

EXPLORING THE IMPORTANCE OF SOCIAL NETWORKS IN  
ADDRESSING ISSUES OF HIV AND AIDS IN AFRICAN IMMIGRANT  
COMMUNITIES

by

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ABSTRACT OF THE DISSERTATION

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Sabrina Chase, PhD

**Problem:** The study examined the role of social networks in influencing access and utilization of healthcare services, and health outcomes in HIV positive immigrants from sub-Saharan Africa. Study hypotheses were: 1) Social networks of SSA immigrants are comprised of higher numbers of strong ties than weak ties; 2) Social networks comprised of weak ties facilitate greater access and utilization of healthcare services, and 3) Higher levels of social integration facilitate positive HIV/AIDS related health outcomes.

Qualitative questions examined the types of activities participants engage in with their social networks, types of support systems their networks provide, influence of these activities and support systems on their access to care and health outcomes, and factors promoting engagement of participants in their care.

**Methodology:** Berkman's social network paradigm guided the mixed method study using a snowball sample of 97 HIV positive SSA immigrants residing in Philadelphia.

Participants completed a survey consisting of a demographic questionnaire and two instruments (Medical Expenditure Panel Survey (2010) and Myer's Social Network

Scale). The qualitative sample comprised of 13 participants who completed the quantitative surveys and were interviewed individually.

**Results:** Triangulation of findings from both quantitative and qualitative methods revealed that participants' social networks comprised mostly of strong ties with kin and co-ethnics. Type of network ties and number of connected relationships were significant in accessing and utilizing healthcare services, as well as influencing HIV related health outcomes. Number of strong ties was significantly and positively correlated with CD4 levels. Weak ties were influential in maintaining engagement of participants in their care, access and utilization of healthcare services and understanding their illness.

**Conclusion:** Social networks structures, including size, density, composition, and function contribute to positive health outcomes. Although participants' social networks were predominantly comprised of strong ties, both strong and weak ties offered distinct and complementary support with profound influence on both the physical and psychosocial well-being of HIV positive African Sub-Saharan immigrants.

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## **Chapter 1 – Problem Statement**

Over the last several decades, the United States has undergone dramatic changes in its population landscape due to growing numbers of racial and ethnic minorities. Population estimates suggest that approximately 213 million people live outside their countries of origin, with the United States being one of six countries with the highest current and projected numbers of international migrants (UN Department of Economic and Social Affairs, 2010). As the number of migrating racial and ethnic minorities continues to grow, the health of these populations is of increasing public health concern. There is increasing awareness of disparities in health outcomes between racial and ethnic minorities as compared to the white population. The term health disparities emerged as a result of health status reports that highlighted health differences among populations such as the 1979 Surgeon General's Report, "Healthy People" and the 1985 Task Force Report on Black and Minority Health (RBMH, 1985).

The 1985 RBMH report from the Department of Health and Human Services identified disparities in health status among Blacks, Hispanics, Asian/Pacific Islanders, and Native Americans in comparison to Whites in six key health indicators, including cancer, cardiovascular disease and stroke, diabetes, chemical dependence, unintentional injuries and homicides, and infant mortality rates. Since the 1985 report, ethnic minority groups continue to have higher morbidity and mortality rates compared to other groups and the health indicators measured have expanded to include 21 conditions and diseases including Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) (CDC, 1986; 2015).

HIV/AIDS is an epidemic affecting populations in every area of the world. Since its discovery in the early 1980s, HIV is estimated to have infected over sixty million individuals (WHO, 2009) and is the sixth leading cause of death worldwide, accounting for 3.1% of the world's total deaths (WHO, 2008). The effects of HIV are numerous and most evident in the number of premature deaths among infected individuals. Global initiatives to control HIV have reduced the overall numbers of new infections, but certain groups continue to be disproportionately infected and affected by the disease.

Many programs and research projects have focused on African Americans and Hispanics, but failed to consider the varying ethnicities within these groups. The 2010 "National HIV/AIDS Strategy for the United States" report details the steps to combat and potentially eliminate HIV and AIDS by reducing healthcare disparities associated with HIV, improving health outcomes and increasing access to healthcare services for those infected. However, the report failed to establish a strategic plan for addressing these issues particularly in groups such as African migrants.

Globalization, a contributing factor to the spread of HIV, has increased the mobility of populations across the globe, and as the US population becomes more diverse, the need to understand the social complexities surrounding HIV/AIDS in migrant communities becomes ever more important in combating the disease. Despite increasing numbers of Africans migrating to the US from regions with high HIV/AIDS prevalence, their access and utilization of healthcare services, and disparities in HIV/AIDS related health outcomes have largely been neglected. African migrants settle in urban centers that are already burdened by HIV/AIDS, which makes it important to keep the health needs of

this sub-population in the forefront. One avenue to understanding the complex issues surrounding HIV is to examine the influence of social networks of African migrants.

Social networks are increasingly recognized as social determinants of health. Berkman (2000) defines social networks as relationships or ties among individuals that can serve as a unit of analysis for examining the composition and functionality of relationships and ties. Analysis of social networks can be instrumental in understanding the spread of sexually transmitted diseases amongst individuals or groups that are linked together (Balfe, et al, 2010; Wylie, et al, 2005). Social networks can also provide insight on how membership influences behaviors such as accessing health care services.

This study explores the role of social networks in influencing access and utilization of healthcare services and health outcomes in HIV positive African immigrant communities. Understanding their social networks can generate early and appropriate targeted interventions that can potentially reduce HIV infection rates and slow down the progression of the disease.

### **International Migration and Settlement of African Migrants**

While historians have tended to focus on the involuntary migration of Africans, voluntary migration is a phenomenon that has been occurring among Africans for many centuries. The Economic Commission for Africa (2002) estimated that 50 million of the world's 150 million voluntary migrants representing a third of the world's migrant population is from Africa. These migrants originate from 53 countries that make up the western, middle, eastern and southern African regions. Considered an impoverished region, Africa continues to face economic decline (Economic Commission for Africa Report, 2002; African Statistical Yearbook, 2010). Slightly over 50% of SSA populations

live in extreme poverty with average incomes equivalent to \$1.25 US dollars per day (African Development Bank, 2011). In 2009, Africa's Gross Domestic Product was only 2.5%, with some countries even recording negative growth (African Statistical Yearbook, 2010).

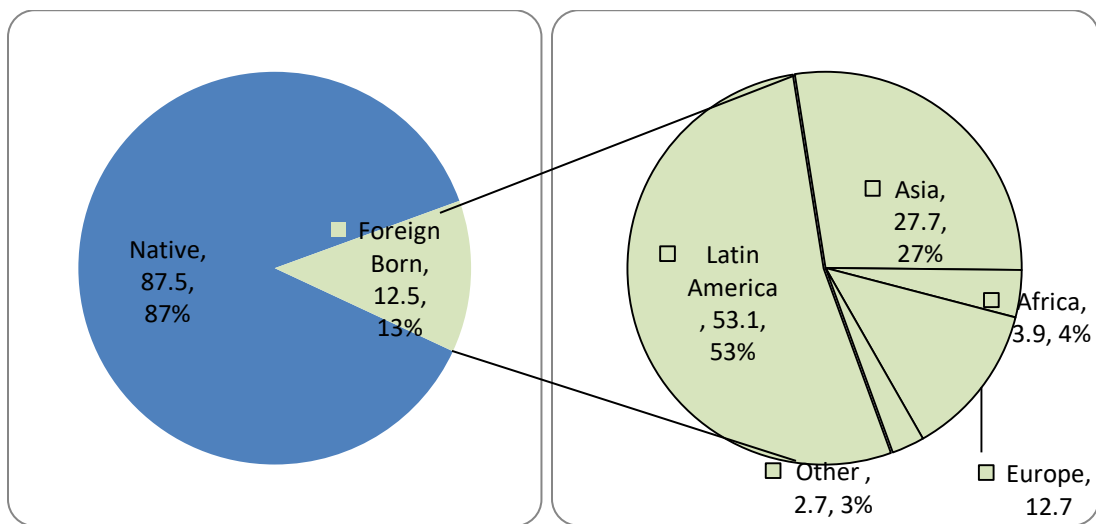
Economic opportunities in other countries attract many Africans to leave their host countries (Taylor & Tuch, 2007; Arthur, 2000). Other reasons for outward migration include political wars/conflict, lack of infrastructure, opportunities for employment and higher education (Getahoun, 2006; El-Khawas, 2004; Arthur, 2000; Takpugang & Tidjani, 2009; Carballo & Nerurkar, 2001).

In SSA, education is viewed as the pathway out of poverty. Compared to all ethnic immigrants, Africans are the most educated (El-Khawas, 2004). Africans have higher educational attainment levels compared to those of Whites and Asians (Logan, 2007). Africans migrate to pursue post-secondary education to better position themselves in their host country or for their ultimate return to Africa. Arthur's study (2000) reported that 60% of African immigrant participants graduated from a university or had some post-secondary education prior to arriving to the United States.

In addition to push factors, pull factors influence the decisions of individuals to migrate. Family reunification has been a major pull factor for Africans migrating to countries such as the United States (Arthur, 2000). Immigration patterns are shaped by policies that determine which groups can migrate and the numbers allowed to enter the host country. Immigration policies often reflect economic and labor market needs, immigration patterns, and social and political climates of the receiving country. For voluntary African immigrants these policies have been favorable and supportive of

African migration to the United States. In 1996, 40% of legal African residents were admitted under policies and programs of the US Immigration and Naturalization Services (INS) (Arthur, 2000). As Figure 1 shows, nearly 39 million foreign born individuals reside in the US with Africans accounting four percent of the foreign born population (US Census Bureau, 2009).

Figure 1: US Foreign Born Population by Country of Origin



Sources Adapted From: Grieco, E.M. & Trevelyan, E.N. (2010). American Community Survey Reports. Race and Hispanic Origin of the Foreign-Born Population in the United States: 2007. US Census; U.S. Census Bureau. (2010). American Community Survey Briefs. Available at <http://www.census.gov/prod/2010pubs/acsbr09-15.pdf>.

In 2007, it was estimated that 34% of the 3 million foreign born blacks were from African countries, with the largest populations coming from Nigeria, Ethiopia and Ghana (Grieco & Trevelyan, 2010). In 2009, the numbers of individuals from those three SSA countries obtaining legal residence in the United States were 15,253 from Nigeria, 15,462 from Ethiopia and 8,401 from Ghana, which represented a 141% increase from 2000 (Year Book of Immigration Stats, 2009).



Unlike other ethnic groups, Africans are widely dispersed throughout the US (Logan, 2007). During the period of 1990 – 2000, there was a significant growth in the number of African-born individuals settling in 10 major US metropolitan regions. As Table 1 below demonstrates, the number of African immigrants has more than doubled in the top 10 metropolitan areas with the largest African immigrants (Logan, 2007). New York, Boston, Atlanta, Chicago, Detroit, Los Angeles, Minnesota, Houston and Washington, D.C were the primary settlement cities for African immigrants (Takpugang, J. & Tidjani, B., 2009; Logan, 2007; Arthur, 2000).

Table 1: Top 10 Metropolitan Areas with Large African Immigrants

Metro Area	African Born		% of Black Total		Growth
	1990 - 2000		1990 – 2000		1990 – 2000
Washington, D.C.– MD-VA-WV	32,248	80,281	3.0	6.1	148.9
New York, NY	31,532	73,851	1.6	3.4	134.2
Atlanta, GA	8,919	34,302	1.2	1.9	284.6
Minneapolis –St. Paul, MN-WI	3,788	27,592	4.3	15.4	628.4
Los Angeles, Long Beach, CA	16,826	25,829	1.8	2.7	53.5
Boston, MA-NH	11,989	24,231	6.0	9.8	102.1
Houston, TX	9,882	22,638	1.6	3.1	129.1
Chicago, IL	8,738	19,438	.6	1.2	122.5
Dallas, TX	7,373	19,134	1.8	3.6	159.5
Philadelphia, PA-NJ	5,098	16,344	0.6	1.6	220.6

Source: Logan, J.R. (2007). Contemporary African and Caribbean Immigrants in the United States. In Taylor, S.Y. & Tuch, S.A (Eds.), *The Other African and Caribbean Immigrants in the United States*, (pgs. 49 – 67). Maryland: Rowman & Littlefield.

Africans migrating to the US have primarily settled in large urban cities because of economic, social and cultural opportunities (Arthur, 2000). Another influential factor is the location of family. Takougang and Tidjani (2009) reported that Africans traditionally settle in cities where preceding family members have settled, thus

establishing communities of families with each successive group of immigrants (2009). Distinct ethnic and cultural groups tend to settle with each other. Ethiopians and Somalians predominantly settle in the Minneapolis area, while Nigerians and Ghanaians settle in areas such as New York, Atlanta and Washington, D.C. (Logan, 2007). These distinct communities of African migrants foster the formation of ethnic enclaves. Ethnic enclaves in a sense provide a home away from home for those of similar racial, ethnic and cultural backgrounds. They promote self-sufficiency for groups of similar backgrounds and provide the resources needed to thrive in the new social and cultural environment. It is in these ethnic enclaves where social interactions occur and social networks form.

### **HIV/AIDS: The African Story**

Individuals of African descent are a growing population migrating to the US. As greater numbers of individuals from the African continent migrate and settle in the US, there is a growing concern with the prevalence of HIV/AIDS in these communities. While the health of African immigrants is generally better than their US counterparts, the HIV/AIDS epidemic has hit this population particularly hard. HIV/AIDS affects more individuals in Africa compared to any other part of the world. While approximately 10% of the world population is in SSA, they account for nearly 64% of the world's population living with HIV/AIDS (CDC, 2006). In 2009, approximately 1.8 million new HIV infections occurred in SSA countries, representing a 0.41 incidence rate (UNAIDS 2010). While this figure represents a twenty percent drop in incidence from 2001, the numbers are still staggering. The World Health Organization (WHO) notes that the majority of new HIV infections occur in SSA countries, such as Nigeria and Ethiopia. HIV/AIDS-

related infections are the leading cause of death in SSA and account for 81 per cent of the world's HIV/AIDS-related deaths (Africa's Population and Development Bulletin, 2002; Economic Commission for Africa Report, 2010).

The epidemiologic profile of HIV/AIDS among Africans is similar in Africa and the US. Women account for higher percentages of those diagnosed with HIV/AIDS; 76.1% and 57.4% of females accounted for HIV/AIDS cases in Africa and the US, respectively (UN Global Report on HIV/AIDS, 2010; Johnson et al, 2010). In both countries, the primary mode of transmission is heterosexual contact, which accounts for 75% of HIV transmissions (Johnson et al, 2010). While heterosexual contact is the primary transmission mode, recent trends show increasing percentages of transmissions in men having sex with other men (MSM) in Africa. Countries with extremely high rates of MSM populations include Kenya and South Africa (UN Global Report on HIV/AIDS, 2010).

To date, the number of African immigrants living with HIV/AIDS in the US is unclear partly because they are often categorized as Blacks or African Americans. Using projection and estimation models, Kerani et al (2008) examined HIV infection rates in Africans by analyzing HIV surveillance data in selected areas of the United States during 2003–2004. African-born persons accounted for 8% of HIV diagnoses in Blacks. In Minnesota, Africans accounted for up to 49% of infections among Blacks. A great number of studies indicated higher rates of HIV in countries experiencing higher influx of African migrants (Williamson et al, 2009; Amo et al, 2004; MacPherson et al, 2006). In Western Europe, 18.6% of new cases were among individuals originating from SSA. Williamson et al, (2009) compared HIV rates between African born immigrants and

Blacks born in Portugal and found alarming disparities in mortality rates from HIV; 67.6% of Blacks born in Portugal as compared to 79.3% of African born individuals died from AIDS during the same period.

Studies have identified many factors that contribute to the increased incidence and prevalence of HIV infections among African immigrants. Two notable factors include testing patterns and access to healthcare services (Williamson et al, 2009; Erwin et al, 2002). Despite free access to healthcare services, HIV positive African immigrants entered into care later than the general population (Williamson et al, 2009). Similar results were observed in a multi-centre study in London which documented that African migrants entered into care with lower CD4 counts (one of the markers of HIV disease progression) than natives (Del-Amo et al, 2004; Page et al, 2009). Similar results were noted in a study by Eteni and Woods (2008) of African immigrants in King County in Seattle, Washington which found that only 35% of participants ever tested for HIV and 15% were infected with HIV. Of those 15% who self-identified as being HIV positive, only 4% reported that they were receiving HIV primary care services. Other factors identified as barriers for African immigrants include denial, language barriers, fear of deportation, late entry to care, difficulty navigating healthcare systems and stigma (Simbiri et al, 2010; Koku, 2010; Greeff et al, 2008).

### **Fear and Stigma of HIV/AIDS**

In African countries, where the diagnosis of HIV/AIDS is far more prevalent and shunned, contracting HIV can lead to social isolation. Among African women living in France, Pourette (2008) found that those diagnosed after recent migration had higher levels of social isolation that resulted in greater vulnerability because of delayed

treatment. In communities where HIV/AIDS was not openly discussed, opportunities for increased awareness, testing and treatment were often hindered and missed due to stigma and fear associated with HIV (Este et al, 2009; Weed, 2008; KoKu, 2010).

Stigma and fear have further negative consequences particularly in developing countries like Africa, where prevention efforts are not as advanced. Progress in the eradication of HIV/AIDS is hindered by misguidance and misconceptions of transmission and treatment of HIV/AIDS (Otokpa et al, 2013; Sano et al, 2016). KoKu (2010) examined fear and stigma in HIV positive African immigrants living in the US and suggested that stigma must be examined in the context of the cultural norms and values of the population affected as they shape negative attitudes and behaviors towards HIV infected individuals both in their countries of origin and in the new environments. Stigma reflected a widespread belief in Africa that only the uneducated or poor contract HIV, and that HIV stems from engaging in immoral and culturally prohibited behaviors and activities. Stigma affected African immigrants in two ways - delaying and avoiding care. Participants experienced high levels of stigma in their immigrant communities and consequently refused care because of fears of being further stigmatized, or sought care in other communities to avoid interactions with other African immigrants in the community. Ultimately, fear of stigma created isolation and delayed treatment.

According to Rosenthal et al, (2003) immigrants have difficulty abandoning traditional health beliefs and deeply held cultural norms about HIV which contributes to the stigma and fear in African immigrant communities. Among African immigrants living in Houston, the authors found that nearly two thirds of participants believed that members of their communities respond to HIV positive individuals with “fear, avoidance and

secrecy” (pg.575) and that half of the community members would make an HIV positive individual feel like a social outcast. The authors also noted a positive correlation between length of stay and decreased levels of stigma. While this finding provides hope in these communities, the length of time it takes to reach this decreased stigma level means time lost in the treatment of the disease.

Foley (2005) identified social and cultural barriers impacting the health of HIV positive African women in Philadelphia suggesting that they face similar issues of language, fear related to migration status, unfamiliarity with the US health care system and lack of understanding of issues surrounding HIV/AIDS. Foley acknowledged that African immigrants are “doubly marginalized” (pg. 1031) by having to deal with external issues common to all immigrants in addition to those within the African migrant population which negatively impact an immigrant’s willingness to access HIV health care services. Consequently, there is greater potential for these individuals to continue to spread the disease to members of their community and the public at large.

Much research has documented HIV/AIDS related disparities in racial and ethnic minorities; however, limited research has focused on HIV related disparities in African communities in the US. There is even less research on the impact of social networks on HIV positive African migrants. Research in the US has examined issues such as sexual risk behaviors associated with HIV/AIDs and testing patterns, but none have examined the role of social networks in influencing access and utilization of services, and health outcomes in HIV infected individuals. Research in this area will be vital in gaining insight on how these communities use their social environments and how such environments can be useful in creating interventions aimed at reducing HIV infections.

As Foley has noted, African immigrants' cultural beliefs about Western medicine and their social environments impact their willingness and ability to access health care services which impede positive health outcomes. Recognizing that culturally and socially appropriate prevention and treatment are two vital components in the fight against HIV/AIDS, this proposed research will examine social networks to understand the social context of HIV/AIDS related disparities amongst HIV positive migrants.

### **Purpose of Study**

The purpose of this mixed-design study is to examine the influence of social networks on access to healthcare services and health outcomes of HIV positive SSA immigrants in the US.

Specifically, the quantitative component of the study will address these three research hypotheses:

H1: Social networks of SSA immigrants are comprised of higher numbers of strong ties than weak ties.

H2: Social networks comprised of weak ties facilitate greater access and utilization of healthcare services.

H3: Higher levels of social integration facilitate positive HIV/AIDS related health outcomes.

The qualitative component of this research study will address the following research questions:

Q1: What types of activities do HIV positive African immigrants engage in with their social networks?



Q2: What types of support systems do networks of HIV positive immigrants provide?

Q3: How do the identified types of activities and support systems shape or influence access to care or HIV health related outcomes?

Q4: What factors keep HIV positive African immigrants engaged in care?

## **Chapter 2: Review of the Literature**

### **Disparities in HIV/AIDS Incidence**

Since it was first recognized in the 1980s, HIV/AIDS has evolved from a disease primarily affecting gay white men to one affecting individuals from poor or underserved communities. HIV/AIDS has no boundaries and has disproportionately affected individuals and communities across race, ethnicity, gender, age, sexual orientation, and geography (Agbaje-Williams, 2007; Levine et al, 2009; Rubin et al, 2010; Meditz et al, 2011). In 2010, nearly 1.2 million individuals were living with HIV and an estimated 18,000 AIDS related deaths occur each year in the United States (CDC, 2011). In the last decade, the HIV/AIDS epidemic has hit Black/African American and Hispanic communities at significantly higher rates than other ethnic and racial groups. Hispanics and African Americans continued to have higher incidence rates compared to other groups (Laffoon et al, 2011).

Surveillance data from 37 states between 2005-2008 showed that Blacks/African Americans accounted for slightly over 50% of new HIV diagnoses, while Whites and Hispanics accounted for 29.4% and 17.8%, respectively, despite the fact that Black/African American and Hispanics represented only 13.6% and 13.4% of the population (Laffoon et al, 2011). HIV/AIDS incidence was higher in African American males and females as compared to all other groups. African American males are nine times more likely to be infected with HIV than their white counterparts (CDC, 2011). The numbers are even more staggering for African American females, who have a 23 times higher AIDS diagnosis rate than non-Hispanic White females (CDC 2008). While incidence rates stabilized across most racial groups, the rates continue to rise in African

American males (Laffoon et al, 2011). One factor contributing to this trend may be the growing number of African American MSM being infected. Black MSM accounted for 37% of new infections in the MSM population and 73% of new infections in Black men (CDC, 2011).

### **Disparities in Access to Health Services**

Disparities in HIV healthcare utilization rates have also been found. A study by Sohler and others (2009) compared utilization patterns in 414 HIV positive individuals living in New York City and found that Blacks and Hispanics had poorer healthcare utilization rates compared to other racial and ethnic groups. Among individuals having less than two primary care visits, Blacks and Hispanics had higher percentages with 54.2% and 31.5%, respectively, as compared to 14.3% among other ethnic groups.

Gender related disparities in healthcare utilization rates were also observed. Sohler et al, (2009) noted that men had statistically significant higher utilization rates than women; 54.3% of men had two or more primary care visits within a six-month period, as compared to 40.6% for women. Eisenman et al (2007) found gender differences in use of anti-retroviral therapy (ART) in 1421 HIV infected adults. While ART use increased during the study across all groups, women were less likely to use ART (48.9%) compared to gay/bisexual men (58.1%) and heterosexual men (57.3%).

Disparities in health care access and quality of care services affect health outcomes. Research suggests that racial and ethnic minority groups have disproportionately lower levels of access to HIV healthcare services. Korthuis et al, (2008) examined the impact of race on clinical HIV outcomes and found that Black and Hispanic patients traveled further distances than their White counterparts to access HIV related services. White participants

averaged 29 minutes, while Blacks and Hispanics averaged over 35 minutes to get to their medical provider. Blacks and Hispanics had longer wait times as compared to Whites. The authors attributed these findings to individual clinic characteristics and the communities where the clinics are located. The findings suggested that differences in access can be explained by the greater proportion of ethnic and minority groups using HIV services at these sites. Factors such as travel and clinic wait time can be a deterrent to accessing health services. Also affecting quality of care is the increased workload of providers as a result of significantly higher HIV rates found in racial and ethnic minority communities (Bennett et al, 1995; Cunningham et al, 2000; Heslin et al, 2005).

### **Disparities in Health Outcomes**

Oramasionwu et al (2009) demonstrated that despite advances in anti-retroviral medications, Blacks continued to have poorer hospitalization outcomes as compared to Whites, based on comparison of hospital mortality rates and lengths of stay during the period between 1996-2006. The study showed that Blacks were six times more likely to be hospitalized from HIV/AIDS related complications. While crude mortality rates between Whites and Blacks were similar, Blacks experienced longer lengths of stay because of co- morbidities, substance use, and socioeconomic status. Blacks also experienced higher rates of opportunistic infections, which is a key indicator of disease progression, as compared to Whites (Oramasionwu et al, 2009).

HIV disparities are influenced by individual and community level factors. The physical environments where individuals live play a role in determining accessibility and utilization of services (Cummins et al, 2005; Galea & Vlahov, 2005). Richardson and Norris (2010) note that physical environments that lack sufficient healthcare resources

result in limited access and, as a consequence, individuals forego receiving healthcare services. Unfortunately, disproportionate numbers of racial and ethnic minorities live in these environments. Limited resources coupled with high prevalence rates of HIV/AIDS in these communities further perpetuate difficulties in accessing appropriate health services.

### **HIV and Poverty**

Higher rates of HIV infection found in racial and ethnic minority communities are attributed to various factors such as poverty (Barnett & Whiteside, 2002; Holtgrave & Crosby, (2003). The gradient between the rich and the poor often shapes health outcomes; outcomes are repeatedly unfavorable among the poor. The disease patterns and outcomes are even more pronounced in urban environments where higher concentrations of racial and ethnic minority groups are found. Globally, HIV/AIDS has been found to significantly increase poverty in households and communities, because of the limitation imposed by the chronic illness on an individual's capacity to work and earning potential (Barnett & Whiteside, 2002). Other studies have noted that merely living in poverty ridden environments induces higher rates of HIV infection (Parkhurst, 2010; Krishnan et al, 2008). Larkin (2000) suggests that poverty often forces women to engage in high risk behaviors such as prostitution which increase the likelihood of contracting HIV/AIDS and other sexually transmitted infections (STIs). Racial and ethnic communities where poverty rates are highest have higher rates of HIV infection. In 2009, the US poverty rates were 14.3 percent and the rates for African Americans and Hispanics were 25.8 percent and 25.3 percent, respectively (US Census, 2010).

A spatial examination of HIV/AIDS infections in Atlanta, Georgia concluded that HIV was associated more with poverty than race. Census tracts having higher rates of poverty, HIV prevalence was 1.34% or 4 times higher than those living outside of these tracts (0.32%) (Hixson et al, 2011). The authors suggested that this may be the result of greater chances of encountering behaviors that place one at higher risk for HIV. In Virginia, higher risks for Gonorrhea (9.51), Chlamydia (10.69), and HIV (4.09) infections were found in census tracts with the highest percentage of people below the poverty line (Dolan & Delcher, 2008).

### **Disparities in Sexually Transmitted Infections**

In addition to poverty, STIs have profound effects on the transmission of HIV. STIs increase the chances of acquiring HIV anywhere from two to five times (CDC, 2007). Racial and ethnic minorities are disproportionately affected. African Americans have the highest percentages of reported cases of Chlamydia, Gonorrhea and Syphilis infections (CDC, 2010). Although the numbers of reported Chlamydia cases in the US during the 2000 – 2009 period stabilized, African Americans had nearly a 24% increase in the number of reported cases. African Americans represented 71% and 52% of reported Gonorrhea and Syphilis cases, respectively during this same period (CDC, 2010). These statistics do not suggest that whites are not affected by STIs; however, the gaps between the two groups continue to draw attention to the importance of addressing health disparities in specific racial and ethnic minority groups and shifting the focus to the influence of cultural and social determinants of these disparities.

## **Culture and HIV**

Cultural and social factors have great effects on the health of communities as they shape or define behaviors and beliefs. Cultural and social differences across populations have made some populations more vulnerable to HIV/AIDS. African American MSM populations, for example, have increased risk for HIV despite engaging in fewer MSM risk behaviors (O’Leary et al, 2007). The risk associated with these behaviors are propelled by homophobic fears embedded in the African American community. African American men conceal their sexuality from their sexual partners. Internalized homophobic perceptions and bisexual behaviors among African American men are speculated to contribute to the HIV epidemic among African women (O’Leary et al, 2007). “Down low” behaviors are observed among African American men who identify as heterosexual, but engage in sexual activity with other men. Down low behaviors have been attributed to the dominant cultural beliefs on sexual behavior, sexual orientation and male gender roles in the African American culture that create lack of acceptance and stigmatization of homosexual behaviors (Lapinski et al, 2010; Bleich & Clark, 2005). Rates of down low sexual engagement in Hispanic/Latino MSM are lower when compared against those of Black MSM. However, Hispanic/Latino MSM have also been shown to more commonly engage in higher risk behaviors than whites. Family and social expectations, and the church have been identified as significant influences on gender roles and sexual behaviors among Latinos (Harper, 2007).

## **Immigrant Health**

Since the 1900s, the US has experienced increased growth in immigrant population. The Kaiser Family Foundation Report (2008) on health disparities projected

that by 2045, more than half of the US population will be persons of color, including immigrant groups. Immigrant populations initially tend to have more favorable health outcomes than their US born counterparts: lower mortality rates from hypertension, cancer, cardio-vascular disease and other chronic diseases (Singh & Siahpush, 2002). These health benefits diminish overtime; acculturation and longer length of stay in the US have been associated with a trajectory towards poorer health outcomes (Lutsey et al, 2008; Viruell-Fuentes, 2007; Singh & Siahpush, 2002). Acculturation, measured by the length of time in a host country, has been found to have an impact on immigrant health status (Ceballos, et al, 2010; Tolbert, 2009). A study of 313 childbearing Latina women found a positive correlation between length of stay and obesity. The odds of being obese were greater, the longer the women resided in the US (Fuentes-Afflick & Hessol, 2008). Similar study results were noted in a study examining obesity in Asian Americans; length of stay and cultural orientation were significantly associated with higher obesity rates; acculturated Asian Americans were nearly twice as likely to be obese than traditional Asian Americans (Wang et al, 2011). The US Department of Health and Human Resources (HRSA, 2010) also reported that length of stay is positively associated with increased prevalence of HIV in immigrants.

Other key determinants of health are ease of navigating the healthcare system and health insurance status. The US healthcare system poses barriers to immigrant populations due to its fragmented and convoluted structure. HRSA (2010) noted that healthcare systems in immigrant countries of origin are often easier to access and navigate, thus promoting better health outcomes. Having health insurance provides an entry point to the healthcare system and influences the ease of accessing health services



(Zsembik & Fennell, 2005; Casey et al, 2004; Steffen, 2006; Baker et al, 2001; Brown et al, 2000; Hargraves et al, 2003). A study comparing breast cancer outcomes by insurance status concluded that women who were uninsured had higher incidence of advanced breast cancer than those who were insured (Ayanian et al, 1993). Women with health insurance had increased access to healthcare providers and breast cancer screenings. Guendelman and others (2005) noted that insurance status was the primary factor influencing healthcare access but even with insurance, immigrants still had lower utilization rates. Casey, et al (2004) reported that Latinos in the rural Midwest underutilized preventive health services because of increased co-payments and fear of deportation resulting in poor continuity of care outcomes.

Access to healthcare services is worse among immigrant populations who lack health insurance. Children of undocumented immigrants face poorer health outcomes as a result of their parents' immigration status and limited access to healthcare services. Children of immigrants are less likely to see a healthcare provider or get well child visits if one or both parents do not have insurance or access to healthcare services (Hirota et al, 2006). The 1999 U.S. General Accounting Office Report, noted that one third of eligible children who did not enroll in Medicaid programs were children of immigrant families (Kelly, 2003). In 2010, the Affordable Care Act (ACA) was passed into law, which provides increased access to health insurance coverage. The success and impact of the act on healthcare access has yet to be determined, particularly on immigrant populations.

### **Health Expenditures for Immigrants**

Healthcare expenditures in the United States have been steadily increasing despite notable measures to decrease healthcare costs. In 2006 alone, healthcare expenditures

reached over two trillion dollars (An, 2008). Late entry or the lack of entry into the healthcare system is often associated with higher costs due to the severity of conditions when immigrants present to the healthcare system. Immigrant populations have borne the blame for the rising healthcare costs, yet many studies have documented that immigrants use less healthcare services as compared to non-immigrant groups (Ng'andu, 2007; Mohanty, 2005). Immigrants accounted for \$39.5 billion in health care expenditures, however these costs were 55% less than healthcare expenditures for non-immigrant groups (Mohanty, 2005). Data from the Rand Corporation illustrate that healthcare expenditures for adult illegal immigrants in 2000 were 1.1 billion dollars (Goldman et al, 2006), reflecting a fraction of the total US healthcare expenditures. Despite such evidence, there is a general public belief that immigrant groups drain available healthcare resources.

The public notion that immigrant populations use ambulatory hospital settings for both urgent and basic primary care needs has been associated with high costs of services in these settings. Estimates of undocumented immigrant use of hospital centers in New Jersey show that over 200 million dollars are spent annually for care of undocumented immigrants (Kelly, 2003). Nevertheless, studies show that immigrants utilize hospitals less frequently for emergency care than non-immigrant populations (Muennig et al, 2002). Mohanty et al, (2005) demonstrated that children of immigrants had fewer hospital emergency room visits than non-immigrants; however, the costs associated with such visits were higher because these children came in sicker. This study suggests that immigrant populations enter the healthcare system later to avoid emergency room settings. Ng'andu (2007) found Mexicans had 50% fewer emergency room visits than

their white counterparts. Latino women, “rely heavily on public clinics for their care and the care of their families” (Derose, 2000, pg. 80) because immigrant women tend to work in lower paying jobs that do not provide health insurance coverage for themselves or their dependents.

### **Social Networks of Immigrants**

Transnationalism is defined as the process by which migrants construct social environments between places of settlement. This process entails building social fields that link together the country of origin and countries of settlement (Portes, 1997; Gielis & Trevelyan 2009). According to Gielis & Trevelyan, transnationalism acknowledges a place as a continuum with internal and external components of social networks. These components create complexities in relationships formed with the outward spread of networks across larger areas. The interplay of social networks in both host country and country of origin creates a “common” factor that engulfs cultural patterns, values and social ties.

Understanding the connections between transnationalism and health is important in addressing the health of immigrant communities. The link between the two is evident in beliefs about health that migrants bring from their country of origin to the host country. These beliefs are influential on individual and network levels as they have the potential to dictate behaviors exhibited in their new environments. Escandell et al, (2010) found among Bolivian migrants in Spain that traditional constructs on health and illness carry over to their new environment. Many of the study participants maintained strong ties to their networks in Bolivia to retain access to ritual healers who were not available in Spain. These ties enabled family members in Bolivia to engage healers to enhance

emotional health of their migrant relatives in Spain. Beliefs from one's country of origin may remain influential in how one acts on information or practices observed in the host country, and can potentially hinder one from engaging in the healthcare system.

Similarly, HIV positive women in Nigeria did not seek healthcare services due to social and structural beliefs associated with HIV/AIDS (Mbounu et al, 2010). Women often have to get approval from their husbands to enter into care as a result of financial dependence (Mbounu et al, 2010). HIV positive women often depend on their husbands to pay for services, further creating a barrier to receiving critical care services. This study noted that disclosure of one's HIV/AIDS status by women did not occur until their husbands passed away due to fears of being expelled from the marriage. As a result women did not disclose nor seek health care services until much later in the disease process. The potential for these practices to transcend into new environments cannot be overlooked as immigrants bring with them beliefs and practices that may be in conflict with those of the new society.

Thomas (2010) found Southern African migrants settling in London to be confused by "contradictory socio-cultural contexts" about when to seek healthcare and treatment services. Migrants engaged relatives and networks in their native countries to send herbal medications and other treatment options to them in order to avoid entering the healthcare system. They also engaged traditional healers in both their country of birth and in their migrant community to perform rituals for their ailments. Networks in the host country became even more important for HIV positive migrants who did not access care in Africa, but came to London and used new networks to gain information on alternative treatment options. Thomas (2010) argued that host countries must acknowledge that

migrants do not engage in unidirectional processes and that the receipt and use of health information flows from both the sending and hosting country.

Social networks serve many functions in health, such as providing forums for information exchange between network members. Social networks also provide supportive systems for individuals. Social networks can have a profound effect on health outcomes and behaviors. A prospective study on the quality of life of breast cancer patients and their social networks concluded that women with lower levels of social networks had poorer outcomes than the comparison group (Michael et al, 2002). Women with higher levels of social networks reported having better health related quality of life indicators. Another study on the relationship between social capital, social networks and health outcomes observed that greater social networks were associated with lower hospitalization visits and fewer health problems (Bosworth & Schaie, 1997). Social networks have also been found to positively influence health behaviors such as increased testing and reduced HIV related risk behaviors. In a study of an MSM population, social networks were found to have an influence on condom use. Individuals reporting having better support for condom use engaged in far fewer unprotected sexual encounters (Carlos et al, 2010).

### **Social Networks of African Immigrants**

Social networks are thought to improve the health status of individuals as a result of collective access to additional resources. These resources promote better health outcomes as a result of increased knowledge and trust, as well as changes in attitudes and values of participating members of the community. Without social networks to assist in the navigation of such complex systems, individuals seeking services can get lost in the

system or avoid seeking treatments altogether. A qualitative study by Hamer and Mazzucato (2009) on social networks of African immigrants in the Netherlands found that informal social networks serve three primary functions: assistance in accessing social services, navigating healthcare systems and navigating unfamiliar environments. Unfamiliarity with how to access health services can pose greater disadvantages to immigrants.

In the United States, the functions of social networks are different than in Africa, where networks are formed based on friendship or family, village, or professional relations (Takpugang & Tidjani, 2009). Africans participate and navigate in multi-level networks comprised of individual and community level factors. In each level, the structural and functional components of networks influence outcomes.

A study by Japheth Kaluyu (2009) exploring sexual behaviors of Kenyan immigrant men in the US found that they identified their individual level social environments as one of isolation and one that requires self-dependency as a result. This feeling of isolation is primarily due to not having family members with them in the host environment. Kaluyu suggested that this change in social environment often induces feelings that inhibit or prevent one from seeking services when faced with an ailment. This isolation is further perpetuated when structural components in the community and political environments are lacking. Structural components can include local and national organizations led by individuals of similar origins that represent their cultural and ethnic backgrounds.

Kamya (2007) noted that African migrants rely on informal ties or networks for support. African immigrants often join membership in associations to get information or

receive services. A down side to the social structures formed in African immigrant communities is that they can also lead to isolation from the dominant society. When members of immigrant groups turn only to members of their community, they isolate themselves from other groups and potential networks (Kamya, 2007; Arthur, 2000). The exchange of information and resources mirror what members of a similar group know. This can be a disadvantage in HIV/AIDS as information regarding the transmission and treatment of HIV as members of the same ethnic group may continue to receive inaccurate data.

Social structures can also influence poor health behaviors. Carpiano et al, (2011) examined behaviors of drug users and the relationship between drug use, social structures and social networks of members of gay enclave communities. The study concluded that structures are developed to address the needs of community members; community structures and the networks found in them are essential to the vitality of these communities. The authors suggested that institutions and organizations in one's networks can have either positive or negative influences on health outcomes of communities.

Gay men who reside in gay neighborhoods — particularly those neighborhoods with high concentrations of gay nightlife venues— may be at greater risk for immersing themselves in a subculture that promotes drug use, given that they may also be isolated from countervailing social norms. In addition, the concentration of such individuals in such a neighborhood may enable a pooling of problematic resources to occur, facilitating the availability of drugs, and thus heightening, for all in the neighborhood, the exposure opportunity to use drugs (Carpiano et al, 2011, p.77).

While the study did not conclusively find associations between social networks and increased drug use in gay enclaves, institutional resources as nightclubs did influence more drug use amongst participants. This study demonstrates that the number and the kinds of institutions in one's community directly or indirectly influence health outcomes.

Globally, the issue of health disparities is a complex phenomenon that requires an understanding of multitude and often concurrent factors that contribute to observed differences in health outcomes. Contributing factors to health disparities include accessibility and availability of healthcare services and resources, inefficiencies within health systems, socio-economic status, technological issues, age and gender differences, language barriers, cultural and social environments of the affected communities. These contributing factors have an impact on health outcomes across populations and disease states. HIV is no different as HIV related disparities are reflective of individual (biological markers and sexual risk behaviors) and community level factors. Key findings from the literature show that despite advancements in technology and improvement in the management of HIV and its consequential diseases, HIV continues to be most prevalent and ill-managed in minority populations because of the factors listed above. Findings from the literature also show that HIV is most pervasive in impoverished and underserved communities, where many immigrant groups settle. What makes this situation even more complex is the scant availability of literature focusing on African immigrants in the US.

Much of the existing literature has generalized issues of HIV in African American and Hispanic communities, and ignored the varying ethnic groups that comprise the underserved. This gap in the literature prevents a thorough understanding of the issues of access to health services in a population that are critical determinants of their health outcomes. One avenue to bridging this gap is by examining their social networks. Studies have suggested that social networks of individuals affect the transmission of HIV/AIDS, but how these social networks influence access to health services in African immigrants



is yet to be explored. This study will contribute to the body of literature on health disparities and immigrant health by providing insight on how social networks of HIV positive African immigrants influence access and utilization and health outcomes. The findings from this study can generate specific interventions for this population.

### **Chapter 3 – Conceptual Framework**

The primary framework that guided this study is the social network paradigm (Granovetter, 1983; Berkman, 2002). The social network paradigm acknowledges the structures of social groups and how these structures influence variables such as health. The social network structures in immigrant populations are complicated by the process of migration that often involves the integration or formation of new social environments and loss or infusion of cultural practices. Thus it is important to explicate the influence of social networks and transnational interactions on individual and collective health behaviors and outcomes.

Social networks include the key concepts of social and cultural capital, and social integration. Individuals possess social and cultural capital as a result of their networks and engagement or integration in their social environment. The process of integration entails using connections or relationships to navigate new environments, obtaining information through these channels, or using one's cultural beliefs; each of these factors influences how immigrants view and act upon matters of health. Understanding the interrelationships of these concepts allows for a more comprehensive understanding of social networks of immigrant populations and their role in access and utilization of healthcare services.

The definition of social capital has evolved since Pierre Bourdieu originally described it. Recent definitions have modified and enriched the understanding of the influence and application of social capital in social networks. Bourdieu (1986) defined social capital as "the aggregate of the actual or potential resources" (p. 248) and the distribution of capital defines social spaces or structures (1985, pg. 734). Social spaces

are multi-dimensional and form social forces, including a system of relations (Bourdieu, 1985). A key principle in Bourdieu's theory is that social capital is reproduced and maintained by a dominant class and that the relations in these social spaces influence member integration. The social structure has distinct layers between members of a community by class and that members of the minority class have little to no access to resources or capital held by the dominant class which prevents attainment of higher levels of success and mobility among the lower class.

James Coleman and Robert Putnam have contributed to the body of research on social capital. Coleman's (1988) work has emerged from the field of education asserting that social capital exists in the structure of relationships between and amongst actors; these structures "facilitate productive activity" (p. S101). Coleman has observed that in households with single parents, dropout rates in children were significantly higher than in households having two parents; additional capital found in two parent headed households promote better graduation rates. Social capital is a collective asset and bi-product of social and structural properties of communities. These structural properties relate to "ties" and interactions that individuals have within a structure (Coleman, 1988; Lauglo, 2000; Baron et al, 2000).

Putnam (1993) defines social capital as the social cohesion resulting from the existence of community networks and density of networking within communities. Putnam asserts that social capital in communities is formed by the interaction and participation of individuals and communities, and these networks allow for coordination and communication amongst members. Putnam further asserts that this dynamic leads both to the resolution of dilemmas and manifests in trust and norms of reciprocity

amongst members (Putnam, 1995, 2001). In essence, the more engaged or embedded an individual is in these networks, the more social capital he or she has to resolve matters that may otherwise be difficult. This “collection” of capital provides for better access to services and information. The extent to which the collection of capital influences behavior and outcomes varies on both individual and community levels. Both Coleman and Putnam frame social capital as a collective good as opposed to Bourdieu who viewed it as a privileged good, facilitated by one’s economic engagement. Despite these differences, the authors share a common position that social networks are an integral measurement of social capital.

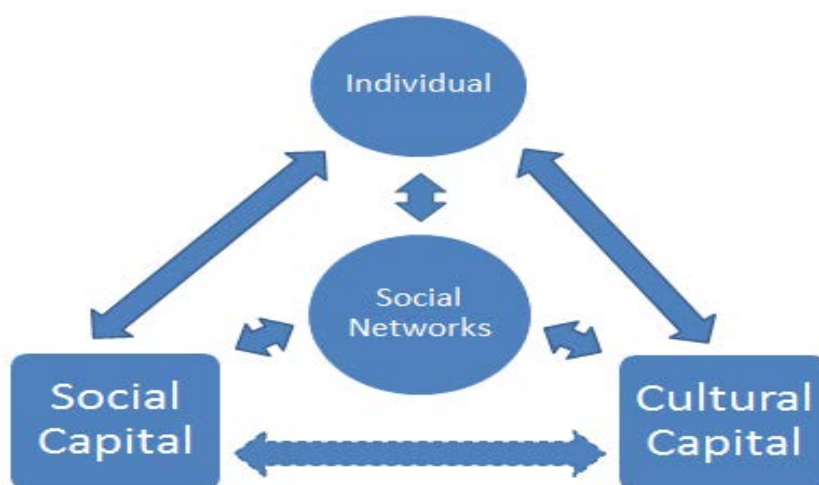
According to Bourdieu (1985, 1986), cultural capital is another form of capital that individuals possess. Cultural capital encompasses the attitudes, knowledge, beliefs or norms that individuals hold and use to make decisions or to exercise behaviors. Cultural capital lies is reproduced in institutions such as schools and that individuals predisposed to high levels of cultural capital are more likely to succeed as a result of environments that are more economically privileged and socially supportive of maintaining high levels of cultural capital. Bourdieu’s description of this concept of cultural capital depicts a linear explanation of how social structures influence outcomes (Figure 2).

Figure 2: Influence of Social Structures on Outcomes



By contrast, this study has adopted a more fluid and multi-directional approach to understanding the exchange and relationship between these concepts as outcomes are not influenced by one factor alone (Figure 3). Individuals contribute to levels of cultural and social capital observed in their communities and similarly, environments rich in social and cultural capital can influence individuals' willingness to engage in social and cultural processes. The process is reciprocal- individuals influence their environments and communities, just as environments and communities influence individual outcomes. Unlike Bourdieu's concepts of social and cultural capital where class structure influences the outcomes, this study has posited a more symbiotic flow among each of these concepts (see Figure 3).

Figure 3: Directional Influence of Social Networks



As figure 3 suggests, an integral and almost central component to the model is that social networks have an influence on an individual's social and cultural capital, that in turn shapes his/her decisions and behaviors. For immigrant groups, social networks affect various aspects of the migration process as social networks often serve as entry points to resources. Thornton (2009) has found that among HIV affected immigrants, migration creates instability and the need to seek out networks and individuals. Areas of instability foster increased risk of HIV transmission as these individuals seek to develop social networks and again ultimately social capital. Thornton has noted a pattern among South Africans that an increase in their social capital is associated with increased sexual networks – a dynamic that can potentially lead to increased risk and exposure to HIV/AIDS. According to Thornton, “sexual networks give access to goods, services and many other kinds of values” (p. 417); individuals use their sexual networks to seek and increase their social networks and social capital.

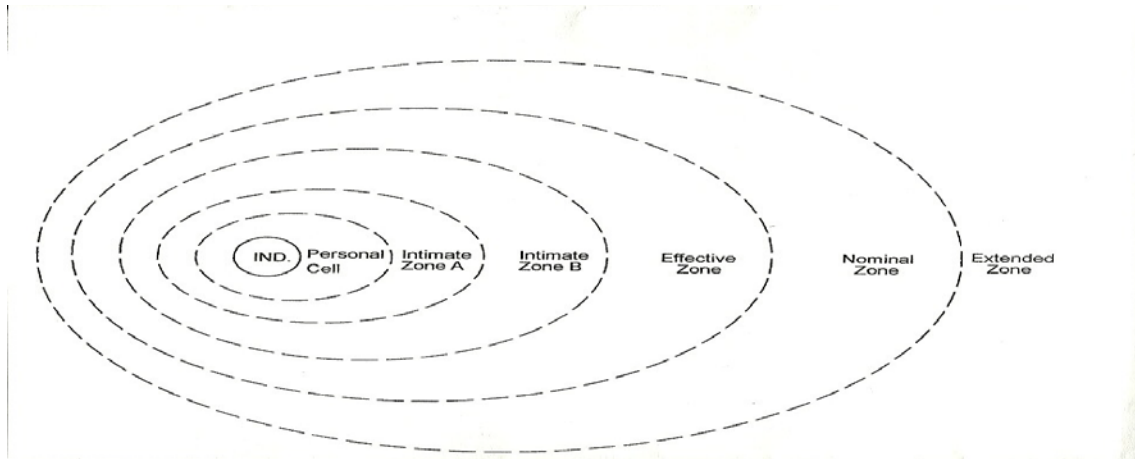
While many immigrants depend on their social networks to access information or services in their environments, a key variable is one's level of social integration.

Durkheim's work on social integration provides a framework for understanding how social structures influence individual behaviors and actions. Durkheim's work highlights the relationship that exists between societies and individuals and the levels of social integration that occur (Turner, 1981; Berkman, 2002; Segre, 2004; Wray et al, 2011).

Social integration is manifested by the frequency and intensity of social interactions between individuals. Durkheim has demonstrated that suicides rates are influenced by the degree or level of social integration of an individual; lower suicide rates occurred with greater social integration (Hassan, 1998; Kposowa et al, 1995).

Durkheim's focus on social integration emphasized the psychosocial aspects. More recently, Lisa Berkman (2000) has focused the relationship between social networks and health outcomes, suggesting that the more embedded one is in a social network, the more favorable is one's health outcomes. Berkman highlights Boisevain's contribution to the topic of social networks. Based on a concentric or "zone" model, each successive layer represents less intimate ties and relationships and decreased levels of integration.

Figure 4: Boisevain's Social Network Model



Source: Berkman, L.F., Glass, T., Brissette, I. & Seeman, T.E. (2000). From Social Integration to Health: Durkheim in the New Millennium. *Journal of Social Science and Medicine*, 51:843 - 857.

Using Boisevain's model of social networks, Berkman (2000) argues that the more one is socially integrated or embedded in the social network, the more favorable is their health outcome. Social networks facilitate the social support needed to have positive health outcomes. Berkman's (2000) study on the relationship between emotional support and mortality in individuals with cardiovascular disease, found that those with higher levels of support and social networks had better health outcomes than individuals having fewer social ties who were two to three times more likely to die from their cardiovascular disease.

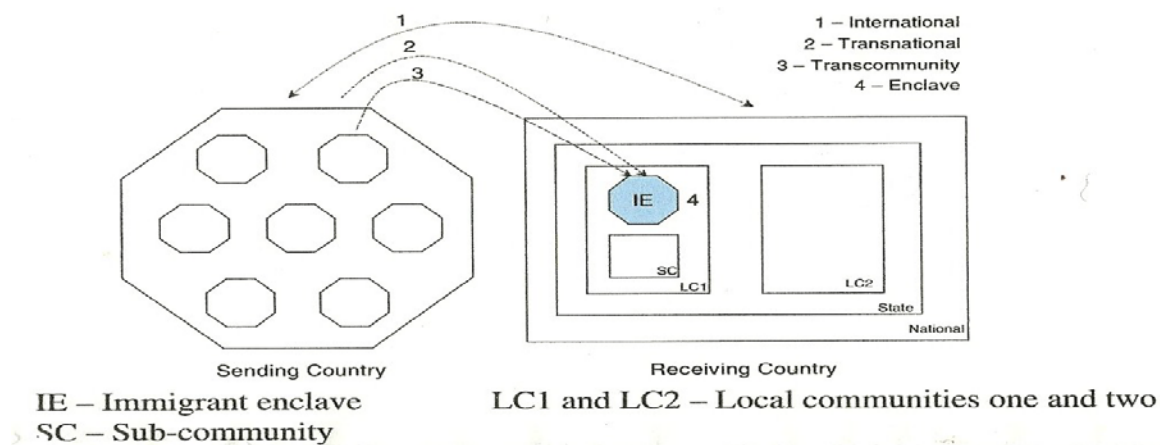
Another important attribute of social networks is the strength of the ties within them. Bonding ties refer relationships of individuals with similar backgrounds (close



ties), whereas bridging ties are with more distant relationships (weak ties). Strong ties have predominantly been described as close intimate ties with family, friends and neighbors (Granovetter, 1973; Kawachi & Berkman, 2001; Greenwell et al, 1997). Weak ties refer to distant ties such as acquaintances (Granovetter, 1983); weak ties provide people with access to information and resources beyond those available in their own social circle and it is through weak ties that individuals have upward mobility (Granovetter, 1983; Berkman, et al, 2000).

When it comes to matters of immigrant health, one must not disregard the role of experiences in the country of origin. Yang (2010) developed a model based on the experiences of Chinese immigrants depicting the interplay of multiple layers affecting their access and utilization of healthcare services. Figure 5 shows that the health of immigrants starts in their country of origin and extends to the host country including structural influences at community and individual levels in immigrant enclaves (Yang, 2010).

Figure 5: Yang's Immigrant Enclaves



Source: Yang, J.S. (2010). Contextualizing Immigrant Access to Health Resources. *Journal of Immigrant Minority Health*, 12:340 – 353.

Yang contends that the immigrant enclave level is where social structures, institutions, norms and beliefs are formed in the new host country. At this level, institutions and organizations supporting the needs of immigrant populations are formed. In order to understand and contextualize access and utilization of healthcare services, one must explore multiple layers such as individual characteristics, and network and community level structures. The model provides a framework for understanding the correlation between networks of immigrant communities between host and sending country but does not elaborate on the levels of social integration and interaction in either environment.

A gap in the literature exists with regards to the connection between social networks, social integration and immigrant health. Figure 6 is a pathway model that seeks to describe the correlation of social networks and health in immigrant communities.

Figure 6: Pathways for Social Integration using Social Networks

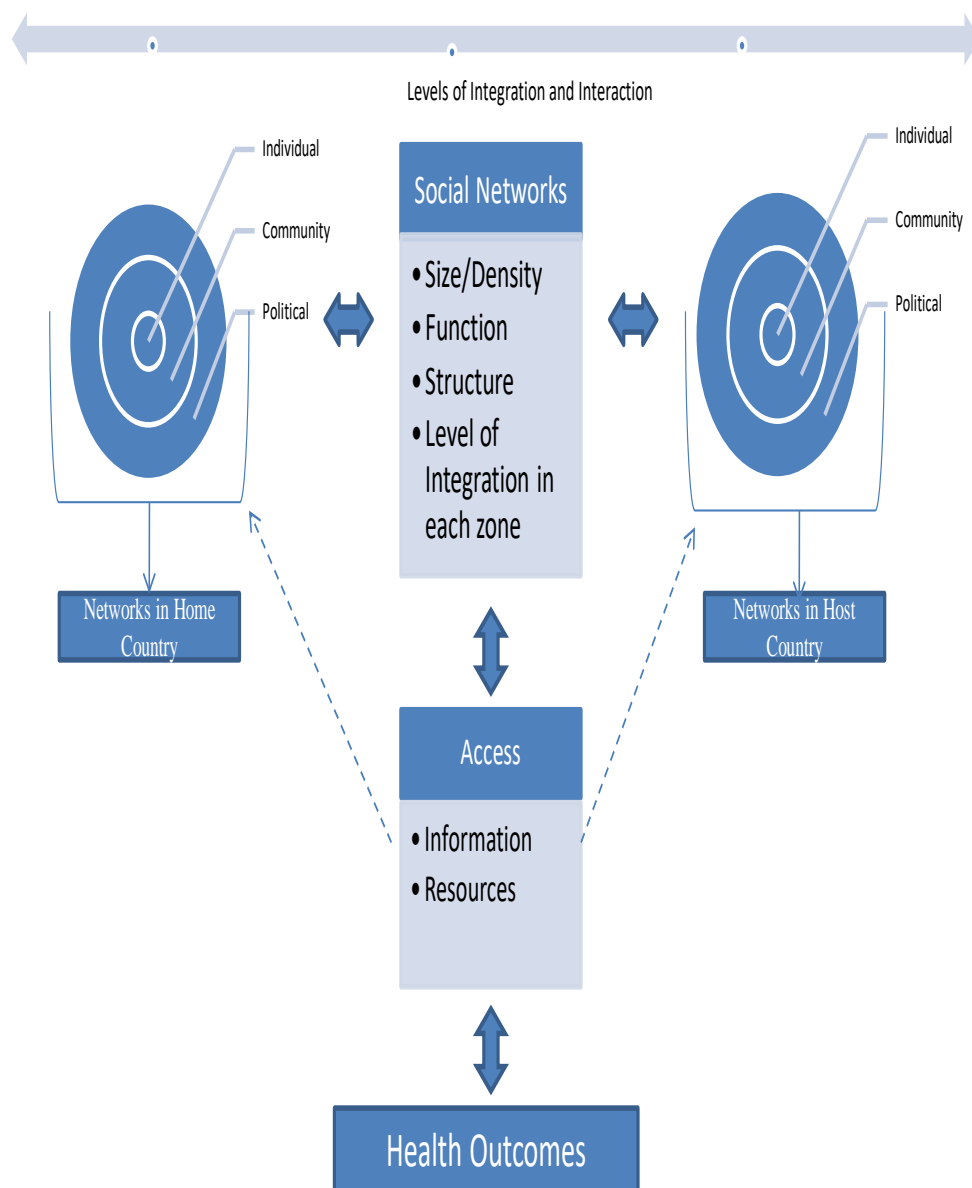


Figure 6 depicts a model for the potential pathway for how social networks of migrant populations shape or influence their access to healthcare services and ultimately

health outcomes. One's social networks in the home country transcend into the host country. The social networks at home and in the host country are nested at the individual, community and political level attributes that influence one's ability to access information and resources. These attributes include the size and density of one's social network, the functionality of the networks, the structure of these networks, and the level of integration within each network zone. Zones can be individual, community or political. The extent to which these zones are integrated depends on the individual and their ability to navigate across these zones.

This model highlights a multi-directional and continual exchange of information and resources that occurs within the home and host environments of migrants. As Figure 5 illustrates, social integration is a function of individual, community and political level factors. As such there is a link between the level of integration and interaction in each environment, access to health resources and services, and health outcomes. It can be argued that how well one is socially integrated in the social environment may increase one's likelihood to access and utilize healthcare services. Factors attributed to one's level of integration vary because of the many complex layers of a network as presented in Table 2; these factors influence integration in the multiple levels of one's social networks.

Table 2: Factors influencing Individual Social Interaction and Integration in Social Networks in Sending and Host Country

Individual	<ul style="list-style-type: none"> <li>• Socio-Economic Status (SES)</li> <li>• Family</li> <li>• Self-Efficacy</li> <li>• Cultural Identity</li> <li>• Race/Ethnicity</li> <li>• Household Environment</li> <li>• Social Support</li> <li>• Acculturation Level</li> <li>• Assimilability</li> <li>• Transnational Exchange</li> </ul>
Community	<ul style="list-style-type: none"> <li>• Ethnic and Cultural Identity</li> <li>• Religious Identity</li> <li>• Neighborhood Environment</li> <li>• Cumulative Neighborhood SES</li> <li>• Community Diversity/Segregation</li> <li>• Community Acceptance</li> <li>• Civic Engagement</li> <li>• Race Relations</li> <li>• Resource Availability</li> <li>• Social Support</li> </ul>
Political	<ul style="list-style-type: none"> <li>• Political Affiliation/Environment</li> <li>• Level of political participation</li> </ul>

## **Chapter 4 – METHODS**

### **Purpose:**

The study examined the influence of social networks on access to healthcare services and health outcomes of HIV positive SSA immigrants in the US.

### **Quantitative Research Hypotheses:**

H1: The social networks of SSA immigrants are comprised of higher numbers of strong ties than weak ties.

H2: Social networks comprised of weak ties facilitate greater access to and utilization of healthcare services.

H3: Higher levels of social integration facilitate positive HIV/AIDS related health outcomes.

### **Qualitative Study Questions:**

Q1: What types of activities do HIV positive African immigrants engage in with their social networks?

Q2: What types of support systems do social networks of HIV positive immigrants provide?

Q3: How do the identified types of activities or support systems shape or influence access to care or HIV health related outcomes?

Q4: What factors keep HIV positive African immigrants engaged in care?

### **Operational Definitions:**

1. Social networks -Social networks are relationships or connections individuals have between people, organizations and political entities (Valente, 2010). In this

study, the composition of social networks will be defined by their size/density, structure and function.

- a. **Size/Density:** The size and density of one's network will be defined by the number of individuals or relationships one has or number of connections.
  - b. **Network Structure:** The structure and composition of social networks refers to the types of social-relationships found in networks and give insight as to who are the actors and the types of relationships among actors (i.e. kin, institutions, religious affiliations or business relationships). Valente defines network structures as the configuration or pattern of relationships (2010).
  - c. **Functionality:** The functionality of social networks is how one uses members of their social networks. In this study it refers to how one uses members of his/her networks to access health services.
2. Weak and strong ties are defined by the composition of relationships in one's network. Strong ties refer to family and kin or co-ethnic (Granovetter, 1973). Weak ties refer to connections outside of kin such as health care workers and agencies (Granovetter, 1973). Using Myers' network scale (1996), weak and strong ties will be measured using network composition scores.
3. Social integration is the degree to which one is embedded in the environment. This environment includes personal and community level networks.
4. Access to health services is defined as accessing medical care and resources outside of one's immediate environment such as government agencies, community based organizations, churches, etc., that impact one's HIV status.

5. Health outcome refers to the health status of a participant measured by self-reported HIV related indicators of disease progression which are CD4 and Viral Load.

### **Study Design**

This study used a concurrent mixed method approach to understand the influence of social networks on access to healthcare services and health outcomes of HIV positive SSA immigrants in the US. The mixed method designs allowed for a better understanding of data through the ‘merging’ or ‘corroboration’ of data found within each respective design (Creswell & Clark, (2011); Creswell, 2006). In a concurrent mixed study design, both qualitative and quantitative designs were conducted at the same time, during a ‘single phase’ (Creswell & Clark, 2011). The qualitative design explored ideas emerging from the quantitative design and allowed for the ‘refinement’ of quantitative findings (Fetters, et al, 2013). This refinement process helped elucidate information obtained from the quantitative inquiry.

### **Quantitative Method**

The quantitative component was a descriptive quantitative study using a cross-sectional survey. A self-administered survey was used to enhance confidentiality of subjects. This approach was critical because of the sensitivity and stigma associated with HIV/AIDS particularly among SSAs. A survey was a relatively inexpensive method for reaching large numbers of participants and obtaining a rapid turnaround (Creswell, 2009).

The survey questionnaire comprised of three sections: 1) socio-demographic, 2) Myer’s Social Network Scale (MSNS) (1996), and 3) component of the Medical Expenditure Panel Survey (MEPS) (2010). The socio-demographic section of the



questionnaire elicited information on participants' income, education, occupation in SSA and the US, marital status, age, migration history, household composition and HIV medical history.

Myers' Social Network Scale (SNS) elicits information on the social networks of individuals and their levels of social embeddedness and integration. This 6 item scale is one of the three scales in Myers' Social Resources and Social Supports (SRSS) Questionnaire (1996). The SRSS questionnaire was developed to examine the characteristics of social networks and determine how social networks impact the stress levels of African Americans.

The SNS measures the size, composition, dimensionality, and density of an individual's social network. Network size is scored by tallying the total number of individuals the participant nominates. The composition of the social network is scored by summing the number of persons nominated in each category. Dimensionality is measured by adding separately the number of unidimensional or multidimensional relationships. Network density is measured by taking each respondent listed and counting the number of persons in the network with whom the participant has an independent relationship. The SNS is a reliable scale with Cronbach alpha reported at 0.63, 0.85 and 0.96 for network size and composition, network dimensionality and network density, respectively. The Myers SNS can be found in the Handbook of Tests and Measures for Black Populations (Myers, 1996).

Wohl and others (2010) used SRSS to examine the social support, stress and social network characteristics of 399 HIV positive Latinos and African Americans in Los Angeles County. The study observed significant differences in the composition, density

and functionality of social networks across the study population. Compared to MSM, women who disclosed to their social networks received more support with regard to their HIV related status. The study also found that the composition or make up of participant networks were primarily relatives, as opposed to, community members, suggesting that participants relied on family members for support.

To assess access and utilization of healthcare services, questions from the Household Component of the Medical Expenditure Panel Survey (MEPS) were used. MEPS is a nationally representative panel survey developed by the Agency of Healthcare Research (1996) to collect information on healthcare related issues and services in the United States. MEPS is comprised of four components: 1) Insurance, 2) Medical Provider, 3) Nursing Home, and 4) Household. Each of these components address varying perspectives of the healthcare system. While MEPS addresses varying topics, only questions from the 2010 Household Component (HC); and more specifically, four questions from the healthcare access module were used. HC collects information annually from individuals and households on health status, health conditions and cost, and coverage, in addition to information on access and utilization of health services by the population. Participants for MEPS comprised a sub-sample from the National Health Interview Survey. Data collection occurred for a 2-year period and respondents were interviewed five times over a 30-month period. There are no published data in the reliability of MEPS from previous studies that used the instrument.

Several studies have used the MEPS to examine the relationship between access and utilization. DeVoe, et al (2011) assessed the association between insurance status and self-reported access and use of health care services. Using MEPS data during the period

of 2002–2007, the authors noted that having health insurance and a usual source of care resulted in lower percentages of unmet medical needs. Individuals with insurance, but without a usual source of care, were more likely to have problems accessing health care services when compared to insured adults who had a usual source of care (adjusted relative risk of 1.27).

Gresenz, et al (2009) used MEPS to collect data collected between 1996 – 2002 to assess the influence of communities on accessing healthcare services among 8,371 participants. They found that the ethnic composition of neighborhoods and social environments play a significant role in accessing healthcare services. The study found that individuals whose environments were of similar ethnic identity demonstrated better access-related outcomes. The impact of living in a predominantly Spanish speaking area was significantly greater in having a usual source of care when comparing immigrants to non-immigrants ( $X^2 = 4.7$ ). Similarly, Bustamante and others (2010) found disparities in the use of preventive health services among Latino subgroups living in the US based on MEPS data collected from 2000-2006, with a sample of 28,781 Latinos and 78,979 non-Latino whites. Mexican and Central American Latinos were less likely to receive preventive care services as compared to non-Latino whites and other Latino subgroups. The study suggested that other factors such as time of migration and acculturation as well as beliefs on preventive health services play a critical role in accessing care. The 2010 MEPS questionnaire can be accessed through [http://meps.ahrq.gov/mepsweb/survey\\_comp/survey.jsp](http://meps.ahrq.gov/mepsweb/survey_comp/survey.jsp). For this study, the researcher developed questions to further assess the utilization of healthcare services and use of one's social networks.

Table 3: Questionnaire Format

<u>Research Hypothesis</u>	<u>Categories of Data To Be Collected</u>	<u>Survey Method(s)</u>
The social networks of SSA immigrants are comprised of higher numbers of strong ties compared to weak ties.	Social Network Characteristics	Demographic, SNS
Social networks comprised of weak ties facilitate greater access and utilization of healthcare services.	Social Network Characteristics, Healthcare Access	MEPS, SNS
Higher levels of social integration facilitate positive HIV/AIDS related health outcomes.	Social Integration, Healthcare Access, Health Status	Demographic, SNS, MEPS

### Qualitative Method

The qualitative component of the research design allowed for a more in depth examination of participants' social networks, level of social integration, and influence on access to care and HIV related health outcomes. Individual and focus group interviews were used to accommodate the time constraints and availability of participants.

Individual interviews allowed for more personal, candid and open dialogue between the researcher and the participant by fostering an environment of mutual respect and control of topics to be covered by researcher. Focus group interviews offered an opportunity for participants to interact and share ideas, "yielding the best information" (Creswell, 2007). Group interviews were also beneficial in reaching a larger number of participants when time constraints were involved. A maximum of 5 participants comprised each focus group allowing maximum participation by each participant.

Interviews were conducted using an interview guide to allow for flexibility that would otherwise not occur with a structured interview format (Fontana & Frey, 2005). An interview guide also allowed the researcher to have control of the interview and provided consistency with in the questions posed to all participants (Fontana & Frey, 2005). Audiotaping of interviews were only conducted when participants had consent, otherwise, the researcher took notes of their responses during the interview. Interviews lasted between 30-45 minutes.

### **Study Setting**

The City of Philadelphia was chosen as the study setting because of its increasing severity of the HIV/AIDS epidemic and large numbers of African migrants residing in the city. Philadelphia is a major metropolitan area with a population of slightly over 1.5 million (US Census Bureau, 2010). Forty-one percent of city residents are white, 44% are African-Americans, 6.3% are Asians and 12.3% are Hispanics or individuals of Latin origin. 11.3% of the population is foreign born with 20% speaking a language other than English at home. The residents have significantly lower per capita and median household income, and higher poverty rates as compared with other counties in the state of Pennsylvania and the nation. In 2010 the per capita income was \$20,882 and the median household income was \$36,959. Nearly 1 in 4 individuals (24.5%) had an annual income at or below the federal poverty level. These statistics represent African-Americans and Latinos who are significantly more likely to live in disadvantaged environments, African-Americans and Latinos are often overrepresented in poverty stricken areas when compared to other racial and ethnic groups. Poor social environments have been linked to disproportionate levels of HIV/AIDS. The Philadelphia AIDS Activities Coordinating

Office (2010) reported that an estimated 20,000 HIV-infected individuals currently live in Philadelphia with African Americans and Hispanics accounting for 78.2% of the HIV/AIDS cases.

Table 4: Living HIV/AIDS Cases in Philadelphia by Race/Ethnicity

Race/Ethnicity	N	Percent (%)
Black	12,920	66.1
White	3,930	20.1
Hispanic	2,371	12.1
Multi-Race	138	0.7
Asian	128	0.6
Other/Unknown	38	0.1
Total	19,525	100

Source: AIDS Activities Coordinating Office. (2010). Surveillance Report. Available at <http://www.phila.gov/health/pdfs/2010%20Surveillance%20Preliminary%20Report.pdf>

According to the Pennsylvania Department of Health Integrated Epidemiologic Profile of HIV/AIDS, Philadelphia County had higher death rates among those infected with HIV/AIDS when compared to all other counties in the state based on data during the period of 2009-2010 (PA Department of Health, 2010). Despite having a more comprehensive network of HIV providers, Philadelphia County lags behind other regions of the state in addressing the needs of individuals living with HIV/AIDS (PA Department of Health, 2010). Statewide, 73% of individuals who were aware of their HIV status received HIV related primary medical care services in a 12-month period as compared to

66% in Philadelphia (PA Department of Health, 2010). This gap underscores issues of access to healthcare services in this region.

Nearly 36% of immigrants settling in Philadelphia are of Caribbean and African descent (Mayor's Commission on African and Caribbean Immigrant Affairs, 2011). A continuing upward increase has been noted in the percentage of Africans migrating to Philadelphia who settle primarily in one of the five clusters of immigrant settlements. Each cluster area is comprised of several census tracts with varying dominant immigrant groups. Cluster area 3, an area with nearly 4000 foreign born immigrants, has 27% African immigrants with the majority comprised of West Africans (Patusky & Ceffalio, 2004).

The City of Philadelphia has an extensive network of community based organizations (CBOs), primary medical and infectious disease providers providing services to Persons Living with HIV/AIDS (PLWHA). Many of these agencies provide free HIV care to PLWHA through funding from the national Ryan White HIV/AIDS program. Funding support help reduce unmet needs in PLWHA who cannot otherwise afford medical or ancillary services and thus eliminating the issue of access that other major cities face.

### **Sample**

The study sample comprised of individuals who met the following criteria: a) between 18 and 65 years, b) self-identify as African and having originated from any of the sub-Saharan African regions, c) first generation immigrant living in Philadelphia, PA, d) diagnosed as HIV positive for at least one year, and e) able to read and write in English.

## **Study Power and Sample Size**

**Quantitative.** A power analysis was conducted using SAS PROC POWER (version 9.3). This analysis showed a sample of 207 subjects would have 80% power at  $\alpha=0.05$  to detect a standardized coefficient of 0.20 between social network measures and CD4 concentrations in a multiple regression with 14 covariates. Although 207 participants were targeted, only a total of 97 participated after one year of data collection.

**Qualitative.** Thirteen participants who completed the quantitative portion of the study comprised the qualitative sample.

## **Sample Recruitment**

Study participants were recruited using opportunistic and purposive sampling as well as snowball sampling. Unlike random sampling where a participant selection is by chance, this study employed these recruitment techniques as the target population is hard to reach, and limited to a specific group (Kish, 1965; Parten, 1966). Snow ball sampling was used because of the limited numbers of the targeted population in the area (Bernard, 1994). This method allowed an informant to supply and potentially recruit other members of the target population. Snowball sampling is ideal in studies examining social networks as the purpose of such studies is “to find out who people know and how they know each other” (Bernard, 2004, p.97). This approach is also used to find “uncommon” or “sensitive” populations.

Participants were recruited from community-based organizations and healthcare organizations servicing HIV positive African immigrants in Philadelphia County. These agencies identified in Table 5 provide primary care services, case management services, and other supportive services to HIV positive individuals. Using groups or organizations



that already cater to the targeted population enhanced recruitment and addressed potential barriers such as language differences.

Each participant received an incentive of \$10.00 gift card to local groceries in Philadelphia after providing verbal consent to participate and completing the survey instrument. Gift cards were distributed by agency point of contacts (POC's) or the researcher.

Table 5: Agencies for Participant Recruitment

COMMUNITY-BASED HIV/AIDS SERVICE PROVIDERS	SERVICES PROVIDED
<ul style="list-style-type: none"> <li>• Greater Philadelphia Health Action, Inc.</li> <li>• Philadelphia Department of Public Health</li> <li>• AIDS Care Group</li> <li>• Albert Einstein Medical Center</li> <li>• Partnership Program</li> <li>• Esperanza Health Center</li> <li>• Kensington Hospital</li> <li>• Abbottsford Community Health Center</li> <li>• Spectrum Health Services</li> <li>• Philadelphia Health Services</li> <li>• Covenant House Health Services</li> <li>• Quality Community Healthcare Inc.</li> <li>• Urban Solutions</li> <li>• Philadelphia Fight</li> </ul>	<ul style="list-style-type: none"> <li>• Primary Care Services</li> <li>• HIV Counseling and Testing Services</li> <li>• Case Management</li> <li>• Care Outreach</li> <li>• HIV Care Services</li> </ul>
<ul style="list-style-type: none"> <li>• Action AIDS</li> <li>• Mazzoni</li> <li>• BEBASHI</li> <li>• Congreso de Latinos Unidos</li> <li>• Intercultural Family Services</li> </ul>	<ul style="list-style-type: none"> <li>• Social Service Case Management</li> <li>• Outreach</li> <li>• Support Groups</li> <li>• HIV Antibody Testing</li> <li>• Diagnostic Funding</li> </ul>

<b>COMMUNITY-BASED HIV/AIDS SERVICE PROVIDERS</b>	<b>SERVICES PROVIDED</b>
<ul style="list-style-type: none"> <li>• Germantown Settlement</li> <li>• African Family and Health Organization</li> </ul>	<ul style="list-style-type: none"> <li>• Crisis Intervention</li> <li>• Advocacy</li> <li>• Health Promotion</li> </ul>

**Qualitative sample.** Individual and focus group interviews were conducted with participants who completed the quantitative survey questionnaire and agreed to be interviewed. Individuals were interviewed immediately after completing the survey, or given an opportunity to schedule an interview on a date and location of their choice. Both individual and focus group interviews were conducted by the researcher. Individuals participating in the interview sessions were given an additional \$20.00 gift card.

### **Data Collection**

After obtaining administrative approval from individual agencies and IRB approval from Rutgers University, the researcher distributed an invitation letter, information sheet, and questionnaire to participants meeting the study criteria. Participants who agreed to participate were asked to orally summarize his or her understanding of each section of the information sheet to the researcher prior to being given a survey questionnaire, as written documentation of consent was not required. Participants' questions pertaining to the survey instrument, were also conveyed to the researcher by agency POC's which were then addressed before each participant completed the surveys.

The study information sheet provided information regarding the study, its impact on participants and expected participation. Each participant was given a review of the study information sheet by the researcher prior to providing verbal consent and survey questionnaire for completion.

Survey questionnaires were distributed by the researcher after verbal consent to participate was received. Surveys were completed on-site at the individual agencies. Surveys were distributed over a three month period to allow for maximum participation as HIV clinical guidelines recommend routine follow up for medical visits every 3-4 months.

Verbal consents of individual participants were obtained, prior to being interviewed. Monthly reminders to the agency contact person (POC) was done to encourage participation via email or phone call based on the preference of the agency contact.

Completed surveys were collected in individually sealed envelopes. The sealed envelopes containing completed surveys were placed in a larger pre-labeled and stamped security envelope, by the agency contact and mailed to the attention of the researcher at Rutgers University, School of Nursing in Newark, NJ 07016. Only the researcher and dissertation chair had access to agency coded surveys and audio taped interviews. All data collected will be kept for six years after the study is completed in a locked file cabinet in PhD Director's locked office at Rutgers University, School of Nursing in Newark, NJ 07016. After this time, all data collected will be destroyed.

**Data Analysis**

**Quantitative.** Surveys were reviewed and 100% were completely answered by participants. Data from the survey were entered into the Statistical Package for Social Sciences (version 20) and then double-checked to ensure the accuracy of the data entry.

Descriptive, bivariate and multivariate logistic regression analysis were conducted as shown in Table 6.

Table 6: Variable Measures

Variable	Variable Type	Measurement
Ethnic Background	Independent	Categorical
Age	Independent	Categorical
Sex	Independent	Categorical
Marital Status	Independent	Categorical
Length of Immigration	Independent	Ordinal/ Continuous
Income	Independent	Interval/ Continuous
Insurance Status	Independent	Categorical
Education	Independent	Categorical
Social Network Characteristics	Independent	Interval Categorical Categorical
Size/Density		Interval
Function		Categorical
Composition		Categorical
Frequency of Access	Mediating	Interval
Utilization	Mediating	Interval
CD4	Dependent	Interval
Viral Load	Dependent	Categorical

A multi-step approach was used to explore the relationships between variables.

One-way Anova was used to test for differences in means between independent variables.

Pearson Correlation was performed to determine relationships between each independent variable and the dependent variables (HIV health outcomes). Logistic regression was performed to examine predictive relationships between independent and dependent variables.

**Qualitative.** Audiotaped interviews were transcribed verbatim and analyzed for emerging categories or domains. A taxonomy of domains was developed to determine relationships among these categories. Major themes were derived from recurrent patterns in participant responses. Emerging themes w identified provided further insight to the research questions.

### **Triangulation of quantitative and qualitative findings**

Findings from both methods were then triangulated to determine similarities and differences. Triangulation is described as a ‘cross checking’ process where ‘convergence in findings’ of methodologies (Chatterji, 2005) occurs. It is through this process, that ‘validity’ of constructs and themes, and ‘reliability’ of findings are established (Chatterji, 2005; Creswell, 2009). Lincoln and Guba (1982) describe this process of establishing validity and reliability synonymous to that of ‘trustworthiness’. Lincoln and Guba also acknowledge that aspects of trustworthiness appear when one establishes ‘dependability’, ‘confirmability’, ‘transferability’, and ‘credibility’ (1982). Varying techniques can be used to establish ‘trustworthiness’.

The first strategy used was across method triangulation to confirm the findings found in the quantitative and qualitative method. The use of across method triangulation has been argued to “circumvent the personal biases of investigators and to overcome the deficiencies intrinsic to a single-investigator, single-theory, or single method study, thus

increasing the validity of the findings” (Tobin & Begley, 2004). A second strategy used was an audit trail which provides “proof of decisions” made along the qualitative journey (Morse, et al, 2002) by auditing the “events, influences and actions of the researcher” (Koch, 2006). The availability and transparency of this information to others, as well as having an individual other than the researcher test deriving the same findings, further establishes trustworthiness.

### **Ethical Considerations and Limitations**

Ensuring the confidentiality of information collected is essential. IRB approval from Rutgers University and participating agencies were obtained before commencing data collection. To protect the identities of participants, only aggregate findings are reported. Participants were informed of the purpose of the study and its protocols through an information sheet attached to the front of the questionnaire. All participants were required to give verbal consent to participate in the study. The invitation letter to participate informed participants of their right to discontinue participation without consequences and that lack of participation will not jeopardize access to services being delivered at the agency.

It was anticipated that fear of participation was a concern because the researcher is of similar ethnic origin as the participants. This was partially addressed by not collecting any personal identification of participants. Individual agency workers were given training by the researcher. Agency workers (POC) determined eligible participants from their enrollees based on the criteria provided and gave them about the study. The researcher met with participants who indicated to the POC their interest to participate in the study.



## **Chapter 5 – Quantitative Research Results**

The study examined the influence of social networks on access to healthcare services and health outcomes of HIV positive SSA immigrants in the US. This chapter reports on results from the quantitative study.

### **Demographic Characteristics**

Table 7 summarizes the demographic characteristics of participants. The study sample comprised of a total of 97 HIV positive African immigrants; 60 were females and 37 were males. A higher percentage were between the ages of 50 – 59 years of age (27.8%). Nearly 79% of participants came from West African countries, particularly Liberia (26.8%) and the Ivory Coast (11.3%).

44% of participants were married, 31% were single and nearly 20% were either separated or divorced. 78% of participants have children, with most having 3 or more. 50% of those with children lived with them.

91.8% of participants reported their annual income to be less than \$25,000. 77% had household incomes less than \$25,000. Nearly 60% reported having a high school diploma or higher from Africa, compared to 33% who achieved it after arriving to the US.

All participants were 1<sup>st</sup> generation immigrants, with most immigrating to the US less than 5 years ago. 60% reported traveling to the US alone and nearly 70% had family members already living in the US upon their arrival. Majority of participants reported migrating primarily to improve their quality of life (29.9%), followed by reuniting with family (18.6) and political reasons (18.6%).

49.5% of the participants were uninsured. Of those insured, nearly 28% had Medicaid as their primary source of coverage. 20% had private or VA insurance, while 2% had Medicare coverage.

Table 7: Sample Characteristics (n=97)

Variables	N	Percent
Gender		
Male	37	38.1
Female	60	61.9
Age (years)		
20-29	13	13.4
30-39	23	23.7
40-49	25	25.8
50-59	27	27.8
60-69	8	8.2
70+	1	1.0
Region of Birth		
West Africa	72	74.2
South Africa	5	5.2
Central Africa	4	4.1
East Africa	14	14.4
Other	2	2.1
Marital Status		
Single	30	30.9
Married	43	44.3
Widowed	5	5.2
Divorced	9	9.3
Separate	10	10.3
Have Children		
Yes	76	78.4
No	21	21.6
Number of Children		
1	27	27.8
2	19	19.6
3 or more	29	29.9
Individual Income		
Don't Know	1	1.0
less than 25,000	89	91.8

	25,000 - 49,999	3	3.1
	50,000-74,999	4	4.1
Household Income			
	Don't Know	9	9.3
	less than 25,000	77	79.4
	25,000 - 49,999	4	4.1
	50,000-74,999	4	4.1
	over 75,000	3	3.1
Highest Educational Level			
<i>In Africa</i>			
	Less than high school	39	40.2
	High school graduate	33	34
	Trade some college certificate program or some university	17	17.5
	Bachelor's degree	4	4.1
	More than 4 year college	4	4.1
<i>In US</i>			
	Less than high school	65	67
	High school graduate	1	1
	Trade some college certificate program or some university	24	24.7
	Bachelor's degree	3	3.1
	More than 4 year college	4	4.1
Reason for Immigrating			
	Other	4	4.1
	Education	11	11.3
	Financial	7	7.2
	Quality of Life (QOL)	29	29.9
	Unite with Family	27	27.8
	Political	18	18.6
	Access to Healthcare	1	1.0
Length of Immigration			
	Less than 5 years	31	32.0
	6-10	19	19.6

11-14	19	19.6
15-19	14	14.4
20+	14	14.4
Who Traveled With		
Family Only	34	35.1
Friends Only	3	3.1
Came Alone	59	60.8
Both Friends and Family	1	1.0
Already Here Upon Arrival		
Family Only	67	69.1
Friends Only	13	13.4
Both Friends and Family	2	2.1
Insurance Status		
Yes	49	50.5
No	48	49.5
Insurance Type		
Private, VA, or Other Insurance	20	20.6
Medicare	2	2.1
Medicaid	27	27.8
No Insurance	48	49.5

### **Health Status and HIV/AIDS Knowledge**

All individuals participating in the study reported being HIV positive. 63% of participants noted never having been diagnosed with AIDS, 31% recalled having been diagnosed with AIDS, while 6% could not recall. Nearly two thirds of participants reported receiving their HIV diagnosis in the United States. One individual could not recall where they were diagnosed and another individual reported being diagnosed in another country prior to coming to the US.

35% of participants reported having been diagnosed with HIV or AIDS less than 5 years, while 65% were diagnosed over 5 years. Of the 30 individuals diagnosed in

Africa, only 63% were prescribed anti-retroviral therapy (ART). All participants were prescribed ART in the US.

CD4 and Viral Load are markers of HIV disease progression. Clinical progression of HIV disease to AIDS is marked by a decline of CD4 levels of 200 or below. 54% of participants could not recall their lowest CD4 count, while 27% recalled having a CD4 count below 200. A cross tabulation of the data shows that 15% of participants who reported not having been diagnosed with AIDS, reported CD4 counts indicative of AIDS. 48% of participants noted having an undetectable viral load at last measurement, while 13% reported having a detectable viral load. 38% could not recall their viral load counts from their last measurement.

Participants were asked about their overall health. Majority of participants rated their overall health as good (43%), 26% reported excellent, 23% as very good, and 6.2% as fair or poor.

Majority of participants (36.1%) reported being more informed than most about HIV/AIDS. 18.6% felt about as well-informed as others and 13.4% felt somewhat better informed than others). In contrast 32% reported being much less informed than others about HIV/AIDS.

### **Social Network Characteristics and Health Outcomes**

**Network Size and Composition.** Participants were asked to identify the number of individuals they considered most important to them. The responses provided represent the number of individuals considered part of their primary social network. The network size for the entire sample ranged between 0 to 11 individuals with ( $M = 3.74$  and  $SD = 2.27$ ). More network members comprised of individuals with strong ties ( $M = 3.87$ ,

SD=2.18), compared to those with weak ties ( $M=3.50$ ,  $SD=2.17$ ), and those with equal number of strong and weak ties ( $M=3.00$ ,  $SD=3.01$ ). One-way ANOVA analysis was used to compare network size and the type of ties found within network members.

Results from the analysis found no significant difference between network size and type of ties ( $M=3.74$ ,  $SD=2.26$ ,  $F=.710$ ,  $p=.494$ ).

The entire sample reported a social network size of 363 individuals. These 363 individuals reflect a composition of family, friends, neighbors, church members, community members, agency worker, and co-workers. As shown in Table 8, of the 363 individuals identified in the sample's network, over 60% were family members ( $M=2.59$ ,  $SD=1.95$ ).

Table 8: Network Composition by Category  
(Sample N = 363)

	N	%	Mean	SD
Family	229	63%	2.69	1.95
Friend	46	13%	1.48	1.09
Neighbor	1	0%	1.00	-
Church Member	15	4%	1.87	1.45
Community member	1	0%	1.00	-
Agency Worker	66	18%	1.29	.54
Co-Worker	5	1%	1.00	.00
Other	0	0%	-	-

Hypothesis 1 of the study suggests that the social networks of SSA immigrants are comprised of higher numbers of strong ties than weak ties. Results from a paired t-test shows statistical significance at a 95% confidence level, ( $t= 7.782$ ,  $p= .000$ ), hence one can conclude that SSA immigrants do have higher numbers of strong ties than weak ties, thus rejecting the null hypothesis.

## Social Networks and Health Outcomes

In this study, CD4 and Viral Load were used as proxy measurements of health. A Chi square analysis was performed to determine if there were any associations between CD4 at last measurement and elements of network characteristics. As seen in Table 9, of the 18 network characteristics measured, relationships were found to be statistically significant in five areas: individuals with children ( $\chi^2=11.42$ ,  $p=.044$ ), the number of children they have ( $\chi^2=27.99$ ,  $p=.022$ ), educational levels obtained in both Africa ( $\chi^2=34.85$ ,  $p=.021$ ) and the US ( $\chi^2=43.48$ ,  $p=.002$ ), and the frequency of clinical visits ( $\chi^2=18.22$ ,  $p=.051$ ).

Table 9: CD4 and Social Network Characteristics

Variables	$\chi^2$	df	p
Age	18.75	25	.809
Sex	4.07	5	.538
Country of Birth	15.01	20	.776
Marital Status	16.47	20	.687
Have Children	11.42	5	.044
Number of Children	27.99	15	.022
Educational Level in Africa	34.85	20	.021
Educational Level in US	43.48	20	.002
Individual Income Level	6.81	15	.963
Household Income Level	19.85	20	.467
Insurance Status	3.01	5	.698
Insurance Type	12.02	5	.678
Traveled with Status	11.25	15	.735
Reason for Immigration	35.04	30	.241
Length of Immigration	23.74	25	.534
Informed Level	20.68	15	.147
Frequency of Visits	18.22	10	.051
Having Disclosed	4.07	5	.539

p < .05

The Chi Square analysis was also used to determine if associations between viral load and elements of network characteristics could also be found (see Table 10). Of the 18 network characteristics, statistical significance was found in 4 characteristics, which include: how well informed an individual was on HIV/AIDS ( $\chi^2=33.12$ ,  $p=.000$ ), travel with family or others to the US ( $\chi^2=14.09$ ,  $p=.029$ ), insurance type ( $\chi^2=16.60$ ,  $p=.011$ ), and age ( $\chi^2=19.99$ ,  $p=.029$ ).

Table 10: Viral Load and Social Network Characteristics

Variables	$\chi^2$	df	P
Age	19.99	10	.029
Sex	1.57	2	.454
Country of Birth	9.45	8	.305
Marital Status	3.85	8	.870
Have Children	2.46	2	.292
Number of Children	10.07	6	.122
Educational Level in Africa	11.00	8	.202
Educational Level in US	14.90	8	.061
Individual Income Level	6.39	6	.381
Household Income Level	9.32	8	.316
Insurance Status	4.82	2	.089
Insurance Type	16.60	6	.011
Traveled with Others to US	14.09	6	.029
Having Disclosed	2.58	2	.274
Frequency of Visits	6.05	4	.195
Informed Level	33.12	8	.000
Length of Immigration	5.93	10	.821
Reason for Immigrating	16.39	12	.174

$p < .05$

One-way ANOVA was performed to determine if any associations between CD4, Viral Load, and network size (see Table 11). Results of this analysis found no association between CD4 at last measurement and the number of network members ( $F=1.25$ ,



$p=.264$ ). Similarly, there were no significant differences in the means between viral load and the number of network members.

Table 11: HIV/AIDS Status and Social Network

Network Size	N	CD4		VL	
		Mean	SD	Mean	SD
0	2	5.00	5.65	5.50	4.94
1	10	5.20	4.02	4.40	3.97
2	23	3.78	3.57	4.30	3.86
3	16	2.81	3.10	3.50	3.82
4	14	5.78	3.86	7.35	3.27
5	15	3.86	3.35	3.80	3.82
6	6	1.66	1.21	2.50	3.20
7	5	1.60	0.54	1.20	0.44
8	1	3.00	—	1.00	—
9	2	5.00	5.65	1.50	0.70
10	2	1.50	0.70	5.00	5.65
11	1	2.00	—	1.00	—
Total	97	3.80	3.47	4.18	3.81
		F= 1.25, $p=.264$		F= 1.70, $p=.086$	

Pearson Correlation tests were performed to determine any relationship between the independent variables (sex and social network size) and the dependent variables related to HIV health outcomes (CD4 and Viral Load at last measurements). No statistically significant correlations were observed between sex and network size ( $r=-.081$ ,  $p=.430$ ), sex and CD4 ( $r=-.069$ ,  $p=.502$ ), and sex and Viral Load ( $r=.038$ ,  $p=.709$ ). No statistically significant correlations were observed between network size and CD4 ( $r=.173$ ,  $p=.113$ ), and Viral Load ( $r=.178$ ,  $p=.102$ ). A significant positive correlation was found between strong ties and CD4 levels ( $r=.214$ ,  $p=.050$ ) but not Viral Load ( $r=.191$ ,  $p=.078$ ). No statistically significant correlation was revealed between weak ties and CD4 levels ( $r=-.098$ ,  $p=.374$ ) and Viral load ( $r=.003$ ,  $p=.982$ ).

Logistic regression was performed to determine whether the number of strong ties found within one's network could predict CD4 counts. CD4 measurements were recoded into 2 categories, CD4 counts below and above 200 at last measurement. The analysis revealed no significant relationship.

### **Access to and Utilization of Healthcare Services**

All participants reported receiving healthcare services from a particular provider. 96% reported receiving healthcare services from community health centers, while 4% of participants received their care from hospital associated clinics. 87.6% reported seeing a medical provider 3 or more times in the past year, while 12.4% reported seeing a medical provider less than three times per year. The Chi Square test was used to determine if there were any differences in the number of times individuals accessed care and the independent variables noted in Table 12. In each of the areas tested there were no significant differences in groups.

Table 12: Access to Care Frequency

Variables	$\chi^2$	df	P
Age	15.65	10	.110
Sex	2.99	2	.224
Country of Birth	14.43	8	.071
Marital Status	5.27	8	.728
Have Children	2.18	2	.335
Number of Children	3.58	6	.732
Educational Level in Africa	4.32	8	.827
Educational Level in US	6.10	8	.569
Individual Income Level	12.02	6	.061
Household Income Level	15.12	8	.057
Insurance Status	2.92	2	.231
Insurance Type	5.53	6	.477
Traveled with Others to US	2.64	6	.852

Having Disclosed	1.13	2	.566
Health Status	.500	8	.757
Informed Level	7.37	6	.287
Length of Immigration	8.70	10	.561
Reason for Immigrating	7.25	12	.841

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p <.05

Hypothesis two (H2) suggests that social networks comprised of weak ties facilitate greater access and utilization of healthcare services. Results from one-way ANOVA analysis performed show a statistically significant difference in the means in access and utilization of healthcare service by type of network tie ( $F=3.80$ ,  $df=2$ ,  $p=.026$ ), thus rejecting the null hypothesis. Higher access and utilization of services were found in members whose networks are comprised of higher numbers of weak ties ( $M=8.00$ ), than strong (4.88) or equal ties (4.70) (see Table 13).

Table 13: Access and Utilization of Healthcare Services by Type of Ties

Type of Tie	N	M	SD
Strong	77	4.88	3.42
Weak	10	8.00	3.77
Equal	10	4.70	2.90

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p<.05

Pearson Correlation tests were used to determine relationships between the frequency of accessing care and HIV health outcomes (CD4 and Viral Load at last measurements). No statistically significant correlations were observed between frequency of visits within the last 12 month period and CD4 ( $r=.146$ ,  $p=.154$ ) or Viral Load ( $r=.130$ ,  $p=.205$ ).

### Social Network Support Characteristics

Using Likert scales, study participants were asked to evaluate the importance and the satisfaction of support received from their social networks in five key areas of support including advice, criticism or praise, socialization, help with problems and emotional support. Table 14 describes the level of importance and satisfaction in each of the 5 areas. Using a Likert scale, participants were asked to rate the quality of the relationship with network members. Indicators used to measure the quality of relationships included both stress and level of support received from network members. The mean score was 1.29, suggesting participants experienced higher levels of support than stress from network members.

Table 14: Support Characteristics

Importance of types of support received from network members <sup>1</sup>			
	N	Mean	SD
Advise	95	4.52	1.04
Criticism or Praise	95	4.13	1.33
Socialization	95	4.66	.87
Help with Problems	95	4.74	.72
Emotional Support	95	4.57	.97
Satisfaction on Types of Support			
Advise	361	4.24	1.58
Criticism or Praise	363	3.94	1.77

<sup>1</sup> 2 individuals reported no social supports

Socialization	365	4.29	1.53
Help with Problems	366	4.40	1.40
Emotional Support	364	4.45	1.35
Quality of Relationship	304	1.29	.77

$p < .05$

When asked who gave more in the relationship, 42% of participants felt that both they and their network members gave equally in the relationship, while 33% felt their network members gave more.

Study participants were asked if they received support related to their HIV in five key areas, and whom they felt provided the most support in each of the areas. A higher percentage of individuals reported receiving support or assistance from members of their networks in areas related to understanding their diagnosis and HIV related labs. Fewer percentages of individuals reported receiving support or assistance in these areas: picking up medications, transportation assistance, and translation/interpreter services (see Table 15).

Table 15: Areas of Support or Assistance Received from Network Members

		N	%
Support picking up or accessing medications		95	
	Yes	36	37.9
	No	59	62.1
Assistance with transportation to doctor's appointment		95	
	Yes	33	34.7
	No	62	65.3
Understanding HIV diagnosis		95	
	Yes	94	98.9
	No	1	1.1
Attends doctor's appointment		94	
	Yes	39	41.5
	No	55	58.5
Understanding HIV labs		95	
	Yes	94	98.9
	No	1	1.1
Providing translation assistance		92	
	Yes	12	13
	No	80	87

In each of the areas of support, participants ranked which network member primarily provided that area of support. In the areas of picking up medications, transportation to the doctors, accompanying one to the doctor, and providing translation service, family members were the primary individuals providing these support. In the areas related to understanding one's HIV diagnosis and lab results, participants ranked agency workers as primarily providing this type of support (see Table 16).

Table 16: Network Member Areas of Support

Variables	N	Percent
Support picking up or accessing medications (N=36)		
Family	28	77.8
Friends	4	11.1
Church Members	-	-
Agency Worker	4	11.1
Other	-	-
Assistance with Transportation to doctor's appointment (N=34)		
Family	28	82.4
Friends	1	2.9
Church Members	-	-
Agency Worker	1	2.9
Other	4	11.8
Understanding HIV Diagnosis (N=94)		
Family	1	1.1
Friends	-	-
Church Members	-	-
Agency Worker	91	96.8
Other	2	2.1
Attends Doctor's Appointments (N=39)		
Family	32	82.1
Friends	5	12.8
Church Members	1	2.6
Agency Worker	-	-
Other	1	2.6
Understanding HIV Labs (N=95)		
Family	-	-
Friends	-	-
Church Members	-	-
Agency Worker	95	100
Other	-	-
Providing Translation Services (N=14)		
Family	9	64.3
Friends	1	7.1
Church Members	-	-
Agency Worker	1	7.1

Other

3

21.4

### Network Dimensionality, Density, and Social Integration

Participants were asked regarding the types of activities they engaged with their network members. 82.4% reported engaging in more than one type of activity with members of their network, while 17.6% reported engaging in just one type of activity with network members. This suggests that more participants are involved with varying types of activities with their network members.

Study participants were also asked to identify the number of network members having connected relationships with other network members, independent of the study participant. The number of connections amongst network members is used to define network density. Higher percentage of participants who reported two network members were connected to other network members. A network density score of .491 was observed, with  $M=3.33$  and  $SD = 2.40$  (see Table 17).

Table 17: Network Connections

Number of Network Members Connected	N	%
0	15	15.5
2	28	28.9
3	14	14.4
4	12	12.4
5	14	14.4
6	4	4.1
7	5	5.2
9	3	3.1
10	1	1
11	1	1



Hypothesis three (H3) suggests that higher levels of social integration facilitates positive HIV/AIDS related outcomes. One measure of integration is how connected one's network members are. One-way Anova was performed to determine if there were any differences amongst network members with higher numbers of connected relationships and HIV related outcomes. As seen in Table 18, no significant difference was found between number of connected network members and CD4 counts ( $F=1.13$ ,  $p=.34$ ); however significant difference was found amongst connected network members and viral load ( $F=2.44$ ,  $p=.016$ ). The importance of these HIV disease indicators are that CD4 indicates how well or strong one's immune system is; while Viral Load indicates the amount of virus in one's blood. While CD4 measurement is deemed the most important of the two indicators, viral load measurements show how well one is responding to treatment or how well one is controlling the disease (Department of Health and Human Services, 2016).

Table 18: Network Connections and CD4 and Viral Load Measurements

# of Network Connections	CD4			VL	
	N	Mean	SD	Mean	SD
0	15	4.93	3.95	4.93	3.95
2	28	3.10	3.18	3.14	3.46
3	14	4.21	3.74	3.92	3.93
4	2	5.75	4.02	7.75	2.92
5	14	3.42	3.17	4.07	3.83
6	4	1.75	1.5	3.00	4.00
7	5	2.00	0.7	1.00	0.00
9	3	3.66	4.61	4.00	4.35
10	1	2.00	--	9.00	--
11	1	2.00	--	1.00	--
		M=3.80	SD= 3.47	M= 4.18	SD= 3.81
		F= 1.13, p=.344		F=2.44, p=.016	

## Chapter 6: Qualitative Results

The purpose of the qualitative research study was to further examine the role of social networks on HIV related health outcomes. Study participants were interviewed to gain further insight on the following research questions:

1. What types of activities do HIV positive African immigrants engage in with their social networks?
2. What types of support systems do networks of HIV positive immigrants provide?
3. How do the identified types of activities and support systems shape or influence access to care or HIV health related outcomes?
4. What factors keep HIV positive African immigrants engaged in care?

### Participants

All participants have previously completed the quantitative survey and were HIV positive sub-Saharan African immigrants. Thirteen individual interviews were conducted with 8 adult males and 5 females. Due to the sensitivity of the research topic, interviews were either recorded or transcribed based on participants' preference. Audiotaping of the interview was only conducted when the individual participant agreed, otherwise, the investigator wrote down the participant's responses during the interview.

### Thematic Findings

The responses from the interviews were analyzed for domains and categories from which major themes were drawn. Each theme is listed with italicized verbatim responses from participants.

- 1. Social networks are comprised predominately of kin and co-ethnics**

The composition of participants' social networks consisted primarily of strong ties. These strong network ties include individuals such as family, friends and co-ethnics. Most individuals in their networks resided primarily in the US. Only 5 out of the 13 (38%) participants had networks comprised of individuals from the US and their homeland.

Nearly all participants identified having frequent or strong communication channels between themselves and members of their network by phone and face-to-face encounters. Telephonic communication was significant in connecting with network members abroad.

## **2. Strong ties network provides holistic and HIV-related support**

Strong ties social network provided emotional support and companionship (travel and leisure), assist in decision-making, maintain social connections and cultural traditions, as well as provide HIV-related support.

*P1: Oh, like when I have a problem or I have to make a decision, I can go to them and they will help me make the right decision.*

*P2: With my husband and I, because we stay together, with my parents, like, we do conversate a lot because they are not here, they are in Africa*

*P6: Just go out to dinner, travel, just hang out, um spend some time together, just that yea.*

*P7: ...like we go on vacations together, like ski trips, ... we go on vacations together, drinking buddies, parties, like weddings, ...like to the shore for labor day or something, we do a lot, we do a lot of things together*

*P8: We just talk, nothing much, not usually about HIV, just regular talk*

P9: ... my sister, sometimes will go to parties, yes, talk with family meetings

P11: ... attending family events, reunion, uh family engagement, family holiday, playing, um, leisure time with family and taking care of family members as well.

P12: ...the community members [co-ethnic], at times we hang we hang out, sometimes like maybe visit new places, especially since my arrival, there are some places, that I didn't know and uh and in order to keep me aware of places I have never been before, for which I am very much grateful.

The types of activities participants have with their strong ties social networks depended on their relationship with identified network members. Participant 13 notes that while she has a relationship with her children, she has a much closer relationship with her daughter-in law.

P13: *Not much* [with her children], *when they come we eat, or go and buy a few things that I need. We really don't do much, my son is usually not around, he works a lot. Most of the things I do is with my daughter in-law... She comes over and checks on me, she talks to me about my diagnosis. She is the one that will go with me sometimes to get things that I need, like toiletries, and things from the store.*

### **3. Disclosure of HIV status to members of strong ties social network promotes expanded and meaningful support**

Participants described various categories of support from their strong ties social network including financial, emotional, disease management and other support critical to their survival and adaptation in the US.

P1: *Oh, I can't mention just one but in all areas of life they support me.*

P2: *My husband supports me because, emotionally he supports me in terms of going to check-ups, you know picking up medications, and he understands what I am going through, yeah and my parents also understand what I am going through, they also support me emotionally, although they are far away from me*

P13: *I don't have any money and sometimes don't have enough food to eat. I don't feel comfortable asking my son since he already pays my rent. I know he has his own thing going on, and I don't want to bother him ... Unless I find work, without the financial support, I will have nowhere to live.*

P2: *yeah, my husband gives me much support financially in everything because we stay together.*

P3: *I feel my family... my family, my family is very important to me. They have been very helpful... in helping me. Especially providing support, emotional support and financial support. Most of all just getting their love, and loving me so much. That has been very, very instrumental in helping me. When you know your family is there for you, that makes a big difference.*

Knowledge of their HIV status among network members enhances social acceptance and support specific to disease management.

P7: *I think with regards to my diagnosis, ...my husband's friends have been very important because before I met them, they already knew. Because my husband already told them, ... so by the time I met them, they were 100% accepting of him, and they have been very loving and supportive. They are always a good ear to listen. It's a part of my life that I could never talk about with my friends. So when I am with them, I can be 100%, ... like, tell them how I feel.*

*You know, tell them how I feel, like how it happened, because that is something I never talk about. They are actually interested. They don't make me feel like I am positive, because it's not like what they want to talk about all the time. It's just if I bring it up, or something, they are always willing to listen.*

*P8: They told me to keep taking my medication everyday, and to not miss it. Since then, I have not missed anything. When they check me, they keep saying my viral load is undetectable, and that I am doing well. At the beginning my CD4 was 14 now it is close to 900.*

Participants admit the critical significance of their strong ties social network to their survival as aptly stated by P10:

*That's a very good question, but very, I mean the answer can be very logical. The answer is like you having your computer, you have the hard drive, you have the mouse, everything works together right. Just like you having car, if you don't have the transmission, the car won't move. You have the transmission, but not the engine, the car still won't move. You have the transmission, the engine, but you don't have the tire, the car still won't move. So in this case, I will say all of them have a special role they play. They are an integral part of my survival. If I pick one, it will affect the other. If I pick one, it won't go well.*

Six participants reported that the level of support has been the same or consistent since being diagnosed; five reported that the level of support of have increased over time.

#### **4. Stigma of HIV/AIDS is a barrier to disclosure to strong tie social network**

Three participants described their experiences with social stigma associated with having HIV/AIDS.

P9: *If you let people know that you have it, it will stop you from coming around, because there is a lot of jealousy going on. They will say he looks good, but don't mind him, he has this. Soon as they start talking about you, it's like they are bullying you because they know you have the sickness, then it puts some pressure on you.*

P12: *I mean from where we come from, I mean it is just very very difficult for such to be exposed. To them in particular it is difficult to be professional, give you support and on the contrary they will try to stigmatize you, demonize you and make you feel like its a curse on you, stuff like that.*

P3: *When I was married to my husband, we really didn't socialize with many people, especially with having this. My husband made sure that we stick to ourselves. He didn't want anyone to find out about this. That's what made this even harder at first. I couldn't talk to anyone about the disease. It was as if we committed a sin by having this.*

Participants noted that social stigma against HIV in Africa is less evident in the US.

P8: *My doctor treats me like a king, when I go there they make me feel like I don't have HIV. It is very different than my country where they reject you.*

P12: *I come to the US and met people that never seen me before empathize with me because of the situation I am in, and they did everything to give me that support with high level of professionalism. And I was like, it brought tears to me and I couldn't help it. I started crying. The doctors' whenever I need them, they talk to me very nicely. Which is unlike back home from where I come from, uh, it*

*is much different from home, even the doctor, as much as they are highly trained, you see the counselors, they push you away, they don't bring you close.*

Most participants have not disclosed to some members of their social network; two participants have not disclosed to any member of their social network. Disclosure is prompted by the increasing severity of the illness and the emerging need for other members of the family to get involved with participants' care.

*P9: ...they tried to kill the tuberculosis, then I went back, I started to have seizures, went back and so-and-so wanted to operate, give me operation on my head and then uh, they asked me if I want to have HIV test on me, I said yes, so when they had HIV test and then they told me I had it. ... So I told my sister, she needs to go to the hospital... And then, ... my medication was somewhere, and they wanted somebody to pick it up in front of the hospital, so I had to send my nephew and then he got to know.*

Lack of disclosure is burdensome and some disclosed to relieve the burden of hiding their diagnosis from members of their network.

*P12: I had something emergent that I couldn't disclose to them and that was killing me slowly from the inside... for the fact that I hang around them and they take me to places, it helps me emotionally without them knowing. I appreciate they take me to one point to another, by interacting and socializing they are helping me emotionally without knowing. Like sometimes I am home and they will call and say hey, what are you doing, I will say I am home watching movies, and then they will say hey we coming to see you, let's hang out. For me I consider*



*that as a huge support despite the fact that they don't know, for me I consider that a support for me.*

*P3: When no one knew, I would do so much to hide it from them. That alone would stress me out. ...in the beginning, I must admit I was so afraid. I was very afraid. I kept it for three years and I finally had the strength, not because I wanted to but because of the negative influence of my ex-husband who always said we couldn't tell anyone or that we couldn't talk about it to anyone. He was afraid of what people would say or think if we told anyone. It was a big burden on me. So I just felt tired and exhausted of keeping secrets so I told my mother one day and she cried and then she kept the secret and then we told everyone. And now I can be myself and live my life.*

Another participant disclosed to only one member of her immediate family who was a HIV health care provider because of her need for medication.

*P7: Well, most of my family doesn't know, but my mom's younger brother knows, because he used to treat people with HIV in the US. When I was trying to move back to Nigeria from the UK, he was in Nigeria and since I needed access to medication, I had to tell someone, so I told him, so he knows. So that's the only person from my side of the family. But on my husband's side, his sister knows and practically all of his friends know.*

Several participants were met with denial, unacceptance or being ignored by members of their social networks after disclosure.

*P13: They don't do much when it comes to my diagnosis. They know, but we don't talk about it. To them, they know I have it, but they rather not talk about it... Only*

*my daughter in-law will talk about it with me. It might be because she is in the medical field. I think she is a CNA or home health aide... With my kids, they act as if I have not told them about it, we don't talk about it. I am happy I can talk about it with my daughter in-law. She is open to talking about it.*

Denial generally occurs when participants appear to be physically healthy.

*P10: ... they still can't believe it unless I prove it to them, yes because I am much stronger than some of them.*

*P9: My sister, from the time she got to know about it, she doesn't talk about it... Because I don't act like I have it, you know, I'm not depressed or anything, even my nephew, so it's almost like they have forgotten I have it, yes... Yeah, it's almost like they don't even know I have it, they act like they don't know, yes, because I don't put that depression on me, and I feel free as I move. I myself, I don't even think like I have it.*

Nevertheless, participants admitted that members of their social network provided other types of support when needed.

*P6: Okay if I need something from them they are always there for me to help me out ...And just their company too is very very important for me to have their company.*

## **5. Weak ties provide distinct support that are more directly related with their HIV status**

Weak ties social network comprised of community members such as members of the women's support group, HIV patients, and care providers such as primary care providers, social workers and therapists. Participants were comfortable in discussing their

HIV status with members of this social network. Members of this weak ties social network provided five categories of support: financial, health maintenance, access to health services (insurance and transportation), encouragement and emotional support. Financial support received from this network included assistance in completing applications for public programs such as SSI or public assistance and subsidy programs. In contrast, financial support from strong ties social network included money for food, rent and daily amenities.

*P7 .... the agency workers, these are the people that render me services. They have rendered me services which include medical, psychosocial and moral support...*

*P5 ...a holistic approach to the care and prevention of HIV.*

*So they don't just give me primary care in terms of medication, but they ensure that I'm able to have my CD4 go up, like go the right groups to make me adhere. They also help me in terms of getting my job and becoming independent.*

Network members especially social workers also assisted with housing, medical coverage, connecting with support networks, encouragement, visit compliance, emotional support, etc.

*P4: Well, I get my medicine from my insurance, and my other insurance will start next month. And I am working, so I am not getting any assistance from anyone right now.*

Network members were significant in managing their disease, monitoring their condition and accessing HIV-related services.

*P3: Yes of course my doctor has influence on my outcomes. My doctor is the one that really sets my care up. When I was diagnosed, they told me what I needed to*

*do to stay healthy, they referred me to the doctors that would be taking care of me. They know about the disease, the medical side.*

*P8: They follow me day by day. I get labs very frequently. Its been five years, and they keep track of me, make sure I take my medicine daily...The doctor and pharmacists support is the most important because every 3 months they guide me on what to do and what not do.*

*P13: Yes, every time I have an appointment, they send a van to come and pick me up, so I don't miss my appointment. Also, my case manager was helpful in finding me this place. It's just a room that I rent, but it's better than not having a place or me staying at my son.*

*P13: One time when I didn't have insurance, my social worker helped me get insurance. She helped me complete the application. She was also the one that helped me get food assistance from the welfare office.*

*P1: Oh in terms of everything because he will take me to the doctor's office, he will go for my meds, I don't have to go and pick up my meds; he will say I will go for it. So there's a whole lot of ways.*

Health provider involvement and support is key to adherence to medication and achieving positive health outcomes.

*P10: If the doctor don't give you the right support or confidence you need to take the medication, then you may be feeling somehow you might not want to take it. That will affect you.*

Weak ties social network help in dealing with emergent problems and complications of HIV.

*P12: ... I remember one time I started to have problem with my eye sight as a cause of the virus, and I contacted my doctor immediately. I remember when I*

*went to meet him. He was trying to explain what was happening, and he checked my eyes and said I think I need to contact another doctor to help me. Immediately he contacted another doctor who said we need to take action right away. With no hesitation, my issue was treated as very very urgent. I can still remember, they immediately sent me to Penn Medicine. I was able to meet a set of doctors who were also confused as to what to do with my situation, and they immediately referred me to another doctor...I could see, I could really see the level of urgency and the level of care and how much they took my issue with real seriousness. That really motivated me, cause from where I come from, that is really far from it. So that's what really motivates me.*

**6. Decisions regarding engagement in care is influenced by self-evaluation and by members of strong and weak ties social networks.**

Participants identified the complimentary and critical role of both social networks in their ability to manage their HIV condition and navigate everyday life. While healthcare providers were credited with influencing HIV related care outcomes, close relations (spouses, boyfriends) were equally influential especially with financial support, encouragement and emotional support. P12 emphasized that African community members and agency workers (health care provider and social worker) were equally important to his well-being. Both networks were significant in disease management; health workers provided education and monitoring while close kin provided reinforcement of education and care plans established by health providers.

While engagement in care is highly influenced by the infrastructure of health services, participants make their own decisions based on their own life context and experience.

P4: ... my insurance asked me to choose a hospital near Woodland. I chose the Woodland Clinic. Its close and sometimes I take the bus or sometimes I drive. It's more convenient for me to go there, so I choose there. My insurance was accepted there and they treat me good.

Health providers make recommendations or referrals regarding the places to receive care, participants eventually make their own decisions. Participants valued convenient services much like a *one-stop shop* care model. P9 eventually decided to access care at a convenient location and based on the quality of care experienced.

P7: I do my research and make my own decision. I've always been proactive, and I never would leave it for people to do that for me, I just did it myself.

P10: ...so that decision is mine, and mine alone, because they don't go with me to see my doctor or my nurse...

Recommendations by other members of their support network weigh more heavily on participants' decisions.

P5: Oh yes they do, because if one member of my network goes to a certain healthcare provider and they don't treat them well, then we all move to another one. We just tell each other. If it's a group and you hear that they discuss someone outside the group, we all abandon and leave that group. If they do it to one person, then they are going to do it to you. Yea, so we do really influence each other a lot. Or like, if someone's case manager is better in a different

*organization, then we try it. For example, if my friend says I got my housing in two weeks and you have been waiting for six months, then I go to that case manager.*

Participants identified factors that keep them motivated or engaged in care. Members of both social networks were credited for motivating participants by providing the body of knowledge and comfort for each other, and fostering mutual trust.

Self-perceived state of well-being and promise of longer life, have motivated others. Participants are buoyed by their seemingly normal physical appearance and experience of a normal life made possible by advancements in healthcare and technology, making them hopeful for a cure. They are motivated by opportunities in America and the availability of medication and treatment for HIV.

*P8: You know, if I was diagnosed there [Africa], it would be different, most times they don't even have the medicine. Having HIV in Africa is very different.*

Participants attributed achievement of positive outcomes to the quality of care and the feeling of importance health providers give them. Participant 12 shared his provider's deep concern for his health which in turn motivated him to take care of himself. Participant 5's health provider offered resources and options such as participating in clinical trials and consistent appointment reminders. She notes, *If they don't see me for a week or two, or if I miss my appointment, they call.*

Participants differentiated support from health providers from those given by members of their strong ties social networks.

P5: *They just want to treat the disease. I go there and it's like do you have a cough, yes, so we are going to prescribe this medication. Or do you have an outbreak of herpes, yes, so we are going to do this test. Go to do your lab work.*

P5: *This is different from my case manager and my group because they want to know if I had supper, do I have food in my house. Do I have transport to get back home? Do I have bed bugs in my home, am I able to sleep. Did I break up with my boyfriend, or did I go taking drugs or alcohol again. You know, they care. The human touch, it's not there with the doctors. They just want to treat the illness. They don't ask me if I have friends or if I have been to church. I guess you can call it the human touch that is missing from the clinician, there clinical.*

P10: *Medication has its own area, while emotional support has its own area. Medication has to do with the doctor, the doctor giving you the assurance that look I have been dealing with different types of people, this medication will not give you side effects. If this one changes, or if you have anything, you can also jump into another option of medication. So you can see the support of the doctor is quite different from that of family members. The doctor gives you assurance that even if you have side effects, there is still something they can do. That assurance to and the professional point of view help you a lot to take your medication as when due regularity without thinking of side effect so.*

The clinical expertise of the health provider is a critical distinction of the support they provide. The clinical management of HIV requires a level of expertise that other network members do not provide as they are not clinically trained individuals.



P11: *Well, the influence there is that the doctors will never bring food to my house, but they know the type of food I should be eating. I tell them what I eat and what I like so they so they can put it in my nutritional support area. The doctor is more on the medical side, and knows more of the HIV and stuff like that. But all the others, they know what I like they supply me with things that I like since they know I like eating and eating well.*

Majority of participants describe a level of support and encouragement provided by their health providers that differed from other network members.

P1: *She always gives me motivation on positive things like you are healthier than me.*

P4: *She tells me that beside this, you have no other sickness. You're healthy and I have no other medicine to give you, you can go and keep it up.*

## **Chapter 7: Discussion**

The study examined the influence of social networks on HIV positive African immigrants' HIV related health outcomes using a mixed method approach. This chapter presents the results derived from the triangulation of findings from both quantitative and qualitative methods. The findings reveal that social networks significantly influence participants' well-being and HIV health outcomes.

### **Social Network Characteristics**

Social networks can be defined by traditional characteristics such as size, composition, and density. These characteristics are defined by the number of individuals in one's network, the number of connected relationships found within one's network, and the type of ties (strong or weak ties) in one's social networks. In addition, social networks can be defined by the roles and functions of network members within these social structures. Social networks provide the structure and avenues for support and exchange of information or resources; higher numbers of network membership facilitate greater sharing of information and resources.

### **Network Size**

The mean network size of participants is 3.74, which is higher than those of other HIV subpopulations such as HIV positive Latino and African American women and MSM (mean= 2.5) (Wohl et al, 2010), and HIV positive drug users (mean=1.36) (Kelly, et al, 2006). However, individuals who are not infected with HIV/AIDS tend to have larger social network sizes than those of people living with HIV/AIDS (Kapadia, et al, 2013; Finneran & Stephenson, 2014). Neblett et al, (2011) found the mean network size of 8.81 among African American women at risk of HIV and other sexually transmitted

diseases. Smaller network size among HIV infected individuals may be related to the difficulty in disclosing to network members and fear of negative repercussions from the disclosure on the individual and family members.

Strong ties predominately comprised the social networks of participants which meant close connections and frequent contacts with members. As residents of ethnic enclaves of other African immigrants, participants have closer connections with other Africans who also comprised their strong ties social network. These characteristics may have compensated for the small numbers of network members in their network.

### **Network Composition**

Nearly 80% of participants were from West African countries who immigrated to the US in search of a better life, reunite with family or escape political persecution. These push factors for immigration are consistent with recent trends observed among African immigrants in the US and other countries. The reasons for emigration has shifted from seeking educational opportunities to reunification with family or to seek better economic opportunities (Takougang & Tidjani, 2009; Tuepker et al, 2011; Boon & Ahenkan, 2012).

Strong ties predominately characterized the composition of participants' social network more specifically, family members ( $M = 2.69$ ) and other Africans with whom they have more frequent, face to face contact. The predominant representation of Africans in their social network supports the idea that immigrants often settle in areas of like ethnic communities or enclaves. Ethnic enclaves are communities where members of similar ethnic background are found in higher concentrations. These communities by defacto form social structures or networks for immigrants embedded in these communities. Ethnic enclaves may exert salutary health effects for African immigrants

with low SES who are living with HIV in the US. This is in contrast to the deleterious effects of racial residential segregation observed among Black Americans.

Participants' social networks also comprised of weak ties from outside their kin and co-ethnics including health care workers from HIV-related agencies, services they use, as well as members of support groups they were referred to by health workers.

### **Network Density**

The study revealed that the number of connected relationships or network density was a predictor of Viral Load being undetectable at last measurement. The number of connected ties is explained as network members consisted of primarily family members who are familiar with each other's needs and committed to their kin who are all embedded in an ethnic enclave that values collective ties. Participants receive supportive and meaningful support from network members who are familiar with their needs and support them in adhering with clinic appointments, HIV education, and medication regimen, as well as negotiating with the daily struggle of living with the disease.

### **Social Network Composition, Roles and Functions**

The role of weak and strong social network ties were distinct based on the relationships, and types of activities they engage with participants. Relationships with members of strong ties were primarily more intimate, emotional, social and cultural, as well as instrumental to their survival as an immigrant and HIV-infected individual. Strong ties provided support such as housing, food, transportation and daily expenses. By contrast, relationships with weak ties tended to be more formal and clinical in nature including HIV education, disease management and monitoring, engagement with care and access to programs/services such as housing, transportation for medical

appointments. Weak ties network provided emotional support that was generally related to their disease progression and management.

Consistent with other studies, weak ties often serve as “bridges” with other network members that provide members access to information and resources (Carpenter et al, 2003). Weak ties connected participants to resources and information related to the clinical management of HIV/AIDS, access to healthcare services, and access to non-monetary financial resources such as housing subsidies which have a positive financial impact, particularly as over 70% of participants had annual household incomes below \$25,000. Many studies have explored associations between income level and HIV outcomes, particularly in the areas of continued engagement and adherence with treatment. Low income has been shown to negatively impact engagement or retention in care (Hoffmann et al, 2016; Abara & Heiman, n.d.; Krause et al, 2013). The outcomes of HIV/AIDS as a chronic disease depend on continued engagement in care and strict adherence to treatment.

Participants experienced difficulty in disclosing their HIV status to members of their strong ties network members; some disclosed to members who they believed to be more understanding and accepting. Social stigma and shame associated with HIV were obstacles to disclosure. While these participants admitted that lack of disclosure was not a hindrance to the level of support derived from strong ties, others admitted that disclosure relieved the burden of hiding the disease and enhanced more meaningful support from network members on HIV-specific problems.

Participants recognized that the stigma attached to HIV is lessened by the assurance of access to advanced treatment that makes a difference in their physical

condition and survival. Participants were hopeful for a cure and buoyed by their normal appearance. Such progress seemed impossible in Africa but achievable in the US, supporting their perception that HIV is no longer a death sentence.

Qualitative and quantitative findings support the critical role both types of social networks have on participants' well-being. Strong ties permitted adaptation to the new social milieu, continuity of valued cultural traditions and negotiating with the daily challenges of their HIV condition. Strong ties provided for necessities of daily life such as food, housing, daily amenities, transportation, love, companionship and encouragement.

The quantitative findings revealed that having children, the number of children, and immigrating with family or others were statistically significant to participants' HIV outcomes, specifically CD4 within the last 12 months. HIV poses daily challenges because of its chronic and catastrophic nature requiring ongoing monitoring and management to prevent disability or ultimately death. While majority of participants were of low income with high school education, family members have been providing for their daily existence and continuing engagement with HIV-related care.

This study also identified the significant effect of socializing with strong ties network members and the emotional support they provide. Emotional support has been documented as vital to improving health outcomes in chronic diseases such as HIV/AIDS. This is particularly true in light of the sequential link between barriers such as status disclosure, isolation, or stigma, and individuals remaining in care (Zeligman et al, 2016; Deichert et al, 2008). Social interactions are linked with health outcomes related to quality of life measures including the physical well-being of an individual (Hsueh et al,

2016; Reis et al, 1985; McHugh & Lawlor, n.d; Fry & Barker, 2002; Gonzalez-Saenz de Tejada et al, 2016).

This study revealed that age (majority were on Medicaid because of income and age requirements), type of insurance, frequency of clinic visits and degree of utilization of healthcare services were statistically associated with weak ties social network. Weak ties provided instrumental HIV-related services support such as HIV education, disease monitoring and management. Participants also received encouragement and emotional support directly related to their continued engagement with care such as appointment reminders and arranging for transportation for medical appointments. Participants were guided in accessing and choosing health services by their providers and support group members, which were helpful in making their own decision on where to obtain these services. Connections with weak ties network promoted higher rates of access and utilization of HIV services such as clinic visit adherence, prevention of medication fatigue, coping with life stressors and other social barriers that may hinder ongoing access and use of health services (Maxwell et al, 2001; Parikh et al, 2010; Kempf et al, 2010).

The successful treatment and management of HIV/AIDS requires infected individuals to be actively engaged in care due to the necessary ongoing monitoring of disease progression. Having networks that support engagement in care ultimately impact HIV outcomes. The role and influence of social networks on chronic disease conditions in different ethnic populations have been found to be both positive and negative. However, with regards to HIV/AIDS, social networks were correlated positively with HIV health outcomes (Wohl et al, 2011; Halperin et al, 2013).

Overall, the findings from the study underscores the importance of social networks on the health outcomes of HIV positive African immigrants. The findings reinforce the notion that roles and functions of networks ties, whether strong or weak, are symbiotic and complementary to the well-being of participants. The network characteristics found within the social structures of this population facilitate positive health outcomes in both physical and psychosocial health of this immigrant population.



## **CHAPTER 8: CONCLUSION**

HIV/AIDS continues to be a global public health issue. While much progress has been made in the fight against the disease, Sub-Sahara Africa continues to be one of the hardest hit areas world-wide. In 2015, Sub-Saharan Africa accounted for 65% of all new HIV infections world-wide. The US continues to make significant progress in its efforts to reduce the number of newly infected individuals and to engage in care those who are aware of their status. Globalization and migration from areas hardest hit by HIV calls for the need to maintain vigilance in prevention and disease management.

This study is particularly important as immigrant populations often face obstacles engaging with the healthcare system as well as accessing healthcare services because of language barriers, migration status, and lack of insurance coverage. The added challenge of stigma and shame associated with HIV/AIDS hinder SSA immigrants from accessing and continuing engagement in care. Social networks have been shown to play a significant influence in accessing and utilizing health services and resources, and in achieving positive HIV related health outcomes. Social networks are also important in combating stigma attached to the disease.

Both the quantitative and qualitative findings highlighted the complimentary roles of strong and weak ties towards improving health outcomes of HIV infected SSA participants. Social network members provided HIV-related support such as clinical management of the disease, adherence to medication, access and utilization of healthcare services, and other resources including insurance and housing. The study highlighted that social network members also provide emotional and psychosocial support, as well as companionship/friendship. The extent of activities participants engaged with network

members varied greatly their composition and relationships with participants. Regardless of the type of social network ties, the greater connections with networks positively contributed to participants' well-being through information sharing, socialization, motivation and encouragement to remain engaged in care.

The study sheds light on a critical gap in the clinical understanding of the disease among the study participants. Critical markers of HIV/AIDS progression are CD4 and Viral Load measurements. The results from the quantitative study suggest existence of a knowledge gap on what these markers mean relevant to their disease progression. While all participants were actively engaged in HIV care, 29% and 38% of participants could not recall their CD4 and Viral Load counts, respectively at the last measurement. An overwhelming number of participants who could not recall their CD4 or Viral Load values reported them as “good” or were informed by their clinician as “fine.” In addition, while some participants reported CD4 counts that clinically categorized them as having progressed to AIDS, they reported not having been told of this diagnosis by health providers.

Jones et al, (2013) found that nearly 53% of participants in their study could not recall either their CD4 or Viral Load measures, and only 37% could recall both figures. The authors noted the discrepancy in adherence or engagement in care and HIV knowledge; while 2/3 of individuals were engaged in care, only 1/3 could recall their CD4 or Viral Load measures; chart review of actual laboratory results found that nearly 47% of participants inaccurately reported CD4 or Viral Load values at last measurements.

Viral Load measures inform on the number of HIV copies per milliliter of blood and are generally reported as  $\leq 20$  or undetectable, and  $\geq 20$  as detectable along with the actual number. CD4 measures are expressed in numerical numbers. Since majority of participants have only high school education, it is possible that qualitative descriptors of their condition that mirror their own personal experiences of well-being tend to be more meaningful than numerical representations of their progress. The findings suggest the need for appropriate interpretation of clinical evidence at the level of participants' understanding.

Many participants credited their social network structures as avenues or forum for information exchange and support for the clinical management of their disease. However, their responses do not indicate accurate and full understanding of clinical indicators and disease progression of their condition. Denial of progress to AIDS status may be linked with the stigma and shame attached to the illness reflecting the cultural interpretation of the disease in SSA and among this immigrant population. The study findings suggest further examination of HIV stigma in this population.

### **Study Limitations**

A limitation of the study is that participants were recruited from among individuals engaged to some degree in care; 100% were recruited from agencies with established rapport or clinical relationship with participants. The sample size did not meet the power size of 207, which can be attributed to the difficulty in enrolling the specific target population. As such, the results of the study may not be generalizable to the larger population. Despite the study's limitation, the study adds to the body of research on

factors influencing the health outcomes of HIV positive SSA immigrants particularly on the impact of social networks on HIV outcomes.

### **Recommendations**

The findings suggest that social networks are useful avenues in information dissemination, HIV education, and patient navigation, decisions and engagement with care. These areas are particularly challenging for new immigrants that are harder to reach because of a stigmatized disease. The role of social networks in combating HIV stigma should be further explored, particularly for immigrant populations nested in a different social environment. Healthcare agencies need to assess early patient social network structures and make referrals to groups that facilitate social engagement or exchanges.

As participants rely on strong ties for information and reinforcement of health education received from health workers, there is need for culturally sensitive and appropriate communication with patients and their kin/co-ethnics. Inclusion of members of strong ties social network in HIV education can help ensure effectiveness and accuracy of messages and information. This is particularly significant when dealing with a highly stigmatized disease with varying perceptions and interpretations existing in the population and in larger society in SSA. Direct positive experiences with the healthcare system and workers can make a difference in combating the stigma and fostering hope among patients, their kin and other African immigrants.

Despite majority of participants being settled in the US for periods of over 5 years, many described having network members who resided in Africa or other countries abroad. The current research does not focus on the influence or impact geographic location of network members and impact on health outcomes. One area of future research

would be to examine what influence transnational relationships or transnational network structures have on the health outcomes of immigrants living with HIV in the United States.

In conclusion, this study underscores the importance of recognizing that African immigrant populations bring with them a different set of issues that need to be considered in the provision of HIV-related services in the US. The study also adds to the discourse on the influence of social networks on health outcomes; and opportunities to use these existing structures to address the goals and objectives highlighted in programs and initiatives such as the National HIV/AIDS strategy.

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### **The SNaHO Project:**

- The Social Networks and Health Outcomes (SNaHO) project is a study designed to understand the influence of social networks on access to healthcare services and health outcomes of HIV positive Sub-Saharan African (SSA) immigrants. Data and information gathered from the study will provide insight to the social environments of SSA immigrants and how these social environments influence access and utilization of healthcare services. These insights will allow for better prevention and treatment intervention strategies for this target population.

### **Participating Agencies:**

- Participating agencies will be agencies in the Philadelphia EMA providing a range of services to African immigrants (i.e., healthcare, social service, immigration).

### **Participant Eligibility Requirements:**

- 18 years of age and over
- Self-Identify as originating from SSA
- First generation immigrant receiving health services in the Philadelphia EMA
- Diagnosed as HIV positive for at least one year
- Able to read and/or write English

### **Project Commencement:**

- The SNaHO project is expected to begin participant recruitment in the summer of 2013.

- The estimated data collection period is 3-4 months.

**Description of Procedures:**

- Individuals who participate in the study will have an opportunity to complete a survey instrument. Following completion of the survey instrument, individuals will with an opportunity to participate in an interview session pertaining to their social networks and health outcomes.

**IRB and Human Subjects Protection:**

- IRB approval will be obtained from Rutgers University
- No participant identifiers will be collected.
- Data analysis and reports will be aggregate information without identifying individual participants.

**Researcher Contact Information:**

If you have any questions regarding this study, please contact the researcher at:

Aramide Ayorinde  
PhD Candidate  
Rutgers University  
[rammy506@yahoo.com](mailto:rammy506@yahoo.com)  
Telephone: 609-820-1961

Dr. Dula Pacquiao  
Professor and Dissertation Advisor  
Rutgers University – School of Nursing  
[pacquidf@umdnj.edu](mailto:pacquidf@umdnj.edu)  
Telephone: 973-972-7448 / 973-972-8536

## INVITATION TO TAKE PART IN SNaHO RESEARCH STUDY

**Title of Study:** Social Networks and Health Outcomes (SNaHO) Project

**Principal Investigator:** Aramide Ayorinde, PhD Candidate

**Co-Investigator(s):** Dula Pacquiao, EdD, RN, Jeffrey Backstrand, PhD, Peijia Zha, PhD

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Dear Prospective Participant,

You are being invited to participate in a Social Networks and Health Outcomes (SNaHO) study. The SNaHO study is a two part study being done to understand the influence of social networks on access to healthcare services and health outcomes of HIV positive Sub-Saharan African (SSA) immigrants. You may agree to participate in Part one, or both Part one and two of the study. You are being asked to take a part in the SNaHO study so researchers can better understand the influence of social networks on HIV related health outcomes.

Eligibility requirements for the study are that participants should: be at least 18 years of age, self-identify as originating from sub-Saharan Africa, be a first generation immigrant receiving HIV-related health services, and diagnosed as HIV positive for at least one year.

Part one of the SnaHO study will require you to complete a survey questionnaire. The information collected in the survey will be about your social networks and HIV related health outcomes (CD4 and Viral Load). If you agree to participate, you will be one of 207 subjects recruited from multiple social service and healthcare provider sites in the Philadelphia area. Your participation will last approximately 20-30 minutes to complete the survey. Your verbal agreement to participate, does not give up any of your legal rights by volunteering for this research study. Additional information regarding the study is outlined below.

Part two of the SnaHO study will require you to participate in an individual or group interview session with the researcher, following completion of the survey. During the interview, additional information about your social networks, access to health services and HIV related health outcomes (CD4 and Viral Load) will be collected. Interviews will be recorded and all information collected will be reported as aggregate data. This means that your responses will be grouped with the information from other participants, and you will not be identified individually in any analysis. Only the researcher and co-investigator(s) will have access to your information. Any information published from this research will not include your name or any identifying information.

If you have questions at any time during the research study process, you should feel free to ask them and should expect to be given answers that you completely understand. Additional information regarding the study or your participation is noted below.

**What are the risks and/or discomforts you might experience if you take part in this study?**

The SNaHO study will pose no to very little risk to you. You may feel minimal discomfort providing information regarding your HIV status.

**Are there any benefits for you if you choose to take part in this research study?**

There is no direct benefit to you for participating in this study. If you take part in this study, you may help others in the future who are infected with HIV because we will be able to better understand how individuals utilize their social networks to access health services. This information will guide future HIV/AIDS prevention and treatment programs.

**What are your alternatives if you don't want to take part in this study?**

If you do not want to take part in the study, your only option is not to take part in this study.

**How will you know if new information is learned that may affect whether you are willing to stay in this research study?**

During the course of the study, you will be updated about any new information that may affect whether you are willing to continue taking part in the study.

**Will there be any cost to you to take part in this study?**

There is no cost for you to participate in the study.

**Will you be paid to take part in this study?**

Participants will be paid a monetary incentive for participating. Upon completing the survey (Part 1), participants will receive a \$10.00 gift certificate to a local grocery chain.

Individuals agreeing to participate in individual or group interviews (Part 2), will receive an additional \$20.00 gift certificate to a local grocery chain.

**How will information about you be kept private or confidential?**

All efforts will be made to keep your personal information in your research record confidential, but total confidentiality cannot be guaranteed. Based on these safeguards, the SNaHO study will pose very little risk to you.

1. No personal identifying data will be collected such as name, date of birth, etc.
2. Information sheet and each page of the survey will remind you not to put any personal identifiers.
3. All data collected will be stored in a locked cabinet in the office of the co-investigator at the Rutgers School of Nursing in 65 Bergen Street, Room 1112, Newark, NJ 07101. Only the researcher and the co-investigator(s) will have access to your information.

**What will happen if you do not wish to take part in the study or if you later decide not to stay in the study?**

Participation in this study is voluntary. You may choose not to participate or you may change your mind at any time.

If you do not want to enter the study or decide to stop participating, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled. This research will not in any way change or have an effect on your medical care or your immigration status.

**What are your rights if you decide to take part in this research study?**

You have the right to ask questions about any part of the study at any time.

**Who can you call if you have any questions?**

If you have any questions about taking part in this study or if you feel you may have suffered a research related injury, you can call the principle investigator or co-investigator:

1. Aramide Ayorinde, Principle Investigator  
Email: [rammy506@yahoo.com](mailto:rammy506@yahoo.com)  
Phone: 609-820-1961
2. Dula Pacquiao, EdD, RN, Co-Investigator  
Email: [pacquidf@sn.rutgers.edu](mailto:pacquidf@sn.rutgers.edu)  
Phone: 973-972-8536

If you have any questions about your rights as a research subject, you can call: Rutgers University IRB office at 973-972-3608.

Thank you for your consideration of participating in the SNaHO study.

Social Network and Access to Healthcare Services Questionnaire

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON ANY OF THE FOLLOWING PAGES**

**IF YOU HAVE PREVIOUSLY COMPLETED THIS SURVEY, PLEASE DO NOT  
NEED TO COMPLETE THE SURVEY AGAIN**

Survey #\_\_\_\_\_

## Social Network and Access to Healthcare Services Questionnaire

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

## Section 1 - Demographics:

1. Sex: ☐ Male ☐ Female
  
2. How old are you? (Please check one of the following)
 

<input type="checkbox"/> 18 – 19	<input type="checkbox"/> 40 – 49	<input type="checkbox"/> 70+
<input type="checkbox"/> 20 – 29	<input type="checkbox"/> 50 – 59	<input type="checkbox"/> Don't Know/Not Sure
<input type="checkbox"/> 30 – 39	<input type="checkbox"/> 60 – 69	<input type="checkbox"/> No Answer
  
3. Country of Birth
 

<input type="checkbox"/> Ghana	<input type="checkbox"/> Mali	<input type="checkbox"/> Ivory Coast
<input type="checkbox"/> Nigeria	<input type="checkbox"/> Egypt	<input type="checkbox"/> Zambia
<input type="checkbox"/> Liberia	<input type="checkbox"/> Somalia	<input type="checkbox"/> Kenya
<input type="checkbox"/> Sierra Leone	<input type="checkbox"/> Ethiopia	<input type="checkbox"/> Uganda
<input type="checkbox"/> Togo	<input type="checkbox"/> Chad	<input type="checkbox"/> Tanzania
<input type="checkbox"/> Senegal	<input type="checkbox"/> Guinea	<input type="checkbox"/> Lesotho
<input type="checkbox"/> Zimbabwe	<input type="checkbox"/> South Africa	<input type="checkbox"/> Suna
<input type="checkbox"/> Botswana	<input type="checkbox"/> Cameroon	<input type="checkbox"/> Niger
<input type="checkbox"/> Malawi	<input type="checkbox"/> Madagascar	<input type="checkbox"/> Cape Verde
<input type="checkbox"/> Zaire	<input type="checkbox"/> Other	<input type="checkbox"/> Don't Know/Not Sure
  
4. What is your marital status?
 

<input type="checkbox"/> Single	<input type="checkbox"/> Married
<input type="checkbox"/> Widowed	<input type="checkbox"/> Divorced
<input type="checkbox"/> Separate	
  
5. Do you have any children?
  1. Yes
  2. No
  3. Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

6. How many children do you have?

- ☐ No children  
☐ 1  
☐ 2  
☐ 3 or more

7. Do you live with your children?

- 1 . Yes  
 2 . No  
 3 . Don't Know/Not Sure

8. What is your individual income?

- |  |  |
|--|--|
| <input type="checkbox"/> \$0 - \$9,999       | <input type="checkbox"/> \$50,000 - \$54,999 |
| <input type="checkbox"/> \$10,000 - \$14,999 | <input type="checkbox"/> \$55,000 - \$59,999 |
| <input type="checkbox"/> \$15,000 - \$19,999 | <input type="checkbox"/> \$60,000 - \$64,999 |
| <input type="checkbox"/> \$20,000 - \$24,999 | <input type="checkbox"/> \$65,000 - \$69,999 |
| <input type="checkbox"/> \$25,000 - \$29,999 | <input type="checkbox"/> \$70,000 - \$74,999 |
| <input type="checkbox"/> \$30,000 - \$34,999 | <input type="checkbox"/> \$75,000 - \$79,999 |
| <input type="checkbox"/> \$35,000 - \$39,999 | <input type="checkbox"/> \$80,000 - \$84,999 |
| <input type="checkbox"/> \$40,000 - \$44,999 | <input type="checkbox"/> \$85,000+           |
| <input type="checkbox"/> \$45,000 - \$49,999 | <input type="checkbox"/> Don't Know/Not Sure |

9. What is your household income?

- |  |  |
|--|--|
| <input type="checkbox"/> \$0 - \$9,999       | <input type="checkbox"/> \$50,000 - \$54,999 |
| <input type="checkbox"/> \$10,000 - \$14,999 | <input type="checkbox"/> \$55,000 - \$59,999 |
| <input type="checkbox"/> \$15,000 - \$19,999 | <input type="checkbox"/> \$60,000 - \$64,999 |
| <input type="checkbox"/> \$20,000 - \$24,999 | <input type="checkbox"/> \$65,000 - \$69,999 |
| <input type="checkbox"/> \$25,000 - \$29,999 | <input type="checkbox"/> \$70,000 - \$74,999 |
| <input type="checkbox"/> \$30,000 - \$34,999 | <input type="checkbox"/> \$75,000 - \$79,999 |
| <input type="checkbox"/> \$35,000 - \$39,999 | <input type="checkbox"/> \$80,000 - \$84,999 |
| <input type="checkbox"/> \$40,000 - \$44,999 | <input type="checkbox"/> \$85,000+           |
| <input type="checkbox"/> \$45,000 - \$49,999 | <input type="checkbox"/> Don't Know/Not Sure |



**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

10. What was the highest level of formal education you received in Africa?

- ☐ No formal education
- ☐ Some elementary school or elementary school completed
- ☐ Some high school
- ☐ High school graduate
- ☐ Trade school or apprenticeship training
- ☐ Some college
- ☐ College diploma or certificate
- ☐ Some university
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Degree in medicine, law or other advanced degree
- ☐ Doctorate
- ☐ Other
- ☐ Don't Know/Not Sure

11. What is the highest level of formal education you received here in the US?

- ☐ No formal education
- ☐ Some elementary school or elementary school completed
- ☐ Some high school
- ☐ High school graduate
- ☐ Trade school or apprenticeship training
- ☐ Some college
- ☐ College diploma or certificate
- ☐ Some university
- ☐ Bachelor's degree
- ☐ Master's degree
- ☐ Degree in medicine, law or other advanced degree
- ☐ Doctorate
- ☐ Other
- ☐ Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

12. What was your most important reason for immigrating to the US?

<input type="checkbox"/> Educational	<input type="checkbox"/> Unite with Family/Relatives
<input type="checkbox"/> Financial/Economic	<input type="checkbox"/> Political
<input type="checkbox"/> Quality of Life	<input type="checkbox"/> Access to Healthcare
<input type="checkbox"/> Religious	<input type="checkbox"/> Other _____
<input type="checkbox"/> Don't Know/Not Sure	

13. How long ago did you immigrate to the US?

<input type="checkbox"/> less than a year	<input type="checkbox"/> 11 - 14 years
<input type="checkbox"/> 1 - 5 years	<input type="checkbox"/> 15 - 19 years
<input type="checkbox"/> 6 - 10 years	<input type="checkbox"/> 20+
<input type="checkbox"/> Don't Know/Not Sure	

14. When you first came to the U.S. to live, did any of the following travel with you?

<input type="checkbox"/> Family Member(s) Only	<input type="checkbox"/> Came Alone
<input type="checkbox"/> Friend(s) Only	<input type="checkbox"/> Both Friends and Family
<input type="checkbox"/> Don't Know/Not Sure	

15. When you first came to the U.S. to live, did you have family or friends already living here?

<input type="checkbox"/> Family Member(s) Only	<input type="checkbox"/> Came Alone
<input type="checkbox"/> Friend(s) Only	<input type="checkbox"/> Both Friends and Family
<input type="checkbox"/> Don't Know/Not Sure	

16. Do you currently have health insurance?

1. Yes
2. No
3. Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

17. What type of health insurance do you currently have?

- 1 . Private (Health insurance through employer, family member or insurance you purchased)
- 2 . Medicare
- 3 . Medicaid
- 4 . VA Insurance
- 5 . I have no insurance
- 6 . Other\_\_\_\_\_

18. Are you HIV positive?

1. Yes
2. No
3. Don't Know/Not Sure

19. Have you been diagnosed as having AIDS?

1. Yes
2. No
3. Don't Know/Not Sure

20. Where were you diagnosed as having HIV/AIDS?

1. In Africa
2. In US
3. Other Country
4. Don't Know/Not Sure

21. How long ago were you diagnosed as HIV positive?

- 1 . 0 – 6 months
- 2 . 6months – 1 year
- 3 . 1 year – 5 years
- 4 . 5 years or more

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

22. Where was the place of your first positive HIV test?

1. Clinic/MD's office
2. Hospital
3. Anonymous test site
4. Other
5. Don't Know/Not Sure

23. How well informed are you about HIV/AIDS?

1. Much better than most
2. Somewhat better than most
3. About as well as most
4. Somewhat/much less than most
5. Don't Know/Not Sure

24. Have you ever been prescribed or treated with HIV medications in Africa or in any other country other than the US?

1. Yes
2. No
3. Don't Know/Not Sure

25. Have you ever been prescribed or treated with HIV medications in the US?

1. Yes
2. No
3. Don't Know/Not Sure

26. About how long has it been since you last visited a doctor for a monitoring check up for your HIV? A monitoring checkup is an exam for your HIV which may have included the following: (monitoring labs, medication adherence, medication reconciliation, HIV related issue, etc)

1. Within past year (anytime less than 12 months ago)
2. Within past 2 years (1 year but less than 2 years ago)
3. Within past 5 years (2 years but less than 5 years ago)
4. 5 or more years ago
5. Never
6. Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

27. In the past month, did you take any of your HIV prescribed medications?

- 1 . Yes
- 2 . No
- 3 . Don't Know/Not Sure

28. What is your lowest documented CD4 count?

1. (>500)
2. 200-499
3. 50-199
4. 0-49
5. Don't Know/Not Sure

29. What is your current CD4 count?

1. (>500)
2. 200-499
3. 50-199
4. 0-49
5. Don't Know/Not Sure

30. How long ago did you have your current CD4 count taken?

- 1 . Less than 3 months
- 2 . 3-6 months
- 3 . 6-12 months
- 4 . Over a year
- 5 . Don't Know/Not Sure

31. Is your viral load less than 20 (<20) or undetectable?

1. Yes
2. No
3. Don't Know/Not Sure

32. Does anyone know you are HIV positive?

1. Yes
2. No
3. Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

33. Have you disclosed your HIV status to? (Mark all that apply)

- |                        |                              |                             |
|------------------------|------------------------------|-----------------------------|
| 1. Family              | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Friends             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Ethnic Organization | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Other Agency        | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Community Members   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Don't Know/Not Sure |                              |                             |

34. In general, have you ever talked about HIV/AIDS with...

- |                        |                              |                             |
|------------------------|------------------------------|-----------------------------|
| 1. Family              | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 2. Friends             | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 3. Ethnic Organization | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 4. Other Agency        | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 5. Community Members   | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| 6. Don't Know/Not Sure |                              |                             |

35. All things considered, how would you describe your health?

1. Excellent
2. Very good
3. Good
4. Fair
5. Poor
6. Don't Know/Not Sure

**DO NOT WRITE YOUR NAME OR ANY IDENTIFYING INFORMATION  
ABOUT YOU ON THIS PAGE**

Section 2 – Social Networks

36. Make a list of the people whom you consider to be important in your life. **Please use only their initials or nickname.** Next indicate each person's relationship to you (e.g. family, friend, neighbor, community member, agency worker, other). Then, for each person, indicate whether you engage in one type of activity with them or more than one type of activity by checking the appropriate column. You might want to consider such activities as going shopping, talking about problems, socializing, working together, etc. Please think about each person separately.

Initial of Individual Important in Your Life (i.e., Jane Doe would be JD)	Relationship to You (Select Only One)	Activity Engagement (Select Only One)
1. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
2. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
3. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
4. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
5. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
6. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
7. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
8. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
9. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
10. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
11. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
12. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
13. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
14. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
15. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
16. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
17. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
18. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
19. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual
20. _____	<input type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Neighbor <input type="checkbox"/> Church Member <input type="checkbox"/> Community member <input type="checkbox"/> Agency worker <input type="checkbox"/> Co-Worker <input type="checkbox"/> Other	<input type="checkbox"/> Engage in 1 Type of Activity with this individual <input type="checkbox"/> Engage in More than 1 Type of Activity with this individual

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37. Now think very carefully about each of the following five types of support or assistance that you might get from the people in your list. Please rate each in terms of how important it is for you to have this type of support. Rate each on a scale from 1 to 5. A rating of 1 should be given to the types of support that are unimportant to you (i.e. not having this support would not be too critical for you), and a rating of 5 should be given to those types of supports that are very important for you to have. Use ratings between 2 and 4 for those types of support that are moderately important to you.

	Completely Unimportant	Somewhat Unimportant	Neither Important nor Unimportant	Somewhat Important	Very Important
1. To be able to get advice.	1	2	3	4	5
2. To get criticism or praise (i.e. social reinforcement.	1	2	3	4	5
3. To have friends to socialize and party with.	1	2	3	4	5
4. To be able to get help for specific problems when needed.	1	2	3	4	5
5. To receive emotional support.	1	2	3	4	5







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40. Please go back to your original list of important people and indicate which ones have relationships with other persons on your list independent of their relationships with you. Take each person separately and count the number of relationships they have with (1) persons who are your relatives, (2) persons who you described as friends, (3) community member, (4) agency worker, and (5) other. Write the appropriate number beside each name and column.

<b>Person 1</b>	<b>Person 2</b>	<b>Person 3</b>	<b>Person 4</b>
# of relatives _____	# of relatives _____	# of relatives _____	# of relatives _____
# of friends _____	# of friends _____	# of friends _____	# of friends _____
# of neighbors _____	# of neighbors _____	# of neighbors _____	# of neighbors _____
# of community members _____	# of community members _____	# of community members _____	# of community members _____
# of agency workers _____	# of agency workers _____	# of agency workers _____	# of agency workers _____
# of others _____	# of others _____	# of others _____	# of others _____
<b>Person 5</b>	<b>Person 6</b>	<b>Person 7</b>	<b>Person 8</b>
# of relatives _____	# of relatives _____	# of relatives _____	# of relatives _____
# of friends _____	# of friends _____	# of friends _____	# of friends _____
# of neighbors _____	# of neighbors _____	# of neighbors _____	# of neighbors _____
# of community members _____	# of community members _____	# of community members _____	# of community members _____
# of agency workers _____	# of agency workers _____	# of agency workers _____	# of agency workers _____
# of others _____	# of others _____	# of others _____	# of others _____
<b>Person 9</b>	<b>Person 10</b>	<b>Person 11</b>	<b>Person 12</b>
# of relatives _____	# of relatives _____	# of relatives _____	# of relatives _____
# of friends _____	# of friends _____	# of friends _____	# of friends _____
# of neighbors _____	# of neighbors _____	# of neighbors _____	# of neighbors _____
# of community members _____	# of community members _____	# of community members _____	# of community members _____
# of agency workers _____	# of agency workers _____	# of agency workers _____	# of agency workers _____
# of others _____	# of others _____	# of others _____	# of others _____
<b>Person 13</b>	<b>Person 14</b>	<b>Person 15</b>	<b>Person 16</b>
# of relatives _____	# of relatives _____	# of relatives _____	# of relatives _____
# of friends _____	# of friends _____	# of friends _____	# of friends _____
# of neighbors _____	# of neighbors _____	# of neighbors _____	# of neighbors _____
# of community members _____	# of community members _____	# of community members _____	# of community members _____
# of agency workers _____	# of agency workers _____	# of agency workers _____	# of agency workers _____
# of others _____	# of others _____	# of others _____	# of others _____
<b>Person 17</b>	<b>Person 18</b>	<b>Person 19</b>	<b>Person 20</b>
# of relatives _____	# of relatives _____	# of relatives _____	# of relatives _____
# of friends _____	# of friends _____	# of friends _____	# of friends _____
# of neighbors _____	# of neighbors _____	# of neighbors _____	# of neighbors _____
# of community members _____	# of community members _____	# of community members _____	# of community members _____
# of agency workers _____	# of agency workers _____	# of agency workers _____	# of agency workers _____
# of others _____	# of others _____	# of others _____	# of others _____

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41. Please rate each person on your list in terms of which of the following statements best describes the quality of your relationship with them. Please rate each person carefully and honestly.

- 1 --- They usually give me a lot of support, but rarely cause me any stress
- 2 --- They usually give me some support, but occasionally also cause me some stress
- 3 --- They occasionally cause me stress, and occasionally also give me support
- 4 --- They usually cause me some stress, but occasionally also give me a little support
- 5 --- They usually cause me a great deal of stress but rarely give me any support

[illegible]

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42. For each item in column 1, please rank from 1 to 6 how individuals from your social networks have helped or supported you as it relates to your HIV diagnoses. **1 represents individuals being the most helpful and 8 being the least helpful.** Below is an example on how to complete the following question.

	Family	Friends	Co- Ethnic s	Neighbors	Church Member s	Healthcare Agency Worker, (Doctor, Case Manager, Nurse, Nurse Case Manager)	Other Type of Agency Worker (Social Worker, Case Manager)	Other
<b>Example</b>	Family	Friends	Co- Ethnic s	Neighbors	Church Member s	Healthcare Agency Worker, (Doctor, Case Manager, Nurse, Nurse Case Manager)	Other Type of Agency Worker (Social Worker, Case Manager)	Other
<b>Picking up or Picking up Meds</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>8</b>	<b>6</b>	<b>5</b>	<b>4</b>	<b>7</b>
<b>Transportatio n to your HIV doctor's office</b>								
<b>Understandin g your HIV diagnosis</b>								
<b>Going with you to your medical appointment</b>								
<b>Understandin g your HIV labs</b>								
<b>Translating</b>								

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Section 3: Access and Utilization

43. About how long has it been since you have had a routine check-up by a doctor or other health professional? A routine check-up is a visit with a doctor or other health professional for assessing overall health, usually **not** prompted by a specific illness or complaint.

1. WITHIN PAST YEAR
2. WITHIN PAST 2
3. WITHIN PAST 3
4. WITHIN PAST 5
5. MORE THAN 5 YEARS
6. NEVER
7. REFUSED
8. DON'T KNOW

44. Is there a particular doctor's office, clinic, health center, or other place that you usually go if you are sick or need advice about your health?

1. YES
2. NO
3. MORE THAN ONE PLACE
4. REFUSED
5. DON'T KNOW

45. Is your usual source of care a clinic in a hospital, a hospital outpatient department, an emergency room at a hospital, or some other kind of place?

1. HOSPITAL CLINIC OR OUTPATIENT DEPARTMENT
2. HOSPITAL EMERGENCY ROOM
3. OTHER KIND OF PLACE
4. REFUSED
5. DON'T KNOW

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46. If you do not have a usual source of care, what is the **main** reason you do not have a usual source of health care?
1. SELDOM OR NEVER GETS SICK
  2. RECENTLY MOVED INTO AREA
  3. DON'T KNOW WHERE TO GO FOR CARE
  4. USUAL SOURCE OF MEDICAL CARE IN THIS AREA IS NO LONGER AVAILABLE
  5. CAN'T FIND A PROVIDER WHO SPEAKS MY LANGUAGE
  6. LIKE TO GO TO DIFFERENT PLACES FOR DIFFERENT HEALTH NEEDS
  7. JUST CHANGED INSURANCE PLANS
  8. DON'T USE DOCTORS/TREAT MYSELF
  9. COST OF MEDICAL CARE
  10. NO HEALTH INSURANCE
  11. REFUSED
  12. DON'T KNOW
47. In the past 12 months, how many times have you seen your doctor/provider regarding your HIV? \_\_\_\_\_

## Social Networks and Health Outcomes (SNaHO) Interview Protocol

### **Facilitator's Guide**

#### **INTRODUCTION**

Thank you for agreeing to participate in the SNaHO project. The purpose of the SNaHO project is to understand what influence social networks may have on HIV related health outcomes and access to health services.

I will be asking you a few questions pertaining to your HIV status, your social networks, and access to healthcare services. I would like you to respond to my questions freely, honestly, and completely. Your responses will provide information that will help develop HIV/AIDS prevention messages in the African community.

This interview session will be conducted by one investigator. Your responses will be audio-recorded to capture your own words and for the interviewer to listen intently to your responses. No one other than my dissertation advisor and study co-investigators will have access to the tape recordings. Please note that your participation in this interview will remain confidential and that no personal identifiers will be collected during the interview and will not be used in reporting the study results.

Before we begin, do you have any questions?

May we now begin?



## Facilitator's Guide SNaHO Project

### Interview Guide

I will now ask you questions about your social networks, which can include, family members, friends, neighbors, community members, and agency workers.

- 1 . How many people would you consider most important to you? What is your relationship with them? In what ways do they help you?

Probe(s):

- a. How do they relate to you?*
- b. What types of activities or things do you do with them?*
- c. Are the individuals you mentioned living primarily here in the US or back in your home country?*
- d. How often do you communicate with these individuals?*
- e. Could you talk about the support you have received from these individuals?*
- f. Are members of your network primarily of the same ethnic background as you?*
- g. Are they mainly family, friends, neighbors, community members, agency workers or other?*
- h. Which individuals in your social network did you share your HIV status?*

2. How do these individuals influence your ability to disclose your illness, seek care or maintain continuity of care? Could you talk about the support or lack of support you have received from anyone in your social network as it relates to your HIV diagnosis?

Probe(s):

- a. In what ways have the individuals you mentioned supported you as it relates to your HIV disease? (This level of support can be emotional, financial, and physical (such as taking you to your doctor's visit)).*
- b. In those areas of support, which is most important to you and why?*
- c. Has this level of support remained the same or changed? Why did it change?*
- d. What support do you provide for them in return? How do you maintain this level of reciprocity with them?*
- e. Within your social network, whom would you say has been most helpful as it relates to your HIV care and why?*

- f. What kind of support do they give in other areas unrelated to your HIV condition? Do you feel more supported in these areas than in those related with your HIV condition?*
- g. Do members of your social networks influence where you receive healthcare services?*
- h. Can you describe how members of your social network influence or inhibit where you access healthcare services?*

3. Which particular groups of people in your network are important in keeping yourself healthy? In what way do they do this? What factors keep you engaged in your care (these factors may include family, friends, provider influence)?

Probe(s):

- a. Do members of your social networks keep you engaged in care, and if so, can you describe how they keep you engaged?*
- b. Give examples of how members of your network helped you access health care services for HIV?*

4. In what way have these people influenced your HIV outcomes? Please describe any influence members of your network have on your HIV outcomes? These outcomes can be related to viral suppression, medication compliance, visit compliance, etc.

Probe(s):

- a. In what way have members of your network affect your achieving positive health outcomes? In what way have they deterred you from achieving positive health outcomes?*
- b. Differentiate the influence by your healthcare providers from that of other members of your social network?*
- c. Which of these individuals have the most positive influence on your achieving optimal HIV outcomes?*