in front of the Home Depot and wait for jobs and I will figure it out.” I go, no, you are making life so much more difficult for yourself unnecessarily. There is more help out there. Let me help you. I will make phone calls for you. But it is easy to bruise an ego, and it is easy for a lifetime of cultural bombardments of “this is what a masculine male is responsible for.” It is easy to bruise that, and it’s really hard to get it back.

Providers indicate that there is a particular difference in service seeking behavior among men and women. As one provider who specifically serves the Hispanic community indicates, “Men feel more independent, they just go out there and get services. Hispanic women are, they are quiet, a little submissive, but smarter than the guys- they learn faster. It’s just they don’t have the voice, they don’t have the cultural support to be all they can be.” Latino gender roles and ideology, as identified by providers, is a huge barrier for women who seek services. Jorge describes that women “might as well just have a zipper [on their mouth].” The Latina women who do speak out and are “boisterous” find themselves, “single, beaten, divorced, criticized, ostracized, kids taken away, kids sent back to Mexico, [they] are on your own. It is unfortunate.”

Providers identified a different family dynamic among Latina women. Usually, men are able to speak English, because they have been here longer, and later bring their families. When Latinas arrive, they usually do so without English language skills and their family support system. Their mothers or grandmothers usually do not immigrate with them, at least not immediately, and many Latinas have no one to turn to. Issues of Hispanic masculinity may also keep Hispanic women from seeking assistance or education. For example during a women’s education course conducted in Spanish, one instructor witnessed what he calls “traditional machismo behavior” from women’s husbands:
Yolanda was in one of my classes and [her husband] was outside the front door of that classroom which was a six-week course. All the men were out there waiting for the wives to come out. The girls would tell me the following week, that the husbands would ask, “what are you guys talking about? Did you guys talk about me? Did you talk about how you got it [HIV]? How I gave it to you? How I got it from a guy and how you are the victim and you are not responsible having HIV or our kids, but it was really me?” They were really concerned about that.

He continues on the punishments women may receive if they talk about their personal experiences with contracting the virus:

You would think that women [in 2013] would not be as caged up and scared to open their mouth. All they want to say is, “just so you know, I am the victim here. He gave it to me or whatever it was. But they can’t even say that. Anything close to that would be cause for a beating, or you can no longer go to [this agency] or [that agency].

Hispanic women are doubly disadvantaged in the Las Vegas area. Many providers indicate that services do not focus on Hispanic women, particularly mental health services. A provider who works with the Hispanic community points out that there are barriers for women who speak with male counselors, and that there need to be more Spanish-speaking female counselors who can engage this population\(^37\). Equally needed are support groups exclusively in Spanish that also provide child care services.

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\(^{37}\) At the time of fieldwork there were two Spanish-speaking female counselors working at Community Counseling Center.
Providers point out that Hispanic women seem to be more sensitive to HIV/AIDS stigma and discrimination. Geraldo, an HIV services case manager who specifically works with the Hispanic community, points out,

> In many occasions I run into clients, women clients, at the pharmacy or when I’m doing fieldwork, or out in public places and they fear that I’m going to say Hi or something. They tend to get nervous and stuff. So when I have them here I say don’t worry, I am never going to acknowledge you in public, ever… to keep your confidentiality because I am afraid they won’t come back and see me.

This sensitivity to being “found out” may come from neighborhood dynamics, where most migrations in certain Las Vegas neighborhoods are from one area in Mexico or Central America. Due to “community migrations” people are more likely to know each other, and have multiple generational relationships with several families across borders. This type of environment heightens sensitivity to stigma.

Each provider was asked to identify barriers to care that they have witnessed or experienced with their clients, as well as services that are needed to serve HIV/AIDS clients. Ultimately, there should be an agreement among providers that needed services should remedy barriers to care that are present in the community. Table 7.4 lists the service providers’ nominations for the top five barriers to care, along with their suggestions for services that are needed in the community.

All providers identified services that may remedy barriers to care found within the Las Vegas population. Although an increase in case management may not remedy the disorganization found with the medical system, it may reduce the wait time for clients. To reduce stigma within the
population, educating not only clients, but also the community, may combat discriminatory actions against PLWHA. Many providers gave solutions to improve the emotional and mental well-being of clients through a variety of support groups, both informal and formal. Support groups that cater to Hispanics are especially needed, and may also assist with de-stigmatizing the disease among this population. Although language barriers are ranked second on the list of barriers to care, not one provider mentioned a service need to remedy the barrier. This may be due to Spanish speaking case managers assisting clients one-on-one for services sought, or more Spanish speaking employees are being hired. Either way, language assistance was not noted in services needed for the community.

<table>
<thead>
<tr>
<th>BARRIERS TO CARE</th>
<th>SERVICES NEEDED (to remedy barriers)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medical system navigation</td>
<td>-Increase # of case managers</td>
</tr>
<tr>
<td>Language Barriers</td>
<td>N/A</td>
</tr>
<tr>
<td>Transportation</td>
<td>-Transportation</td>
</tr>
<tr>
<td>Stigma</td>
<td>-HIV Education</td>
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<td></td>
<td>-Secondary school sex education</td>
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<td>Lack of Support Groups</td>
<td>-Socialization among homosexual Latinos</td>
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<td></td>
<td>-Mental health services for Hispanics</td>
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<tr>
<td></td>
<td>-Latina Counselors</td>
</tr>
<tr>
<td></td>
<td>-Latina Support groups</td>
</tr>
<tr>
<td></td>
<td>-Buddy program</td>
</tr>
</tbody>
</table>

Table 7.4. Comparison of barriers to care and services needed.
CHAPTER EIGHT

Results

Part II: PLWHA

The second half of the results chapters focuses on PLWHA. First, the results of the freelisted exercise, disaggregated by race/ethnicity (African-American/black and Hispanic) and sex, are presented. The table describes the most frequented agencies among each group. Second, individual narratives of PLWHA, disaggregated by race/ethnicity and sex, focus on the experiences and understandings of how these groups access and are retained within the health care system. African-American narratives are presented first, followed by Hispanic narratives. The similarities of these narratives are examined and presented at the end of each section as two specific cultural models of healthcare, the African-American self-advocacy model and the Hispanic cultural provider model.

Freelists

There are slight variations in usage among racial/ethnic groups. AFAN is the most mentioned ASO across all groups (80% for the entire sample population) (Table 8.1). This is primarily because the agency manages the Ryan White part A grant that covers drug assistance, which needs to be updated every six months. At the time of fieldwork, Access to Health Care recently took on management of Ryan White part B grant, which is access to medical services, as well as drug assistance, from AFAN. This could explain why so few participants (18%) mentioned Access to Health Care during the field year. Participants must be current with both organizations in order to qualify and access these most used services.
The Wellness Center, St. Therese and HELP of Southern Nevada were among the top four agencies most frequented by all participants during 2012-2013. The Wellness Center is the primary public clinic for infectious disease. St. Therese is an HIV-specific food pantry that allows patrons to shop one time per week. Many individuals praise St. Therese in their ability to provide fresh, canned and refrigerated foods. One participant exclaimed that their neighbors inquire which food pantry they go to, since they have never seen any location give out cakes, frozen meat and fresh fruits and vegetables. HELP of Southern Nevada gives out $100 food gift cards every 3-months. They are a non-HIV organization, but through word-of-mouth many PLWHA retrieve these gift cards.

Hispanic males’ top three agencies centered on medical services and medication (Lied pharmacy). Hispanics also mentioned Community Outreach Medical Center as a source for medical care, whereas African-Americans did not. African-American women’s top agencies, in contrast, were centered on social service assistance, such as St. Therese (food pantry), Golden Rainbow (housing assistance), and HELP of Southern Nevada (food gift cards). African-American participants mainly used golden rainbow, with only one Hispanic male utilizing this service. HELP of Southern Nevada was mainly used by African-American populations, ranking 3rd among females.

There also appears to be a difference in the number of agencies each racial/ethnic group utilizes. Hispanic women mentioned the least number of agencies/clinics they seek assistance from (9),
whereas African-American women mentioned the most (16). Hispanics are also likely to mention agencies that are ASO; African-Americans tend to utilize ASOs and non-ASOs.

<table>
<thead>
<tr>
<th>Agencies Freelisted</th>
<th>Total Sample (N = 45)</th>
<th>African American Females (n=11)</th>
<th>African American Males (n=19)</th>
<th>Hispanic Males (n=11)</th>
<th>Hispanic Females (n=4)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq</td>
<td>%</td>
<td>Rnk</td>
<td>Freq</td>
<td>%</td>
</tr>
<tr>
<td>Access to Healthcare</td>
<td>8</td>
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<td>6</td>
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<tr>
<td>Action Red</td>
<td>12</td>
<td>27%</td>
<td>6</td>
<td>2</td>
<td>18%</td>
</tr>
<tr>
<td>AFAN</td>
<td>36</td>
<td>80%</td>
<td>1</td>
<td>10</td>
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<tr>
<td>Clark County Social Services</td>
<td>12</td>
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<td>5</td>
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</tr>
<tr>
<td>CCC</td>
<td>10</td>
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<td>COMC</td>
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<td>Counselors Plus</td>
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<td>7</td>
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Table 8.1. Freelisted frequencies, rank and proportion per racial/ethnic and sex groups. Top four for each group is in red.
African-American Females

“You have to find some kind of good out of it, so you can go on with your life. A lot of people don’t make it. A lot of people they don’t want to take the medication, or you know, whatever is going on with them. I just made that choice. I am going to live. I choose life. So that is what I did.” – Victoria, African-American female, March 2013, Las Vegas, Nevada.

Eleven African-American females were interviewed over the course of the 13-month field period. Of the eleven, three females participated in joint interviews with their partners, and eight completed follow-up interviews. Most interviews were conducted at kitchen tables or living rooms in each participant’s residence, or occasionally, in a private room at the library. One follow-up interview was conducted in the cafeteria of a local hospital, and another in the lobby of a local HIV service organization. Interviews were primarily one-on-one, with the exception of partner interviews. Although many females lived with other family members, such as their children and grandchildren, most family members knew their HIV status, and thus women were able to talk freely during all in-home interviews.

Participant residences were scattered across the city of Las Vegas and North Las Vegas, and no participants lived in the Henderson, or Summerlin suburbs. One out of the eleven females interviewed was employed as a part-time live-in home health care attendant, and most received Social Security disability payments. The average age of the population was 49 years old, with the youngest being 36 and the oldest 58. All participants had lived, on average, 14 years with HIV, with the shortest being 5 years and the longest 23 years. Most who were not born or raised in Las
Vegas (n=9) have lived the city an average of 11 ½ years, with 3 years being the shortest and 18 years being the longest. Participants who moved to Las Vegas from elsewhere came from neighboring states, such as California, as well as from further east, such as Louisiana, Ohio and Alabama. Nine participants were prescribed HIV medication and 10 were currently in routine care with no missed doctor’s visits within the last 6 months.

Although standard sets of questions were asked of each participant, specific themes informed the narratives of African-American women. These include social support, relationships, self-advocacy, medications, and medical care.

Employment, Income and “Getting by”

All women in the study, with the exception of one live-in home healthcare attendant, were unemployed during the field study. Women who did not receive disability payments listed their occupation as “homemaker” or “charity worker.” Eight women received Social Security disability benefits and two others were currently applying for benefits, having been denied multiple times. Women who received disability benefits were able to pay the majority of their household bills with their monthly checks; however, partners’ or other family members’ income, along with other social service agencies, supplemented payments for monthly expenses. For these women, self-advocacy involves not only medical treatment and medication, but also social service seeking. Four women lived with partners who worked either in steady, full-time positions, or through temporary, on-call positions. Heather, who receives disability benefits, indicated that her boyfriend’s temporary convention work and St. Theresa food pantry and vouchers supplement their household expenses:
I am on disability so my check pays for the rent and the lights and the phone. He [boyfriend] goes to work and that pays for everything else, like food. We get food stamps, but I am diabetic and so I need insulin. With the food stamps they go quick with the diabetic food because it’s so expensive! My food stamps only last a week between us. If he wasn’t working, we’d be hungry. There are missions to go to, but we can go to St. Theresa once a week because everything is more nutritious for us.

Women, such as Monica, who does not receive disability, rely heavily on family members to get by and but considers working to earn a bit of income. She has had multiple issues with uterine fibroids over the past few years in addition to side effects from HIV medication. Her SSI application was denied twice and it has been three years since she has had a steady income:

My son pays for everything. He will get it for me, my daughters will buy enough for me, but they don’t give you any money. They [government] should give you some kind of relief or something. I am getting job calls, but there ain’t no transportation. I would work anywhere. I don’t care- I just want to be making me some money. All money spends.

Yolanda, in her younger years, engaged in prostitution to supplement her income, but she eventually was arrested. Since her arrest, she has not worked as a prostitute; instead, she participates in various public aid programs, such as Section 8 housing:

In my younger years I was prostitute. So I wind up, it wasn’t for no drugs, which I were doing them back then. But I was staying on [Montoya] and [Green Passage Way] so I was kinda homeless like, but I was staying at the hotel so I had to pay for the room every night, and so I wind up prostituting; wind up getting in the car with an undercover, wind up going to prison. From prison to staying with my nephew to being homeless, to staying in low income, to section 8.
Many women emphasized “playing the field” among social service agencies in order to seek out and obtain needed services, including medical care. It was common to turn to their social network to inquire constantly about services within the city. Many women agreed that, “you can live very well with HIV, if you know the right resources and where to go to get help.” When women did run into certain hiccups with agencies, most used persistence to obtain needed services:

I was about to lose my apartment and I went to social services. The guy that I was staying with wrote me a letter and I lost the letter so I had to write the letter myself. The next month, this is when you could get it [rental assistance] once a month, but you can only get it once a year now. For some reason the lady told me, I had lost my job, and she told me that I [could] come back in 30 days, just bring the termination stuff [from the previous job]. So I went over there and told the lady and she said something different. She said, “I ain’t giving you no money!” She didn’t try to find out the facts, and she said “I ain’t giving you any money.” It hurt my feelings, I thought it was rude. But I went to another agency and they gave me the money. I didn’t give up on it. I was persistent about it. A lot of people would just turn over and not do anything about it.

Social Support

Social support is an important aspect of women’s lives and is prevalent in many areas of each woman’s narrative. Social support, however, is linked to a specific group of cognitive categories: family support, support groups, networking, diagnosis story, isolation, and AFAN (a social service agency) (Figure 8.1).
Figure 8.1. Social support and its association with several cognitive categories.

Social support can be classified in two ways: family support and community support. Although most African-American females identify that receiving family support after their diagnosis or subsequent disclosure was an important occurrence in their initial self-processing of the disease, family did not play a large role in the emotional support needed for day-to-day functioning. For example, most women when narrating their diagnosis story emphasize disclosure to family; however, when asked specifically who provides daily social support, overwhelmingly it is friends formed during support groups that are hosted by one HIV specific social service agency, AFAN. AFAN’s programs, such as “Lunch and Learns”, “Healthy Relationships,” and “Mothers, Sisters, Daughters” also serve as a basis for promoting self-advocacy, as later identified in this chapter. Case managers agree that these support groups often bring women out of isolation and help them feel that they are not alone in their disease diagnosis. One woman explains:

I remember I kept myself sick for that first year because I was just so depressed and that depression wore on my body. But once I said, hey, I got this. I’m a have to find a way to live with it. I’m gonna have to find some good in it and once I started to go to group meetings and meeting
other women that had it and stuff….that cloud started to go away a little bit. It was a dark time in the beginning, you know. It was a dark time and I didn’t want to go nowhere, I didn’t want to talk to nobody. I kept myself isolated. The second year I started feeling better about myself and I attribute that to that’s when I found out about AFAN and started going to their meetings and their classes and I started educating myself. I was meeting other people, other women that had been living with it for like twenty years and that was just good motivation for me. So that did a lot for me being around them type of people like that, that really helped out a lot.

Women identify that having woman-specific support groups is more beneficial than attending mixed support groups for other individuals, such as gay men or heterosexual men. One woman stopped going to mixed support groups because she felt that attending a group with gay males did not fit her social or emotional needs.

Case managers and their female clients agree that being connected to support groups assists with getting out of isolation, especially after diagnosis. Women, however, more often associate support groups with educating themselves on the disease in order to alleviate misunderstandings, and they use education to empower themselves through self-advocacy in their medical care and networking. Marta, for example, explains that,

I wish I would have got involved after I was diagnosed and took care with what I needed to and got into a group. They will tell you what you need to do. They will call you in a minute. They’re like, “give me your number; I will call you” and they call! They call!

These support groups educate women on the disease and empower them to be advocates of their own health. Establishing their own informal social support network also assists in learning about
services available in the community. The majority of African-American females stated that case managers do not assist with referrals for services needed. Instead, they find out about certain services amongst themselves, as one female reveals: “Interviewer: so do you learn about services through your (case manager)? Participant: they don’t tell you nothing, we the clients is so nosy we find out by ourselves. And if one finds out, we will tell the next one.”

These informal sources of social and cultural capital enable clients to navigate a difficult medical care and social service system. Although case managers are supposed to be on the front lines, assisting with navigating the social service sector, some African-American women do not feel that they are a good source of assistance. This may be attributed to a significant loss of funding over the past several years, or a recent event where one agency’s employee was caught laundering money. Loss of funds and changes in services have been a source of frustration for some women, as one explained: “It wasn’t our fault that they stole from each other. It’s not our fault. We didn’t have an opportunity to steal bus passes, or gift cards. So why are you punishing us?”

The bus pass program at AFAN, for example, was changed a few years ago, according to one provider, because there were problems with clients selling the bus passes they had received from the agency. Outside agencies that funded the bus pass program were also concerned about giving out 30-day passes to some clients and 1-day passes to others. Because of these conflicts AFAN, the only ASO with a bus pass program, changed their protocol. One woman describes the current protocol and the challenges that come with it:
You have this envelope and you have to have everybody that you go to sign the envelope. Then you have to save your bus passes, the used bus passes, and turn them in. If you don’t have all your bus passes and have all your signatures you get sanctioned. I don’t mind getting signatures, but then some people, some doctor’s offices you go to they will not sign it. They want to know what am I putting my signature on. So they want a receptionist to sign it. Then they say what am I signing? The nurses are like, what am I signing? And the doctors are like, “no that is not my job to sign it.” It’s a good thing [that they have bus passes], but it is too much!

Since the client is affiliated with a publically run mental health program she is able to get a 30-day bus pass without subjecting herself to AFAN’s restrictive policy. Many women are familiar with multiple service providers outside of ASOs due to their networking and social support and can solicit services from a range of sources that have different eligibility requirements.

Self-Advocacy

Women’s narratives encompass several cognitive categories that create an overarching theme of “self-advocacy” as a strategy of self-care. These cognitive categories include: HIV management education, the establishment of social support, networking and stigma management (Figure 8.2). Self-advocating is a high priority for all of the African-American women interviewed and is a common theme in health behavior narratives. However, many women did not initially become involved in self-advocacy immediately after diagnosis. Instead, investing in the necessary components that promote self-care was a process that required significant time, energy and humility over a period of years. Providers identify self-advocacy as a crucial part of the healthcare retention process, as one peer-advocate states, “clients are the ones who need to
advocate for themselves… the bottom line is, if you don’t know who to ask, what to ask and how to ask it, then you are gonna get nothing and chances are you will fall out of care.”

Figure 8.2. Self-advocacy is dependent on four specific cognitive categories: HIV Management Education, Social Support, Networking and Stigma Management.

There are two immediate stages that take place for women after diagnosis: shock and disclosure.

Marietta’s diagnosis and disclosure is typical among most women interviewed:

I didn’t know what to do, I didn’t know anything about HIV or AIDS. I think I heard it a couple times but that’s it. And I went down to the school-I had to pick up my son, he was 15 at the time, my oldest one. And I was talking to him and I was quiet and so I picked my son up and I took him to Palms Mortuary… you know, what we doing here? I said I’m fennin’ to die! And you got to help keep these kids together… because I had four kids and he was the oldest and I tell him don’t let them be broken up keep them together. And he’s like why you dying T? And I told him. And he said you ain’t gonna die. And I’m like how do you know? He knew something I didn’t know! And he’s like all you got to do is take your medicine and you gonna be okay! He said you go to stay healthy and take your medicines… I say who told you that? He said the school. And I’m
like… wow. So when I went to the doctors I take my son. He would talk to the doctor while I sit in the corner and cry.

Typically, as stated earlier, women first disclose to their families and then subsequently to acquaintances at social service agencies or while obtaining HIV education. These acquaintances may later form primary support networks for women. The combination of HIV management education and establishing social support networks provides women with a sense of confidence to manage stigma. Social support networks established through peers, as well as networking among agencies (for example, AFAN) provides vital social service information. These four activities enable women to become self-advocates in their own care. During the course of fieldwork there were concerns about cutbacks involving HIV education. Corina’s response to the importance of HIV management education gives us insight into how individuals value this aspect of care:

The education needs to stay in place, because that is what really helped me, you know. I didn’t know anything. I didn’t know if I was going to… I’m thinking I am gonna die soon. I didn’t know. Like I said, AFAN saved my life because they gave me the tools and they showed me the places I need to go and I went through the counseling classes and you need that. Boy do you need that! Some people don’t realize but it really helps to have somebody else to talk to or to be around other people that is also living with what you are living with. It makes you feel a little better about yourself- that you are not the only one.

Once women achieve self-advocacy, they are better able to communicate with their doctors, make informed medical decisions and the weigh cost of certain procedures or requested laboratory blood work. For example, one sero-positive couple had two different types of health
insurance plans. The wife, Corina, received Ryan White and the husband, Mack, paid for private insurance. Although he was able to get his lab work covered through his insurance, he still had to pay a portion of the cost. Usually, a Ryan White funded program supplemented his insurance and paid his portion of laboratory costs; however, there recently was a transfer of management for public funds and the couple was told that they would no longer receive supplemental assistance for lab work. After his last blood draw, he was responsible for over $400. Corina, an avid self-advocate, suggested a solution:

I told my husband the other day, tell your doctor to keep it simple! Only because you got to pay for it [the blood work and labs]. You got to pay your portion of it. Tell him to only order the necessary stuff and not this other crazy stuff. Because they be sometimes ordering tests we don’t need. but then again we probably do need it. You know, like I say we are both getting older so there are other things they are checking for now, you know.

Corina used her knowledge of HIV management and treatment in an attempt to lower the cost of retaining her husband in care. She also suggested that he (the patient) recommend to his doctor to order only the “necessary stuff” and none of the “other crazy stuff.” In her labeling of necessary and unnecessary treatments, the patient becomes actively involved in the design of the treatment and weighs not only health information and monitoring, but also cost. She also considers the treatment of aging individuals and HIV progression, an area of focus for most self-advocating women in this cohort. Corina’s knowledge of standard laboratory work, and the recommendations of HIV management of aging populations, makes her an expert in creating a care plan that balances the needs of her and her husband alongside infectious disease practices.
Persistence is a necessary personality trait for women living with HIV. Another example of innovative strategies comes from a woman who had not been to the doctor in over a year due to issues with obtaining a social service medical card. She was insistent that she have her blood work done to identify her cd4 count and viral load. Although she never started medication, she typically monitored her cd4 cells and viral loads regularly. She had no income, and had applied for disability 3 times over the past 5 years. She lived in section 8 housing and received assistance from St. Theresa food pantry and other service agencies. She explains below how she solved her issue with obtaining her medical card this most recent time:

That medical card thing, it puts you through so much! It’s a big help when you get it, especially when you have no insurance, no money coming in, but you have to go through so much, so much to get a medical card. I kinda wish they had like a place out, free. You know, where they just do your blood work. But you have to go through so much. It’s so hard.

[So you have to go to access to health network? And you have to go to Clark county social services?]

And then sometimes they be booked up and you have to wait a whole month to get in to see somebody. I be telling the lady I haven’t gotten my blood work done for a whole year. What is the purpose of the medical card? To get my blood work done to see the doctor. That is all I am trying to do! They got me hot down there! I didn’t go off on them, I kept my cool. But she’s like what is the purpose for you getting in… I said ma’am I haven’t gotten blood work done in a year. I am trying to see what my cd4 count is. I had to call Social Security. The lady wanted me to wait, I was already down there at 8 o’clock in the morning. She wanted me to wait until 3 in the evening [to come back]. I had to call Social Security to make sure that I applied to SSI and SSD and then they were able to get me a medical card. And she’s like okay, you can sit around and wait till three o’clock. And then I will call. I said no, better yet, I will call them. She’s like, “I can't give out the information.” I am like okay… I am in the room with the worker [on the phone], will you tell her that I applied for both of them so that I can get my medical card. And they okayed that and I finally got my medical card. Then when you get it, it only lasts you three months.
Corina had her first appointment with the doctor scheduled after our interview. I dropped her off at the Wellness Center and watched her go inside. A few months later I learned that she never saw the doctor that day; she had walked in and they cancelled her appointment. Six months later, while visiting with her, she still had not seen the doctor and was already due to renew her medical card. She did, however, obtain her blood work results and since she could not read them, had her caseworker interpret the numbers. She carries her lab work results in her purse and showed them to me. She was happy since her numbers were still high (or low) in all the right places, and so she was not concerned with seeing the doctor just yet. This would be the third doctor’s appointment missed within the last two years.

Health Behaviors

**Frustrated**

I’m tired of people walking around like Typhoid Mary not taking care of their health because they are in such a hurry.

Not getting treatment.

Not using protection.

Not taking care of that pesky infection.

Not being responsible or even dreaming that a future is possible.

I cry as I write because of this poem I used to be the one singing this song.

I’m not judging or meaning any harm but I just want everyone to know the fight against HIV has not been won.

[Poem by anonymous, wowreallytab, found on *A Girl Like Me* (website), June 3rd 2014]
The maintenance of healthy behaviors among African-American women is primarily influenced by their HIV status and includes a series of activities that women engage in to support their physical and mental health. Women were asked to define health and identify health behaviors that are important to individuals living with HIV/AIDS. Many women admit that they did not begin routine preventative care until they were eligible to receive health benefits through federal and state programs, such as Clark County Social Services and the Ryan White CARE Act, after their HIV diagnosis. Victoria describes her transition from pre-diagnosis to after diagnosis:

I think everyone should have health insurance. Before I found out my status I don’t think I really ever went to the doctor. The only time I went to the doctor is if I had a cold, or I cut my foot, but there was nothing that happened where I needed to go to the doctor every three months. I really like doing this now because if there is something wrong with me it can get caught. Something could have been built up in me and never been caught. I like going every three months… maybe this is a good thing.

The majority of responses to health behaviors included a) a focus on diet and exercise, b) adherence to doctor’s appointments, lab work and medications, and c) retaining a healthy mental attitude by seeking support from peers (e.g. a support group) or disclosing one’s status to family members. Women also identified that education about the disease, treatment, and prevention are also a necessary area of health behaviors. Routine medical care is necessary for women’s health maintenance, as Lilly describes:

It means seeing a doctor on a regular basis like I am supposed to every month. Making sure I take my lab and um, staying with a positive attitude, which leads to these different groups so I learn more and be around more positive people who are like me. It’s healthy to be around someone else like another woman.
However, participation in routine medical care is a treatment cascade, where access to medication is contingent on a doctor’s visit, which is, in turn, contingent on up-to-date lab work. As Cindy explains:

If you can’t get the lab works, the doctor will not see you if you don’t have the current labs. And if they don’t see you, they are not writing no more prescriptions for your medications until you come in and see them.

Women maintain healthcare retention and continuously participate in the treatment cascade by becoming self-advocates of their own care. Self-advocacy involves four key cognitive categories, as presented above, that must be present in order to become a successful self-advocate. An outcome of self-advocacy is routinely participating in the aforementioned health behaviors.

Romantic Relationships

“I don’t love like I used to.”
– Monique, African-American female, May 2013, Las Vegas, Nevada

All African-American women in this study were connected to a current or former partner (boyfriend, spouse, ex-husband) who extended financial, social, or emotional support. The majority of women (82%) had a partner, with 55% living with a partner during the study period (Table 8.2). Three women became involved in relationships with men during the study period.
Two out of the three women began to live with their new partners less than six months after meeting them.

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<tr>
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<tr>
<td>Married, not living with spouse (separated)</td>
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<tr>
<td>Partnership, living with partner*</td>
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<tr>
<td>Partnership, living alone</td>
<td>3 (28%)</td>
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<tr>
<td>Single, living alone</td>
<td>1 (9%)</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>11 (100%)</strong></td>
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Table 8.2. Current relationship and household status among African-American women during study period. *Includes women who became involved with a new partner during study period.

Women who reflected on their relationships stated that their partners provide emotional support and companionship; however, many single women stated that because of past relationships they were wary of rushing into a new partnership. Monique became romantically involved with Jeff, a man whom she had met at the Salvation Army during the study period. Monique, her three daughters and their five small children have shared an apartment for several years since Monique became sick and was no longer able to work. As a result, she was living with them and sleeping on the couch. I met Jeff at her apartment during our follow-up interview and learned that he was staying with her, on the couch where she slept. When I asked about their relationship, she focused on how her past affected her current relationship:

He just wants to rush into stuff, and I don’t do that. He said that you all, all you? womens do that [you] got to wait and check and stuff. He just [goes] head on into it. I am like I love, but I don’t love hard like I used to. That loving hard stuff and putting others’ needs before mine, never did nothing for me…but with him I still
got my guards up.. if you gonna leave I ain’t gonna get hurt. I don’t love like I used to.

In addition to companionship, partners also provide informal financial assistance. Beatrice, after years of separation from her husband, the father of her eldest daughter, receives not only emotional assistance, but also financial assistance from him. Their “unofficial” separation, as opposed to an “official” divorce, has limited her social service eligibility. For example, although she is currently in Section 8 housing, the agency frequently requests information about her husband since they are technically still married. Additionally, she is not eligible for dental services through Ryan White because they must count both incomes. Although she states that he is probably involved in another relationship, he is still a big help. I call him up and I am like I need you to do such and such and… it ain’t nothing that he wouldn’t do for me. So that is a good thing…. he get unemployment, I mean not the unemployment SSI. They don’t give him his full, you know. He ain’t never give none [money] to me, he give it to his daughter. But I’m like trying to get my house done and he been helping me out giving his daughter some money to get my carpet fixed. So I am getting it done little by little. That’s fine by me!

As stated in the excerpt above, her husband has recently assisted her with buying carpet in her rental home since the landlord had not changed the carpet in over three years. Although the couple is not together, he provides her with emotional and financial support when needed.

Although relationships provide emotional support and companionship, many women stated that they were not interested in sex and that other things in their lives took priority over sexual relations. Women stated that they are direct with their partners from the beginning. Monique told
her partner that she is, “not a sexual person. [He’d] be lucky if [he] gets it once a week. [I] told him that if [he is] gonna hang with [me] [he] ain’t gonna get sex all the time.” She stated that her lack of interest in sex may stem from her medications for HIV and other illnesses. However, she is unwilling to change her regiment for sex. Similarly, before Felicia began to live with her current boyfriend, she discussed her dislike of sex:

I met somebody who has HIV and sex is not even an issue. I can take it or leave it. I usually don’t date and I would shut them down. I’ve been called a dyke and I’m like it’s something you will never understand…

*Relationships and Conflict*

Although relationships provide stability and companionship, they are also a source of frustration and guilt. All but two women felt that their relationships were particularly negative; however, conflict that arose within relationships for most occurred mostly around the cognitive category of “blame.” Whether it is blaming oneself, being blamed by another, or blaming a spouse for transmitting the virus there is a deep sense of blame and guilt among women that centers on modes of transmission in current relationships.

Marta, for example, after twelve years of marriage, still had feelings of extreme betrayal toward her husband, whom she identifies as the person who transmitted the virus to her. She describes that her anger is “difficult to cover up” and that although, “[he] hurt me, to hurt [him] back is not going to cure the problem. But I be very truthful to you, it’s hard. It’s hard not to want him to
pay for what he did, but it would be wrong because I am his wife.” She rationalizes that ultimately it is her fault for “becoming infected” because of her negligent behavior:

What did I not do to protect myself? Because usually I get an HIV test with a person [before sex]. I didn’t do that this time, so I hold myself accountable. I was assuming because he was 50,60 years old that that part of his life [promiscuity] is over with and I should have did an HIV test myself, like I known. So that is why I hold myself accountable because before we even got involved with each other it should have been done. But his appearance was healthy and I just assumed… that is the wrong thing for a person to do just because he looks healthy.

An example of women being blamed for transmitting the virus comes from Marion. She was currently involved in a relationship, but felt that it was more of a nuisance than a benefit. In fact, she claims that when she and her partner are split up, he still believes that they are a couple. She states that he is in denial of his HIV status and yet frequently blames her for infecting him. Although he is accusatory, she sympathizes with him and continuously offers assistance on the contingency that he is infected. She states,

He is still taking the test every year. I think he is drinking a little too much, too, so I think that get to him, thinking about being HIV. He say he is, but I never seen no papers. The last papers I seen he was negative. So I think if he is not, he knows I am not gonna be bothered with him no more. Which I really don’t want to be bothered with him any more. I am just tired of a partner. But if he is, I would help him. Help him with resources and show him how to go through about it.

This type of mindset is similar to Marta’s, in that despite her anger toward her husband, she is willing to assist him with the navigation of resources and looks after his health; “I make sure he
[gets his blood work done]. I try to tell him what to do to keep his [viral] levels down, but I don’t know what he’s doing [sexually].”

Both Marta and Marion each have someone to blame or are being blamed for transmitting the virus. Victoria, on the other hand, blames herself for transmitting the virus to her husband:

We don’t really… my husband doesn’t like to talk about it and I understand that. We encourage each other but, we don’t sit up and harp on it {cries}. Because I still feel like I was the one who got him sick. I have to live with that. And he told me “no,” but he didn’t sign up…for this. That was not the plan. He is such a good person. I just knew, I knew in my heart when they told me that [HIV status], he was going to leave me and he didn’t. So I love him even more for that…

Summary

Women’s prevalent themes within their narratives consist of intertwining cognitive categories of social support, self-advocacy, relationships and health behaviors that work in tandem to enable emotional, medical and physical survival after an HIV diagnosis. The presence of ASOs provides a foundation of educational and social strength from which these women can rebuild their lives into more meaningful and relevant futures for themselves, and their families. Emotional categories of blame and guilt may persistent among some women, especially within romantic relationships, and serve as a constant reminder of the social sanctions surrounding sexuality within sex and gender categories within the U.S.
African-American Males

Nineteen African-American males were interviewed over the course of the 13-month field period. Of the nineteen, three males participated in joint interviews with their partners and seven completed follow-up interviews. As with African-American females, all interviews were conducted either on kitchen tables or living room couches in the residencies of participants. On a few occasions, interviews were held at casinos in quiet food establishments or on park benches. Most males lived alone, with their partners, or in community housing, such as a rented room sponsored by a social service agency.

All male participant residences were scattered across the city of Las Vegas and North Las Vegas and, as was true for African-American females, no participants lived in the Henderson or Summerlin suburbs. Most males interviewed were not employed (n=15) and those who were (n=4) retained temporary, or on-call positions in their places of employment. The average age of the population was 54 years old, with the youngest being 29 years and the oldest 60 years. All participants had lived, on average, 12 years with HIV, with the shortest being 4 years and the longest 20 years. Most who were not born and raised in Las Vegas have lived in the city an average of 10 years, with two months being the shortest and 20 years being the longest. Participants who moved to Las Vegas from elsewhere came mainly from California; however, Southern and Midwestern states were also represented, such as Ohio, Illinois and Alabama. Seventeen participants were prescribed HIV medication and 15 were currently in routine HIV care with no missed doctor’s visits within the last 6 months (Table 1).
Narratives among African-American males revealed four prevalent themes: healthy behaviors related to physical and emotional well-being, housing transitions, lack of choice (in healthcare, relationships and housing) and HIV-status disclosure.

*Health and Healthy Behaviors*

Males define health and healthy behaviors as consisting of physical and emotional well-being. Physical health includes four main areas: exercise, diet, doctor’s visits and medication adherence. The majority of participants report that engaging in healthy behaviors means eating right and exercising. However, to maintain a healthy immune system, certain behaviors require retention within the healthcare system, which includes taking prescribed medications and visiting doctors. Almost all (89%) African-American males were prescribed ART within the last year (Table 1). As indicated by many participants, sticking to routine doctor’s visits is critical for maintaining medication adherence. If one does not obtain blood work, one cannot see the doctor. If one cannot see the doctor, ART prescriptions are not renewed. Healthy behaviors first and
foremost must consist of routine lab work and doctor’s appointments. One participant succinctly identifies healthy behaviors that involve the treatment cascade:

Take your meds on time, seeing your doctor on a regular basis. Staying up with new information about prevention and HIV. Getting information on what to do [for prevention].

<table>
<thead>
<tr>
<th>Prevention Opportunity</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prescribed ART (within 1 year)</td>
<td>17 (89%)</td>
</tr>
<tr>
<td>Medication Adherent</td>
<td>14 (74 %)</td>
</tr>
<tr>
<td>ID* Physician Adherent</td>
<td>15 (79%)</td>
</tr>
</tbody>
</table>

**Table 8.3.** Number and Percentage of African-American males (N=19) prescribed ART, adherent to ART, and regularly attending doctor’s visits.
* ID = Infectious Disease. One participant does not have an ID doctor, however, sees a primary physician on a regular basis, at least every 6 months.

Education about the virus, transmission risk and how medications function in the body to actively suppress the virus is important for establishing a foundation of knowledge that supports physical and emotional well-being. As one participant explains,

The medicine stabilizes and blocks the destruction from growing and as you take your meds and as you become more stable to eventually be zero, undetectable, that is pretty much what you want. That is the goal as opposed to not taking your meds, because you immune system is going down. Even psychologically you feel better knowing that you have something to take and it keeps it from being destructive. This is why if I miss an hour of a scheduled time to take my pill I immediately take it when I can because I know the benefits of it. When I take my meds, I can rest for the day because I done my part of it. Once we take our medicine it solidifies the whole medical supports we get. Education is not enough.
Once an individual is knowledgeable about the benefits of ART, medication adherence is most likely to occur. Individuals who have had delays in their medication suggest that they can “feel” themselves getting sick more often, or that “something” is not right in their bodies. Education on HIV/AIDS treatment has directed them to believe that continuous medication establishes the foundation for maintaining one’s health: a healthy immune system. Although most participants are not 100% adherent with their medications on a daily basis, they actively work to maintain their schedules as closely as possible. One participant who had used heroin and crack-cocaine for several years off and on noted that even when using he has always been adherent to his medications.

The establishment of a routine that consists of seeing a doctor and taking medications on time is time consuming for individuals engaged in chronic care and may have repercussions. For example, the most cited incident of falling out of routine care is constant engagement in these very behaviors that promote health. The constant reminders of having the disease (medication adherence), coupled with regular blood draws and doctor’s visits (every 3-6 months) may exhaust individuals, even if they have been educated on best practices in HIV/AIDS treatment. Cody had been living with the disease for 7 years before he started taking medications. He is affiliated with a well-known ASO and frequently talks openly about his experiences living with HIV to groups within the community. He is also in training to become a peer-support navigator to assist others living with the disease. He recently began taking ART medication to lower his viral load to undetectable, a recommendation of most ID doctors in the Las Vegas area that is based on the TasP (Treatment as Prevention) initiative. Cody had been on medication for 6 months when he began to feel differently toward his daily regiment, as he describes:
It wasn’t too long ago that I stopped taking my medication and I was mentally and emotionally exhausted with everything, with doctor’s visits, blood draws, taking meds… I didn’t want to do it any more. I reached a moment where I was like, I can’t do this any more.

Cody received his “second wind” when he received his blood test results back and found that he was finally undetectable after several years of having more than 200 copies of the virus in his bloodstream. He identified this moment of significance that motivated him to continue to stick with his regiment. Another individual also recognizes the monotony of adhering to treatment, and occasionally partakes in a few days of drinking alcohol to break up his routine:

Every once in a while I will neglect taking my medication. I will get overwhelmed with something and I will drink for about 2-3 days. I will go off [meds] because it is not good to take meds and drink. But that is how I deal with things. So every so often I will go on “vacation…” I get tired going to my parents’ house. I sit in my room and get lonely. You can only watch so much sports, or listen to music. I drink for a couple days and that breaks up the monotony. And then I feel better about myself.

One of the significant barriers to maintaining medication adherence and doctor’s visits is establishing a residence. Many males, unlike females in this study, had significant challenges to securing safe housing. This more often than not contributed to a disruption of treatment and care and thus, a disruption of healthy behaviors. In the following section of the chapter I highlight specific barriers individuals face during housing transitions.

Participants also highlight that mental and emotional health is equally important. As one participant notes:
You need to be healthy physically, but it is also a state of mind. The way a person feels has to do with his health also. I try to be uplifted all the time. To think good, happy thoughts. Although with life you have to live with the ups and the downs, some things might depress you, but state of mind has a lot to do with your well-being. Your mental state has something to do with your immune system….

African-American narratives of emotional health consist of three elements: education, self-acceptance, and companionship. In order to obtain mental wellness about one’s self a mentally healthy attitude toward oneself it is important to understand the course of the disease, as well as treatment and prevention. Education on HIV/AIDS supports self-acceptance, which establishes a healthy mindset for entering into a relationship. Participants, especially heterosexual participants, note that a large part of being emotionally healthy is to have the romantic companionship of another individual. One may be physically in shape and able to function; however, mental wellness is difficult to achieve without the romantic companionship of another person. Alex, for example, noted that he had his “fair share” of women in the past. However, he notes that since he was diagnosed, he has not had any type of partner. Although he typically sticks to a normal regimen of exercise, diet, medical appointments and medication, he explains

That other part is missing, the companionship part. I kind of have just been putting that on the side for a long time now. I am getting these anxiety attacks now. I used to get them when I was younger, but they are stronger now. I am trying to figure out why and I think its because there is no one that I feel comfortable talking to. There’s just not….

A barrier that prevents heterosexual participants from actualizing their emotional component of health is the fear that an intimate relationship with a woman would be impossible. Eleven out of
19 participants identified as heterosexual. Out of the eleven, five were either in a partnership with a seropositive partner (n=3), or pursuing a partnership with a seropositive (n=1) or seronegative (n=1) female. Three out of the remaining six males expressed concern about the possibility of future partnerships and realized that the only way they were to establish a partnership would be if both partners were seropositive. Clyde describes a hypothetical scenario on the possible repercussions of disclosing one’s status to an HIV-negative female:

> When you pop that pill you always remember you have AIDS. They say you can pop that pill and forget about it and live a normal life. Keep remembering that no matter how healthy you are now do not fall in love with this girl and do not take this girl to bed without telling her. You want to live a normal life and grow old with her without having this madness in your life. You want to get Valentine’s Day, and right in the middle of it you tell her you have AIDS. So now she doesn’t love you no more. She at the beauty salon, “oh he got AIDS.” Now there are rumors around, and you don’t want everyone to know.

Elroy pursued a woman who was HIV negative and planned to take her to his doctor to educate her on safe sexual practices, HIV transmission and risk. He had disclosed his status to her and even though they have not had sexual relations, they had been spending significant time together. He has the same concerns as many of the heterosexual males identified above:

> The last time I had a girlfriend… it’s been a while because I don’t want to get anyone infected. And when you do tell a girl, they hit the road. So having her around with me, I get butterflies in my stomach. I don’t think I eat very well because I am so nervous.
Residence Transitions

“I didn’t fall out of care, I was forced out of care.” – 56 years old, African-American male, diagnosed 1996.

Six out of 19 participants (32%) have had recent housing issues within the past few months at the time of their interviews. Secure housing, as the literature shows, is fundamental to the maintenance of healthy behaviors. These housing issues significantly affect participation in the treatment cascade, such as doctor’s visits and medication adherence. Most housing issues among African-American males seem to occur when participants move across states. Clyde, for example, experienced significant delays in establishing himself within the Las Vegas public assistance medical system (Ryan White) due to requests for specific documentation, such as a Nevada Drivers’ License and birth certificate. These requests require significant time to complete. For example, requesting a birth certificate from a county hospital can take up to 4 weeks in some states. Obtaining a driver’s license in the state of Nevada requires proof of identity, which includes a birth certificate, a social security card, and proof of Nevada residency. Nevada residency requirements may include rental agreements, utility bills, or bank accounts with no fewer than 30 days of consecutive residency. These documents must then be taken to the Ryan White granting agency during a scheduled appointment, which may have to be scheduled up to 2-3 weeks in advance. The term “fall out of care” does not resonate with individuals who are establishing medical care in a new city; instead, they feel that they are “forced out of care” due to the medical system’s stringent requirements. One participant stated that he didn’t see a doctor for a whole year because his private insurance had a $500 deductible. It wasn’t until he
could become established within the public insurance system that he was able to return to his routine appointments.

Other housing issues occur when living situations change, as a result of job loss, for example. Individuals who are constantly in flux with their living arrangements are less likely to be medically adherent. Long-time secure housing for individuals is the first step to maintaining adherence to the HIV treatment cascade, especially when establishing a medication regimen. Although there are programs for emergency and short-term housing (less than 6-months) for individuals who do not have steady housing, constant worry interferes with medical adherence. As Frank puts it:

I was homeless for a while, from December to the end of February because one of those programs that pay rent ran out. I was homeless for a year before that for about four months. That usually happens when you transition from one program to another… I am here [in this apartment] for this month and I don’t know where I will be next month… [Taking] meds is not regular [when you are homeless]. It’s hard to get everything in place when you don’t have a place. You don’t have normalcy. Without normalcy you are not going to do well with HIV.

Individuals may rely on chance opportunities from social service agencies. This was true of Frank, who states that he went into an agency to see if he could obtain a co-pay for a pair of reading glasses, and the worker “just decided to pay [his] rent.” He indicated that she figured he was close to securing his disability and that she was going to try to keep his housing secure until then.
Most long-term housing comes from non-HIV related social service agencies, such as Section 8 or HELP of Southern Nevada. HIV-specific agencies, such as AFAN, provide transitional housing for PLWHA who qualify and are under the Section 8 program; however, enrollment into Section 8 is required. One male participant was referred to the Women’s Development Center (WDC) where they were able to subsidize a large portion of his monthly rent for up to one year. Although, this provided housing for the individual, he did not have a choice as to where he lived. Instead, he was provided a specific WDC apartment in an area that he would not have looked into otherwise.

Those who have been approved for Social Security Income (SSI) or disability are more likely to live in stable and secure housing. This monthly income, along with assistance from other social service agencies to assist with food and other medical expenses such as dental care, which is outside the realm of Medicaid/Medicare, can make daily living much more comfortable and provide a sense of independence. Robert was waiting for his Social Security application (SSI) to be approved by the judge during our first interview. He was living with his family and borrowing their second vehicle for doctor’s appointments since he first moved in with them several years earlier. At the time of his second interview the judge had approved his application and he was already receiving Social Security checks that were backdated for several months. With his Social Security approved, he sought to become independent from his family and talked of finding his own apartment and buying a used vehicle of his own. Several other participants on SSI had moved into their own apartments and had no issues with their living accommodations. These participants were more likely to have fewer barriers to care and adhere to the treatment cascade.
Many African-American men, similar to African-American women, stated that they are no longer able to work because of HIV symptoms, especially if they exhibited opportunistic infections at the time of diagnosis that rendered them bed ridden or in the hospital for several weeks. It was common in participants’ diagnosis stories to be admitted to the hospital and remain there for weeks before being diagnosed, or admit oneself due to opportunistic infections after diagnosis. These disruptions in employment often left individuals out of work for significant periods of time. Many male participants worked physical jobs, such as in construction and home improvement, which made returning to work nearly impossible after several weeks in the hospital. During this period of unemployment, HIV social service agencies may provide short-term rental, food, and other assistance to individuals who cannot support themselves while recovering from their illness.

For those who are unable to return to work long term due to complications from HIV or in their medication regimen, typically apply for SSI. Participants state that SSI approval is not guaranteed and that judges are less likely to approve applications based on HIV status alone due to advances in HIV medications that have more or less controlled the serious life threatening symptoms of HIV. This is why many participants have applied at least twice and have been rejected at least once during their application process. Many who are currently waiting for SSI approval have either went back to work temporarily, or are currently looking for employment. Although SSI provides stability, many who receive it state that they are limited with their fixed income and desire more flexibility. Some individuals who are currently healthy and medically stable consider going back to work part-time to earn extra money. One participant went through
8-months of Nevada Job Connect, a program that provides training and assistance to those searching for employment. After multiple trainings and job applications he received an interview for a part-time position. He said that his health is stable and that he is able to maintain his medical appointments with relative ease and that working two or three days a week would get him out of the house and some spending money.

[Lack of] Choice

Cognitive concepts of limited “choice” are common among African-American male narratives. Many identify that they have limited options for ID doctors and clinics, pharmacies, dating women (as identified above) and housing (as identified above). 18 out of the 19 participants have public insurance, which limits one’s options of choosing an ID doctor and clinic. For example, insurance from Clark County Social Services, Ryan White and Medicaid all refer to the UMC Wellness Center. If one wants to go out of this network, an additional cost accrues to the patient. Community Outreach Medical Center (COMC) is another option for patients eligible under Ryan White (part A), however, this center is less well known among documented citizens and generally serves undocumented individuals. Prescriptions were limited to the UMC pharmacy, where patients would spend up to an entire day waiting for their prescriptions to be filled. However, recent advances in local lobbying have opened up more options for patients. For example, Walgreens has agreed to fill prescriptions under public insurance, such as Ryan White. Additionally, independent pharmacies, such as All in One Pharmacy, will deliver medications, as opposed having them picked up or mailed.
Men who have not experienced a lack of choice in medical care include veterans who are able to see ID doctors within the Veteran’s Administration (VA) healthcare system. Three men had been established within the VA healthcare system since their diagnosis and report no issues or problems. One participant states that he consistently hears “horror stories” from people trying to get their medications from the public hospital (UMC) or to reschedule an appointment to renew a medical card for public assistance. However, his experiences have been “smooth” with the VA. The VA also makes transitioning care between states relatively easy since the VA is a federal system.

When one is educated about the importance of taking medication, and is adherent to the medication for many years, barriers that prevent one’s adherence are doubly frustrating, especially when choice is limited. As one participant who was in a state of residency flux when interviewed described not only his knowledge about how anti-retrovirals affect the virus in his body, but also the despair that prevents him from consistently acting on the basis of this knowledge. His options for care were limited since he sought public assistance from Ryan White and Clark County Social services. He highlights not only the importance of understanding the disease trajectory, but also the importance of tertiary HIV prevention:

"Why are you telling me I have the disease? They say, “so you don’t’ spread it to anyone else.” Okay, but what is it? What am I giving to everybody else? AIDS. Well what is it? It’s in your blood system; your immune system is being destroyed by it. It is a virus that is tearing your immune system down, branch by branch. It tears down the right, then left arm. The leg. The foot. It works your way to your mind. But it can’t destroy your heart. But your heart says, you can’t give it to anybody else. It is a disease that is going to kill you. You are going to die. We don’t know when, but you are going to die. But don’t get discouraged, they got medicine you can take they call it a cocktail. You take these three
If given a choice, this participant would take the necessary actions to be medically adherent. Even if choice is limited within multiple areas of the chronic care spectrum, many feel grateful for the services offered.

Many men note, however, that there are structural difficulties that are embedded within the medical system. Although these difficulties are identified by most individuals, some see them as barriers that bar their engagement with services, and others see them as nuisance, yet necessary to access care. Many agree that most agencies, such as AFAN, make you “jump through hoops” to receive services. For example obtaining signatures for their bus pass program, or maintaining up to date files every six months to access public assistance insurance services. All agree that funding has decreased and that this has also correlated with stringent restrictions on services provided. Many do not like the changes that frequently occur with documentation, such as registering every six months or requiring certain types of documentation. Establishing a relationship with a case manager at AFAN has recently been difficult for clients due to frequent changes in staff. Although participants had established relationships in the past, most individuals now see whoever is available. This adds to the frustration of clients seeking assistance because each new caseworker a client comes into contact with does not know about his/her specific circumstance or issues. Thus, limiting the caseworker’s scope of knowledge to assist clients in
need. Because of these structural issues, many participants explain why informal networking is important—“If you don’t ask, they ain’t going to give it to you.”

**Disclosure**

Most male participants disclosed their HIV status to family members and perhaps a few close friends. However, almost all stated that if they had the chance to disclose their status again, they would choose to limit the number of individuals, even family members, to whom they would disclose their status. Many individuals stated that this is due to a difference in how they have been treated. Ronald, for example, upon being diagnosed in 2001, chose to tell a variety of family members and close friends of his status since he thought he was immediately going to die from the disease. He stated that once he became knowledgeable about the disease, which was a few years later, he would not have told all the people he did:

> [HIV] is something we have to address and those who are close to you…if I know today, if I had it all over again…if I just found out today, I wouldn’t tell anyone. No one. I regret that. As long as I know, and I know how to maintain it and control it where no one else can get it. I ended up telling certain people, certain family. You can see a difference, and you know there is a difference there.

Some participants are reluctant to tell their family members. Levi, for example, is able to discuss his status with friends with whom he has established a network through various HIV organizations, but his ex-wife and children has yet to know about his status:

> No one in my family knows about my diagnosis. I don’t know how they will react. I don’t want to be stigmatized [by them]. It will also get through the grapevine. It is my choice. It is my personal issue. I don’t think I will ever disclose to them.
Many individuals who choose not to disclose to family members are afraid of their news traveling to other individuals. Many have identified family members who have told other people, both inside and outside the family, of their diagnosis. Elroy, upon meeting another woman and attempting to court her, disclosed his status early in their relationship. He was surprised to find out that she had already heard about his HIV status through mutual friends from their childhood. Although she didn’t know if this “rumor” was true or not, Elroy confirmed it. To his relief his status did not scare her away and they were still together during our last interview.

Another area of concern is disclosure to an employer due to missing work or having their doctor contact their employer. Adrian was forced to disclose his status to his employer several years ago:

I have been terminated at jobs for being HIV positive. I [disclosed because] I had been out for surgeries and I have been sick for a little bit and I had to explain to HR and she explained it to the owner of the company. They made it look like there was downsizing of the company when they fired me.

Another participant adds that he would never consider disclosing his status to his employer due to the stigma and discrimination he would face, even as an employee in the medical field. These participants’ fears typically erupt from the misconceptions that society has had surrounding individuals living with HIV/AIDS. For example, many participants identified that when people hear the word “HIV” they automatically think of AIDS, which causes much frustration due to the distinct differences between living with HIV and having AIDS. The historical misconceptions that surround “AIDS” derive from the early 1980s and 1990s where the term was synonymous
with disease, contagion and death, most notably from undesirable behaviors such as prostitution, drug use and homosexuality. All participants are sensitive to these misconceptions and frequently mention the fear of social stigma as a deterrent to disclose.

Summary

African-American male narratives revealed common themes related to health, healthy behaviors, medical care, [lack of] choice, housing issues and disclosure of HIV-status. Males define health in both physical and emotional aspects. One key cognitive category of health for this population includes establishing a romantic relationship, particularly among heterosexual men. The maintenance of one’s physical health encompasses a regimen of adhering to the treatment cascade, which includes blood work, doctor’s visits and taking medication. However, this regimen is contingent on stable housing, which African-American males are least likely to secure when compared with African-American women in the study. Narratives also revealed that many males perceive that they have limited options for assistance with housing, medical care, and even relationships due to their HIV-status. Perhaps due to the continued stigma many PLWHA face in the U.S., males also have a sense of regret for past status disclosure, citing that they fear others whom they have not told knowing their status through gossip. These themes are predominant among most African-American males and differ slightly when compared with African-American females.

The African-American Self-Advocacy Cultural Model of Access and Retention to Care

For many African-Americans, participation in case management programs is fraught with uncertainty. Many people, as indicated in the above narratives, are not able to establish trusting
relationships with providers that provide consistent assistance with various medical and social needs. As a result, the African-American community, in particular females, tends to assist each other with emotional and informational support. Strong friendships with other PLWHA, initiated during various ASO events, produce the best strategic outcomes for this population to access and remain in care due to the social and medical information provided by these networks. Although in the past relationships with ASOs were a boon to the well-being of this community, the maintenance of informal social networks, with the continued cordial, but distant relationships with case managers, currently best supports retention to care efforts. The cultural propensity to rely on others in the community for support, coupled with the current disorganization of agencies that employ case managers, are the main reasons for forming these networks and the adoption of the current model.

**Hispanic Females**

Four Hispanic females were interviewed during the 13-months of fieldwork: Lourdes, Mariana, Evelyn and Patricia. Lourdes and Mariana were born outside the United States and came to the US in the mid-nineties, while Evelyn and Patricia were born in the US, Evelyn having been born and raised in Las Vegas and Patricia having relocating to the city approximately 8 years ago. I visited each woman in her home for the initial interview and completed three follow-up interviews (Mariana, Evelyn and Patricia). Evelyn and Patricia, having been born in the US, were more similar to each other than the non-US born women. For example, neither woman held a job; both received disability for an illness other than HIV, were overweight, had had violent past relationships with men, and were diagnosed with HIV before succumbing to opportunistic
infections. In contrast, Lourdes and Mariana were undocumented, worked in under-the-table occupations for their income, had partners who passed away before their own diagnoses, were diagnosed with HIV while hospitalized for opportunistic infections after coming to the US. Additionally, Lourdes and Mariana were primarily connected to Hispanic specific services in the community.

Although there are unique differences among all the women, as a group they all have similarities, as well. Each woman receives some sort of public assistance for her healthcare, whether it is Medicaid, Medicare, or Ryan White services, and each one is currently compliant with her care. All continue to receive mental health counseling at Community Counseling Center. Issues that were brought up among the four women include economic hardship, undocumented status, food security and relationships.

Economic Hardships

Three out of four Hispanic women noted significant financial hardships. Each woman receives assistance either from general social service programs, or HIV specific organizations; however, the assistance may vary significantly. Although receiving disability is a huge financial boon, living solely off it is extremely difficult and is considered below the poverty line. Evelyn, who received substantial assistance from state services due to her mental health condition, broke down her monthly income for me:

I am on a program here with mental health and the state where I pay my own rent, but I get utilities paid, I get a bus pass and $200 a month for grocery money. I wouldn't be able to make it on my own. I only get $890 a month [for disability]...$890 is not that much. If your rent is $800, you
don’t have much to pay for utilities, bus passes, clothes… it wouldn’t be enough, so the program helps.

Evelyn also gets $16 in food stamps every month. She finds, however, that $216 a month for food does not get her very far. In our first interview she mentioned that she has been running out of food at the end of each month and frequenting shelters in the evenings for dinner. Eating once a day has taken a toll on her body because ever since she was diagnosed with HIV she has needed to eat more frequently. She has recently expanded her knowledge of food pantries, and has located one nearby to supplement end-of-the-month shortages. Although she notes St. Theresa’s food pantry has a list of services she is familiar with, her lack of a vehicle and distance from this location prohibits her use of the facility.

Lourdes and Mariana’s undocumented status places them in a precarious financial position. Although the two women have been in the United States, specifically Las Vegas, for over a decade, they have worked several under-the-table positions to stay financially afloat. Since both are single, they do not have assistance from a partner to defray everyday living costs. Lourdes, however, does live with one of her daughters, who receives social assistance services for herself and her children.

Lourdes has worked for several years with other Hispanic women, cleaning homes at a per hour rate. Years of cleaning have taken a severe toll on her body, and she now has developed arthritis, particularly in her knees. In order to decrease her cleaning schedule and still receive an income, she has begun to sell tamales on the street. She sells tamales for $1 each and frequently takes orders and delivers them every Saturday. Similarly, Mariana’s work for the past several years has
also been physically demanding. As a personal care attendant she must be able to care for immobile individuals and/or provide assistance with household chores. During our first interview she revealed that it was difficult for her to find clients and often worked only two or three hours a day. She frequently had trouble obtaining gas money to drive long distances to clients’ homes. As an undocumented employee, her hourly wage had stayed at $10 for several years. When accounting for travel time and expenses, her wage was closer to $6 per hour. During this time her longtime friend assisted her food supply by bringing her milk and bread. Over the course of the next several months, she was able to obtain more clients, although the prospect of making more money significantly affected her physical and mental health. During our second interview she revealed that her 12-hour workdays were exhausting and that she would come home and immediately go to sleep without eating. She determined that even though she was able to make more money, working seven days a week was physically and emotionally harmful. She had recently made the decision to enjoy life and do things she felt enabled her to live well, such as go to meetings at the ASO Action Red, an HIV/AIDS support group, meet friends for coffee and spend time with a prospective partner.

Relationships

All Hispanic females brought up relationships, either past, present or prospective, during the interviews. Three out of four women identified the prospect of future companionship as a possibility. Patricia, however, was not keen on being in a relationship. After leaving a verbally abusive fiancé and contracting HIV from a previous boyfriend, she has not attempted to form any relationships over the past 8 years. Although her roommate suggests that she should date, she is hesitant:
I don’t want to date. I have been single all this time. I have been engaged once and it was a bad relationship. I know I can’t ever think every relationship is going to be bad. But since I’ve been single for so long, I have been set in my ways. I don’t want to be told “where are you going? What time are you coming home?” Things like that.

Evelyn also disclosed relationship violence with her last boyfriend and that one of the men she was currently dating was so “rough” with her during one of their most recent sexual encounters that he hurt her back. During our second interview Evelyn disclosed that she was dating about four men at once and that she had met them on a free local “chat line.” Although she had sexual encounters with each one, she felt particularly regretful about not using condoms with two individuals. She justified her injury with one of the men as “punishment” for not using condoms. Although she was seeing four men at once, she mentioned her loneliness and the link between having HIV and being stigmatized in relationships:

I am still gonna feel loneliness, but I have to do what I have to do. But think about it, if I keep doing what I am doing, I am gonna keep getting what I am getting and this guy hurt me and now it is costing me money [for physical therapy]. Living with HIV is very difficult because there is a lot of stigma with the disease. There is a lot of people once they know you have it they ain’t gonna talk to you any more. They abandon you if you have sex with them or not. I have been dumped both ways, either with or without sex… I am gonna see how it goes [with this other guy] because he said that he would accept me with the HIV. He still wanted to see me. I got to be patient.

Evelyn’s solution to curbing her loneliness is to become involved in a relationship. Although she has friends and a counselor, she feels that a partner will satisfy her need for support in her life.
She describes listening to women in a recent support group and feeling disbelief that the women who did have husbands were not being supported:

I have gone to counseling sessions and some of the women are married. This is the weird part. I am lonely and don’t have a man and that is why I feel I need counseling. It is not the only reason, but it is a big part of the reason why. But they have a man and they have someone and they still need counseling? How is that possible? It is weird that some women who are married would go to counseling because if you have a husband or boyfriend you would have all the support you need.

These beliefs explain her most recent behavior dating multiple men in order to find a supporting relationship that may continue on into a marriage. The stigma that is associated with HIV creates a double hurdle to finding eligible and willing bachelors. Evelyn’s counselor was aware of her actions and during this time she worked with her on disclosing her status to her most recent partners.

Lourdes’s and Mariana’s male partners died in their home countries before they found out they were HIV positive, and both came to the US to seek new opportunities. Both women said that they had current prospective partners who were US citizens and contemplated the possibility of marrying to obtain either permanent residency cards or US citizenship. Mariana stated that she had not yet disclosed her medical or legal status to her prospective partner:

I am seeing someone right now. It is early yet; we are just starting to see each other. It’s a bit difficult for me because he doesn’t know my legal status, or my sickness. I had a relationship with a man [in the past] and I told him I was positive. He was scared and ended it. In the right moment I
can tell him, but not now. It is my right to not tell him now. I feel that if he knows and he loves me, he will stay with me. It is difficult.

Like Evelyn, Mariana has also experienced relationship difficulties with HIV negative men. Lourdes’ relationship was a bit different, since her prospective partner specifically asked her to marry him for residency status. She was hesitant during our interview, and contemplated the benefits and consequences of marrying for legal status. She did not like the idea of marrying not for love, but for necessity and her current economic hardship increased this man’s offer.

Access to Healthcare

All women were able to successfully access healthcare services through assistance agencies during the interview period. Mariana, however, had difficulty at first due to not being familiar with public assistance programs when she was first diagnosed with HIV. She initially sought care on a sliding scale fee that also included the income of her partner at the UMC Wellness Center. However, when she was unable to work due to a shortage of clients, and her relationship ended, she had double the financial burden and ended up owing several hundred dollars. She attempted to speak with the Wellness Center staff to remedy the issue, but no one was able to assist her. They eventually stopped her services, and she was without healthcare for one and a half years. She stopped monitoring her CD4 cell count, viral load, attending doctor’s visits and taking medications. She overheard a discussion about the Community Medical Outreach Center (COMC), where many Hispanic individuals go for free healthcare. She became acquainted with an HIV specific medical case manger at the center and he guided her through the process of
obtaining Ryan White services. Although she says that she may wait to see her doctor for up to two hours, she knows that she is getting the best care possible at the clinic.

Patricia also had difficulties connecting with healthcare organizations when she was first diagnosed 8 ½ years ago. She stated that she felt “brushed aside” and that she had to go to several different agencies in order to obtain assistance from one agency:

I was not being helped. It was frustrating. It took me three to four years to get anything accomplished [like] getting into a doctor, learning about the medications and getting counseling services. They finally did help with dental issues I was having. I was feeling like I was being dropped or brushed aside. It was like, oh, you have to go to this agency first before you can go to AFAN.

Patricia had recently sought assistance to pay for an eye exam, since her insurance would pay for the doctor’s visit, but not the eye exam, itself. Her case manager at AFAN let her know that they would be able to cover the eye exam as a reimbursement or if she brought in a bill from the doctor’s office. Since the doctor’s office was unwilling to provide a bill, she labeled it as a catch 22 situation: “well if I don’t have the money, how can I pay for it?” She inquired about different resources, and her case manager told her that he would be back in touch with her. A month later she is still waiting for his call.

Patricia continues to have difficulties with her healthcare providers. She has switched infectious disease physicians four times since her diagnosis, claiming that she fell out of care in the past
because of how she was treated by physicians; however, with family support she found herself back in care:

[I fell out of care] for about a year. I thought I wasn’t getting the right type of treatment. I was not being treated like a person, not getting answers. I got frustrated and fed up and just quit going. That was about 8 years ago. My friends and family kept pushing me, “well you need to go, it’s important.” About the same time I found out I was a diabetic and they were like, “if you can take care of one, you can take care of both.” Having the support from family and friends got me back into treatment.

Since reentering care Patricia has been an advocate for her health and well-being, attending lunch and learns at the local HIV organization, adhering to the treatment cascade, and going to counseling on a regular basis. Six months later, during our second meeting, she had become extremely depressed and was tired of how she was being treated by her physician’s office, counselor and others in her life:

The doctor here is starting to get more harder to get into and see. It’s just, I can’t keep rescheduling and them canceling. I have to keep on with my appointments, making sure I am healthy and making sure I have the right medications and the right doses of medications. I am getting frustrated. When I go in and talk to him, well this issue is coming up, this issue is coming up, and it’s like, okay go home. I’m like aren’t you listening to what I am trying to tell you? It’s like they rush me out. It’s not the right type of treatment. I have been feeling depressed for about 8 months and with the weight gain… I go to community counseling center. It helps a little but, but I am trying to lose weight, and she’s more on the weight issue than mental health. She’s like, you don’t want to lose weight. And I’m like that is not helping my mental issue. I get depressed even then….
Patricia’s lack of trust in her health care providing team has escalated to the point of depression. She is so unsatisfied that she has decided to move to another city within the next two years.

Hispanic Males

“Back then, we were a bunch of immigrants. In high school we always thought about coming here [to America]. All of us. And some of them, they didn’t have a chance to take advantage of the medications we have now. They just didn’t make it. I was very blessed. I was diagnosed in 1992 and on April 23rd 2011 I became a US citizen after they told me I couldn’t be a resident. I signed waivers, and I became a US citizen!” – Hispanic male, 44 years old

Eleven Hispanic males were interviewed during 13-months of fieldwork. Ten males identified as being homosexual or having engaged in male-to-male (MSM) sex as a possible mode of HIV transmission. Seven males were born outside the United States, with six born in Mexico and one born in Central America. Five interviews were conducted in Spanish and all five completed the study’s Spanish version of the FAHI and MOS-HIV questionnaires. Four males were undocumented, and two had obtained their citizenship after their diagnosis. The average age of all Hispanic males was 42.5 years old, with 27 years being the youngest and 52 being the oldest. None of the men was originally from Las Vegas, and the average time spent in the city was 11.6 years. Two males reported having children.

Six men disclosed current partners, with two reporting serodiscordant partnerships. Three US-born males lived in a group house provided by an ASO, three lived alone, two lived with their partners and two lived with extended family members, such as sisters and parents. At the time of the interviews all eleven participants were currently receiving medical care with one participant
on private insurance. All were prescribed ART and were currently adherent to their medication regimen. Participants had lived with HIV, on average 14 years, with six men being diagnosed in the 1980s and 1990s and the most recent diagnoses in 2011 and 2013.

Employment and Finances

Most Hispanic males worked temporary jobs or were actively seeking employment (Table 8.4). Five Hispanic males were either working temporarily and/or actively seeking employment opportunities. Four of the Hispanic men working or actively seeking work were non-US-born. These males were typically involved with temporary employment agencies, which are known for requesting up to four or five consecutive days of employment with several delays in-between scheduling. Convention and catering work was the most common type of service provided. One man worked in landscaping, but was only able to work intermittently over the previous several months. Out of the six participants not employed or not actively seeking employment, one US-born man received SSI-disability for his condition. All other males either volunteered their time assisting others at a local ASO, or were not employed.

<table>
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<th>Income Source</th>
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<th>Non-US-Born</th>
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<td>0</td>
</tr>
<tr>
<td>Seeking employment (not working)</td>
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<td>0</td>
</tr>
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<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 8.4. Hispanic males employment status, N = 11.
Some Hispanic males, particularly those not born in the US, were frustrated with the current economy and had spent up to several years attempting to secure full-time employment. Ronaldo came to the US in the early 1990s from Mexico. As an undocumented worker, he found employment with relative ease within the city, and eventually worked for a catering company in various capacities for over 10 years. However, the 2009 recession affected the company and when they closed, Ronaldo was left without work. During the time we began our interview sessions he mostly washed dishes at a Chinese Restaurant “under the table” for $5 an hour. Although he would not work everyday, he would stay for 10-11 hours at a time and come home with $55, on average, in his pocket. His workday is typically non-stop; when there were no dishes to wash the owners would direct him to various parts of the restaurant to clean. Although there were times when other workers received a break, especially the cooks, they were not directed to other chores within the establishment. Ronaldo worked on and off for this restaurant during the 6-month interview period. His undocumented status made it particularly difficult for him to secure full-time work, even as the economy began bounced back from its recession.

Similarly, George was actively seeking full-time employment while currently working for a temporary agency, on average, a few days a week. George, who is a non-US-born American citizen, has been employed in the hospitality industry since the early 1980s and takes great pride in his work history and accomplishments, serving high-end hotels in California and Nevada.

When human resource issues came up during his last full-time employment position, he decided to quit and seek employment elsewhere. This was during the beginning of the recession, and since then he has not found anything more than temporary work. His enthusiasm is strong, and
he treats every temporary position as if it will lead to full-time work. Although it has been several years, he has stayed afloat using various temporary employment agencies, and ASOs, such as Golden Rainbow, to help pay his rent and utilities. Martin was in a similar boat, having been laid off from a large casino after several management changes. Unemployed and homeless, he sought assistance through an ASO that provides him housing and other types of assistance until he is able to ‘get back on his feet.’

Not all Hispanic males, however, are physically able to participate in gainful employment. As Mark notes, the side effects he experiences with his medications would prevent him from maintaining a full-time work schedule:

It’s difficult to do a 40-hour workweek. Some days I can’t get out of bed; other days I spend half the day on the toilet. In a month I have at least 3 or 4 medical appointments. Employers don’t want you to leave work like that. It’s almost impossible to keep the job going. And I have been in temp jobs, and for 1 day or so; I can’t do it. I get dizzy, or if I need to go to the bathroom… if it was a permanent job I would lose it.

Mark, after being diagnosed in 2011, has been denied Social Security Insurance Disability twice and now has a lawyer to assist him with the appeals process. During this process he is unable to work and earn income in order to show the judge that he is indeed disabled and unable to work. For Ronaldo, George and Mark, social and medical services are critical because they are economically stressed and in need of medical care. However, each man has had to approach and navigate the medical system in a slightly different way in order to successfully obtain
community access to maintain services and maintain treatment and medication adherence.

Service Utilization and Medication Adherence

Many individuals took advantage of services found in the local community to assist them with daily living needs and expenses. All participants were informed of various services provided by ASOs in Las Vegas, as well as how to obtain medical cards, medicine and receive blood work. However, the extent of this information varied among individuals. For example, all individuals were familiar with St. Theresa’s food pantry and the gift cards that are given once a month to clients. There was, however, suspicion among some participants, particularly those who were undocumented, about the availability of services. Ramon lived with his large extended family and occasionally worked in landscaping when it was available. Due to his undocumented status, coupled with the recession, it has been difficult for him over the last few years to obtain full-time employment. Although he is satisfied with his medical care and is currently on ART, he states that there are certain services that are not available to him due to his immigration status. He says that he knows people who can get free rent and utilities paid, but he cannot because he is undocumented. He adds that this makes navigating the system a bit stressful for undocumented individuals. However, another undocumented man, Aaron, was able to receive assistance for rent even without his documentation status. Hispanic case managers and volunteer peer navigators have contended that many in the Hispanic population do not know what they are and are not entitled to as PLWHA, due to their status as undocumented individuals. This inevitably prevents many Hispanics from communicating with agencies because they assume they will not qualify for programs based on their immigration status.
Figure 8.4. Service utilization access and barriers for Hispanic males.

Hector, a peer navigator, tried to explain the thought process of many Hispanic individuals who attempt to seek assistance:

The services are there, but the clients have no idea that they are there, or they feel like they don’t qualify for them. They have no idea that if they have a Clark County medical card you can go to UMC and go get your blood work there. If you go to the clinic they have to wait. They don’t know they can get it. It’s like, you are looking at [this] cup of coffee [sitting in front of you], and they are like, I don’t know if I can take [the cup]…. oh, I better not.

This type of behavior, a reluctance to inquire about obtaining services provided, prevents many Hispanic males from receiving timely services needed to become economically or medically stable. This passive approach to medical system navigation was truer of Hispanic males than females, and even more so with undocumented males. The reason for this may be found in the
narrative of a Hispanic peer navigator, who stressed the importance of maintaining cultural male pride, *machismo*, and being able to support oneself without assistance from others. Another reason for this may be immigrant status, where the more services you seek, the more personal information you will need to forfeit thus casting a wider net of possible exposure (Figure 8.4).

*Medication Adherence*

All Hispanic males interviewed report being prescribed ART and adhering to their regimens on a regular basis. Although there are times when participants have admitted to missing an occasional dose, they directly attribute ART adherence to decreased viral loads, high CD4 cell count and ultimately, a longer life. The importance of medication adherence is strong within this community, as one participant explains:

> If you have HIV, you have to be adherent to your pills. You wake up in the morning, have your shower, brush your teeth, you take a pill. It needs to be like a reflex. It has to be routine. Like shaving, then you take a pill. Like breakfast, then you take a pill. It shouldn’t be a big deal. It was for me before, I was like, Oh my god, it is time for a pill. Oh my god. It shouldn’t be a burden. It will keep you alive. and then when it becomes part of your life it isn’t a big deal. But even though it is because it is keeping you alive… but it’s just a pill, or a couple of pills.

Most Hispanic males were educated on the importance of ART not by their doctors, but by an ASO, Action Red. Most are active in the community and frequently attend Action Red’s Spanish language Lead for Life program that focuses on medication education and adherence. The program brings together Hispanic community workers from other ASOs who attend the program alongside their clients in a form of community solidarity- a gesture to vouch for the legitimacy of the program and to maintain solidarity within the Hispanic community. These ASOs also support
men’s emotional transition from a seronegative to a seropositive lifestyle. Hispanic community members have had personal and positive emotional effects on many Hispanic males interviewed. Hispanic case managers and counselors form relationships with their clients, and this trust enables them to communicate and remain in care. For example, Edward switched over to a new pharmacy and feels more positive about the service, as well as his confidence in managing his health conditions:

"Action Red told me that they have this new pharmacy in town. I was using the UMC pharmacy and it was bad. Just to give [them] a prescription is a two-hour wait and to get the medication is a four hour wait. Lines and lines and everyone is impatient and in a hurry and it’s horrible. And when I tried the Lead for Life it was different. It was better. They come to your house and you don’t have to drive or anything. Or sit there for three hours. So I really like them a lot. We became really good friends. It makes it better because I can be open and ask about anything with my medication. I can be informed and not be hesitant to ask them. I feel comfortable with my doctor, but I feel like family with them. And they are Hispanic and I am Hispanic and so I can speak in Spanish if I want to."

**Barriers to Care**

Three major themes revolved around barriers to care among Hispanic males: language, legal status, and complex medical system navigation. These three major themes also speak to Hispanic males’ sense of non-entitlement to services, which creates additional barriers to receiving adequate treatment.
Language

Participants who spoke English and assisted non-English speaking peers stated that language is the number one barrier. Hector describes how showing up for a doctor’s visit can cause anxiety for an individual:

> Language is a really, really big barrier. Especially when you show up and you know they don’t speak Spanish, and you don’t want to go up there and speak Spanish and they are going to speak to you in English, and you don’t understand… it’s a big barrier!

Legal status is also a barrier to seeking services. When individuals attempt to receive care at a medical establishment or hospital they worry about the authorities being called and getting deported. These two areas of concern prevent undocumented individuals from seeking timely and routine care. As Hector states:

> We have clients here who have no papers, they show up basically in fear. If they go to the hospital to get any kind of bloodwork they are going to be exposed as an illegal alien and get deported. There is a lot of fear, even though there are reforms, they are still afraid.

All participants reported that they felt comfortable talking with their doctors about their medications and trusted that their doctors kept them informed and healthy. However, the level of involvement with understanding their medical condition and treatment options varied among participants. Individuals who were most recently diagnosed displayed limited knowledge or interest, with knowledge and interest increasing as time went on. Mark, a US-born Hispanic male
who was diagnosed in 2011, states that he communicates with his doctor, but not on the level he can with one particular friend:

I would like to know what is available and the side effects of each one, but that is not really happening. Pretty much [the doctor] says, we will try this and this is what it does, but I don’t really understand what it does. If I really made it a mission to find out, I could, but I am putting myself in the hands of my doctor. My friend who referred me to the VA is my main source of information to let me know what a t cell count means and stuff like that… he is a good source to talk to…

Additionally, the combination of communication barriers and legal status pose a significant threat to the sustainment of care through patient/doctor communication and trust. These two barriers also factor into an individual’s perception of doctors as authority figures and their dominant role in the patient/provider relationship. Because of these compounding factors, Hispanic males who do not speak English are less likely than those who do to communicate with their providers about the intricacies of their health:

[Interviewer: Can you talk with your doctor about your meds and other illnesses you are having?] Yeah. It helps because I speak English. Some friends who are Mexican, or from Guatemala that are in Las Vegas [who don’t speak English]… they go… the doctor didn’t tell me anything. I am like, did you ask him anything? They are like, uh? And shrugs. They don’t know how to say it in English. So the doc is sitting, and he has a robe and it’s a very strong presence and you don’t speak English and sometimes you don’t have papers. And the guy is just going to agree… and then they complain. They complain to me…. the doc didn’t say anything to me… I’m like did you ask him anything? They are like no.
As the above peer navigator identifies, patients agree with their doctors as authority figures on their illness; however, patients still seek knowledge of their condition and communication from their doctors. In order to assist Hispanics with communicating with their doctors and navigating the medical system, ASOs such as Action Red hold several Spanish language courses directed at medical provider communication, medication adherence, and other important topics in the community. Ronaldo, for example, who has lived in Las Vegas and with HIV since the 1990s, frequently attends these community meetings. As a result, when he lost his Ryan White insurance due to a change in eligibility, he was already knowledgeable with who to ask, where to go and what to do in order to get emergency supplies of ART for nearly three months until his insurance was approved. He not only utilized a variety of ASOs, but also pulled from his informal support networks that were able to assist him with a few days’ worth of pills until his supply was replenished.

*Medical System Navigation*

The combination of language barriers, legal status, and the difficulties to obtain medical assistance through the application system compounds one’s ability to successfully enter medical treatment. Hispanic males stress that there are so many different types of organizations that do different things, it is difficult to initially obtain the correct documentation and see the correct organizations to sign up for Ryan White medical care, or even rental assistance. A prevalent theme among individuals is that there are too many ASO workers and that most are so overburdened with clients that responses may take a week or more. Client overburden also leads to strict rules and procedures that delay a client’s ability to obtain care. Mark for example explains:
They sent my friend away four times to get one signature to get his health care card. And then they say, you are an hour late we are not going to see you. They don’t have any compassion for our situation. They are more than happy to send you away. For them it’s just a car ride, for us it could be all day to get somewhere.

Hispanic males are required to update their information with ASO agencies that manage public insurance funds, such as Ryan White services for doctor’s visits and obtaining medication. Robert explains why it is so stressful to be on Ryan White services:

With the workers, they sometimes want so many documents and they ask for so much paperwork. It’s stressful more than anything, it’s like every 6 months and you need to return there for something and another thing and another thing. If you have a job, you are not able to leave your job to keep going back there to give them paperwork.

Nick also states that there are too many organizations that want documentation at different times:

Sometimes you have to go renew this and renew that and sometimes you bring the paperwork and they still want more paperwork from you. Sometimes it’s hard to get the paperwork. You have to go to school, you have to go to work. You can’t be around all the time. I wish it would change. I hope in Vegas it does change, especially with the paperwork with Ryan White. Before if was every year, and now it is every six months. It changed last year, but I always keep my paperwork good.

Due to many issues with ASOs, individuals have sought assistance from peers to navigate a complex medical system that may not provide adequate case management for all clients. Jeff
describes how his informal network was crucial to getting him back into care after a particularly bad experience with an ASO:

I don’t know where I would be if I didn’t find out about AFAN and get into here. I was very stubborn about treatment and the outreach center made it difficult. If they make it difficult for somebody who is already overburdened they give up. If it weren’t for my friend who pushed me I wouldn’t be here. I was off of meds for like 6 months. I got really sick. They didn’t care. Their rules are set this way and that is it. They don’t push and sometimes people need a push. Now I am ready to fight, but I wouldn’t have gotten here if no one pushed me.

ASOs, such as Action Red, are now training English and Spanish peer navigators, to assist individuals in navigating the medical system, as well as to provide emotional support for newly diagnosed clients, or those who are at risk of falling out of care.

Summary

Although there are several barriers that prevent Spanish-speaking clients from being retained in the system, these are currently in the process of being circumvented by ASOs that provide exclusive services in Spanish in order to educate and serve the Hispanic population. These ASOs provide culturally relevant and unique services that educate and build community among Hispanics, especially for Spanish-speaking clients. Hispanic males also build their own safety networks so that they may have emotional, financial, and medical service stability outside of ASOs. Despite complaints about medical system navigation, all Hispanic participants were currently ART adherent and regularly attended doctor’s visits. Non-US-born and undocumented
Hispanic men and women are more likely to work temporary jobs in order to support themselves due to not being eligible for certain public assistance programs.

The Hispanic Ethnic Provider Cultural Model of Access and Retention to Care

Hispanic providers are able to use important cultural information to engage and retain Hispanic PLWHA. As a result, Hispanic men and women found Hispanic providers to be indispensable in their medication and mental health challenges, as well as their social service requests. Hispanic providers in Las Vegas engage in trusting and open relationships more often than non-Hispanic providers. Case managers and counselors mimic culturally relevant norms, such as language, interpersonal communication, and collectivist values. Even among Hispanics who speak English, being able to communicate with others who speak their native language is an important aspect of care retention. Hispanic clients are more responsive to this type of management and report more relationship satisfaction among Hispanic providers than their counterparts. Homosexual Hispanics who can also relate to their case managers and counselors’ sexuality is another strong association for maintaining relationships with their case managers. HIV programs that serve the Hispanic population are successful from a top-down perspective, where county, state and federal employees have garnered the trust of local populations. This “care community” supplies many important services that keep Hispanic clients healthy with positive health outcomes.

*FAHI Scores*

The average scores for each category among all participants (N = 45), taken as a percentage of the highest domain, reveal that on average, each category falls within the 60-70 percent range.
The lowest scores include those in the social well-being category (64%) and the highest scores include those in the physical well-being category (73%).

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<th>Category</th>
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<td>Physical Well-being</td>
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</tbody>
</table>

Table 8.5. FAHI mean scores and the percentage of the highest domain among N = 45.

Many participants identified that once one is diagnosed with HIV, one’s social activity drops significantly. This is why isolation is of major concern to many case managers and counselors. During my observations at a social service organization, I befriended a man who volunteered his time assisting with chores around the center. Around the holidays I noticed that he was particularly distraught. He mentioned that he has no friends, and that the only people he has contact with are at the center and occasionally, with his roommate. His best friend was his dog, who many people criticized him for because he could barely feed himself. He emphasized that he took care of the dog since he was a puppy and couldn’t part with his only friend. His contact was so limited that he received a total of five text messages during the whole year. The center’s staff, mainly comprised of PLWHA was aware of the majority of their clients suffering from social isolation and made it a point to have positive contact with all coming through the door.

The three lowest scores were from Ronaldo (58), an undocumented Hispanic MSM, Monique (41), an African-American female and Frank (59), an African-American heterosexual male. All
participants were not employed and were actively seeking employment or Social Security
disability during both the baseline and follow-up interviews.

Recall that Monique was living with her daughters, sleeping on the couch and had been
unemployed for several years and denied disability twice. She was taking HIV medication in
addition to several other medications for “nerve” pain in her legs and uterine fibroids. Her lowest
scores on the FAHI were in the cognitive functioning category (0 out of 12 points possible) and
the physical well-being category (3 out of 40 points possible).

Frank’s lowest scores were also in the physical well-being (10 out of 40 points possible) and
cognitive functioning category (3 out of 12 points possible). He had been denied disability twice
and lived in a weekly rental studio temporarily paid for by a local service agency. His primary
occupation was bricklayer, and with his current health status he was not able to work within his
skill set. Frank’s low social well-being scores may be correlated to his low emotional well-being
due to his secrecy with the disease, as his family does not know about it.

Ronaldo’s lowest scores were in physical well-being (10 out of 40 points possible) and emotional
well-being (6 out of 40 points possible). Ronaldo was undocumented and had been laid off of his
job a year prior to our first interview. He worked “under the table” for $5 dollars an hour
washing dishes at a Chinese restaurant. Although he had been successful in the past, having paid
his vehicle off, he was just scraping by without a roommate. He also had difficulty obtaining his
medical cards for his medication due to his *tanda*\(^{38}\) money in his bank account. As a result he went to great lengths from various medication assistance programs and friends to continue adherence and not skip a dose. At the time of the interview, he had been soliciting various types of emergency medication assistance programs for three months as the county resolved his case.

Despite each one’s low scores, all three are currently connected to care and medication adherent. All, for the time being, have their basic needs met—housing, food, and medical care, but these needs are constantly being threatened. None of the three receives social security disability, which is a boon to individuals living with this disease. Ronaldo is not qualified for it due to not being a citizen, and Frank and Monique have been denied twice. Frank and Monique are on the verge of homelessness, and are most at risk for falling out of the care system. Although both would like to work, they are physically not fit (Frank due to his line of work as a brick layer and Monique due to her neurological medical diagnosis).

The three highest scores among this population were from Jay (176), a MSM Hispanic male, Eduardo (172), a homosexual, undocumented Hispanic male and Cindy (167), an African-American female. These three individuals were not “struggling” when I met them. Each had sufficient housing, with Jay living in HOPWA approved housing and Eduardo and Cindy living with family. Each was connected to medical care and currently adherent to medication. Cindy is able to work on her own schedule and does not have difficulty finding work. Although Jay is struggling to find work, he is able to enjoy safe housing, food, and medical care. Similar to Jay,

\(^{38}\) *Tanda* is a Spanish term (predominately Mexico) for a type of money lending circle among friends or trusted associates. For example, ten individuals who are part of the tanda contribute $100 dollars to the main organizer every two weeks for a month. One person ends up with $2,000 at the end of the month. This goes on for 10 months until everyone has had $2,000.
Eduardo lives with his family and is able to see the doctor not only for his HIV, but other medical conditions he has recently monitored. All three individuals have people or programs they can rely on for emotional, health and economic assistance.

The primary difference among individuals in these two groups, besides being in either low or high quality of life scores, is housing stability. Even though all the low scored individuals currently had housing, Frank was staying in a weekly hotel paid for by a social service program and Ronaldo was struggling to pay his rent without a roommate. Also, recall that Monique was sleeping on her children’s couch. What is interesting to note is that although overall mean scores reveal that social well-being has the lowest proportion among all participants in all categories, individuals with the lowest scores had higher social well-being scores compared with other categories.
CHAPTER NINE

Discussion

The population presented in this research study is an aging set of minority men and women living in Las Vegas, both from the United States and abroad, who maintain engagement with the healthcare system in order to control their HIV. Although the landscape of social services for PLWHA has changed since many of these individuals were first acquainted with services, most have developed specific cultural models for maintaining their health and healthcare access, as well as for living with the HIV virus. Although older individuals have higher adherence to medication and health care (Hinkin et al. 2004; Barclay et al. 2007), understanding the strategies of these older PLWHA to stay in care is important for future policies and other PLWHA who struggle to adhere to the cascade of HIV treatment. Narratives reveal that the most frustrating area for those individuals seeking healthcare access from public entities is the system structure itself, which contains a plethora of paperwork, policies and procedures that are obscure to novice navigators and troublesome to seasoned navigators. Despite these major areas of concern, many participants have received assistance from ASO professionals, particularly in the past, to obtain medical and social services. Where once certain ASOs were highly respected for their work, they have now obtained minimal importance in the lives of some clients. Although many have sought, or continue to seek navigation services, during the fieldwork year many individuals relied on informal networks to obtain service information.

This study has documented how PLWHA access and are retained in the healthcare system that contribute to positive health outcomes in an urban environment. The strategies and protective
factors that minority populations use in order to overcome barriers and secure their health and well-being are varied, but effective and culturally relevant. These strategies have developed over time due to the medical system’s current landscape. Methods for accessing and retaining healthcare, social service assistance, as well as seeking emotional and social well-being, all work together to contribute to positive health outcomes for this specific population.

*Negotiating Healthcare Retention- Systemic Issues and Responding to Care*

Medical treatment standards of the access and retention to healthcare, recommended to patients by doctors, form the framework from which minority men and women in Las Vegas monitor their own healthcare quality. These medical treatment recipes for wellness are to take medication, obtain blood draws, and to see an infectious disease physician to monitor viral loads and t-cell counts. There are, however, important prerequisite steps for patients in order to successfully follow this recipe and maintain it. For some it involves applying for assistance and obtaining insurance cards every six months to be allowed access to physicians and obtain medication. For others it involves peer navigation or case management to maintain these assistance services and remain in care. Essentially, PLWHA are required to act like NCOs in the army, where the officers are the doctors giving out treatment plans, and the patients act by any means necessary to follow the treatment plan. Utilizing various services in the area is essential to carry out “doctor’s orders,” which include two to four doctor visits per year, medication adherence (having a current prescription and taking meds as prescribed), obtaining blood work before each doctor’s visit and receiving medical cards/insurance. African-American and Hispanic PLWHA achieve access to social, economic and health systems in different ways and thus construct differing cultural models of healthcare retention and wellness.
Las Vegas’ services are comparable with other major US cities, offering medical and ancillary services to clients. Federal funding from Ryan White assists individuals without health insurance to access both medical and ancillary services. Although these sources are critical for most of the participants in this study, all agree that navigating the medical system is stressful and nearly impossible without assistance. Case managers themselves agree that the system is a confusing maze of policy, procedures and paperwork. So much so that during my fieldwork even one newly appointed case manager was on the brink of quitting after attempting to understand basic navigation of the system. Case managers and participants both cited the medical system structure and its policies as the number one barrier to obtaining services.

The systems for economic, social and health services are fragmented and procedures are not clear to clients. Many clients have several workers at different locations. These issues are not new to PLWHA and have been documented elsewhere (Wohl et al. 2011). A more “streamlined” delivery of services would fix many issues participants had of the current system. Of note, many complained of having so many case workers and going to many locations. Either having one location where case workers can visit with clients, or one case worker that can address numerous issues (insurance, rental assistance, medication, child care, etc.) may be a possible solution. Dedicated interpreters for patients visiting physicians may also be an important addition specifically for the Hispanic population.

Case managers, peer advocates and outreach workers are on the front lines and typically are the “first respondents” to individuals in crisis to assist with medical and ancillary service navigation
(“doctor’s orders”). Research has shown that individuals who engage in ancillary services, especially case management, have increased ambulatory care visits (Cunningham et al. 2007) and are better retained in the healthcare system (Ashman et al. 2002). Although service integration was the number one issue across all racial and ethnic families, African-American women in particular were vocal about the uselessness of case management. Many participants, even when fully adherent in the healthcare system, identified case managers as unhelpful and described them as “too busy.” As a result, many participants, especially African-American men and women, relied on informal networks to exchange pertinent service information and provide emotional support. In fact, most of my participant pool was recruited from word of mouth solicitations between PLWHA and not case managers, themselves. The Las Vegas TGA Ryan White 2013 women’s needs assessment survey support these data. African American women, in particular, predominately identified case management as the number one gap in services. One of my participants summarizes her extended experiences with AFAN case managers as, “they don’t do anything! They don’t tell you anything!” In addition, the TGA survey reported that African-American women ranked case managers as the number 2 “services needed” in the community. Hispanics, in contrast feel that providers, especially case managers and counselors, are essential to their management of HIV and knowledge of services.

Provider-patient interactions are considered to be a key determinant in medication adherence (Bakken et al., 2000; Heyer & Ogunbanjo, 2006; Wagner, Justice, Chesney, Sinclair, Weissman, & Rodriguez-Barradas, 2001). Rajabium et al. (2007) found five provider interventions important to PLWHA that contribute to successful engagement and retention in care. Their five interventions include the following: 1) dispelling myths and improving knowledge; 2) helping
with HIV care; 3) building skills and ability to deal with HIV; 4) providing services to reduce barriers; and 5) providing support networks. The providers in this study display all five intervention strategies to engage and retain PLWHA into care (Table 9.1). If clients are not engaged with providers, however, these important interventions are not applied.

<table>
<thead>
<tr>
<th>Rajabium et al. (2007) Interventions</th>
<th>Las Vegas Providers</th>
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<tbody>
<tr>
<td>Dispelling myths and improving knowledge</td>
<td>Education</td>
</tr>
<tr>
<td>Helping with HIV care</td>
<td>Coaching</td>
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<tr>
<td>Building skills and ability to deal with HIV</td>
<td>Education; coaching</td>
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<tr>
<td>Providing services to reduce barriers</td>
<td>Coaching</td>
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<tr>
<td>Providing support networks</td>
<td>Trust, similarity, importance</td>
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Table 9.1. Rajabium et al. (2007) provider interventions alongside Las Vegas providers’ techniques for successful case management.

Las Vegas providers’ use of trust, similarity, and importance to retain individuals in care create a safe space for clients that extends beyond education and coaching, into the emotional treatment of health services. The use of similarity and sharing personal experiences is often used among peer advocates to engage clients and give emotional support (Dutcher et al. 2011), as well as educate about HIV prevention (Raja et al. 2017). Hispanic providers, in particular, are able to use these important categories to engage and retain Hispanic PLWHA. This “care community” supplies many important services that keep Hispanic clients healthy with positive health outcomes.

Hispanic men and women found Hispanic providers to be indispensable in their medication and mental health challenges. Rivero-Mendez et al. (2010) found that Puerto Rican providers show more love and engagement with patients in a friend-like manner and established trusting relationships with HIV-positive women in order to be effective providers. Puerto Rican providers
indicated that these strategies help to secure trust and share information more openly. Interview data with Hispanic providers in Las Vegas is similar in that they tend to engage in trusting and open relationships more often than non-Hispanic providers. Hispanic clients are more responsive to this type of management and in narrative interviews report more relationship satisfaction among Hispanic providers than their counterparts. This close relationship with providers contributes to differences of information seeking between Hispanic and African-American PLWHA in Las Vegas.

Care communities, in effect, are comprised of different actors between the two racial/ethnic groups within this study. Knowledge of the HIV/AIDS service landscape is not homogenous. Instead, it consists of varying amounts of knowledge and social networking. The Hispanic community’s case managers and counselors mimic culturally relevant norms, such as social norms, that emphasize communication (Salimbene 2000) and collectivist values. Even among Hispanics who speak English, being able to communicate with others who speak their native language is an important aspect of care retention. Homosexual Hispanics who can also relate to their case managers and counselors’ sexuality is another strong association for maintaining care. HIV programs that serve the Hispanic population are successful from a top-down perspective, where county, state and federal employees have garnered the trust of local populations.

In contrast, for African-Americans, case management programs are not successful from a top-down perspective. The African-American community, in particular females, tends to assist each other with emotional and informational support. Although in the past relationships with ASOs were a boon to the well-being of this community, the maintenance of informal social networks,
with the continued cordial relationships with case managers, currently best supports retention to care efforts. Historically, African-Americans in the US have formed their own networks for generations in order to assist with the everyday necessities of living (Stack 1974). For example, anthropologist, Carol B. Stack, in her ethnography, *All Our Kin* (1974), documents how friendships are solutions to survive among a Midwestern African-American community. As one community member put it, “You got to go out and meet people, because the very day you go out that first person you meet may be the person that can help you get the things you want” (1974:58). The cultural propensity to rely on others in the community for support, coupled with the current disorganization of agencies that employ case managers, are the main reasons for forming these networks and the adoption of the current self-advocacy model.

Formal ASO established groups that bring Hispanics together secure a safe space where issues can be talked about and healing can begin. Hispanic case-managers are already culturally sensitive to the needs of this population and have the cultural capital to develop rapport and trust among Hispanic PLWHA. In contrast, there are limited numbers of African-American case managers, this could be a reason why this population is not reliant on case managers and have developed their own strategy of sharing information among their peers.

Hispanics may be able to create and maintain their own care communities, as African-Americans have done, if similar conditions of mistrust were to exist toward Hispanic case managers. However, Hispanics have a different set of cultural challenges to overcome. Although both groups equally face social stigma from the larger population, negative social attitudes toward Hispanic married MSM may further prevent establishing supportive social groups among
husbands and wives. Additionally, Hispanic cultural traditions, such as *machismo*, may prevent socializing with female Hispanics. Recall, for example, the peer advocate who worked with female clients whose husbands would prevent them from attending ASO groups and events. Finally, misconceptions about HIV among Hispanic communities, as well as clusters of communities who have direct ties to Mexico or specific Central American neighborhoods where the spread of information can cross borders are also barriers for the formation of informal Hispanic groups. MSM males, who are unmarried and publically identify as gay, may have a significantly easier time establishing informal care communities amongst themselves.

Although both groups have more or less the same access to HIV information, Hispanic populations are limited in that they primarily receive their information from certain case managers. This one-source strategy restricts the variety of information received, and thus limits one’s assistance options. In contrast, African-Americans disseminate information among peers after obtaining it from various origination sources, such as ASOs, and case managers (for those who are tied to case managers for organization dependent services, such as Ryan White and Section 8) and others from past experiences. These differing cultural models of care and retention are important areas of knowledge for implementing policies and new programs for culturally specific groups.

*Physicians and Culturally Competent Care*

Cultural competency training in public health and the clinical sciences highlight specific techniques of care that elicit important information from the patient by way of communication. The popular mnemonic techniques (BATHE, LEARN, etc), described in previous chapters,
initiate a conversation with the patient to establish rapport and gather important cultural and personal information about one’s disease. Furthermore, establishing rapport improves patient-physician interactions which has a direct and positive effect on patient satisfaction, medication adherence and quality of life (Oetzel et al. 2015). Many participants focused on the doctor’s mannerisms and ability to provide information when needed in order to establish rapport. Many participants who were not satisfied with their care reported physicians not listening to them or asking them any specific questions about their health. One participant specifically wants his doctor to “look him in the eyes.” Many reflect on doctors simply looking at their laboratory work, where the most recent viral loads and t-cells are reported for each patient. Participants report that if you are unable to get your blood draw before the appointment, doctors will not see patients. Without an appointment, prescriptions cannot be renewed and medication adherence cannot be achieved. In this manner, patients are essentially reduced to their t-cell and viral load numbers, devoid of any social context.

Karus et al. (2004) found adequate agreement between staff and clients in three U.S. locations on medical and social service needs. The authors cite that major need differences between the two groups may be due to clients’ unrealistic levels of health and functioning, whereas staff may be more realistic regarding prognosis. A comparison of client and staff perceptions of service needs in Las Vegas to determine client-staff agreement differed from Karus et al. (2004). African-Americans identified that they needed a variety of services, such as improved long-term housing options, more choices for infectious disease doctors while on Ryan White, and improved pharmaceutical choices. These services differ from provider perceptions of needed services within the community, such as female physicians, transportation services and childcare, as
described in previous chapters. This is not a matter of unrealistic levels of health and functioning, but of a lack of knowledge of the population served. Ryan White contracts with a data solutions firm that surveys the HIV community once a year to identify gaps, services needed and barriers to care. These surveys are intended to keep organizations on track and help determine future funding areas.

Cultural Models of the Ethnic Provider and Self-Advocacy

As stated throughout this dissertation and highlighted above, the availability of information is not straightforward or easy to obtain if you are not connected to specific individuals in the community (formal and informal). Although few individuals stated that they found specific services through the Internet, most individuals received their information about assistance agencies through other clients in the community. In many cases, especially among African-American populations, even case managers were not a reliable source of information. To remedy this, clients use the opportunity of meeting other PLWHA to establish informal networks, which I label “care communities.”

While case managers are perceived as unsupportive among African-American populations, they do consider other areas of ASOs as essential. In particular, agencies that offer a range of educational classes, from HIV-101 to healthy relationships and medication adherence are a gateway to establishing healthcare retention. The pervasive nature of HIV education in this population and the importance of sustaining education to improve stigma management and prevent isolation are critical. These classes not only provide important information for clients and their families to understand and cope with the disease, but also to practice secondary
prevention among PLWHA and primary infection for sero-negative individuals (Fisher and Smith 2009). This type of strategy, called the Information Motivation Behavioral (IMB) model, is typically used to decrease risk behaviors for HIV-transmission, where risk reduction information and motivation increase knowledge of risk reduction behavioral skills that lead to HIV-preventative behavior (Fisher and Smith 2009). Plach’s et al. (2011) work with older (50 plus years) women living with HIV/AIDS found that daily health-promoting activities supported their nurturing of physical and mental health. Similarly, women in my study used the skills they acquired from education classes to maintain physical and mental health.

One of the main contributors to healthcare adherence among African-American women is involvement with these HIV educational classes and support groups. These women state that their involvement with AFAN’s Mothers, Sisters, Daughters support group was an emotionally powerful experience where they could learn about HIV, form personal relationships with other group members and increase their social capital within the HIV community. These three experiences formed the foundation of African-American women’s self-advocacy cultural model. The establishment of social connections increased one’s knowledge about HIV and non-HIV related ancillary services available in the community. These social connections contributed to meeting everyday basic needs and were also a protective factor from social isolation. Individuals themselves in the community solved this type of environmental constraint, for example, unknown sources of assistance and case managers not doing their job, by establishing informal networks. Facilitators of access and retention among this groups population is similar to Williams et al.’s (2011) findings among African-American groups in the south with support from peer groups, and being actively engaged in care.
Veinot’s (2009) research with PLWHA identified a term called *network-mediated information exposure* that “exposed” HIV/AIDS information to others when it was not actively sought. This process of information exchange occurs during everyday interactions with others. This information is already available in the network and is not explicitly sought out by network members. Based on freelists of all African-American participants, services that were listed by the majority of group members included AFAN, St. Therese, HELP of Southern Nevada and Golden Rainbow. These are baseline services about which, if you are part of a particular network, you will most likely receive information, even when not looking for it. Freelists among Hispanic groups differed slightly in that Hispanic freelists tended to focus on health care specific agencies, such as Community Outreach Medical Center, Wellness Center and Lied Pharmacy. AFAN, however, was still the number one ranked agency for all racial/ethnic groups in this study.

For many Americans, the Internet is a widely used source of community information. In 2013, 74.4% of American households had Internet connections compared with 18% in 1997 (File and Ryan 2014). Most American libraries offer the use of Internet connected computers and free wifi for laptops to their patrons. Despite the increased access to the Internet among Americans in general, only one participant identified using the internet to look for services in Las Vegas. The mean age of the population (45), may contribute to the absence of using the Internet to look for local agencies. Additionally, many individuals initially sought assistance for HIV over a decade ago, when they were either diagnosed or began experiencing symptoms. These specific behaviors, namely a lack of computer literacy and abundant social networking, may be specific to this set of participants due to their age and year of diagnosis.
Individual and Environmental Risk Factors: Barriers for Access and Retention

Three decades after the discovery of HIV, racial and ethnic minorities’ accessibility and retention to care continue to be challenging in the United States (Hall 2012 et al; Torian and Wiewel 2011). Challenges to medical care retention include drug use, homelessness (Muthulingam et al. 2013), absence of insurance, mental health issues and health beliefs (Tobias et al. 2007). Research and training programs are constantly being conducted to rectify the gaps found in our current health care system (Raja et al. 2007). All participants, from various racial and ethnic groups, were affected by at least one of these aforementioned challenges.

Drug/Alcohol Use: African-American women and men, in particular, with a few Hispanic males, discussed past and/or present drug and alcohol use. When individuals are “out there in the wilderness” engaging in drug use, one’s health is the least important issue. Studies have confirmed that drug use and severe alcohol use hinders medication adherence (Arnsten et al. 2002; Hinken et al. 2007; and Cook 2001). Connecting individuals who are currently using to drug treatment programs is essential. One participant’s struggle with drug use and his physician’s constant care and concern led to his eventual treatment to become sober. The constant attention of physicians, case managers, and counselors to retain individuals in care and to refer life saving options is critical for this population.

Homelessness: The National Healthcare for the Homeless Council defines being homeless as, “an individual without permanent housing who may live on the streets…or in any other unstable or non-permanent situation” (National Healthcare 2015). According to this definition, three
individuals, all African-American males, in this study were homeless. George only had a week left on his weekly rental for which a social service agency had paid. A couple, Ken and Michael, had just moved into a weekly rental paid for by another social service agency after a bad falling out at a friend’s home. Unstable housing is negatively associated with medication adherence (Kidde et al. 2007). Ken and Michael report that they were helping each other remember to take their medication, but with the moving around it was a bit difficult. Ken’s experience with medication resistance due to not taking his medication as scheduled during a past period of homelessness has led him to become diligent. Still, when asked how often they are able to take their medication, they both respond with “about 80% of the time.”

There is one HOPWA (Housing Opportunities for People Living With AIDS) affordable housing program available in Las Vegas and a few participants in this study had lived there for several months. The building was remodeled to accommodate twelve individuals in the main house with eight independent smaller cottages in the back. These accommodations significantly prevent individuals from becoming homeless. To date, this is the only HOPWA program available to clients in a city that holds two million people. An expansion of services that prevents homelessness is needed in order to support HIV treatment and prevention efforts.

Uninsured/Underinsured: The greatest predictor for healthcare retention is having health insurance (Warren-Jean Piere et al. 2014). Whether it is Medicaid, Medicare, Ryan White, or Clark County Social Services, without insurance one is not able to afford physician visits, blood work or medications. Yolanda was technically out of care due to not having seen a physician for over a year because of barriers to obtaining her medical card. When she finally received it,
however, she was able to get her blood work drawn, but was never able to see the doctor. She scheduled an appointment with her doctor, and after they cancelled her appointment, her rescheduled appointment was not until her medical card expired. Yolanda fits what O’Daniel (2011) identifies as a “Temporarily (un)stable” category of service seeking, where seekers sometimes struggle to get the documentation needed to qualify for services. For Yolanda it was obtaining a non-expired Nevada ID card and other documents to qualify her for medical benefits.

It is important not only for social services to refer individuals to care, but also for clinicians and nursing staff who come into contact with PLWHA. When Mariana could not pay her bill at the Wellness Center, instead of referring her to social service agencies, she was out of care for one and a half years struggling to pay off her debt. Without being knowledgeable of ASOs and with no one to assist with the navigation of public resources, she felt she had no opportunity to resume her healthcare until her bill was paid off. Similarly, George used the Wellness Center through his employer’s insurance and when he quit, he figured he could not see his doctor because of the cost and so went without health care for a number of years. It was not until he became extremely ill that a low-cost urgent care physician suggested he go to AFAN for services.

There is an assumption within the clinical community that because individuals are currently receiving medical care, they are not in need of referrals to other agencies. These assumptions must be broken down by clinical staff through the use of culturally relevant care models that incorporate knowledge about patients’ environmental contexts into the clinic. Unexamined assumptions can create barriers that allow the most vulnerable patients to slip through the system. Culturally based assessments, such as mnemonic techniques, such as BATHE and
LEARN, addressed previously, and treatment plans provide protection from falling out of care (National Minority AIDS Education and Training Center, 2005). Many participants in this study identified physicians who were involved in their care, while a minority were unsatisfied.

**Cultural:** Many Hispanic case managers and peer navigators commented on the ethnic norms of the Hispanic clients they assist. The dominant cultural model of social service navigation is non-persistence, where once Hispanics are told “no” after asking for specific services, they do not persist in trying to obtain assistance. This behavior is in stark contrast to African-American women, as displayed in the results section. Data from the freelist exercise reveal that knowledge and use of Las Vegas services is significantly lower among Hispanics than African-American populations. However, Hispanics who were able to speak English listed more agencies than those who did not. Other studies have identified that speaking English is essential for navigating the complex medical system (Bowden et al. 2006). The ability to speak English is an advantage that lifts many barriers. However, having reliable translators or bilingual staff greatly reduces the fear many Hispanic have of clinics and other services.

**Relationships**

Most single African-American heterosexual men who were interviewed sought prevention education and abstained from sexual relationships due to fear of spreading the disease. Those men who did have sexual relationships tended to seek out women who were already HIV positive, having met them at various ASOs. This is in direct contradiction to the “vulnerability paradigm” coined by Higgens et al. (2011) where women are victims to HIV because of biological differences and “men’s sexual power and privilege.” Additionally, men are active
vectors of spreading the disease to women and are not agents of prevention. By contrast, men in my sample did not fit this paradigm; they were overly cautious and emotional about discussing relationships, especially the possibility of sexual ones. Many men, despite having lived with the virus for several years, lived in fear that an intimate relationship with a woman would be impossible. These men avoided relationships, but felt emotional discomfort at the thought of being single for the rest of their lives. They also prepared themselves on HIV prevention by attending education courses and in one case, asking their physician to talk to their girlfriend about safe sex and HIV.

Although relationships may be difficult to initiate at first, they do have emotional and psychological benefits. McCoy et al. (2009) found that married PLWHA reported higher levels of social and emotional support. My data support this for men, but do not necessarily support this for women. Similar to House et al. (1988), other studies have reported that women may provide better support to men, than men do for women. For example, Edwards et al. 2011 found that HIV-positive women more often cared for their HIV-positive husbands to the detriment of their own care; often forgetting to take their medications or eat right. However, Warren-JeanPiere et al. 2014 found that older women (50+ years old) specifically, identify that supportive romantic relationships contribute to positive self-management of HIV. Women in my study had relatively healthy partners and although a few reported caring for them in times of need, most never risked their healthcare regimen to take care of a partner. As older women, many who have not had a relationship in many years, they are “set in their ways.” Age may be a factor for this phenomenon, as many women have had relationships in the past where they were taken advantage of mentally or emotionally. Rebecca, for example, became emotionally involved with
a partner during the field year and when things got serious I asked if they would move in together since he did not have a steady place to live. She replied that she could not take it to that level; she had her own way of doing things, and she didn’t want anyone “messing it up.” Romantic relationships are an important part of being human and the participants in this study did not let HIV deter them from seeking a bit of happiness.

Health Related Quality of Life

Researchers have examined a variety of factors that may affect quality of life measures among PLWHA. Socio-demographic, clinical, psychological and behavioral factors may identify or explain the nuances in the everyday lives of people that may affect quality of life. In a review of 49 HRQL studies, employment, immunological status, presence of symptoms, depression, social support and adherence to ART were the most frequently and consistently reported association (Degroote et al. 2014). All three participants who had the lowest FAHI scores were not employed, two were looking for work and were denied disability twice and one did not have stable housing. These factors could contribute to low HRQL scores.

It is assumed that quality of life measures are lower for older individuals due to their declining health. However, Nokes et al. 2000 found no differences, despite older individuals reporting more co-morbidities. When taking into consideration external factors, such as drug use, Crystal et al. 2003 found that older gay men had high levels of emotional well-being, whereas IDUs had low levels of physical functional and emotional well-being in contrast to their younger counterparts. Researchers have hypothesized that quality of life is associated with the viral loads and CD4 cell count, where the higher the viral load and lower the CD4 cell count, the lower the
quality of life, and vice versa. The literature, however, reveals that the relationship between HRQL, CD4 cell count and viral load is mixed. Some studies have shown that there is a significant effect of HRQL and CD4 cell count and viral load (Schroecksnadel et al. 2008). Others have shown a poor association (Cella et al. 2010).

Hays et al. (2001) compared HRQL among HIV patients and persons suffering from other chronic conditions to determine disease severity and found that HIV patients who were symptomatic had significantly worse physical functioning, and all PLWHA, regardless of symptomology, had worse emotional well-being than that of participants living with other chronic conditions besides HIV. Additionally, Rodriguez-Penny et al. (2013) found that co-morbidities among PLWHA negatively affected total quality of life scores. HIV infection may produce a synergistic effect of increased risk of common conditions, such as heart disease, cancer and dementia (Henry, 2009). Many participants in this study were ART adherent and low physical functioning, which may be part of the toxic side effects. Some ART combinations are found to cause kidney failure and other illnesses, which may physically impair patients, causing lowered physical well-being (Reust 2011). Furthermore, ART adverse effects may occur more frequently in older PLWHA, who must be monitored more closely (AIDS Info 2012). Diminished physical functioning may also be associated with co-morbidities, but to a lesser extent, such as physical pain from unrelated injuries and occupational accidents.

The stigma that continues to be prevalent surrounding HIV/AIDS may contribute to low social well-being scores cross-culturally (Hasanah et al. 2011). Stigma affects not only one’s self-esteem, but social stigma, specifically, may contribute to isolation and inability to disclose status.
to family members and friends. All participants mentioned stigma being present either in their communities, or having had direct encounters with people who have been stigmatized by providers and/or community members. It is interesting, though, that those who had the lowest scores overall in the sample did not have low scores for social well-being. It is possible that there is an association between low physical and cognitive well-being and reduced social well-being. Quality of life scores should be taken into consideration when developing culturally specific programs in order to address concerns within a specific population. Incorporating narratives with HRQL scores yields richly detailed information to complement quantitative data. A limitation of the FAHI, however, is that it is a self-report, which has the potential for bias.

Thinking about the Future

Sangaramoorthy (2014) documents how HIV/AIDS prevention is focused exclusively on disparities in its morbidity and mortality. This practice is reactive to the epidemic and may leave room for other populations to become affected. Las Vegas case managers at RAGE attempt outreach to the Asian community, a population that has to date been invisible in HIV/AIDS public health efforts. When asked why this specific population has not been targeted in the past, Sara replied that “funding tends to follow populations who have it [HIV].” As a result, there were resources available for African American and Latinos, but very few outreach activities or resources for Asian Americans.

In an effort to curb new HIV diagnosis rates, cultural modeling of specific cultural domains, such as knowledge and perceptions of HIV/AIDS, can assist culturally relevant primary prevention efforts to prevent minority populations from becoming disproportionally affected by the disease.
Allocating resources to prevent disparities before they happen, as opposed to taking a reactionary approach, is good public health practice. The future for all PLWHA is living with a chronic disease. The shift from treating HIV as an infectious disease to a chronic disease will be a significant burden on our health system with increases in non-AIDS Morbidity, treatment toxicity, immune dysfunction/inflammation and geriatric syndromes (Deeks et al. 2013). As of 2009 only 25% of the HIV population in the US was able to achieve viral suppression (Hall et al. 2013), if increased, our health system would need to be reevaluated to accommodate services. When appointments for infectious disease doctors are already scheduled two months out, and specialists up to 9 months, Las Vegas will need significantly more physicians to respond.

The push towards getting all HIV positive individuals, regardless of CD4 cell count, known as the Treatment as Prevention (TasP) strategy, was heavily felt within the minority HIV community, and many spoke with their doctors about beginning an ART regimen. During the 2012-2013 field year, many participants who were not on medications brought up that it was “almost their time” or that they should “probably get on it.” Medication adherence, however, is a major responsibility, and the risks of beginning and stopping medication are high for viral resistance. The lack of policies within the state of Nevada that facilitate data sharing may contribute to the complicated nature of medical system navigation. Subsequently, the addition of medications to the mix of HIV management further complicates participant routines, and increases their reliance on “hard to navigate” community resources to ensure proper adherence. If TasP will be another tool in our toolbox for HIV/AIDS prevention, we must address current barriers to care among the most at-risk populations and apply successful programs.
The Care and Prevention in the United States (CAPUS) demonstration project, for example, has attempted to ameliorate barriers to care found locally by funding states that targeted at-risk and most in need populations. These states then funded programs to reduce the gap in HIV prevention education and service usage. Many states suggested the addition of navigators and culturally competent training, which basically invests in and expands the work force that has direct contact with PLWHA. The executive plan summaries (GEAR 2013) acknowledge the poverty that many of these populations are subject to and offer incentives, such as gift cards, for completing appointments and/or being virally suppressed. We must remember, however, that incentives are a short-term solution. Temporarily addressing economic inequalities that are structurally prevalent have limited reach and could place individuals into an even more precarious situation once incentives run dry. HIV prevention and treatment policy begins at the economic level, where education, occupation, housing, and healthcare access can be addressed. These social determinants of health need to be addressed alongside specific HIV/AIDS prevention activities. It is not until we reach total social, economic and health equity that we will see a reduction in the disproportionately affected.

An alternative route to addressing these disparities is to start thinking about how minority populations are successful in their health maintenance and understand the protective factors that promote positive health outcomes. The area of “health resilience” is “the capability of communities to ‘cope successfully’ [in terms of health] in the face of significant adversity or risk” (Tunstall et al. 2007:337). Cairns-Nagi and Bambra (2013), for example, found that in one “deprived” area in London community members relied on place attachment, the natural environment and social capital to mediate the negative health effects of deprivation. Similarly,
Tunstall et al. 2007 found sociocultural protective factors that included political, economic, ethnic and religious categories among similar populations. Among older PLWHA, Emlet et al. 2011 found self-acceptance, optimism, will to live, generativity, self-management and independence to be major themes of resilience that promoted healthy lifestyles and well-being. Among many African-American groups in this study, self-acceptance was present among PLWHA, which reinforced optimism for the future. Additionally, education provided by ASOs encourages self-management and independence of medications and health care visits. Certain aspects of ASO programs are successful when clients can successfully navigate the medical system. Thus, the repair of a complicated health system is required to reach the full potential of current and future programs.

The current research study has documented specific health resilient strategies among a small sample of Las Vegas minorities. Self-advocacy behaviors for African-Americans and culturally relevant navigation leaders for Hispanics, for example, assist resource limited individuals with responding to their own healthcare. In both cases, however, the community’s response was instrumental in providing these resources. This health resiliency toward barriers to care, despite these groups’ disadvantages (Crystal et al. 2003), deserves more research and attention in order to provide culturally competent strategies for policies and program development.
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