

2015

Stories of Challenge and Resilience: The Impact of Ecological Factors on the Lived Experiences of Low Income, Urban Young Adults Living with HIV/AIDS

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Stories of Challenge and Resilience: The Impact of Ecological Factors on the Lived
Experiences of Low Income, Urban Young Adults Living with HIV/AIDS

by

Kathleen Anne Thoma

A dissertation submitted to the Department of Leadership, School Counseling,
and Sport Management

in partial fulfillment of the requirements for the degree of

Doctor of Education

UNIVERSITY OF NORTH FLORIDA

COLLEGE OF EDUCATION AND HUMAN SERVICES

November, 2015

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Dedication

I would like to dedicate this effort to my parents: my mother, Ramona King Thoma, who was a life-long educator and always inspired me to keep learning, and my father, James Henry Thoma, who always inspired me to do my best.

Acknowledgments

I would like to acknowledge and thank the following individuals for their continuous assistance and support during this wondrous learning experience:

- My dissertation chair, Dr. Francis Godwyll, for his positive attitude, motivating spirit, and supportive assistance. He went above and beyond with his time and helpfulness and I will always be grateful.
- My dissertation committee members, Dr. Jerry Johnson, Dr. Sophie Maxis, and Dr. Jeffry Will, for giving their valuable time, support, and guidance.
- The Graduate College at the University of North Florida for awarding me a research grant to support this project.
- My husband, Dr. James Stittsworth, for his support, words of wisdom, editing help, and general assistance during this long process.
- My family, especially my children, Shannon and Shaun (who allowed me to practice my interview techniques on him and his friends), my father, Jim, my brother, Jim, my stepdaughters, Toni, Melissa, and Jessica, and their families, my sister and brother-in-law, Royce Ann and David, my cousin, Nancy, and my wonderful pets.
- Alma Biba, Dr. Tabetha Gayton, Dr. Tina Holland, Dr. Mobeen Rathore, Dr. Paul Sammak, Christine Tyler, and Dr. Ann Usitalo for their valuable ideas and support.
- The members of Cohort 17 for their comradery along the way.
- The outstanding UNF faculty who taught the classes for Cohort 17.
- The study participants for their willingness to share their heart-felt stories of challenge and resilience. Listening to them changed and enriched my life. I hope that others may learn about their lives through this study.

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Abstract

Transitioning to adulthood is a challenging experience for all young adults, but especially for those who are living with HIV/AIDS and residing in low income, urban areas. Young adults, particularly those who live in low income, urban areas, have the highest rate of new HIV cases among all age groups in the United States. The purpose of this study was to examine the lived experiences of a purposive sample of young adults living with HIV/AIDS who resided in a selected low income, urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping. This is an important topic because this age group has the highest rate of new HIV cases. Decreasing HIV health disparities is a top priority of the U.S. Office of AIDS Research, the National HIV/AIDS Strategy, and Healthy People 2020.

Semi-structured, in-depth interviews were conducted on a purposive sample of 16 young adults 18-29 years of age living with HIV/AIDS from a selected low income, urban area in the southeast region of the United States. Data from the interviews were analyzed for significant statements, meanings, and themes. Major challenges and barriers indicated by the participants included issues related to mental health, stigma and disclosure, relationships, marriage and children, inadequate health/sex education in the schools, lack of HIV/AIDS knowledge in their communities, and medication adherence. Major strengths and supports included internal resilience and positive attitudes, small support networks of family and friends, HIV support groups, and an array of available medical and support services. Participants' suggestions for improving the lives of young adults living with HIV/AIDS included integrating HIV/AIDS services with other services, enhancing mental health services, particularly at the time of diagnosis,

providing assistance when disclosing their HIV status to others, enhancing health/sex education in the schools, increasing community education about HIV/AIDS, using motivational speakers to educate other young adults, creating community resource centers for those living with HIV/AIDS, and conducting more research studies on the topic. This information may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services and policies to help this group transition to adulthood, care for themselves, and prevent transmission of the virus to others.

Chapter 1: Introduction

Young adults who live in low income, urban areas in the United States often face numerous challenges including high rates of unemployment, lower performing schools that are often under-resourced, poor access to health care, and higher morbidity (disease) and mortality rates (Haushofer & Fehr, 2014; Santiago, Wadsworth, & Stump, 2011; Storer et al., 2012; Viner et al., 2011). They also often experience greater exposure to gangs, violence and illegal drugs, more environmental toxins, less green areas for recreation, and a greater concentration of fast food establishments, convenient marts, and liquor stores (Goldsmith & Blakely, 2010; Lee & Maheswaran, 2011; Shimotsu et al., 2012; Walker, Keane, & Burke, 2010). The U.S. Census Bureau defines low income, areas as census tracts with poverty rates of 20% or more (Bishaw, 2011). Young adults who live in these areas are more likely to live below the federal poverty line, experience higher high school dropout rates and lower overall educational achievement rates, have higher incarceration rates, have less social and political power, and experience higher mortality and morbidity (disease) rates (Biddle, 2013; Bishaw, 2011; Nkansah-Amankra, Agbanu, & Miller, 2013). All of these social factors have a direct impact on their lives.

One of the most disturbing health trends among young adults is that recent data from the Centers for Disease Control and Prevention (CDC, n.d.c.) indicated that the age group with the highest rate of new HIV diagnoses in the United States in 2011 was 20-24 year olds at 36.4 per 100,000. The age group with the second highest rate of new HIV

cases was young adults 25-29 years of age (35.5 per 100,000). Additionally, the rate of new HIV cases among African American young adults was higher than among other races/ethnicities. In 2012, the rate of new HIV cases for African Americans 20-24 years of age was 141.3 per 100,000 compared to 43.2 for mixed race young adults, 34.0 for Hispanic young adults, and 12.0 for Caucasian young adults. There was a similar trend among young adults 25-29 years of age. The CDC also reported that HIV is more concentrated among urban areas and in the southern region of the United States (CDC, n.d.c.). Therefore, young adults who live in urban areas in the southern region of the United States, especially African Americans, are at the highest risk for contracting HIV.

Transitioning to adulthood is a challenging experience for all young adults. It is especially challenging for those who live in low income, urban areas and are burdened by a highly stigmatized chronic health condition like HIV/AIDS. A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

Background and Conceptualization of the Issue

HIV/AIDS

Because this study concerns young adults living with HIV/AIDS, it is important to understand some basic information about HIV/AIDS. Even though the death rate from AIDS has decreased significantly since the 1980s and 1990s due to the advent of more effective medications, HIV/AIDS is still considered to be a serious medical condition with many behavioral, cultural, social, psychological, and biological ramifications (Samji

et al., 2013). As of 2012, there were approximately 1,200,000 people living in the United States with the HIV virus (CDC, n.d.c; CDC, 2015). The number of annual new HIV cases has remained steady at approximately 50,000 per year for the last 10 years.

Young adults 18-29 years of age have the highest rate of new HIV cases among all age groups (CDC, n.d.c.). In 2012, 80% of new adolescent and adult HIV cases were among men and 20% were among women. Among men, 81% of the new cases were transmitted by men having sex with men, 10% by heterosexual contact, 5% through sharing injection drug equipment, 3% through a combination of above, and less than 1% through other means such as blood transfusion, perinatal transmission or unknown. Among women, 87% of the new cases were transmitted through heterosexual contact, 12% through sharing injection drug equipment, and 1% through other means such as blood transfusion, perinatal transmission or unknown. Additionally, minorities, individuals who live in urban areas and people who live in the southern region of the United States had higher rates of infection than other groups.

Acquired Immunodeficiency Syndrome (AIDS) is a condition caused by the Human Immunodeficiency Virus (HIV) which destroys the body's immune system (Quinn, 2011). The HIV virus lives in blood, pre-semen, semen, rectal fluids, vaginal fluids, and breast milk. It is transmitted by having sex with an HIV-positive person, sharing needles with an HIV-positive person, and receiving a blood transfusion or organ donation from an HIV-positive person. It can also be transmitted from an HIV-positive mother to her baby during pregnancy, childbirth, and breastfeeding.

When someone initially acquires HIV, there is an acute phase that lasts 2-4 weeks during which the virus replicates rapidly in the body and begins to destroy primarily the

CD4 cells (T-helper cells of the immune system) (Quinn, 2011). Some individuals may experience flu-like symptoms during this phase while other people have no symptoms. The body's immune system counteracts the infection process by acting to bring down the amount of virus to a stable level and the individual enters a latent phase which can last up to 10 years. Individuals may or may not experience symptoms during this latent phase but the virus continues to silently destroy the immune cells during this time. If left untreated, an HIV-positive person eventually moves into the AIDS stage which occurs when the CD4 cell count falls below 200 cells per cubic millimeter of blood or a serious opportunistic infection develops such as pneumocystis pneumonia, tuberculosis, or toxoplasmosis.

In the early 1980s before treatment was available, most people who were diagnosed with AIDS only lived an average of 20 months (Lifson, Hessel, & Rutherford, 1992). The rate of new HIV cases along with the mortality rate increased steadily until the mid-1990s when Highly Active Antiviral Therapy (HAART) was invented (Ives, Gazzard, & Easterbrook, 2001). Highly Active Antiviral Therapy is a combination of antiviral medications that work by reducing the level of the HIV virus in the body, thus preserving the body's immune system and delaying the progressions to AIDS. Since the invention of HAART, the mortality rate from HIV/AIDS has decreased dramatically. If HAART treatment is begun in the latent stage, individuals living with HIV/AIDS can now live close to an average lifespan, with female and Caucasian individuals living the longest (Harrison, Song, & Zhang, 2010; Van Sighem, Gras, Reiss, Brinkman, & de Wolf, 2010). Therefore, it is very important to diagnose and treat HIV as early as possible.

In 1981, the CDC reported that small groups of Caucasian homosexual males in several major U.S. cities were dying of rare cases of cancer and pneumonia (CDC, 1981). The condition was initially referred to as “GRID” or “Gay-related Immune Deficiency” (Horowitz, Benson, Gottlieb, Davos, & Bentson, 1982). The CDC identified gay males, Haitian immigrants, injection drug users, and hemophiliacs as the high risk groups for contracting the virus. At this time, individuals who were diagnosed with AIDS only lived an average of 20 months (Lifson, Hessol, & Rutherford, 1992). There was a great deal of hysteria and confusion surrounding HIV/AIDS at the beginning of the epidemic (Shilts, 1987).

In 1983, the French Pasteur Institute (Barré-Sinoussi et al., 1983) and the National Institutes of Health (Gallo et al., 1984) announced the discovery of the virus that caused the infection which they called the Human Immunodeficiency Virus (HIV). The CDC renamed the condition AIDS or Acquired Immunodeficiency Syndrome (CDC, 2011). Female partners of men with HIV were added as a high risk group for contracting the virus. The first documented cases of women living with HIV/AIDS passing the virus to their infants during pregnancy, labor, and delivery were reported in 1983. Congress enacted the Orphan Drug Act in order to encourage pharmaceutical companies to design medications to fight AIDS and other rare health conditions (Arno, Bonuck, & Davis, 1995, USDHHS, n.d.k.). Other types of policies and funding in the early 1980s for HIV/AIDS were slow to emerge. There was a great deal of stigma surrounding the condition because it was most prevalent in groups that were considered socially unacceptable at the time; namely homosexual males and injection drug users (Shilts, 1987).

By 1986, approximately 425,000 Americans were living with HIV/AIDS and 5,000 Americans died from AIDS that year (CDC, n.d.d.; see Figure 1 and Figure 2). The Health Resources and Services Administration (HRSA) responded to the situation by awarding \$15.3 million for AIDS Service Demonstration Grants (HRSA, n.d.b.). The first medication to treat AIDS, azidothymidine or AZT, was approved for use in 1987 and HRSA instituted the AZT Drug Reimbursement Program for people who could not afford the medication (HRSA, n.d.c.). However, AZT only delayed the progression of HIV into AIDS for a short time and the death rate continued to increase.

Research conducted in 1994 found that using AZT during the pregnancy and delivery of women living with HIV/AIDS reduced the rate of transmission of the virus to the baby to less than 2% (Connor et al., 1994). By 1995, the number of Americans living with HIV/AIDS had almost doubled and the number of annual deaths from AIDS peaked at 50,000 (CDC, n.d.d.). A major breakthrough came in 1996 in the form of new medications called HAART or Highly Active Antiretroviral Therapy which drastically reduced the progression of HIV infection to AIDS (Palella et al., 1998) The number of AIDS-related deaths decreased to 30,000 by 1997 (Granich et al., 2015; see Figure 1 and Figure 2). It has steadily decreased since that time to approximately 15,000 deaths per year.

Below are two graphs that show the total number of individuals living with HIV/AIDS from 1981 through 2011 and the number of individuals who died from AIDS from 1981 through 2011 (see Figures 1 and 2). Figure 2 shows the impact that the introduction of HAART had on lowering the number of deaths from AIDS.

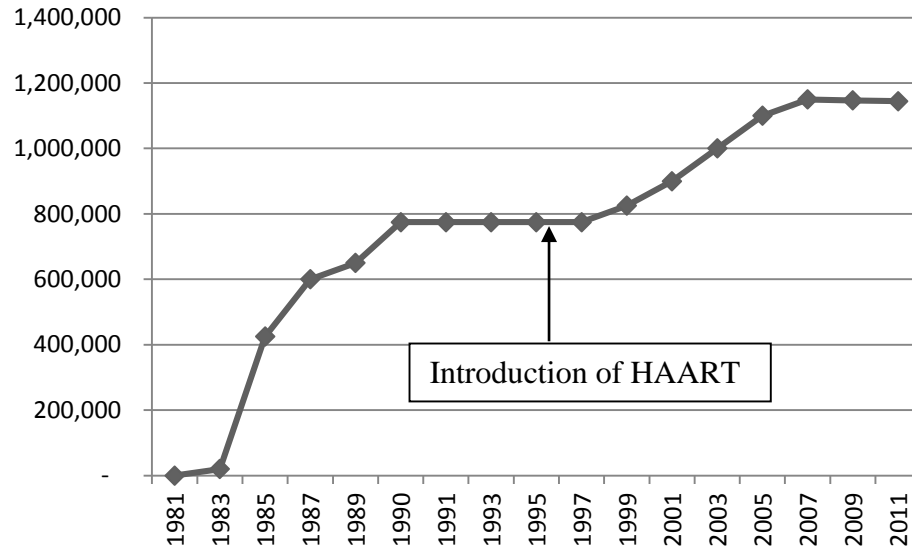


Figure 1. The total number of individuals living with HIV/AIDS by year in the United States. Adapted from “HIV in the United States: At a glance,” Centers for Disease Control and Prevention, n.d.d., retrieved from <http://www.cdc.gov/hiv/statistics/basics/ataglace.html>.

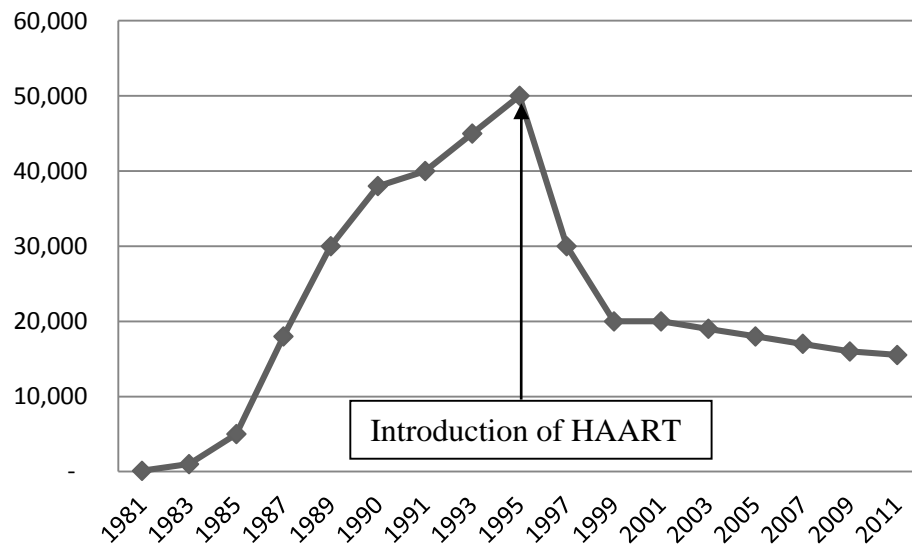


Figure 2. The number of reported deaths from AIDS by year in the United States. Adapted from “HIV in the United States: At a glance,” Centers for Disease Control and

Prevention, n.d.d., retrieved from <http://www.cdc.gov/hiv/statistics/basics/ataglance.html>.

In 2000, the CDC announced that the rate of HIV cases among African American and Hispanic males had exceeded the rate for Caucasian males in the United States for the first time (CDC, 2006b). By 2013, 55.9% of all new HIV diagnoses were among African Americans, 18.7% were among Hispanics, and 6.6% were among Caucasians (CDC, 2015). Research by epidemiologists at the CDC indicated that poverty, poor access to testing, diagnosis, and healthcare, lower levels of education, and homophobia fueled the increase among low income minorities. This is an example of how social factors impacted the distribution of HIV/AIDS.

The current goals of the CDC and the U.S. Department of Health and Human Services (USDHHS) HIV/AIDS programs are to expand treatment and prevention programs to low income minorities. In 2013, HRSA focused on targeting the areas and population groups with the highest rates of HIV cases with a program called high-impact prevention (USDHHS, n.d.j.). The Health Resources and Services Administration also funded AIDS Education and Training Centers, Special Project of National Significance and the in+care Campaign which focused on prevention education, testing, and linkages to care. In 2013, the White House announced a new executive order called the HIV Care Continuum Initiative (The White House, n.d.). Additionally, the Affordable Care Act mandated that HIV testing must be covered by all health insurance plans by 2014 and individuals living with HIV/AIDS cannot be discriminated against by most health plans.

Therefore, investigating the lived experiences of low income, urban young adults

living with HIV is important because they are the highest risk group and the focus of several important federal HIV/AIDS strategic programs.

The Link between Socioeconomic Status and Health

Another important topic for background information is the link between socioeconomic status and health. This is of particular importance to educational leaders because of the educational component. Individuals with low socioeconomic status, which is a combination of one's income, occupation, education level, and social rank, are more likely to experience poorer physical and mental health which leads to health disparities in many areas (Halleröd & Gustafsson, 2011; Schreier & Chen, 2013; Williams, Mohammed, Leavell, & Collins, 2010). Lin, Rogot, Johnson, Sorlie and Arias (2003) analyzed data from the National Longitudinal Mortality Study and National Death Index and found a direct correlation between income, education, race, and marital status. Individuals who were poor, unmarried, members of a minority group, and had low levels of education were most likely to have the shortest life expectancy.

Data released by the National Center for Health Statistics (2012) indicated that in 2006, a 25 year old man with at least a Bachelor's degree was expected to live an average of 9.3 years longer than one without a high school diploma. The difference for women was 8.6 years. Results from the 2009 National Health Interview Survey indicated that the incidence of heart disease, stroke, and hypertension all decreased as level of educational attainment increased (Pleis, Ward, & Lucas, 2010). Additionally, adults with college degrees were less likely to report emphysema, chronic bronchitis, ulcers, liver disease, kidney disease, migraines, neck pain, back pain, and chronic joint problems than other adults. As educational level decreased, the incidence of feelings of worthlessness,

hopelessness, sadness, and nervousness increased. As educational level increased, adults were more likely to report having a regular place for health care, such as a doctor's office, were more likely to have seen a doctor and a dentist in the past year, and were more likely to have been tested for the HIV virus.

Various explanations have been proposed for the relationship between level of education and health. Several studies have noted a strong correlation between socioeconomic status and items such as power, privilege, and access to various resources in a society (Demakakos, Nazroo, Breeze, & Marmot, 2008; Hanson & Chen, 2007; Wilkinson & Pickett, 2006). Education, income, and occupation impact each other and often work in tandem to influence items such as health. Therefore, researchers often report the influence of one of the variables on the other. For example, Risa Lavizzo-Mourey, MD, MBA, president and CEO of the Robert Wood Johnson Foundation, noted that people with low levels of educational attainment are less able to secure good paying jobs which results in less income and the inability to afford safe living environments, healthy foods, and access to quality medical care (Zimmer & Gujral, 2010).

However, income alone does not fully explain the relationship between education and health. In a 2007 policy brief released by the National Poverty Center, authors Cutler and Lleras-Muney (2007) analyzed data from the National Health Interview Survey and found a strong association between education and health that remained even after controlling for income, family background characteristics, and labor market factors. In 2010, Cutler and Lleras-Muney conducted additional research using data from five U.S. national datasets and one United Kingdom national dataset. They found that income, family background, and access to resources accounted for approximately 30% of the

education-health relationship, cognitive ability and knowledge accounted for another 30%, social networks explained 10%, and personality factors such as risk aversion and future orientation accounted for the rest.

Ross and Wu (1995) analyzed two large U.S. national datasets and found that the reasons for the association between education and health fell into three groups: 1) the higher the level of education, the better the working and economic conditions, and thus better access to resources, 2) better educated people had more control over their lives and their health, and often had higher levels of social support and acceptance, and 3) better educated people were more likely to follow healthy lifestyles in regards to the use of tobacco, alcohol, illicit drugs, physical activity, and preventive medical care.

Geyer, Hemström, Peter, and Våger (2006) showed that although researchers often substitute level of education, income, and occupational class for each other in health outcomes research, they should never be used in this manner because of the independent and separate impact of each variable. They found a correlation between type of health outcome and strength of each influential variable, with level of education being the strongest predictor in diabetes outcomes. They also found that education and occupational class were the strongest predictors of myocardial infarctions.

One of the ways in which socioeconomic status and health intersects for young adults is seen in recent data about HIV/AIDS in the United States. As noted above, young adults 18-24 years of age have the highest rate of new HIV cases followed by young adults 25-29 years of age (CDC, n.d.c.). Minority young adults have a much higher rate of new HIV cases than non-minority young adults. Research suggests that African Americans in the United States have a higher rate of HIV cases because they are

more likely to live in lower socioeconomic circumstances (Adimora, Schoenbach, & Floris-Moore, 2009; Aral, Adimora, & Fenton, 2008; Vaughan, Rosenberg, Shouse, & Sullivan, 2014). People living in lower socioeconomic circumstances experience higher poverty rates, higher unemployment rates, lower levels of education, and greater instability within marital relationships. They are also more likely to have poorer access to resources such as income, education, quality housing, and quality healthcare, and lower levels of social and political power. This leads to profound disparities in health outcomes, such as higher mortality and morbidity rates. Thus, social conditions have a strong influence on the distribution of health status in American society.

Health Literacy

Another important concept that links education and health is health literacy. Health literacy has been described as the capacity of an individual to be able to obtain and use health information and services to make important decisions related to health (Ratzan & Parker, 2000). It is influenced by level of education as well as socioeconomic and cultural factors (Nielsen-Bohlman, Panzer, & Kindig, 2004). It also depends on the communication level between the individual and his/her healthcare providers. This report cited the 2003 National Assessment of Adult Literacy Study that found that approximately 90 million American adults have trouble understanding basic health information and 40 million American adults cannot read and understand complicated medical documents such as consumer privacy notices and informed consents for research (Kutner, Greenberg, Jin, & Paulsen, 2006). In addition to having difficulty understanding basic health information and reading complicated medical documents, people with low levels of health literacy have trouble understanding medication and clinician instructions,

giving their medical histories, answering questions about their health, and communicating with their health providers in general (Ngoh, 2009; Safeer & Keenan, 2005; Schwartzberg, Cowett, VanGeest, & Wolf, 2007). Negative outcomes of low health literacy included poorer health outcomes, higher overall health care costs, and the inability to benefit from health education programs and media campaigns (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Norman & Skinner, 2006; Zarcadoolas, Pleasant, & Greer, 2005).

One of the important ways in which researchers believe that health literacy influences health outcomes is in its impact on influencing health behaviors. Research conducted by Paasche-Orlow and Wolf in 2007 found that a person's health literacy skills impacted his/her health outcomes at three important junctures: accessing and using healthcare, during the patient-provider interaction, and choosing healthy/self-care behaviors. Low levels of health literacy can negatively influence a person's understanding of health information, their health knowledge content level and problem-solving ability, and their motivation and self-efficacy to perform healthy/self-care behaviors.

There have been several studies that have examined the relationship between health literacy and HIV/AIDS. Kalichman et al. (2008) surveyed 145 adults and found a strong association between low health literacy and poor medication adherence. Another study by Kalichman and Grebler (2010) showed that this association was magnified if the person was under emotional stress or living in poverty. Barragan, Hicks, Williams, Franco-Paredes, Duffus, & Del Rio, (2005) surveyed 372 adults and found that those with low levels of health literacy were less likely to get tested for HIV.

Palumbo (2015) conducted a literature review of studies involving HIV/AIDS and health literacy. He found an association between low health literacy, low use of healthcare services, and low treatment adherence among adults living with HIV/AIDS. He referred to low health literacy as a *silent epidemic* because it is not always noticeable but has important negative effects on a wide variety of health-related issues from how well someone understands important health information to their informed use of the healthcare system. Health literacy is an important factor in the lives of individuals living with HIV/AIDS and should be on the radar of educational and healthcare leaders.

Therefore, it is important to examine the lived experiences of young adults who live in low income, urban areas and are living with HIV. It is important to understand their challenges, barriers, assets, and strengths in order to capitalize on factors to enhance resilience, thriving, and empowerment. A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

Problem Statement

Transitioning to adulthood is a challenging experience for all young adults, but especially for those who are living with HIV/AIDS and residing in low income, urban areas. Young adults living with HIV/AIDS who live in low income areas are often faced with additional stressors such as poverty, unemployment, violence, racial/ethnic discrimination, homophobia, and poor access to educational and healthcare resources (Haushofer & Fehr, 2014; Santiago, Wadsworth, & Stump, 2011; Storer et al., 2012;

Viner et al., 2011). This group has the highest rate of new HIV cases of all age groups (CDC, n.d.c.).

Purpose Statement

The purpose of this study was to examine the lived experiences of a purposive sample of young adults living with HIV/AIDS who resided in a selected low income, urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping. This information may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies to help this group transition to adulthood, care for themselves, and prevent transmission of the virus to others.

Research Questions

The following research questions were investigated:

1. What are the challenges, barriers, and stressors that serve as vulnerability factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?
2. What are the individual, social, structural, and institutional assets, strengths, and supports that serve as protective factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?
3. What needs and suggestions do young adults living with HIV/AIDS who reside in a selected low income, urban area have for improving programs, services, and policies to help them transition to adulthood, care for themselves, and prevent transmission of the virus to others?

Overview of the Conceptual Framework

The conceptual framework for this study was composed of the ecological model of human development and the concept of resilience. These theories were used to review and describe the data.

The ecological model of human development proposed by Bronfenbrenner (1994, 2000, 2005) was part of the conceptual framework for this study. Bronfenbrenner proposed that an individual's development was influenced by the interaction between his/her entire ecological environment and the self. He believed that proximal processes, which are the ongoing reciprocal interactions between a developing individual and the objects, people, and symbols in his/her immediate environment, strongly influenced psychological development and behavior. Development is influenced by the strength, content, form, and direction of these proximal processes. Additionally, the quality of one's proximal processes interacts with the ecological context to influence behavioral outcomes. He believed that one's ecological environment functioned like a series of nested, concentric circles (see Figure 3).

The first circle around the individual is the microsystem which includes the family, peers, school, and the workplace (Bronfenbrenner, 1994, 2000, 2005). The next circle is the mesosystem which includes the interactions and links between parts of the microsystem, such as interactions between the family and school. The third circle which surrounds the mesosystem is the exosystem. This system includes the interactions between elements that have an indirect influence on the developing individual, such as the neighborhood environment.

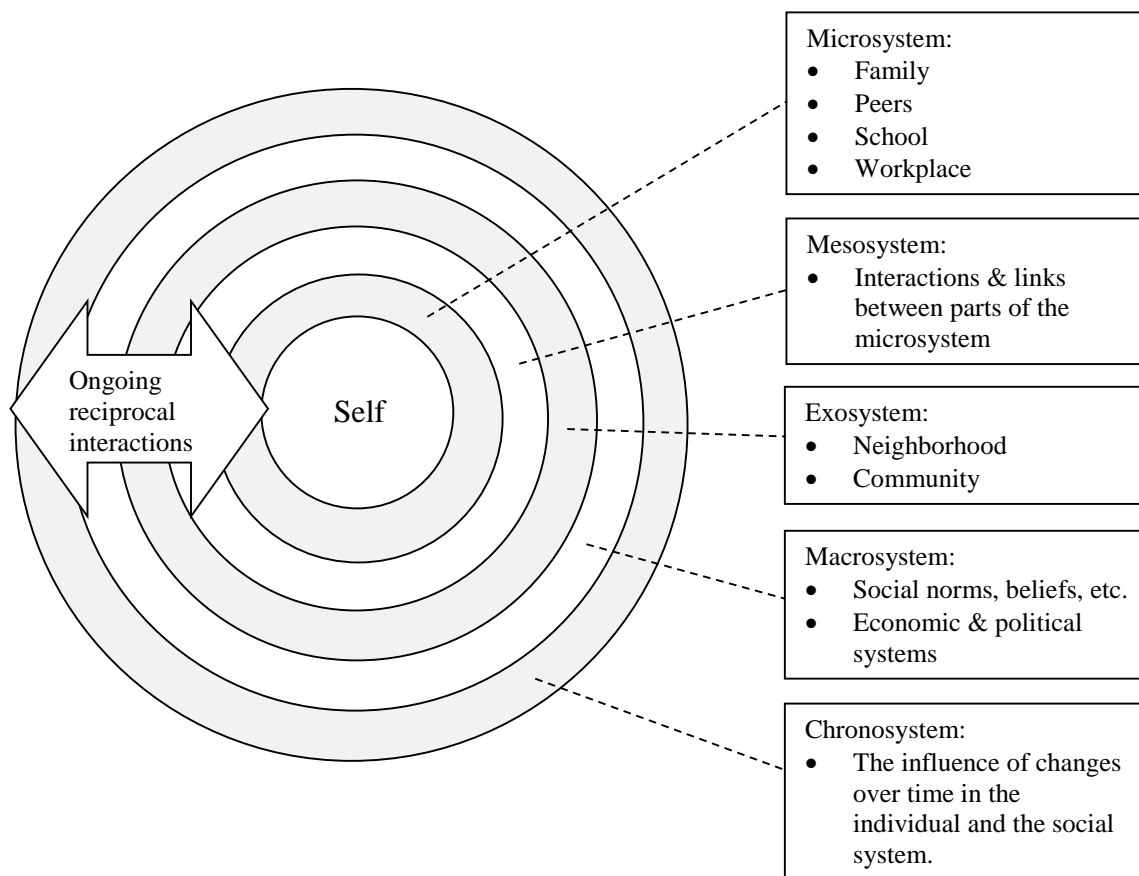


Figure 3. The ecological model of human development. Adapted from “Ecological models of human development.” by U. Bronfenbrenner, 1993, in *International Encyclopedia of Education, Vol. 3, 2nd Ed.* Oxford: Elsevier. Reprinted in: Gauvain, M. & Cole, M. (Eds.), *Reading on the development of children, 2nd Ed.*, pp. 37-43). NY: Freeman.

Outside of the exosystem is the macrosystem which includes one’s culture, norms, beliefs, access to knowledge, access to resources, experiences, opportunities, barriers, and other broader social factors such as the economic and political systems. The outermost circle is called the chronosystem. This includes the influence of changes over time such as life transitions and societal changes.

Edberg (2007), a medical anthropologist, referred to the influence of one’s ecological environment as the *complex social-ecological web*. He emphasized that the

complex relationships and interactions between an individual and the social, cultural, political, socioeconomic, structural, and environmental factors in his/her life strongly influenced health outcomes. This same concept was used in the social determinants of health model (Marmot & Wilkinson, 2005; USDHHS, n.d.f.). This model emphasized that economic conditions and opportunities, access to quality education and job training, availability of quality health care, social and cultural beliefs and norms, exposure to violence, unsafe neighborhoods, and other hazards, access to social and political power, and other similar factors influenced health outcomes and health disparities. In this study, the ecological model of human development was used to examine the data in order to determine how the proximal processes in each participant's different systems influenced their life experiences related to living with HIV/AIDS.

These young adults face many challenges including transitioning to self-care, ongoing health issues, obtaining and understanding health information, medication adherence, relationship and disclosure issues, stigma and discrimination, prevention of transmission, psychosocial issues, and access to affordable, quality healthcare and medications. Furthermore, young adults living with HIV/AIDS who live in low income, urban areas often experience additional challenges and stressors such as the inability to afford the basic necessities, exposure to gangs, violence and illegal drugs, poor access to health care, lower performing schools, lower social capital, prejudice and discrimination, more environmental toxins, less green areas for recreation, more fast food establishments, convenient marts, and liquor stores, and less access to healthy food establishments (Mooney, Knox, & Schacht, 2012).

Therefore, it is important to understand the lived experiences of these young adults and their challenges, barriers, assets, and strengths in order to capitalize on factors to enhance resilience, thriving, and empowerment. A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

The concept of resilience was also part of the conceptual framework for this study. Resilience is how well an individual can adapt to situations of great adversity (Hakansson, 2010; Luthar & Cicchetti, 2000; Schetter & Dolbier, 2011). Protective factors are those that enhance resilience. Examples of protective factors include having a positive attributional style, high self-efficacy, an internal locus of control, and a supportive environment. Vulnerability factors are those that detract from the ability to adapt to a negative situation. These include many internal and external factors that are often dependent upon the context or situation. Examples of internal factors include a negative attributional style, poor social skills, poor impulse control, low cognition, and having an external locus of control. Examples of external factors include not having a support network and living in a stressful or low income environment.

Schetter and Dolbier (2011) grouped resilience resources into six categories: 1) personality and dispositional factors, such as optimism, positive affect, emotional stability, hardiness, and persistence; 2) self-related factors, such as high self-efficacy, self-confidence, self-esteem, autonomy, and personal agency; 3) social and interpersonal factors, such as high quality relationships, strong social support network, and

connectedness; 4) world views and culturally-based beliefs and values, such as strong spirituality, values that include justice and benevolence, collectivism, and a strong purpose; 5) behavioral and cognitive skills, such as good social, problem-solving, and planning skills, flexibility, good emotional management, and relaxation skills; and 6) other resources such as higher socioeconomic status, good access to resources, higher social capital, good genetic and physical health, higher intelligence and creativity, and stable temperament. Factors often work in combination.

Resilience can be viewed on a continuum with flourishing or thriving as the most positive outcome, and languishing as the most negative outcome (Benzies & Mychasiuk, 2009; Fredrickson & Losada, 2005). The purpose of viewing resilience on a continuum is to move towards a strengths-based model rather than focusing on vulnerabilities and deficits. The strengths-based model notes that challenges and adversity are often the impetus for positive growth. Fredrickson and Losada (2005) noted that flourishing or thriving included having a positive affect, and experiencing maximum growth and resilience. This has resulted in the broaden-and-build theory which proposes that positive emotions result in a broader range of successful adaptive thoughts and behaviors while negative emotions result in a very narrow range of adaptive thoughts and actions (Fredrickson & Branigan, 2005). For example, individuals with broadened mindsets are more likely to explore new learning and adaptive opportunities, think creatively, and build stronger social connections, while those with negative mindsets are more likely to be cynical and avoid new opportunities and people. Individuals with higher ratios of positive to negative affect are more likely to flourish than those with lower ratios.

Siegel and Schrimshaw (2000) conducted interviews with 54 women living with HIV and found that even though the women reported that living with HIV was very stressful, most of them reported an array of positive outcomes which they referred to as stress-related growth. This included providing them with a wake-up call to appreciate their lives more and to work on improving their personal relationships. Many of them reported that finding out they were HIV positive motivated them to improve their health behaviors, become more assertive about their health, and to set new personal and career goals. Several reported a deepening or return to their religious faith. A large portion of the participants also said that it inspired them to be more empathetic and caring.

These two concepts complemented each other and enhanced the ability to describe, examine, and interpret the data from this study. The concept of resilience complements the ecological model of human development because many factors in one's environment serve as either protective factors or vulnerability factors that affect resilience. Therefore, the lived experiences of the study population were examined through the lenses of these two complementary concepts in order to enhance interpretation and understanding.

Overview of the Methodology

The qualitative research approach was used as the research paradigm for this study. This is an inductive approach that examines human behavior from a socially constructed viewpoint and seeks to understand the meanings that people assign to their experiences and behaviors (Johnson and Christensen, 2004). Narrative data was collected and examined for themes and patterns that represented the participants' point of view. The research paradigm for this study was also influenced by phenomenology, a

type of inquiry with a strong philosophical background that strives to understand the lived experiences of a group of people regarding a particular phenomenon (Patton, 2002). It attempts to understand the individual and shared meanings that people construct in response to experiencing a phenomenon and produces a rich description of their lives from their vantage point. The phenomenon in this case was the experience of living with HIV/AIDS as a young adult in a selected low income, urban environment. In order to capture the experiences of this group, in-depth, semi-structured interviews were conducted with a purposive sample of 16 young adults 18-29 years of age living with HIV/AIDS who resided in a low income, urban area in the southeast region of the United States.

Significance of the Research

This study is significant because young adults, especially those who live in low income, urban areas, have the highest rates of new HIV cases among all age groups in the United States (CDC, n.d.c.). This is a significant health disparity and combatting this disparity is a national priority. Decreasing the spread of HIV, increasing access to quality HIV care, improving health outcomes, and reducing HIV health disparities among different groups are the goals for the Office of AIDS Research at the National Institutes of Health (NIH Office of AIDS Research, n.d.) and the Obama Administration's National HIV/AIDS Strategy (The White House: Office of National AIDS Policy, n.d.). Additionally, these are among the goals of the USDHSS's Healthy People 2020 which is the department's 10 year plan for improving the health of the American public (Riegelman & Garr, 2011).

Information from this study may be valuable for professionals who design and conduct programs, services, and policies for this group including educators and educational leaders, health care and mental health workers, social workers and case managers, health department personnel, program planners, policy makers, and researchers. Additionally, the study data gives a voice to and raises awareness about a highly vulnerable population with enormous challenges and complex needs. This study is a step towards illuminating and understanding the opportunities and challenges in the lives of low income, urban young adults living with HIV/AIDS.

Delimitations and Limitations of the Study

The delimitations or boundaries that I set for this study included the choice and location of the study population, the questions asked, the methodology and research paradigm used, and the conceptual framework that I selected. I chose to study 18-29 year olds living with HIV/AIDS in a low income, urban environment because I thought that examining this population was warranted by the fact that young adults in this age group have the highest rate of new HIV cases and living in a low income, urban environment typically presents a great deal of stressors that compounds the struggles associated with living with HIV/AIDS. I chose to recruit these individuals from a clinic and social service agencies that served low income, urban young adults living with HIV/AIDS in a particular urban area because it met the enrollment criteria. I focused the interview questions broadly on their lived experiences along with their challenges and strengths instead of focusing on one or two key issues in order to capture the important facets of their lives. I selected a qualitative research paradigm because I wanted to capture deep, rich descriptions of their lived experiences. I chose the ecological model of human

development and the concept of resilience as the conceptual framework because I thought these two concepts would be beneficial at explaining how the factors in their environment influenced their lives and dealing with HIV/AIDS.

The above delimitations also led to some limitations. Because of the recruitment plan, only young adults who were actively receiving medical care for their HIV/AIDS were enrolled in the study. Those that were not actively receiving medical care were not accessed by my recruitment plan. These individuals may have very different lived experiences, strengths, assets, barriers, challenges, needs, and suggestions. Therefore, this is a limitation of the study and an area for future research.

Additionally, recruitment was limited to a small group in one selected urban area. Young adults who live in a different urban area may have different experiences due to factors related to their location of residence. This is another limitation of this study as well as another area for future research. Another study limitation was the self-reported nature of the data that was captured through the interviewing process. It was not possible to determine the accuracy or completeness of the data. Participants' responses may have been influenced by the sensitive nature of the topic. Therefore, the data was a reflection of their interpretation of their experiences and what they chose to share.

Also, only five participants returned for a second visit which included reviewing their responses from the first interview for clarity of meaning. I was not able to review the responses of the other 11 participants at a second visit. I offset this limitation by reviewing their responses at the end of each first interview in case the participant was not able to return for a second visit.

Additionally, researchers have noted that the results and conclusions of single-investigator, qualitative studies can be influenced by the skills and attitudes of the single investigator because s/he is the only collector and interpreter of the data (Creswell, 2007; Patton, 2002). Therefore, I took great care to follow accepted research principles, maintain an unbiased and open attitude, and fully disclosed my educational training, perspectives, skills, connoisseurship, and schemas of understanding in Chapter 3 in order to minimize this limitation.

Definitions of Key Terms and Acronyms

AIDS. Acquired Immunodeficiency Syndrome is the last stage of HIV infection when the body's immune system has been destroyed by the virus and the body can no longer fight off certain potentially fatal infections and cancers (Quinn, 2011). The use of Highly Active Antiretroviral Treatment (HAART) helps to decrease the level of the HIV virus in the body and delays or stops the progression to AIDS (USDHHS, n.d.c.).

Behaviorally acquired HIV. Individuals who acquired HIV through sexual behavior, injection drug use, or other behavioral means.

CDC. The Centers for Disease Control and Prevention is an organization within the U.S. Department of Health and Human Services. It serves as the main health protection agency for the country (CDC, n.d.a).

Ecological factors. These are the factors that compose one's social, cultural, political, and physical environment. They interact to influence the life of an individual (Edberg, 2007).

Ecological model of human development. This model proposes that an individual's development is the result of reciprocal interactions between the different

parts of his/her socio-cultural and physical environment, and the self (Bronfenbrenner, 1994, 2000, 2005).

HAART. Highly Active Antiretroviral Treatment (HAART) is composed of a group of medications invented in the mid-1990s that work by decreasing the level of the HIV virus in the body, thus delaying or stopping the progression to AIDS (Palella et al., 1998). Use of HAART is balanced by the stage of infection, side effects of the medications, and other factors (USDHHS, n.d.b.).

Health disparities. This term refers to differences in the distribution of various health conditions and is usually the result of differences in economic, social, and ecological conditions. People from the lower socioeconomic strata and other disadvantaged or disenfranchised groups often have poorer health outcomes due to poverty, unemployment, lower levels of educational attainment, discrimination, poorer access to quality health care and health insurance, poor housing, and lower levels of social and political power. They are more likely to be members of racial and ethnic minority groups (USDHHS, n.d.e.).

HIV. The Human Immunodeficiency Virus is a virus that destroys the immune system in the body which makes it vulnerable to different types of cancers and infections (Quinn, 2011). The virus lives in certain body fluids and can only be transmitted to others through blood transfusions with HIV-positive blood, an organ transplant from an HIV-positive person, needle sharing or needles sticks from an HIV-positive person, sexual contact with an HIV-positive person, or from an HIV-positive mother to her infant during pregnancy, childbirth, and breastfeeding (also known as perinatally acquired). Currently, there is no cure for HIV/AIDS and it can be fatal if left untreated. However, it can be

controlled by certain medications called Highly Active Antiretroviral Treatment or HAART (USDHHS, n.d.b.).

HRSA. The Health Resources and Services Administration is an agency within the USDHHS whose purpose is to increase access to health services and resources in order to achieve health equity (HRSA, n.d.a).

LBGTQ. LBGTQ is an acronym for people who are lesbian, bisexual, gay, transgender, transsexual, or questioning their sexual orientation (Kane-Lee & Bayer, 2012).

Morbidity. This is a term used when referring to health data and is another term for disease. Morbidity is usually reported by incidence rates, which are the number of new cases of a particular disease per 100,000 people for a certain period of time, or by prevalence rates, which are the total number of current cases of a particular disease per 100,000 people in a population or group and are often reported by gender, ethnicity or other characteristics (Fletcher, Fletcher, & Fletcher, 2012).

Mortality. This is a term used when referring to health data and is another term for death. Mortality rates report the number of deaths per 100,000 people in a population or group and are often reported by disease, gender, ethnicity, or other characteristics (Fletcher, Fletcher, & Fletcher, 2012).

MSMs. Epidemiologists created the term “MSMs” in the 1990s as a neutral term to identify all men who have sex with men, including those who do not identify themselves as gay, bisexual, homosexual, transsexual or transgender for various reasons (Glick, Muzyka, Salkin, & Lurie, 1994).

Perinatally acquired HIV. Individuals who acquired HIV from their HIV-positive mother. They acquired HIV in utero, during childbirth, or through breastfeeding.

Phenomenology. This is a philosophical tradition that influences inquiry in qualitative research. It strives to elucidate the personal meanings of the lived experiences of a particular group who experience a common phenomenon in order to develop a deep and rich understanding of their experiences (Johnson & Christensen, 2004).

Resilience. Resilience is how well an individual can positively adapt to situations of great adversity (Hakansson, 2010; Luthar & Cicchetti, 2000; Schetter & Dolbier, 2011). Protective factors are those that enhance resilience. Vulnerability factors are those that detract from the ability to adapt to a negative situation. Resilience can be viewed on a continuum with flourishing or thriving as the most positive outcome, and languishing as the most negative outcome (Fredrickson & Losada, 2005).

Social Determinants of Health. These are the social and ecological factors that strongly influence one's level of health and health outcomes, and often results in health disparities. It includes economic conditions and opportunities, access to quality education and job training, availability of quality health care, social and cultural beliefs and norms, exposure to violence, unsafe neighborhoods, and other hazards, access to social and political power, and other similar factors (Marmot & Wilkinson, 2005; USDHHS, n.d.f.).

USDHHS. The United States Department of Health and Human Services is a department within the cabinet of the U.S. federal government. Its purpose is to protect the health and safety of all citizens. It administers the CDC, HRSA, the Food and Drug

Administration, the National Institutes of Health, and other important health and safety governmental organizations (USDHHS, n.d.a).

Organization of the Study

Chapter 1 is composed of the introduction, background information, the problem statement, the purpose of the study, and the research questions. It also includes a summary of the conceptual framework, a brief overview of the literature review, the significance of the study, the summary of methods, the limitations of the study, the definition of key terms, and a summary of the study.

Chapter 2 consists of an in-depth literature review on the developmental aspects of adulthood, the influence of being part of the Millennial birth cohort, the impact of living in a low income, urban environment, and the impact of living with HIV/AIDS.

The research design, methodology, data collection plan, and analytical plan are thoroughly explained in Chapter 3. Chapter 4 presents the study data results. A discussion of the study data along with implications, conclusions, and recommendations for future research are located in Chapter 5.

Chapter Summary

In this study, I examined the lived experiences of a purposive sample of 16 young adults 18-29 years of age living with HIV/AIDS who resided in a selected low income, urban area in the southeast region of the United States in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping. Semi-structured, in-depth individual interviews were used to capture rich, descriptive, narrative data. Data from the interviews were analyzed for significant statements, meanings, and themes in order to provide a rich description of the lived

experiences of these young adults. A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

Below is a table that summarizes the important components of the study.

Table 1

Summary of the Study

Study Population	Purposive sample of 16 young adults living with HIV/AIDS from a selected low income, urban area in the southeastern United States.
Problem Statement	This group has one of the highest rates of new HIV cases and experiences significant challenges because of their low income environment.
Purpose of the Study	The purpose of this study was to examine the lived experiences of a purposive sample of young adults living with HIV/AIDS who resided in a selected low income, urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping.
Research Questions	<ol style="list-style-type: none"> 1. What are the challenges, barriers, and stressors that serve as vulnerability factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area? 2. What are the individual, social, structural, and institutional assets, strengths, and supports that serve as protective factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults who reside in a selected low income, urban area? 3. What needs and suggestions do young adults living with HIV/AIDS who reside in a selected low income, urban area have for better programs,

services, and policies to help them transition to adulthood, care for themselves, and prevent transmission of the virus to others?

Conceptual Framework	The ecological model of human development (Bronfenbrenner, 1994, 2000, 2005) and the concept of resilience (Hakansson, 2010; Luthar & Cicchetti, 2000; Schetter & Dolbier, 2011).
Brief Overview of the Literature Review	<ul style="list-style-type: none"> • Developmental aspects of young adulthood • The influence of being part of the Millennial birth cohort • The impact of living in an low income, urban environment • The impact of living with HIV/AIDS
Significance of the Study	<ul style="list-style-type: none"> • Significant health disparity • National priority for the Obama Administration and the U. S. Department of Health and Human Services • Important information for educational and healthcare leaders who serve this population • Gives voice to a highly vulnerable population with enormous challenges and complex needs
Methods and Procedures	<ul style="list-style-type: none"> • Qualitative research influenced by phenomenology; the examination of how individuals experience a phenomena • Semi-structured, in-depth interviews • Narrative data were analyzed for significant statements, meanings, and themes

Chapter 2: Review of the Literature

The literature review for the study is presented in this chapter. A comprehensive literature review lays the groundwork for the development of a thoughtful, warranted, and timely scientific inquiry (Boote & Beile, 2005; Machi & McEvoy, 2009). It puts the study into perspective by placing it within the context of the literature. This allows for generativity which is the important academic process of building upon previous research. The purpose of this literature review is to place this study within the context of living with HIV/AIDS as a young adult in a low income, urban area.

The focus of this study was the lived experiences of 18-29 year old young adults living with HIV/AIDS who lived in a low income, urban environment. Therefore, the following topics are presented in the literature review: the developmental aspects of young adulthood, the influence of being part of the Millennial birth cohort, the impact of living in a low income, urban environment, and the impact of living with HIV/AIDS. The presentation and critique of the current literature on these topics inform and lend credence to the current study.

Developmental Aspects of Young Adulthood

Since this study was focused on young adults 18-29 years of age, it is important to review the developmental aspects of young adulthood. Erikson (1968), who conducted early seminal work in this area, referred to this period in industrialized societies as prolonged adolescence which was marked by a psychosocial moratorium on role expectations. Levinson (1978), another early researcher in this area, referred to this

period as the novice phase of development because individuals in this age group are still exploring the various possibilities for their future.

In 2000, Arnett conducted interviews with over 300 young adults across the United States and found many similarities despite differences in demographic characteristics. He coined the phrase *emerging adulthood* to denote the period of time from the late teens through the middle to late twenties. He proposed that this time period constituted a distinct category because of its distinctive features. In general, this is a time period that is marked by great change and exploration for most young people (Arnett, 2000; Arnett, 2012; Arnett, 2014). Emerging adulthood has been extended in industrialized countries over the last century because the age of first marriage and parenthood has risen. Additionally, the number of young adults attending college or post-secondary vocational training has steadily increased. Individuals in this stage of life are between the dependency of childhood and the responsibilities of adulthood. They have more independence from social roles and expectations than any other age group. Most young people in this age group are still exploring their future possibilities. Many individuals in this age group move out of the family home for the first time, often moving in and out several times.

Characteristics

Arnett (2014) described five distinct characteristics of emerging adults: intense identity exploration, focus on self, instability concerning residence, relationships and careers, feeling caught between adolescence and adulthood, and optimism about future possibilities. He found that many emerging adults have unrealistically high expectations

that have not been tempered yet by life experiences. He also found that many struggle between being independent but still somewhat dependent on family.

This is also a time when risky behaviors including substance use, unprotected sex, and sensation-type behaviors tend to peak (Arnett, 2000; Arnett, 2014; Eaton et al., 2012). This is an important phenomenon for this study because acquiring HIV is related to having unprotected sex which is often accentuated by overconsumption of drugs and alcohol (Rehm, Shield, Joharchi, & Shuper, 2012). This is also related to a pervasive feeling of invincibility that is common among this age group which is also a very important characteristic when assessing health behavior. According to the Health Belief Model, individuals who do not feel susceptible to a particular illness or condition are less likely to use preventive behaviors (Champion & Skinner, 2008). Rao, Kekwaletswe, Hosek, Martinez, and Rodriguez (2007) found that invincibility interacted with stigma among youth living with HIV/AIDS to influence poor medication adherence.

Additionally, this tends to be one of the healthiest periods of life where individuals are at their physical peak (Kail & Cavanaugh, 2010). These are also the peak fertility years for females (Dye, 2008). Therefore, there is extra stress and anxiety for young adults who are experiencing a chronic illness while their friends are relatively healthy (Verhoof, Maurice-Stam, Heymans, Evers, & Grootenhuis, 2014). Individuals in this age group are becoming independent in terms of caring for their own health so easy access to high quality resources, information, and health literacy skills are important for carrying out these tasks. Young adults are often still unstable financially which sometimes compromises their access to health-related resources. This is often accentuated for young adults who live in low income areas.

Sociocultural Aspects

Lower income, minority adults often take on more responsibilities at an earlier age for economic reasons (Cauce, Stewart, Rodriguez, Cochran, & Ginzler, 2003; Phinney, 2006). They are often called upon to provide financial support for family members. Phinney, Ong, and Madden (2000) found that minority young adults often have closer family relationships than non-minority young adults which make them feel obligated to help financially. Minority and immigrant young adults also tend to struggle more in terms of their identity because of their minority and immigrant status (Phinney, 2006). Their identity and cultural values may conflict with those of the mainstream culture which often creates internal conflict. Additionally, Phinney (2006) found that minority and immigrant young adults often feel that their future possibilities are more limited than non-minority young adults.

The Millennial Generation

Yang and Land (2013) noted that an individual's behaviors, values, and attitudes are strongly influenced by birth cohort, time period, and developmental age. In addition to examining the impact of young adulthood on the study population, it is also important to examine the impact of birth cohort and the influence of generational characteristics. Individuals born between the early 1980s and early 2000s and raised in the United States have been termed the Millennial Generation (Howe & Strauss, 2009). Researchers have noted that people born within a particular period of time share some similar characteristics due to having experienced similar historical, social, and cultural events and having been socialized together in schools, neighborhoods, etc. (Gentile, Campbell, & Twenge, 2012). This similar period of time usually spans 20 years and is termed a

generation or birth cohort. Strauss and Howe (2009) noted that people who grow up within a particular generation often share a peer personality which is composed of similar beliefs, attitudes, norms, roles, likes, etc.

Characteristics

Sandeen (2008) noted that the most similar generational characteristics are shared by those within the dominant middle class. The characteristics vary somewhat by social class, race, religion, gender, and other demographic characteristics. Given these caveats, researchers have proposed the following portrait of the Millennial Generation.

Millennials, in general, have experienced a smaller family size and were the products of a more child-focused style of parenting than previous generations. The divorce rate peaked during this time period and many grew up in single-family homes. The terms *soccer mom* and *helicopter parents* began during this generation.

In terms of personality characteristics, Twenge, Campbell, and Freeman (2012) analyzed data from two large national surveys and found that Millennials tend to be more materialistic and image conscious, and are less concerned with others, politics, their community, social problems, and the environment than previous generations. The number of Millennials involved with community service has increased but this is often related to increased school program requirements.

These results are different than those proposed by Howe and Strauss (2009) who found that Millennials tended to be more confident and team-oriented than the previous two generations and more motivated to improve the environment and their community. Johnson (2006) noted that Millennials tended to have high expectations on the job and expect special treatment. They tended to be multi-taskers who were less focused on one

stable career path. Millennials have lived with computers for most of their lives and are more technologically savvy and connected to technology than previous birth cohorts.

Attitudes

Millennials tend to have more liberal opinions about homosexuality, same-sex marriage, and abortion than previous generations (Becker, 2012; Pew Research Center, 2013). The Millennial Generation is more ethnically diverse than previous generations. Concerning their opinions about race, however, recent research indicates that a racial divide still exists among Millennials even though they seem to be more congruent on other social issues. Surveys conducted by researchers at the University of Chicago found that African American Millennials still have very skeptical attitudes about jobs, economics, the government, and health care (Cohen, 2011).

Sociocultural Aspects

A survey conducted in 2005 for the Black Youth Project found that 59% of African American Millennials believed that African Americans were treated less fairly than Caucasians by the healthcare system compared to 52% of Hispanic young adults and 32% of Caucasian young adults (Cohen, 2011). Sixty-eight percent of African American young adults believed that the government would do more about AIDS if more Caucasians were affected by it compared to 50% of Hispanic young adults and 34% of Caucasian young adults.

Since the lived experiences of young adults living with HIV/AIDS in a selected low income area were examined in this study, it is important to keep the impact of the developmental aspects of young adulthood and being a part of the Millennial Generation in mind when examining their experiences.

Implications of Living in a Low Income, Urban Area

Since this study examined young adults living with HIV/AIDS who lived in a selected low income, urban area, it is important to understand how living in that kind of area affects an individual's health and life in general. This is another example of how sociocultural factors affect the lives of individuals.

White Flight and Racial Discrimination

The trend towards the concentration of poverty in certain urban areas in the United States began rapidly after World War II (Bier & Howe, 1998; Frey, n.d.). Beginning in this era, many white middle and upper class individuals moved out of many urban areas into new suburban areas that offered safer, less concentrated, greener, and more affluent environments. Additionally, there was a large migration of African Americans from rural areas into central city urban areas. The discrimination that existed at that time prevented them from moving into most suburban areas. This was fueled by unscrupulous block-busting practices used at the time by many real estate agents in inner city areas who encouraged white owners to move out by using negative stories about poor African Americans (Aalbers, 2006). The agents then bought the houses at low prices and sold them to African Americans at even lower prices for a handsome profit. This was made illegal by the Fair Housing Act of 1968, however it still exists to some degree in indirect ways.

Orfield and Katz (2002) noted that white home owners often moved out of an urban area when the majority of residents shifted to primarily minorities because they were worried about issues such as declining property values and crime. Their houses

were often bought by lower income minorities. This decreased the economic value of the neighborhood, thus creating a self-fulfilling prophecy.

Concentration of Low Income, Minorities in the Inner City

Additionally, lower property values often led to lower tax revenues which caused public school budgets to decline, thus creating an overall decline in the quality and resources of the schools (Orfield & Katz, 2002). This fueled the movement of middle and upper class individuals out of inner city areas. Suburban areas often used exclusionary zoning practices to limit the availability of low income housing which further limited the options of low income individuals. As housing discrimination changed, this trend was accentuated when middle and upper income African Americans began to move out of central urban areas in the 1970s and 1980s, leaving behind the poorest residents (Wilson, 2012). Middle and upper income African Americans had previously been a stabilizing force in central city areas. This led to a concentration of low income, minorities in poor inner city areas. This concentration led to isolation from mainstream social and job networks.

Poverty and Social Problems

Even though gentrification efforts have revitalized some of these areas, pockets of poverty remain (Orfield & Katz, 2002). Many businesses are less likely to locate themselves in these areas leading to poor job opportunities for the residents. High rates of unemployment, lower resourced schools, and social isolation lead to hopelessness, stress, and an increase in a variety of social problems. Williams Julius Wilson (1996) noted that being low income combined with being jobless is infinitely more devastating to the psyche than being low income and employed. He believed that this phenomenon

has led to many social problems for inner city residents such as increased social disorganization, the dissolution of families, increased crime rates, and welfare dependence. Increased social disorganization, the dissolution of families, poor educational attainment which leads to poor health literacy, along other social problems such as crack cocaine use, intravenous drug use, and prostitution are all risk factors for transmitting the HIV virus.

Low Socioeconomic Status and Poor Health Outcomes

Lack of income and poor educational attainment along with stress leads to poorer health status and health outcomes (Chen & Miller, 2013). High quality healthcare establishments are less likely to be located in inner city areas and low income residents are less able to afford health care. In terms of a healthy diet, inner city residents are less likely to be able to afford healthy food. Low income, urban neighborhoods have a higher concentration of fast food restaurants, convenience stores, and liquor stores along with a lower concentration of high quality grocery stores and restaurants (Zenk et al., 2011). These areas also have less green areas for recreation and are more likely to be affected by air, water, and land pollution than suburban areas. These issues were highlighted in an episode of the PBS documentary miniseries *Unnatural causes...is inequality making us sick? Place matters* (National Association of County & City Health Officials, 2008). This episode showed how living in a low income area which often included socioeconomic and racial inequalities influenced health disparities.

There is a great deal of research that links the systemic issues related to low socioeconomic status and poor health (Chen & Miller, 2013; Cutler & Lleras-Muney, 2007; Cutler & Lleras-Muney, 2010; Deaton, 2003; Lantz, Golberstein, House, &

Morenoff, 2010; Zimmer & Gujral, 2010). Data from the National Longitudinal Mortality Survey showed that individuals in the top 5% of incomes lived 25% longer on the average than those in the lowest 5% (Deaton, 2003). There are several major ways in which educational attainment impacts health (Cutler & Lleras-Muney, 2007; Cutler & Lleras-Muney, 2010; Zimmer & Gujral, 2010). Better educational attainment leads to better health knowledge and health literacy which influences healthier behaviors such as exercising, better nutrition, less smoking, and more frequent health screenings. It leads to better employability and a higher income which allows individuals to live in higher quality, safer neighborhoods, afford health insurance and health care, and have sick leave and retirement benefits. It also leads to a higher social standing, more control over life, and more social support due to increased family stability.

Results from the National Longitudinal Mortality Study (Lantz, Golberstein, House, & Morenoff, 2010) showed that people with a college degree lived five or more years longer on the average than people who did not complete high school. The infant mortality rate in 2004 for babies whose mothers did not have a high school diploma was twice as high as the rate for mothers who had a college degree (Matthews & MacDorman, 2007). Teens from lower income families are more likely to drop out of high school than those from higher income families (Snyder, Dillow, & Hoffman, 2009). They are also much less likely to be able to go to any college (Hunt, Carruthers, Callan, & Ewell, 2006).

Additionally, 49% of individuals without a high school diploma had below basic health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). Only 15% of those with a high

school diploma and 3% of those who had a college degree were found to have below basic health literacy.

Bolland (2003) surveyed 2,468 adolescents who lived in high poverty, inner city areas and found that 25% of the females and 50% of the males reported feelings of moderate to severe hopelessness. He also found that these feelings were strongly correlated with incidences of high risk sexual and substance use behaviors. Therefore, there is a reciprocal relationship between income, education, residential area, and health.

Young adults living with HIV/AIDS who live in a low income, urban area were specifically chosen as the study population for this project because they represent a group with enormous challenges and barriers who need to be examined and understood. A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

Implications of Living with HIV/AIDS

The literature about how living with HIV/AIDS impacts young adults will be presented in this section. It is important to examine this topic in the literature review because it is the central phenomenon in the lived experiences of these young adults. When considering the effects of living with an illness, it is important to examine the physical/biological, social, and psychological aspects. In each illness, there are certain physical and biological aspects such as level of disability, interference with daily activities, prognosis, cognitive challenges, and so forth (Saylor, 2004). Additionally,

there are a variety of psychological effects that often develop such as stress, depression, fear, anger, denial, regression, withdrawal, and sometimes guilt and shame (Falvo, 2014).

Social Aspects

Each social group defines health and illness in different ways (Freund, McGuire, & Podhurst, 2003). For example, some societies are more accepting of people with disabilities than others. There are social and cultural norms, attitudes, and beliefs that surround health and illness. These factors combine with the physical and psychological aspects to impact how an individual experiences that illness. Additionally, the social system also determines many aspects of the healthcare system (Sallis, Owen, & Fisher, 2008). One's socioeconomic status often influences the resources available to him or her to deal with the illness.

Life Stage Implications

An illness also often interrupts an individual's life plans, independence, self-concept, relationships, and economic well-being (Freund, McGuire, & Podhurst, 2003). Young adults with a chronic illness must deal with the issues related to their developmental stage along with the issues related to their illness. A chronic illness at this stage often results in interfering with or delaying identity formation and vocational and relationship goals. Individuals in this age group often do not have the maturity, coping skills, or financial stability to effectively deal with a chronic illness without considerable support. There is often a push-pull experience that results between wanting to be independent and needing support.

General Stigma

Another social aspect of illness is that some diseases are judged negatively and have become stigmatized by society. In his ground-breaking work on stigma, Erving Goffman (1963) noted that the term originated with the Greeks who would burn or cut a sign into the skins of criminals and other *undesirables* in order to permanently brand them as socially tainted. Individuals with immoral or unwanted physical attributes were added to the concept in early Christian times. Goffman noted all societies implicitly categorized and judged individuals based on various characteristics and attributes. This led to a social identity that consisted of a wide range of socially-ranked attributes from occupation to physical and personality characteristics.

Undesirable characteristics are referred to as stigmas and they can be physical, personal, or demographic in nature (Major & O'Brien, 2005; Scambler, 2006). Individuals with stigmas are often considered to be different, inferior, and tainted which results in a discredited and spoiled social identity. Link and Phelan (2001) emphasized that stigmatization links the labeling that occurs to stereotyped beliefs which often results in discrimination, loss of social status, and poorer life chances. Additionally, the labeling that occurs separates groups of people into *us* versus *them* or into the *in group* or desired group versus the *out group* or the undesirable or *minority* group. The process of stigmatization can become a self-fulfilling prophecy when stigmatized individuals internalize the labeling and then act in a less confident manner because they expect discrimination. This was called *stigma consciousness* by Pinel and Bosson (2013).

Stigmatization is dependent on social, political, and economic power because it is the powerful groups in a society who define the desirable characteristics and have the

power to create the social hierarchies (Link & Phelan; 2001; Scambler, 2006). Diseases become stigmatized due to negative characteristics such as the negative nature or source of the disease, the type of people who typically acquire it, fear and misconceptions surrounding it, the type of treatment required, the prognosis, any negative physical or mental anomalies that result from it, and so forth (Ablon, 2002).

Common stigmatized diseases include mental illness, epilepsy, sexually transmitted infections like HIV/AIDS, leprosy, and dwarfism to name a few (Ablon, 2002). People with stigmatized diseases are often discriminated against, insulted, ostracized, and rejected. Therefore, young adults with a stigmatized chronic illness have a great deal of challenges and stressors to deal with along with the normal challenges of transitioning to adulthood. Herek, Capitanio, and Widaman (2003) found that the stigma related to HIV/AIDS was compounded by the social group the individual belonged to as well as the method of transmission. They found that individuals who acquired HIV through a blood transfusion were viewed more sympathetically than intravenous drug users, sex workers, or men who acquired it through having sex with other men.

Stigma and Discrimination Related to Living with HIV/AIDS

One of the major challenges for all individuals living with HIV/AIDS is dealing with stigma and discrimination (Mahajan et al., 2008). HIV/AIDS has become a stigmatized illness because many of the behaviors connected with transmission are considered to be against some of the accepted social norms such as intravenous drug use, homosexuality, sex work, and frequent sex partners. At the beginning of the epidemic in the United States, it was considered a fatal illness with no cure which engendered a great deal of fear (Shilts, 1987). The invention of highly active antiretroviral therapies in the

1990s turned the illness to a manageable chronic condition (although still incurable) but fear and misconceptions still remained (Palella et al., 1998).

Dealing with stigma, discrimination, and rejection is a common occurrence for individuals living with HIV/AIDS (Mahajan et al., 2008). Stigma in HIV/AIDS has been related to delayed testing, entry into health care, treatment, and supportive services because individuals do not want others to know about their condition and/or they are often in denial or do not want to acknowledge their condition (Herek, Capitano, & Widaman, 2003; Obermeyer, & Osborn, 2007). Delaying testing, treatment, and supportive services can exacerbate their condition. Because of stigma, individuals living with HIV/AIDS are often reluctant to disclose their status to others.

According to the Adolescent AIDS Program, adolescents and young adults living with HIV/AIDS encounter many challenges including coming to terms with their diagnosis, stigma, fear, and choosing whether or not to disclose to family, friends, and acquaintances. They also challenges with understanding the complicated concepts related to HIV as a disease, and transitioning to independent self-care and health care (Catalozzi & Futterman, 2005). Furthermore, individuals living with HIV/AIDS in this age group exhibit a higher degree of depression and substance abuse than other age groups. Futterman, Chabon, and Hoffman (2000) noted that young adults in general are the least insured among all age groups and this serves as a barrier to care for young adults living with HIV/AIDS. They also found that young adults living with HIV/AIDS often do not trust the healthcare system and are afraid to disclose their status because they do not understand confidentiality regulations.

Studies about Living with HIV/AIDS

There have only been a few studies that have examined the lives of young adults living with HIV/AIDS. Most of them show a close association between the social-ecological environment, their experiences, and coping. Rydström, Ygge, Tinberg, Naver, and Eriksson (2013) conducted interviews with ten perinatally acquired young adults living with HIV who grew up in Sweden. The most common themes were hiding their status to avoid stigma, controlling who knew they were HIV positive, dealing with life losses related to their HIV, putting their HIV into perspective, a heavy reliance on their health care providers for support, and an overall positive attitude despite having HIV. Rodríguez (2009) interviewed 13 adolescents living with HIV in Puerto Rico. The central theme of their lives was striving to be thought of as normal and living a normal life in spite of being HIV positive.

Several researchers have found significant mental health issues related to living with HIV/AIDS. Radcliffe et al. (2007) surveyed 30 young adults 18-24 years of age who were living with HIV to measure the level of stress and traumatic events in their lives. They reported that 93% felt that finding out they were HIV positive was a traumatic event, 20% experienced significant symptoms related to post-traumatic stress when diagnosed, and 13.3% fit the criteria for post-traumatic stress disorder immediately after diagnosis. Another 47% had experienced post-traumatic stress symptoms because of other violent and abusive situations in their lives. Katz and Nevid (2005) and Tsao, Dobalian, and Naliboff (2004) also found that adults living with HIV/AIDS experienced a greater degree of panic disorders and post-traumatic stress disorders related to their HIV.

Szelag (2011) interviewed 17 young adults 13-24 years of age living with HIV/AIDS who acquired it at birth along with five clinicians who provided their care. She also conducted a focus group with six of their biological mothers. She noted that youth who were told their diagnosis at a young age, grew up in a supportive environment, were more engaged in care, and had built trusting relationships with their clinicians were better able to cope with their illness. She also found that many of them did not understand the relationship between medication adherence, resistance, and transmission. Most were reluctant to disclose their HIV-positive status to friends. The biological mothers also expressed anxiety about disclosing their status and often kept it a secret from family and friends. The author emphasized that disclosure should happen at an early age and parents/guardians should be assisted with the disclosure process. Mothers should receive more support when disclosing their own statuses. Better educational programs about the long term effects of HIV treatment need to be designed for young adults living with HIV/AIDS.

In 2012, Ramjohn conducted interviews with 26 African American and Hispanic females 16-24 years of age living with HIV/AIDS who lived in the New York City area. She found that the integration of being HIV positive with identity development and coping outcomes were strongly related to socioeconomic status and the availability of supportive resources. She found four different identity types among the participants. *Immersers* continued to engage in the identity process, were more likely to set and pursue positive goals, tried to maintain their health, and established positive relationships with clinicians and supportive services. They were more likely to live in psychologically and financially stable environments with supportive families. *Withdrawers* avoided identity

development, often continued risky behaviors, avoided setting future goals, were often socially isolated, and did not pursue treatment or supportive services. They were more likely to be from less psychologically and financially stable family environments.

Bootstrappers also came from less financially stable environments but established positive relationships with clinicians and supportive services, were more engaged in their care, and set goals for the future. *Suspenders* gave up on identity development, suspended their career goals, continued with risky behaviors, and often did not comply with treatment and medications. They often came from financially stable environments but were frequently distant from their families. All participants reported that they experienced a biographical disruption and loss of self upon learning of their HIV-positive status.

Several studies have found an association between being HIV positive and continuing risky behaviors. Stock, Gibbons, Peterson, and Gerrard (2013) examined the effects of racial discrimination on 833 African American young adults living with HIV/AIDS. They found a correlation between perceived discrimination, risky sex behaviors, and substance use behaviors. The researchers believed that this association was due to feelings of exclusion, anger, and stress that were related to the discrimination. Hsin (2011) examined markers of adulthood and a variety of health behaviors among 48 young adults 18-30 years of age living with HIV/AIDS. She found that these young adults reported higher rates of friendlessness, lower consumption of vegetables and fruits, and higher rates of risky sexual and substance abuse behaviors than similar young adults who were not HIV positive. She also found that the participants chose the same markers

of adulthood as young adults not living with HIV/AIDS, including increased personal responsibility for actions and increased independent choice making.

Sexuality and LGBTQ Issues

A large percentage of young adults who are living with HIV/AIDS are young men who have sex with men (MSMs) (CDC, n.d.c.). Epidemiologists created the term *MSMs* in the 1990s as a neutral term to identify all men who have sex with men, including those who do not identify themselves as gay, bisexual, homosexual, transsexual, or transgender for various reasons (Glick, Muzyka, Salkin, & Lurie, 1994). There is a great deal of research that relates compromised mental health and depression with stigma and discrimination among LGBTQ youth (Almeida, Johnson, Corliss, Molnar, & Azrael, 2009; Huebner, Rebchook, & Kegeles, 2004; Mays & Cochran, 2001; Meyer, 2013). Thus, issues related to sexual orientation often compound the issues of dealing with HIV for many young adults and augments the associated stigma. Dowshen, Binns, and Garofalo (2009) surveyed 42 young adult MSMs and found high stigma scores that were related to depression, loneliness, low self-esteem, and the reluctance to HIV-positive disclose their status to other sexual partners.

Voisin, Bird, Shiu, and Krieger (2013) conducted focus groups with 18-24 year old African American urban MSMs. They found that living in a low income area with poor resources was a risk factor for acquiring HIV along with the fact that most of these young men only had relationships with others in their small social group which already had a high incidence of HIV. Additionally, they found that many of these young men felt powerless to prevent the spread of HIV. Adopting health information and behaviors for

preventing HIV were hindered by feelings of apathy, marginalization, social isolation, and discrimination due to their race and sexual orientation.

Jeffries, Marks, Lauby, Murrill, and Millett (2013) conducted surveys with 1,154 African American MSMs and found that those who had experienced homophobia were less motivated to practice preventive sex behaviors. They found that these men often internalized the homophobia which resulted in feelings of depression, apathy, stress, denial, low self-esteem, and loneliness.

Yet another factor is the difference in attitudes towards homosexuality by race and location. Glick and Golden (2010) analyzed data from the 2006 General Social Survey which is a large, nationally-representative survey that has been conducted on U.S. adults every year since 1972. They found that 72.3% of African Americans believed that homosexuality was always wrong compared to 51.6% of Caucasians. Furthermore, 57.1% of African American MSMs felt that homosexuality was always wrong compared to 26.8% Caucasian MSMs.

Results from a random sample survey of 1,515 U.S. adults by the Pew Research Center in 2003 indicated that 58% of those who resided in the southern area of the United States had an unfavorable view of gay men compared to 53% of those who resided in the Midwest, 45% of those who resided in the West, and 41% of those who resided in the East. Additionally, the results of the study showed that conservatives, people with lower levels of education, and those who were more religious, especially evangelical Protestants, were more likely to have unfavorable views of LGBTQ individuals.

Racial and Historical Issues

Another important aspect of the HIV epidemic, particularly because a large proportion of the young adults living with HIV/AIDS who live in low income, urban areas are African American, is the subject of trust in the U.S. healthcare system (Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Nelson, Smedley, & Stith, 2002). This mistrust dates back to the 1800s when African American slaves were often used for medical and surgical experimentation (Gamble, 1995; Washington, 2006,).

Anthropologist Gladys-Marie Fry wrote that many African Americans around 1900 believed in *night doctors* who kidnapped Blacks at night and used them for experimentation (Fry, 2001). These fears led Dr. Daniel Hale Williams to establish the first African American-owned hospital in Chicago in 1891 (Gamble, 1995). The belief by African Americans that they were typically placed in segregated wards where they received inferior care led to the establishment of several African American-owned hospitals across the country.

One of the most notorious cases of exploitation took place from 1932 to 1972 by the U.S. Public Health Service (Warren, Williams, & Wilson, 2012). The USPHS conducted the *Tuskegee Study of Untreated Syphilis in the Negro Male* on several hundred poor Black men in Alabama (CDC, n.d.e.). The purpose of the study was to investigate the natural history of syphilis however the men were misled about their diagnosis, were not properly consented, and were not offered penicillin when it became available. Because they were not properly treated, many of the men died of untreated syphilis, their wives/partners were infected, and their children were born with congenital syphilis. The study came to light in a 1972 Associated Press article which resulted in

public outrage, a class-action lawsuit, and more stringent federal regulations regarding human subject protection in research studies.

Bogart and Thorburn (2005) conducted a phone survey of 500 African American adults and found that 60% of the respondents felt that important information about HIV/AIDS was being withheld from the public. Almost half believed that the HIV virus was man-made. Thirty-one percent of males and 25% of females believed that the virus was created in a government laboratory. Slightly more than half felt that there was a cure for HIV/AIDS but it was being withheld from poor individuals. More than one third felt that government was not telling the public the truth about HIV/AIDS. Forty-four percent of all respondents felt that people who participated in HIV clinical trials for new medications were really human guinea pigs for the government. Twenty-one percent of the male respondents and 12% of the female respondents still believed that the government created the HIV virus as a form of genocide for the African American community. Male respondents who believed in the conspiracy theory were less likely to report consistent condom use. On a positive note, 75% felt that the public health and healthcare systems were conducting programs in the African American community to halt the spread of HIV/AIDS.

Similarly, Ross, Essien, and Torres (2006) surveyed 1,494 individuals from community locations in Houston, TX and found that over one-quarter of the African American respondents and one-fifth of the Hispanic respondents believed in the conspiracy theory that the HIV virus was created by the government to kill minority individuals. Gillman et al. (2013) recently interviewed 47 young men 13-24 years of age living with HIV/AIDS of whom 83% were African American. They found that 57%

believed in at least one of the five conspiracy theory questions that were on the survey, including the belief that either the government or the pharmaceutical companies had a cure for HIV/AIDS but were withholding it. They found a correlation between conspiracy theory beliefs and negative attitudes towards HIV medications in this group. Respondents who expressed trust in their physician reported a more positive attitude towards HIV medications. Neither belief in conspiracy theories nor trust in physician correlated with linkage and retention in care or delays in being diagnosed.

The literature about living with HIV/AIDS has captured the struggles with stigma, disclosure, and discrimination as well as the impact of poverty and race. It has also revealed some stories of resilience. The data from this study was viewed in the light of this literature and will be discussed in Chapter 5.

Chapter Summary

The important aspects of young adulthood, the influence of being part of the Millennial birth cohort, the impact of living in a low income, urban environment, and the impact of living with HIV/AIDS were presented in this literature review. Studies were presented that gave a glimpse into the lives of individuals living with HIV/AIDS. This study may add to the literature by presenting an additional view of the lived experiences of young adults living with HIV/AIDS who live in a selected low income, urban area through the lenses of the ecological development model and the concept of resilience.

Additionally, I hope that I was able to give voice to these individuals and show how their particular set of challenges and strengths could be turned into opportunities to help enhance their lives. This information may be valuable for educational leaders, healthcare leaders, policymakers, and other professionals who design and conduct

programs, services and policies to help this group transition to adulthood, care for themselves, and prevent transmission of the virus to others.

Chapter 3: Procedures and Methods

The Qualitative Paradigm

The qualitative research paradigm is concerned with collecting and analyzing narrative data directly using an inductive or theory generating approach (Johnson & Christensen, 2004). It is concerned with collecting socially-constructed meanings and the emic or insider's viewpoint. Patton (2002) noted that the strength of the qualitative approach is in the depth and detail of data that is generated. Classical Anthropologist Clifford Geertz (1973) called this *thick description*, noting that humans are suspended in webs of significance (culture) of their own creation which warrants an interpretive analysis that looks for meaning rather than an experimental one that looks for laws. Thick description includes moving beyond merely describing an action to interpreting it within its thickly and richly described context.

Denzin (1989) expanded this definition of thick description to apply to all types of qualitative research beyond anthropological ethnographies and to include the influence of interacting social relationships. Schwandt (2001) emphasized that thick description has a deep, interpretive aspect that includes the actors' intentions, meanings, and motivations. Ponterotto (2006) noted that when using thick description with interviews, the researcher should fully describe the participants in both demographic and psychological terms, provide a description of the context of the participant in general, and a description of the location of the interview. The researcher should also describe the relationship and emotional state that existed between the participant and the researcher during the

interview, and present long, detailed excerpts. He believes that this will help give *voice* to the participants and set the interview within a context.

The qualitative approach is not constrained by pre-determined response categories like in quantitative research (Bogdan & Biklen, 2003). It allows for the probing of responses which is also not possible using a quantitative approach. The one-on-one interaction between the researcher and participant that takes place in the qualitative approach allows the researcher to also collect important non-verbal and naturalistic data. By using qualitative techniques, the researcher can collect deeper emotions that cannot be collected using quantitative methods.

Since the purpose of this study was to capture the point of view of low income, urban young adults living with HIV/AIDS along with the socially-driven meanings they attached to their experiences, the qualitative research paradigm was the methodology of choice. Done well, qualitative research methods generate richly detailed, deep, and descriptive data from a relatively small number of subjects compared to quantitative research methods which are used to generate broad, general data from a large group of subjects. Since my goal was to understand how the experience of living with HIV/AIDS impacted the lives of low income, urban, young adults and what it meant to them, I chose the qualitative research paradigm in order to capture the depth and meaning of their experiences.

Qualitative Method: Phenomenology

As mentioned in Chapter 1, the research paradigm for this study was also influenced by phenomenology, a type of inquiry with a strong philosophical background that strives to understand the lived experiences of a group of people regarding a particular

phenomenon (Moustakas, 1994; Patton, 2002; Van Manen, 1990). It attempts to enter the participant's inner life-world and to understand the personal meanings he/she assigns to experiences. The phenomenological tradition also seeks to find the commonalities among human experiences across participants. It attempts to understand the individual and shared meanings that people construct in response to experiencing a phenomenon and produces a rich description of their lives from their vantage point. The phenomenon in this case was the experience of living with HIV/AIDS as a young adult in a selected low income, urban environment.

The data collection method of choice for this study was open-ended, in-depth interviews that encouraged the participant to relive and describe particular experiences in rich detail (Seidman, 2013). This method of data collection follows the purpose of the qualitative research paradigm, which is to collect richly descriptive narrative data from the participant's viewpoint that contains deep meanings rather than broad generalizations.

Site Selection: Context and Access

According to Patton (2002), one of the distinctive differences between qualitative and quantitative research is the sampling procedure. Because generalizability of results to large populations is the goal of most quantitative studies, random sampling techniques are usually employed in order to develop large, representative samples. However, since the purpose of qualitative studies is to collect deeply detailed and nuanced data, depth is more important than breadth. It takes considerably more time to collect this type of data than to field surveys or tests. Additionally the unit of analysis in most qualitative studies is individuals as opposed to groups, events, or programs. A researcher can learn more in-depth information from a small, purposefully selected group than from a large, general

sample. Therefore, purposive sampling is considered the most appropriate, useful, and feasible method to collect deeply detailed and nuanced data that will answer the research questions in most qualitative studies.

Since the purpose of my study was to collect deeply detailed and nuanced data about the lives of low income, urban young adults living with HIV/AIDS, I selected purposive sampling as my sampling procedure. I enrolled 16 young adults 18 to 29 years of age living with HIV/AIDS who lived in a selected low income, urban area in the southeastern region of the United States using the methods described below. This was an example of extreme case sampling because this group represented a high risk group living in a high risk environment. Onwuegbuzie and Leech (2001) list extreme case sampling as a way of magnifying the phenomenon being studied because it deliberately selects individuals who possess an extreme form of the characteristics under study. Johnson and Christensen (2004) list extreme case sampling as a method of capturing extremely rich information because of the extreme nature of the characteristics possessed by the study population.

I used several methods to identify and recruit participants. I used data from the area's health department to identify zip codes that had the lowest household incomes and the highest morbidity and mortality rates in the area. These zip codes comprised the low income, urban area for this study. Initially, a list of young adults 18-24 years of age living with HIV/AIDS who lived in this selected low income, urban area was generated from the patient database of a local infectious disease clinic for recruitment purposes. I received IRB approval to approach these young adults at their next clinic visit (see Appendices J and K). I also received IRB approval to call them using an IRB-approved

telephone script to set up a meeting if they did not have an appointment scheduled in the near future (see Appendices B and D). Individuals who did not speak English or who were not cognitively able to consent to study participation were excluded because they were not able to participate in the study interviews.

Flyers announcing the study were displayed in the infectious disease clinic and the study was announced at the clinic's adolescent and adult support group meetings. Flyers were also distributed to case management and social service agencies in the area that served young adults living with HIV/AIDS. I received IRB approval to return the calls of interested individuals using an IRB-approved telephone script to set up a meeting to discuss the study (see Appendices C and E).

Participants were asked to inform friends or acquaintances that fit the eligibility criteria about the study and instruct them to contact me if they were interested in learning more about participating. This last method is an example of snowball sampling and is a technique that is often used to locate hard-to-find, rich sources of information that might be friends or acquaintances of current subjects (Atkinson & Flint, 2001; Johnson & Christensen, 2004). It is often used in social research to access vulnerable, deviant, stigmatized, and other groups that are hard to access and are outside the mainstream. If each subject informs another eligible individual, the sample size often begins to *snowball*. Unfortunately, none of the participants referred anyone for study participation so no one was recruited using snowball sampling.

I began data collection in August 2014. At the end of December 2014, I had only completed eight interviews. I was not getting any responses from the posters at the local service agencies and I noticed a very high no-show rate among the 18-24 year old patient

population at the infectious disease clinic. For example, 15 patients who fit the study criteria were scheduled for a clinic visit during a particular week and only three came to their appointments. Therefore, I decided to increase the age range to 29 years in order to widen my possibilities of individuals for enrollment. The 25-29 year old age group has the second highest rate of new HIV cases after the 18-24 year old age group so this is also an important group to study (CDC, n.c.d). I received IRB approval to increase the age range and started recruiting from the 18-29 year old age group starting January 1, 2015. I enrolled an additional eight individuals during January 2015 and concluded enrollment at the end of that month because a review of the data indicated that I had collected an adequately rich data set.

Participants and Participant Selection

The study sample included nine males and seven females between the ages of 18 and 29 years of age (see Table 2). Eight of the males had acquired HIV behaviorally while one of the males had acquired HIV perinatally at birth. Six of the females had acquired HIV perinatally at birth while one of the females had acquired it behaviorally. Fourteen of the participants were African American while one was Hispanic and one was Caucasian. Because of the extremely sensitive nature of being HIV positive and because the disclosure of medical information is protected by the Health Insurance Portability, and Accountability Act (HIPAA), I cannot identify each participant individually by his/her gender, race/ethnicity, age, and mode of transmission (Bova, Drexler, & Sullivan-Bolyai, 2012; USDHHS, n.d.d.). I also cannot identify the urban location or the name of the infectious disease clinic for the same reasons. Piecing together these bits of information could result in deductive disclosure because of the small population from

which the study sample was drawn. Many of the participants indicated that they had only disclosed their status to a very small number of their friends and family because of fear of stigma, discrimination, and rejection, therefore it was important that I made sure to protect their confidentiality.

Table 2

Characteristics of the Study Sample

Variable	N
Total	16
Males	
Behaviorally acquired	8
Perinatally acquired	1
Females	
Behaviorally acquired	1
Perinatally acquired	6
Race/ethnicity	
African American	14
Hispanic	1
Caucasian	1
Age range	
18-20 years of age	6
21-23 years of age	5
24-26 years of age	3
27-29 years of age	2

Data Collection Procedures

All of the participants were patients at a local infectious disease clinic. No one responded to the flyers that were placed at the local social service agencies and none of the participants referred anyone. Upon meeting with a potential participant, I explained the study in depth and went through the consent form with the participant. The participant was given an unlimited amount of time to ask questions about the study and was allowed to take the consent form home to think it over and/or to discuss the study

with family and friends before making a decision about participation. After the individual signed the consent form, I conducted the interview. I conducted all of the interviews in a private room at the infectious disease clinic. I gave each individual a copy of the signed consent form for their records. All of the participants consented to the digital recording of their interviews.

All of the interviews were digitally recorded using two recorders in case of breakdown or battery failure. The interviews ranged from 15 to 60 minutes in length. I made brief notes during and after each interview to record details that took place but were not captured by the digital recordings such as body language and other non-verbal events. Additionally, I created a reflexive journal where I recorded impressions and other thoughts and ideas that emerged during the interview process.

After each interview was completed, I thanked the participant for his/her participation and gave him/her either \$10 in cash or a \$10 gift card to compensate for time and travel. Each participant was asked to return to the clinic or a private location several weeks later to participate in a second interview in order to review the results from the first interview and answer additional questions. Only five participants came back for the second interview. Two declined and the rest could not be reached. I noticed this trend early in the interviewing process so I began to review the first interview at the end of the first meeting with each participant and asked any additional questions that I had in case they were not able to return for the second interview. Participants who returned for the second visit received \$10 in cash or a \$10 gift card to compensate them for their time and travel.

The preferred method to determine sample size in qualitative research studies is currently being debated among researchers. Some researchers believe that data collection should conclude when data saturation has been achieved and no new data is being generated (Crouch & McKenzie, 2006; Mason, 2010, Ritchie, Lewis, & Elam, 2003). This method is often used when conducting grounded theory research. Researchers that pursue phenomenological research generally believe that data saturation is a nebulous concept and additional study cases will always add more richness and depth to the data set (Guest, Bunce, & Johnson, 2006; O'Reilly & Parker, 2012). Therefore, they suggest concluding data collection when an adequately rich collection of data has been collected. I decided to end data collection after interviewing 16 individuals because I believed I had collected a very rich dataset at that point and I was only capturing variations on the same themes.

Data Sources

The main source of data was through semi-structured, in-depth interviews. To prepare for the interviewing process, I reviewed several resources including works by Gubrium and Holstein (2002) and Seidman (2006). These resources included suggestions for recruitment, establishing rapport, attentive listening, and interviewing different types of people. In social research, the researcher must be able to obtain access to the study population, establish rapport, and gain trust in order to obtain valid, insider information (Patton, 2002). Gubrium and Holstein (2002) noted that using a gatekeeper or someone who is known to and trusted by the study population can assist with accessing a particular group. Additionally, recruiting participants in a trusted situation or location also assists with accessing a particular group. In my situation, I used colleagues who were known to

the study population as well as trusted locations including the clinic and social service agencies where they received their HIV care and related services to access the study population. To gain some experience and to test the process, I practiced interviewing several colleagues and family members.

The goal of the interview process was to examine how young adults who lived in a selected low income, urban area perceived their experiences living with HIV/AIDS. I explored their challenges, barriers, strengths, assets, and needs, and collected suggestions for improving programs, services, and policies for them. Because the goal was to collect rich descriptions from their perspective, I began each interview by asking them to tell me what it was like to live with HIV. This was followed by probing for clarifications and explanations. An interview guide was developed that was used during the semi-structured interviews (see Appendix A). The interview guide was aligned with the research questions and the conceptual framework to make sure that appropriate data were collected. The interviews lasted between 15 and 60 minutes.

Data Credibility, Trustworthiness, and Rigor

Data credibility or trustworthiness, which is the degree to which the interpretations of the data accurately reflect the meanings given to it by the study participants, was promoted and strengthened through the following methods (Creswell & Miller, 2000; Kolb, 2012; Lincoln & Guba, 1985; Marshall & Rossman, 2006; Patton, 2002; Whittemore, Chase, & Mandle, 2001):

- presenting a thorough literature review of the salient topics;
- thoroughly explaining the data collection and data analysis process;

- employing rigorous engagement, probing, and observation during the data collection process;
- looking for negative cases which may either strengthen the emerging patterns if not found, broaden the current patterns if found, change the analysis if found, or simply prove to be exceptions;
- being reflexive which included continually being aware of and minimizing my effect on the research setting;
- explaining how I decided to end data collection;
- creating a verbatim transcript of the interviews;
- asking participants for clarification about different aspects of their experiences;
- providing narrative evidence to support interpretations;
- presenting thick, rich descriptions of the participants' experiences;
- using the constant comparative methods during data analysis which included continuously comparing and contrasting the data to the theories in the conceptual framework and hypotheses that were developing;
- employing a conceptual framework that included multiple concepts that had been used in the past to explain similar phenomena;
- testing rival and alternative explanations;
- establishing my credibility by presenting details about my training and experience;
- explaining my perspectives and indicating how bias was minimized;
- including a discussion about transferability which in qualitative research is promoted by linking the data closely to the concepts in the conceptual framework which allows others who are using the same concepts to apply the study results to similar contexts.

The concept of transferability in qualitative research is similar to the concept of generalizability in quantitative research (Lincoln & Guba, 1985). It refers to the ability to transfer the results of a qualitative study to similar situations or contexts. To accomplish this, the researcher must thoroughly describe the context, phenomenon, conceptual framework, and data collection and analysis methods so that others can determine the extent of transferability. I promoted transferability by including a thorough description of these items in this document.

I promoted confirmability of the data by collecting data from multiple participants that confirmed emerging themes and patterns, asked participants to clarify their experiences, and justified interpretations through presenting similar findings in the literature and employing complementary theories in the conceptual framework (Patton, 2002). Using these methods also enhanced rigor, confirmability, and dependability which ultimately made the study results more valid, reliable, and credible (Douglas et al., 2010).

Self as Researcher

Another important aspect of the qualitative research paradigm is that the researcher is considered to be the data collection instrument and the analytical tool (Patton, 2002). In quantitative research, a validated measurement device such as a survey or test is used as the data collection instrument. The careful construction of these measurement devices is important to the validity of the data collected. Data analysis in quantitative research relies on descriptive and inferential statistics. In qualitative research, there are no measurement devices that collect data. The researcher is the measurement device and the data collection instrument. Patton (2002) noted that data

quality for qualitative research is highly dependent on the researcher's skills, rigor, and credibility.

Eisner (1998) noted that the quality of a qualitative research study also relies on the connoisseurship or expertise of the researcher. The researcher is a major part of the interpretation of the data. Just by the nature of being human, every researcher has preconceptions and it is his or her job to be as transparent, impartial, and unbiased as possible. Therefore, all researchers should state the level of their training, experience, and expertise along with any personal or professional factors that might influence the conduct of the study and interpretation of the data. I will do that in the next section.

In my case, I have a bachelor's and master's degree in anthropology with a medical focus. I have more than 10 years of post-masters experience as a research project manager in both educational and healthcare research. My educational research experience has included survey research, institutional research and planning, and assessment and evaluation at several higher education institutions. My healthcare research experience has included research project management experience at several universities and at a national pediatric professional association. I have worked on research projects investigating the effects of socioeconomic status on access to prenatal health care by low income women, motivational interviewing to reduce obesity in children, smoking cessation in adolescents, and aspects of patient safety.

I am currently employed as a clinical research specialist for an academically-based center that provides medical care and access to clinical, behavioral, and observational research studies for individuals with infectious diseases. I have experience fielding surveys, conducting interviews and focus groups, and performing both

qualitative and quantitative data analysis. I have completed doctoral-level coursework in educational leadership and a significant amount of public health coursework as part of my master's degree program and as the cognate for my doctoral program. I have developed a deep interest in the social determinants of health and health disparities.

I am particularly interested in the link between education and health. I have developed a high degree of expertise and connoisseurship in conducting health care and educational research studies, and a high degree of interest and training in the social sciences, public health, and educational leadership. I am not HIV positive but I have worked directly with individuals living with HIV/AIDS for the past 8 years in my position as a clinical research specialist at an academic-based center that provides medical care and access to research studies for patients with infectious diseases.

I was different from the research participants in terms of race, age, education level, and socioeconomic status. However, I do not believe that this was a limitation for me in conducting the study and analyzing/reporting the data because of my previous experiences working with the study population and my skill level as a researcher. I have worked with the study population for 8 years as a clinical research coordinator in an infectious disease clinic. Also, I believe that I have developed a deep understanding and interest in different cultures and the effect of social and cultural factors on the development of the individual through my anthropological training and my work experience. This helped me to remain open and unbiased when interacting with the study population. I was also guided by the suggestions in Tillman's article (2008) about using a culturally sensitive research approach which included being aware of and acknowledging the cultural differences between me and the study population. This also

involved going one step beyond remaining open and unbiased by placing their cultural characteristics front and center when interpreting their experiences. Since I have worked with the study population for 8 years, I have developed an understanding of their culture which helped me when recruiting, interviewing, and voicing their experiences. Therefore, I believe that my training and experience lends credence to my skill level and credibility as a researcher who is grounded in social theory and scientific inquiry.

Insider versus Outsider Perspective

In social research, the researcher must be able to obtain access to the study population, establish rapport, and gain trust in order to obtain valid, insider information (Patton, 2002). One of the challenges inherent in conducting social research is that there is often a difference between the researcher and the participants regarding certain characteristics such as age, gender, social class, income level, education level, and race/ethnicity. This will establish the researcher as either an *insider* (a person with very similar characteristics which may facilitate acceptance and trust by the participants) or an *outsider* (a person with very different characteristics which may engender suspicion and reluctance to divulge information).

On the one hand, I differed in terms of age, social class, income level, education level, and race/ethnicity than most of the study participants. However, as mentioned above, I have worked at the center for 8 years, I am known to the participants as someone who works there, and I am familiar with some of the participants. Therefore, I served as both an outsider and an insider to the participants in different respects. I believe that serving in the capacity as clinical research specialist at the clinic helped to establish

legitimacy and trust with the participants even though I was different from them in many characteristics, such as race and age.

Researchers who are outsiders often use gatekeepers (important or accepted individuals within the study population) to facilitate access and vouch for them so that members of the study population do not view them as total strangers. Outsider researchers must work to build trust and rapport with their participants. I used clinic staff as well as staff at other agencies that served individuals living with HIV/AIDS that were known and accepted by the study population as gatekeepers to introduce my study to this population. Staff at this clinic work very hard to establish trust with the surrounding HIV community by involving patients in a Community Action Board which captures their input about clinic matters. The clinic also sponsors other events to enhance the relationship with patients such as holding support groups for different ages, baby showers for pregnant women living with HIV/AIDS, a holiday present drive for children living with HIV/AIDS, and other events. The clinic is well-accepted in the surrounding HIV community. The clinic staff itself is also very diverse in terms of race, ethnicity, age, and sexual orientation. This helps to establish rapport with the patients.

At the beginning of each interview, I also worked to establish rapport and trust with each participant by explaining how I would keep their information confidential and by asking them about themselves. I showed interest in them by validating and exploring their responses while suspending any judgments. In order to bridge some of the racial differences between the participants and me, I strived to use a culturally sensitive research approach by being cognizant of the different cultural aspects and experiences of the study population and to work hard to understand, respect, and validate their beliefs

and experiences from their perspective while avoiding a deficit perspective (Tillman, 2008).

There has been a great deal of discussion in the research literature about whether being an insider versus an outsider helps or hinders understanding, interpretation, and data analysis (Creswell, 2007; Marshall & Rossman, 2006; Patton, 2002;). Insiders may already have an inherent understanding of the participants because of their similarities yet this can sometimes be clouded by over familiarity. Outsiders might lack this initial level of understanding and rapport, but should use their outsider perspective to step back and critically analyze parts of another culture or group.

McCracken (1988) noted that one of the positive aspects of being an outsider included that everything about the study population was new and mysterious to them. This gives them a critical distance and a sharper eye. He noted that researchers who are insiders are more likely to take the beliefs and actions of the study population for granted and therefore might miss some of the nuances. They have already developed an array of assumptions that lie beneath their subconscious. Therefore, McCracken (1988) believes that all researchers must be able to step back and manufacture distance so they can view the study population with an analytical rather than a familiar eye. He also maintains that researchers must get the study participants to step back and manufacture distance from themselves through probing and reflection so they, too, are not clouded by assumptions and over-familiarity about their own actions and motivations. I believe that I was able to step back and view the participants with an analytical eye which helped me to give importance to all aspects of their experiences.

Patton (2002) proposed the concept of *Verstehen* where the researcher combines insight with empathy in order to move from the outside to the inside of the participants' world. This involves empathetic identification and psychological reenactment on the part of the researcher which Patton felt was essential to successful qualitative research. I combined the use of my analytical eye as an outsider to step back and assess the study population while employing empathy and insight to attempt to understand their world. I also used my status as an insider at the clinic to enhance trust with the participants. I strived to use a culturally sensitive approach in order to understand, respect, and interpret the study population from their perspective while still being able to step back and view the data with a critical awareness and sharp eye.

Ethical Issues

Before I undertook any research activities with human subjects, I obtained Institutional Review Board (IRB) approval for the study in order to ensure that it did not pose any unnecessary physical or psychological harm to the participants and that the participants' confidentiality and rights were protected (see Appendices J and K). An IRB-approved participant consent form that explained the study's purpose, duration, procedures, discomforts, risks, benefits, alternatives, confidentiality procedures, and study contacts was presented and explained to each potential participant (see Appendices H and I). The consent form emphasized that participation in the study was voluntary and that there would not be any negative consequences for individuals who did not wish to participate. The consent form explained that study participants could withdraw from the study at any time without any negative repercussions. I thoroughly explained the study

and the elements of informed consent, answered any questions, and obtained each participant's signature on the consent form before beginning any research activities.

Participants' privacy was protected by assigning each person a confidential identification number which was used on the digital recordings, transcriptions, and study notes instead of their names or any other identifying characteristics as explained above. I also reiterated throughout the process that all of their information and data would be kept strictly confidential. This was particularly important because of the stigmatized nature of being HIV positive and because a participant might reveal sensitive and private information.

I was also bound to maintain participant confidentiality by the Health Insurance Portability and Accountability Act (HIPAA), the Privacy Rule, and the Common Rule which prohibits the disclosure of protected and identifiable health information including HIV status without the individual's permission (Bova, Drexler, & Sullivan-Bolyai, 2012; USDHHS, n.d.d.). These rules are mandated by the USDHHS and enforced by Institutional Review Boards. They require that disseminated data must be de-identified by removing 18 types of identifiers of the participant and his/her relatives, employers, and household members in order to protect the confidentiality of the research participants. These identifiers include names, geographic location information smaller than state, birth and death dates, medical admission and discharge dates, telephone numbers, fax numbers, email addresses, social security numbers, medical record numbers, account numbers, license numbers, or any other information which could identify an individual if combined. Therefore, the participants are only identified by a

pseudonym, an age range, and the month and year of their interview in the results section in order to protect their confidentiality.

The enrollment log which links the participant's name with his/her confidential identification number is being stored in an electronic file on my institution's secure dedicated research server as required. My institution sets up a separate secure electronic folder for every research study on their secure dedicated research server that is only accessible by the research team. My institution set up a secure electronic folder for my study on their secure dedicated research server that was only accessible by me and the IRB administrator.

Additionally, I asked participants not to use their name, or the names of family, friends, or associates during the recording. As soon as possible after each interview, the recordings were uploaded to a file in my electronic study folder on my institution's secure dedicated research server and the original digital recordings were erased from the recorder. The written transcriptions are stored in a file in my electronic study folder on my institution's secure dedicated research server and all print-outs are stored in a locked file cabinet in my office at my institution. The interviews took place in a private room at the infectious disease clinic in order to ensure privacy and confidentiality.

Because of the in-depth nature of the interview process, it was a deeply reflective and cathartic process for many of the participants. As explained above, some participants revealed very sensitive, emotional and private information during the course of their interview. As an ethical interviewer, I maintained an unbiased, non-judgmental, and supportive perspective during each interview. Additionally, I was sensitive to each subject's mood, emotions, and reactions, and paused when participants needed to

compose themselves. I did not have to stop any interviews because of participants' reactions. At the end of each interview, I thanked each participant for his/her time and information, and assessed their emotional condition again to determine if they needed any additional professional assistance. I gave each participant the contact information of the clinic psychologist, the hospital's Emergency Department, and the phone number of a local suicide hotline in case they needed psychological assistance after the interview. To my knowledge, none of the participants needed this type of assistance.

Data Analysis

The purpose of this study was to produce a deep, detailed, and nuanced description of the essence of the lived experiences of young adults 18-29 years of age living with HIV/AIDS from a selected low income, urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping. The concept of phenomenology was used to guide the data analysis. Phenomenology seeks to understand the lived experiences of a group of people concerning a particular phenomenon (Patton, 2002). It attempts to understand the individual and shared meanings that people construct in response to experiencing a phenomenon and produces a rich description of their lives from their vantage point. The phenomenon in this case was the experience of living with HIV/AIDS as a young adult in a low income, urban environment. In order to capture the experiences of this group, in-depth, semi-structured interviews were conducted with a purposive sample of low income, young adults living with HIV/AIDS as described above. The interviews were guided by the literature in this area, the research questions, and the concepts that composed the conceptual framework.

Since the data was narrative, the analysis included finding themes, patterns, and insider meanings of the data (Marshall & Rossman, 2006; Patton, 2002; Saldana, 2011). I segmented and assigned codes to the data by topic, concept, typology, and category. This included categories that were created before the analysis that were based on the literature, the research questions, and the concepts in the conceptual framework. It also included new categories called analyst-constructed typologies that were created by me during the review of the data (Patton, 2002).

I coded the data for indigenous concepts, categories, and typologies which were created by the participants themselves as part of their culture and were based on the behaviors and language terms that were meaningful to them. Each interview was transcribed and placed in a Microsoft Word Table for ease of coding and tabulating. This Microsoft Word Table included several columns for coding each segment. I conducted several intense reviews of the recordings, transcripts, and field notes in order to code the data. I arranged the codes into a codebook which included a definition for each code. After all of the interviews were transcribed and coded, I merged the individual tables into a master table that could then be sorted by code. This allowed me to view all of the similar themes together.

After coding the data, I conducted a content analysis to look for themes, patterns, embedded meanings, and relationships. I examined nuances, isolated cases and other data that did not fit in with the common themes and patterns in order to check for alternative explanations. I conducted an emic or insider analysis by looking for behaviors, activities, and meanings that the participants created to make sense of their HIV experience.

Finally, I used the conceptual framework to review the data. This assisted me in drawing conclusions, offering inferences, attaching significances, and telling the story of the participants (Marshall & Rossman, 2006). This included the consideration of alternative explanations and looking for the best fit. A description and interpretation of the data is found in Chapters 5 and 6.

Chapter Summary

Below is a table that summarizes the research design and methodology of the study.

Table 3

Summary of the Research Design and Methodology

Research Design	A qualitative design influenced by phenomenology
Methodology	Semi-structured, in-depth interviews
Study Participants	Purposive sample of 16 young adults 18-29 years of age living with HIV/AIDS from a low income, urban area in the southeastern United States.
Recruitment Plan	<ul style="list-style-type: none"> • Approached patients at a local infectious disease clinic who lived in certain low income zip codes • Posted flyers at agencies throughout the area that served the study population • Asked participants to refer family, friends, and acquaintances who met the eligibility criteria
Research Questions	<ol style="list-style-type: none"> 1. What are the challenges, barriers, and stressors that served as vulnerability factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area? 2. What are the individual, social, structural, and institutional assets, strengths, and supports that served as protective factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with

HIV/AIDS who resided in a selected low income, urban area?

3. What needs and suggestions do young adults living with HIV/AIDS who resided in a selected low income, urban area have for improving programs, services, and policies to help them transition to adulthood, care for themselves, and prevent transmission of the virus to others?

Instrumentation	<ul style="list-style-type: none"> • Semi-structured interview guide (see Appendix A) • Probing to collect rich descriptions
Data Analysis	<ul style="list-style-type: none"> • Constant comparative process • Looked for themes, patterns, and insider meanings
Data Credibility, Trustworthiness, and Rigor	<ul style="list-style-type: none"> • Thorough literature review • Thorough explanation of all methods • Rigorous engagement and probing • Negative case sampling • Reflexivity • Verbatim transcripts • Narrative evidence • Thick, rich descriptions • Tested rival and alternative hypotheses • Multiple theories (ecological model of human development and resilience) in conceptual framework • Constant comparative method • Transparency of my training, skills, and perspectives • Linked data to theories in conceptual framework which enhanced transferability
Self as a Researcher	<ul style="list-style-type: none"> • Researcher is the data collection instrument and analytical tool in qualitative research • Detailed information about my training, skills, and perspective • Used a culturally sensitive research approach in order to focus the study from the participants' perspectives
Insider versus Outsider Perspective	<ul style="list-style-type: none"> • Effects of being similar versus dissimilar to the participants • Insider: similar but may miss items because of over-familiarity

- Outsider: different but easier to step back and have a sharper, critical eye
- Important to establish trust and rapport
- Used trusted others as gatekeepers for access
- Used my status as clinic insider to enhance trust with the participants
- Verstehen: combined insight with empathy in order to move inside the participant's world

Ethical Issues

- Obtained approval from IRBs
- Protected participants' privacy and confidentiality
- Maintained awareness of psychological issues

Chapter 4: Data Analysis and Results

In this chapter, I will present the significant themes and patterns that I observed upon reviewing the data. Patton (2002) noted that guidelines and examples exist for conducting qualitative data analysis, but there are no definitive rules. The analysis of qualitative data relies on the skills, intellect, and creativity of the researcher. Thus it is just as important to report the analytical processes as it is to disseminate the narrative data and findings. He also noted that the analysis should revolve around the purpose of the study, the research questions, and the conceptual framework. The purpose of this study was to examine the lived experiences of a purposive sample of young adults living with HIV/AIDS who resided in a selected low income urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping.

The research questions were:

1. What are the challenges, barriers, and stressors that served as vulnerability factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?
2. What are the individual, social, structural, and institutional assets, strengths, and supports that serve as protective factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?

3. What needs and suggestions do young adults living with HIV/AIDS who reside in a selected low income, urban area have for improving programs, services, and policies to help them transition to adulthood, care for themselves, and prevent transmission of the virus to others?

The conceptual framework for this study was composed of the ecological model of human development and the concept of resilience.

Participants

As noted above, I interviewed 16 young adults living with HIV/AIDS from a low income, urban area in the southeast region of the United States. I have provided a short description of each participant below based on their interviews. Because of the extremely sensitive nature of being HIV positive, participant confidentiality was of the utmost importance because many of the participants had only disclosed their status to a small number of people in their lives.

Additionally, the Health Insurance Portability and Accountability Act (HIPAA) and the Privacy Rule prohibit the disclosure of medical information including HIV status without the individual's permission. Data must be de-identified by removing any identifiers such as name, birthdate, social security number, and geographic location smaller than state (Bova, Drexler, & Sullivan-Bolyai, 2012; USDHHS, n.d.d.). Therefore, each participant was randomly assigned a pseudonym to protect their privacy. Additionally, their race/ethnicity was not identified because there was only one Caucasian and one Hispanic among the study participants and identification might result in accidental disclosure when combined with other characteristics. Age was identified by

range only and certain details such as exact job title and college major were not specified in order to protect confidentiality.

Below is a table that summarizes the characteristics of the participants.

Table 4

Participant Characteristics

Pseudonym	Age Range	Gender	Mode of Transmission	On HAART	Goal	Time HIV Positive
Ella	21-23	Female	Perinatal	Yes	Health Field	Since Birth
Noah	18-20	Male	Behavioral	No	Music & Coaching	Several Years
Olivia	24-26	Female	Perinatal	Yes	Health Field	Since Birth
Jacob	21-23	Male	Behavioral	No	Health Field	Several Months
Jack	18-20	Male	Behavioral	Yes	Own Business	Several Years
Ava	21-23	Female	Behavioral	No	Health Field	Several Years
Mia	21-23	Female	Perinatal	Yes	Health Field	Since Birth
Emily	18-20	Female	Perinatal	Yes	Criminal Justice	Since Birth
William	24-26	Male	Behavioral	No	Computers or Electronics	Several Months
Nathan	18-20	Male	Behavioral	No	Own Business	Several Years

Lily	18-20	Female	Perinatal	Yes	Health or Law Field	Since Birth
Pseudonym	Age Range	Gender	Mode Of Transmission	On HAART	Goal	Time HIV Positive
Nicholas	27-29	Male	Behavioral	No	Health, Law or Business	One Year
Leo	27-29	Male	Behavioral	Yes	Education	Several Years
Henry	21-23	Male	Perinatal	Yes	Writer	Since Birth
Isaac	24-26	Male	Behavioral	No	Own Business	Several Years
Charlotte	18-20	Female	Behavioral	Yes	Health Field	One Year

Participant Descriptions

Below are some brief descriptions of the participants based on their interviews.

Each participant is identified by a randomly selected pseudonym in order to protect their privacy.

Emily

Emily was in the 18-20 year old age group and had acquired HIV perinatally at birth. She was currently employed and eventually wanted to go to college to study criminal justice. She did not find out she was HIV positive until her mid-teens. She had taken HIV medications all of her life but thought she was taking them for something other than HIV. She found out she was HIV positive when she was at summer camp and went to the medical office for her medications. She saw a list that said she was HIV

positive. She was extremely upset and asked her mother about it when she got home but her mother refused to talk to her about it. Her mother had been a drug addict all of her life and was in denial about her drug problems and HIV. Her father died when she was in grade school so she was raised by a relative because her mother was not able to raise her. The relative made her leave when she graduated from high school so she had been living on her own since then.

She noted that she had a strong faith in God which was her main source of support. She believed that God gave HIV to her for a reason so she had to think positive and try to help others. She mentioned that there were many other health conditions that were far worse such as blindness or cancer so she did not feel that bad about having HIV. She felt that she had it easy because the only thing she had to do to stay healthy was to take to her medications. It had been hard for her to deal with having HIV but she said that she worked hard at staying positive and strong. She noted that she tried to ignore the stigma and live like a normal person. She mentioned that when she was asked to take part in this study, she really wanted to participate because she thought her story might help others.

It upset her that no one in her family ever sat down with her and explained the situation in an honest way because she had to learn everything on her own. She had not told many people about her HIV status because of fear of rejection. She said that she wished she had known about it when she was younger so she could have had more time to adjust to it. She had to take a large number of pills which was very difficult. She prayed about it and finally was placed on a one pill-a-day regimen for her HIV. She believed that this was a miracle from God. She said that she had also forgiven her mother

and prayed daily about her mother's drug problem. She did not know much about HIV before she found out she was HIV positive. She said that there should be more in-depth sex/health education in the schools at earlier ages. When she found out she was HIV positive, she started educating herself by reading information on the internet. She had observed that the level of HIV knowledge in her community was very low which she felt led to stigma and discrimination. She felt that there should be more community-level education about HIV/AIDS.

She had attended several HIV support groups which had helped her to be positive and not feel alone. She thought that having young adult motivational speakers who were living with HIV/AIDS would be an effective way to educate young people. She would like to start a center for young women who came from troubled childhoods so that she could teach them positive self-esteem and behaviors. Her suggestion to young people who were living with HIV/AIDS was to try to stay positive and look at every day as a gift.

William

William was in the 24-26 year old age group and had acquired HIV behaviorally from a male partner. He was not currently employed because of recent health issues. He had taken a few courses at a local college and was planning on going back to school when he felt better. He was interested in pursuing a career in computer science or electronics. He found out he was HIV positive recently when he was tested at the blood center where he regularly donated plasma. He believed he had only been positive a few weeks when he found out because he had been regularly tested at the center every 4-6 weeks. He said that he felt lucky he found out early because some people do not find out

for years. He had felt severe flu-like symptoms at the beginning and was still experiencing night sweats. He had only disclosed his status to his mother and a few other people. He was in shock when he found out he was HIV positive because he could only remember one time when he did not wear protection. He felt that one time cost him everything.

He mentioned that his faith and going to church had been a big support for him. Before he became HIV positive, he thought that HIV was a death sentence. Since he became HIV positive, he had read a lot about HIV on the internet. He believed that living with HIV/AIDS made him strive harder and appreciate life more. He said that he was worried that he would not be able to have kids but he did not think having HIV would affect his other goals. He noticed that there were a lot of people who did not understand much about HIV and he had observed a great deal of misunderstanding about it in his community.

He felt that some of the risk factors for participating in risky behaviors were due to loneliness, growing up in an unstable home, or not having proper guidance at home. He felt that young people in those situations were more likely to trust the wrong people too quickly. He believed that these teens needed guidance and support. He expressed a strong need to help others in order to decrease transmission but he was afraid to share his HIV status because of fear of rejection. He suggested that there should be more services to counsel and console people when they first learned about their HIV-positive status because this was a very vulnerable time. When he found out he was HIV positive, he ran out to his car and sped away, almost causing an accident. He had to pull over and compose himself.

He credited the way he was raised and his faith in God with helping him cope. He believed that God had called him for a bigger purpose which included helping others. He would like to tell others that life isn't over if you become HIV positive because there are now effective treatments and medications. He wanted others to know that everyone makes mistakes and that there are a lot of innocent people living with HIV. His advice was to protect yourself and if you're not going to do that, protect the other person. He said that he tries to keep moving forward so that having HIV doesn't paralyze him.

Mia

Mia was in the 21-23 year old age group and had acquired HIV perinatally at birth. She was in the process of finishing her GED and wanted to pursue a career in the health field. She found out that she was HIV positive in her early teens and was shocked at first because she didn't understand what it meant. She was upset because she was the only one of her siblings who had acquired HIV at birth and she often wondered why it was her. She overcame that feeling by telling herself that she was only human and she needed to keep her head up. After she found out she was HIV positive, she started going to a support group which really helped her because she realized that she was not alone. She did not know much about HIV before she knew that she was HIV positive. She said that she did not learn much about HIV in school. Most of what she knew about HIV was information she had read on various internet sites.

She mentioned significant stigma issues that she was having with her boyfriend's family related to being HIV positive. She said that they did not want her to date their son, they called her names, and frequently disrespected her. They mentioned that they were afraid their son was going to catch HIV from her. They did not understand how she

had acquired HIV and had accused her of being a prostitute. She did not feel comfortable going outside in her neighborhood because they lived nearby and made fun of her situation in front of neighbors. Some people in her neighborhood had put her down because of her HIV but she saw them as ignorant and tried to not let it bother her. She liked to write about her feelings in her diary because she did not have many people she could talk to. Her boyfriend was very supportive and told her not to listen to what his family said. They assured his family that they were using protection but the family was still not happy about it.

She mentioned that she always tells her partners about her HIV-positive status and uses protection because she doesn't want to spread HIV to others. She said that she does not want to see others in her predicament. She has been taking HIV medications since birth and it has been going okay for her. However, she often thinks about her mom who died of AIDS when she was a child and wished she could have had access to the current HIV medications. She tries to take her HIV medications every day because she realizes that she needs to take them to stay healthy so she can pursue her goals, but sometimes forgets. She said that she prays a lot as a method of coping. She suggested that people who were having problems living with HIV should listen to music, write about it, talk to someone who is supportive, and try to ignore negative things that others say. She noted that she tries to keep on going and pursuing her goals in spite of being HIV positive.

Leo

Leo was in the 27-29 years old age group and had acquired HIV after he had been raped. He wanted to obtain a degree in education and help children who grew up in traumatic situations. He had been working to overcome drug addiction and

homelessness. After he had been raped and became HIV positive, he was so traumatized that he turned to drugs which contributed to his homelessness. He had lost so much weight that he almost died but was encouraged by a clinic doctor to seek treatment. He went cold turkey to get off drugs, started getting treatment, and began to turn his life around. He was still experiencing post-traumatic stress disorder (PTSD) and depression because of the situation.

He had recently moved to the area at the urging of some friends. He believed that the services in this area were much better than the area that he came from. He had joined several HIV-related committees and was becoming an activist. He had revealed his HIV status to his mom and several other family members who had been very supportive, but was reluctant to tell his siblings. He was taking a one pill HIV regimen which he liked because he had been taking several pills per day which had been very cumbersome. He thought that he would be fine as long as he continued to take his HIV medication.

He did not think that living with HIV/AIDS would affect his future. He said that he was very open about his status if others asked and had found that most people were accepting. He would like to start a resource/community/drop-in center for LBGTQs and PLWHAs. He didn't know much about HIV before he became positive, but he had been educating himself through his providers, organizations, websites, and magazines. He strongly felt that there should be more in-depth sex education in the schools. His motto was that the past cannot be changed, it can only be accepted. He believed that HIV and his past would not keep him down and he was trying very hard to keep going forward.

Lily

Lily was in the 18-20 year old age group and had acquired HIV perinatally at birth. She brought her best female friend with her and insisted that she stay in the room during the interview. Lily was planning on studying for a career in health or law. She found out about her status when she was a pre-teen but did not fully comprehend it until after her mother died of AIDS when she was in her mid-teens. That incident forced her to grow up fast because she was suddenly on her own. Her dad was still alive and was also HIV positive, but she had moved out of his house right after her mother died because he wasn't responsible. She has had a difficult time living with HIV, but has coped by living one day at a time and tries to avoid negative people. She has learned to accept it and do her best with it.

She has received a lot of support from the clinic and noted that she has been more open with them than anyone else about her situation. She also has a small group of family and friends who are supportive. She experienced some issues with kids taunting her and treating her differently at school because she was HIV positive. She ended up transferring high schools because of the taunting. She has been taking HIV medications all of her life. It has been challenging for her, but she said that she tries to take her pills every day because she realizes how important they are for her health. When she found out she was positive, she educated herself about HIV/AIDS by reading websites and asking questions at the clinic. She has participated in several HIV support groups and has benefitted from them. She mentioned that she would like to open a center for people with HIV/AIDS where they could come to socialize, have something to eat, learn more about HIV/AIDS, relax, and be happy.

Henry

Henry was in the 21-23 year old age group and was the only male participant who had acquired HIV perinatally at birth. Henry wanted to be a writer and was going to finance his writing by working in a blue collar job. He said that he would like to use his writing to spread more awareness about HIV/AIDS and other important issues such as suicide and accidental deaths. He was still working on his high school diploma. He did not believe that having HIV was going to affect his future career because he said that he was very focused. He did not comprehend the ramifications of his health condition until his late teens. His mother had told him earlier, but he did not understand what she was telling him. He was devastated when he realized what he had and felt like he did not deserve it. He said that he wished he would wake up and it would be gone. He said that it changed his life because all of a sudden, he had to be careful when dating someone because he was afraid he would end up in jail if he passed the virus on to someone else.

He had taken HIV medications all of his life and had experienced a great deal of challenges due to negative side effects like nausea and upset stomach. Even with the side effects, he said that he tried to be adherent because he realized how important they were for his health. He had a small support network that consisted of his mother, a sibling, and a friend but had not told anyone else due to fear of rejection. He was worried about finding a mate who would accept him and was worried that he could never have children. He had met some women who would not date him unless he brought them a negative HIV test result.

He had been coming to the clinic all of his life and was very satisfied with the services. He had attended some summer camps for children with HIV/AIDS which he

found to be very helpful. He did not know much about HIV before he became aware of his status. He said that he was not taught much about HIV/AIDS at school. After he learned he was positive, he started reading about it on the internet in order to educate himself. He believed that there was still a great deal of stigma about HIV/AIDS. He thought that testimonials given by HIV-positive people would be an effective form of education and should be presented to school children. He mentioned that people should be more supportive of those who were HIV positive by being more caring and treating them like normal human beings.

Isaac

Isaac was in the 24-26 year old age group and had acquired HIV behaviorally from a male partner. He said that he wanted to have his own business someday. He acquired HIV several years ago and remembered the exact date and time when he tested positive because it had been so traumatic for him. At first, he just wanted to let the virus kill him, but then he realized that his mother and several other family members cared about him deeply and that inspired him to go on. He had experienced rejection from several friends which upset him deeply. He had also experienced some stigma from a healthcare worker when he was in the hospital recently. He felt sad by the level of stigma he saw in society towards people with HIV/AIDS. He had been hurt by this rejection but he realized that he was a good person and was trying to live for himself and his family.

He said that he used prayer as a coping mechanism and believed that God let him become HIV positive so that he could help others. He said that he tried to spread awareness and prevention information to family members and friends. He did not know much about HIV before he became HIV positive and started reading about it on the

internet after he was diagnosed. He had experienced ongoing issues with depression since he tested HIV positive and had been seeing a mental health counselor for support. His motto for other young adults living with HIV/AIDS was to live life and not to let HIV live it for you. He advised others to get treatment, take medications, exercise, and eat health foods in order to stay healthy.

Nathan

Nathan was in the 18-20 year old age group and had acquired HIV behaviorally from a male partner. He had recently been in the hospital so was not working or going to school. He wanted to complete his GED and then start his own business. He had moved to the area a couple of years ago and thought that this area was more violent than where he had lived before. He recently experienced a bullet going through a window in his current home. He found out he was HIV positive in his early teens when he went in for a physical exam. He was very upset and had experienced on-going depression since that time. He didn't think it could happen to him. He said he had experienced several serious infections and hospitalizations related to HIV since he had become positive.

He had disclosed his HIV status to his mother and a few other family members. His mother had been supportive but some of the other family members had shunned him. One of his relatives would not let him bathe her baby because of his HIV status. He had also been rejected by several friends so he was reluctant to disclose his status to others. He listened to gospel music for support. He did not know much about HIV before he became HIV positive and did not feel like he learned a lot in school. He felt that there should be more sex/health education in the schools at earlier ages. After he found out his HIV status, he went to the health department and became a certified HIV tester to help

the cause. He said that he obtained a great deal of information about HIV from the testing course. He had also looked up information on the internet.

He noted that he did not think that having HIV/AIDS was going to affect his future. However, he mentioned that he was afraid that he would end up in hospice when he was older. He suggested that clubs, HIV support groups, and HIV-positive young adult motivational speakers would be good ways to help young adults with HIV and to educate others. He mentioned that he might like to be a motivational speaker someday but he was still afraid of stigma and rejection if he disclosed his status. He had been to several HIV support groups and had found them helpful. He noted that living with HIV/AIDS was very challenging and that he often felt like an outcast. However, he was trying to stop feeling sorry for himself and was learning not to care about what others thought about his situation.

Charlotte

Charlotte was in the 18-20 year old age group and had acquired HIV behaviorally last year from a male partner. She was planning on pursuing a career in the health field. She was devastated when she tested HIV positive because she felt betrayed by her partner and because she was very young. She got tested because she was having some gynecological issues. Charlotte was living on her own and was estranged from her family because she had been having some ongoing issues with them. She had told one family about her HIV status and this person had gone behind her back and gossiped about it to other family members. Her family had been very negative about her HIV status.

Charlotte was satisfied with the services she had been receiving from the clinic and several social service agencies. She had been taking HIV medications but was

having some issues with nausea and vomiting. She knew a little about HIV/AIDS before she tested positive but always thought that it was a death sentence. She was feeling better about her prognosis because the clinic had given her information about how to manage her condition. She had also looked up information on the internet.

She was taking her condition day by day by coming to the clinic for care and by taking her medications. Her biggest challenges right now were finding a stable job, housing, and transportation because she was on her own due to family issues. She was starting a new job the following week but was having some transportation issues. She was not concerned about relationship issues because she thought the right person would love her regardless. She said that she had noticed a lot of misinformation about HIV/AIDS in her community which she thought led to stigma. She thought that billboards and other ads for free testing would be a good way to spread awareness about HIV/AIDS. She said that she believed that in the long run, she was going to be able to deal positively with being HIV positive and was going to have a satisfying life.

Olivia

Olivia was in the 24-26 year old age group and had acquired HIV perinatally at birth. She was studying for a career in the health field because she wanted to help others with HIV/AIDS. She had a young child who was not HIV positive. She felt that she didn't deserve to be born with HIV but she had to learn to live with it every day. It had been a *heavy duty thing* for her to live with. She believed that HIV shouldn't stop people from pursuing their goals because they can still work and do almost everything else.

She had experienced a great deal of stigma from her family. Her mother died of AIDS when she was young and left her with non-relatives to raise her because her family

did not approve of her mother's lifestyle. This caused an on-going rift in her family that was still going on today. Family members have isolated her and verbally and mentally abused her. Several family members told her that she would not amount to anything and that she was going to die from AIDS before them. She heard that they were jealous now because they didn't expect her to make it and she was now doing something positive with her life. She let some family members babysit her child a few years ago and when she returned, they had told the child that she had AIDS and was going to die. She felt that was inappropriate because of the child's age. Recently, she offered to watch a family member's baby but the individual wouldn't let her because of her HIV status. She believed that a lot of her family's attitudes came from fear and misunderstanding because most of them had very low levels of education. Fortunately, she had a very supportive boyfriend. She rated herself as very healthy.

She had to restart HIV medications a couple of years ago after having been off them for a few years. This upset her, especially when the physician told her that she would have to take them for the rest of life. She had obtained a lot of information about HIV through her health career program which had helped her to understand her condition. She had never been to an HIV support group but would like to try one because she often felt alone and had no one to talk to about her HIV. She did not want to have another child because she did not want to leave him or her behind if something happened to her because she had felt very alone when her mother had died. She said that she did not know anyone who she would trust with her child.

She felt that HIV care should not be in a separate clinic but should be integrated into a regular clinic so that people living with HIV did not feel different. She used to feel

uncomfortable about coming to the clinic but does not feel uncomfortable any more. Her message to others was to always use protection and to take the proper medications if they had HIV, especially if they were pregnant. She said that individuals living with HIV/AIDS should stay around positive people, avoid negative people, be positive, and live every day like it was their last.

Noah

Noah was in the 18-20 year old age group and had acquired HIV behaviorally from a male partner a couple of years ago. Noah was a musician and was trying to get into the local magnet arts high school. He had not attended high school consistently because of a death in his family, finding out he was HIV positive, and several other traumatic events in his life. He was still working on his high school diploma. After high school, he would like to pursue a double major in music and coaching at a college. He was also very active in sports and said that he gets his aggression, anger, and bitterness out when playing sports. He noted that he used music to let out his softer side. It helped him to release his sadness and depression. He said that he hides those feelings from others on a regular basis and acts like nothing bothers him because he doesn't know how to bring his feelings out.

Noah got tested for HIV because he was attending an organization for LGBTQ youth and was urged to get tested every three months. A member of the organization went with him when he got tested. When he found out that he was HIV positive, he said that he was shocked and his world stopped for a moment. But he quickly told himself that having HIV was not going to defeat him and he was going to learn to live with it. The first several months were very tough for him. He started coming to the clinic for

medical care and was happy with the services and support he received. He also has received support from the LBTGQ organization that he attends.

He said that finding out he was HIV positive opened his eyes to how people discriminate against others for having a simple disease. Some days, he doesn't think much about his HIV status but he has other days where he becomes depressed when thinking about it. He said that he was trying to move forward and think about the people who loved him as a motivator. Playing music was also therapy for him and made him feel empowered. He had told several family members and friends about his HIV status and everyone had been supportive so far.

It was a challenge for Noah to take HIV medications because it was a constant reminder of his status, but he tried to remind himself how important it was to take them. He had been taking three pills a day but he was getting ready to switch to a one pill-a-day regimen which he thought would be easier for him. He had stopped taking them for a while when a close family member became sick and died but he had started taking them again recently because he thought that person would have wanted him to stay healthy and make something of himself. At the time of the interview, he had only disclosed his HIV status to a few people that he trusted but he eventually wanted to be an HIV activist in order to show others that having HIV should not stop them.

He knew a lot about HIV before he became positive because he had an older sister who did a project about sexually transmitted infections (STIs) in school and shared the information with him. He also had dreamed that he was going to become HIV positive someday. However, he was still in shock when he tested HIV positive. He said that he learned additional information about HIV at his clinic visits, but he typically doesn't look

up information on his own. He said that the best way to spread awareness is for individuals who are not HIV positive to get to know someone who is HIV positive so that they realize that they are normal people just like them.

Ella

Ella was in the 21-23 year old age range and had acquired HIV perinatally at birth. She was studying for a career in the health field because she wanted to help others living with HIV/AIDS. She often had questions about her medical condition but rarely asked anyone because she was shy. She had been HIV positive all of her life and found out when she was in grade school. She didn't really understand what it was at first. By the time she understood what it meant, she was used to having it. She didn't have a problem with it, but she didn't want to tell anyone about it. It upset her when her main caregiver told her not to tell others about her condition but would then turn around and tell others about it behind her back.

Ella had been on HIV medications all of her life and it had been an up and down experience for her. When she was in grade school, she used to pretend to take her HIV medications but would throw them away because she was tired of taking them. She was still having a hard time taking her medications every day and often missed doses. For support, she had a couple of family members and friends who she could confide in. Her friends and family members supported her by encouraging her to take her medications.

It bothered her that a lot of people in her community didn't know the difference between HIV and AIDS. They automatically thought that if someone was HIV positive, they had AIDS and were going to die. She had a family member who kept telling her she was going to die. She felt that there was a need for more community education about

HIV/AIDS. She had experienced a great deal of stigma from family members. Her main caregiver had not wanted her to use their dishes or touch certain things because she was HIV positive. This hurt her feelings. Her attempts to educate them about HIV/AIDS, though, had been generally positive.

She had been coming to the clinic all of her life and trusted her healthcare providers. Her main challenges right now were related to completing her education. She felt like she didn't get a lot of information about HIV from school when she was younger and thought that there should be more sex/health education in the schools. She did not think that having HIV would impact her future goals and said she was coping fairly well. She had regularly attended HIV support groups and said that they had helped her a great deal. She liked attending HIV support groups because it made her realize that there were other people who were going through the same thing. She thought that having young adult motivational speakers with HIV would be a good idea for educating young adults.

Jacob

Jacob was in the 21-23 year old age group and had acquired HIV behaviorally from a male partner. He was studying for a career in a health field so he could have a better life. He found out he was positive last year when he went to the hospital because he wasn't feeling well. When his test results came back positive for HIV, he was extremely shocked. He said it was the worst experience of his life. He went home and tried to pretend everything was normal because he was afraid to tell anyone. He had recently told his mother who had been extremely upset at first but has been very supportive. He has been very depressed about being HIV positive and has not told many other people. He has been struggling with why it happened to him because he felt that he

was not living a risky lifestyle and had a steady partner. Being HIV positive has changed his life because it has made him realize how precious life is.

Jacob did not know much about HIV before he became positive so he had been trying to educate himself and his mother by reading books and websites about HIV. He felt that people in general needed more education about HIV and HIV prevention. He thought that many people avoided being tested for HIV because they were scared. He said that it really saddens him to see other people acquire HIV and he tries to educate others about prevention. He noted that more education might have helped him to prevent acquiring HIV. He thought that it was important to raise awareness about HIV. He also thought that it was important to educate parents about HIV/AIDS so they could talk to their children about it because family support was very important. He felt that conducting more research studies about living with HIV/AIDS and increasing community education about HIV/AIDS was important. He believed that he would probably tell other family members about his HIV status when he became more comfortable with his condition, but he was not ready at the time of the interview.

Jack

Jack was in the 18-20 year old age group and had acquired HIV behaviorally a year ago from a male partner. He was working towards a business degree. He identified himself as bisexual. When he first found out he was HIV positive, he thought it was a death sentence and tried to end his life but was saved by a family member. He acquired HIV when he was in a relationship with someone he thought he could trust so he stopped using protection. He became very depressed, hid his condition at first, and denied any questions about it. Jack felt that his life turned around after he started taking medication

which brought his HIV viral load down to an undetectable level. That experience made him feel more hopeful and he now believes that he has a bright future.

Jack was dating a young woman when he found out he was HIV positive. She rejected him when he told her he was HIV positive which really upset him. He has since told several other family members who have been supportive. He has a new girlfriend who is very supportive and is willing to have children with him in spite of his HIV status which is very important to him.

He wanted to go into the military and was upset because he was rejected because of his HIV status. He was settling for a career in business. He noted that he had read a lot in order to educate himself about HIV because he did not know much about it before he became positive. He now believed that he had a high level of knowledge about HIV. He had attended an HIV support group which had helped him deal with living with HIV. He said that he actively encourages others to get tested for HIV. He has helped at least two friends get tested and then get into treatment. He was on HIV medication and noted that he took them faithfully because he wanted to stay undetectable and maintain his health. He would like others to know that getting HIV was not the end of the world because of the new medications that were available.

Ava

Ava was in the 21-23 year old age group and had acquired HIV behaviorally from a boyfriend. She was currently employed and was planning on starting a degree in a health area in a couple of months. She found out she was positive in her early teens when she was tested because she was having some other health issues. She contracted HIV from a boyfriend who she thought cared about her so she felt very shocked and betrayed.

Several family members were at the clinic visit when she found out she was HIV positive and have been very supportive. She liked the care that she has been getting at the clinic and was not currently taking any HIV medications.

She had experienced rejection several times from several different partners when she told them that she was HIV positive. She said that she was now hesitant to tell her partners about her status but she always uses protection such as condoms because she does not want to spread the virus to others. She had educated herself about HIV after she became positive by reading information on the internet. She said that she tries to stay away from the negative websites that talk about HIV/AIDS as a death sentence. She also obtained information about HIV/AIDS from a family member who was in the health field. When others are talking about HIV, she usually tries to encourage acceptance of HIV-positive individuals but sometimes others have put her down when she does that. She has had people come back to her later and apologize.

Ava did not think that people her age had enough information about HIV to prevent it. She said that they had rarely talked about it in school. She noted that she might have been able to prevent herself from getting HIV if she had known more about it at an earlier age. She felt that educating young people about HIV prevention was more important than teaching abstinence because many teens were already having sex. She thought that Florida had not done a good job educating kids about sex and STDs compared to other states. She thought that young people in Florida would benefit from enhanced sex/health education in the schools.

She believed that using HIV-positive motivational speakers would be a great way to educate young people and raise awareness so people weren't so scared and judgmental.

She had participated in an HIV/AIDS support group when she was in high school and had benefited by hearing how other kids coped with it. It helped her to not feel alone. She was upset and depressed about it at first but had adjusted to it and was trying to take care of herself. She only thought about it when she had to protect herself/others or had a doctor's appointment.

She was worried about marriage, especially telling a prospective spouse about her HIV status, and was worried about having children. She was worried about her longevity at first but was reassured by a family member that she should not be worried because of new treatments and medications. She suggested that there should be a service that helps individuals living with HIV/AIDS disclose their status to friends and family members. She suggested having a doctor or counselor present who could answer questions, help with support, and cut down on the fear.

Nicholas

Nicholas was in the 27-29 year old age group and had acquired HIV behaviorally from a male partner. He wanted to pursue a career in the health field, law, or business. He described himself as very independent, hardworking, and out-going. He found out that he was HIV positive a few months ago and it had been a struggle for him. When he first found out, he sat around the house and cried for days. He finally called a good friend who listened to him and gave him support. He started seeing a psychologist who helped him cope with his situation. He had received emotional support from his mother and his partner, but was reluctant to tell other family members.

He said that he was trying to get back to being the fun-loving, out-going person that he used to be. He mentioned that this situation would not beat him and the only

person he had to answer to was God. He had been recently stressed out about his job, bills, and his health situation. He was struggling with the feelings that he was a bad person because he had acquired HIV and he was trying to work past that. He had also lashed out recently at friends and family because of stress and was working at getting past that, too.

Nicholas mentioned that someday he would like to share his story with others so that they could see how to overcome a challenge like this, but was not ready now due to fear of rejection and stigma. He believed that it was important for everyone to protect their health and listen to their bodies. He had been reading a lot about nutrition and had been trying to eat healthier as a way of maintaining his health. He had learned some information about HIV in school, but felt that there should be more in-depth sex/health education in the schools.

His suggestion to others was to be careful about whom they were intimate with and to know their HIV status so they could protect themselves and others. He was not taking HIV medications yet because his lab tests did not indicate the need but he said that he would definitely take them when advised by his doctors. He felt that all young people needed to know the risks because everyone only gets one life. He encouraged people who were depressed to seek help so that they did not end up hurting themselves or others. He had not gone to any HIV support groups but was open to going to one so he could find out how others were dealing with living with HIV/AIDS.

He felt that there should be more community-level education because he had noticed a lot of misinformation and misconceptions about HIV/AIDS in his community. He felt that parents needed to talk with their kids more about sex and sexual health, and

kids should receive in-depth sex/health education before they hit puberty. He believed that he had good sources of information about HIV from his doctors. Living with HIV had been hard for him, but he was trying to move forward. He advised other young people to be aware, be safe, be cautious, and always use protection.

This completes the section on the short biographies of the participants. In the next sections, I will discuss the treatment of the data as well as the results of the data analysis.

Treatment, Cleaning, and Sorting of Data

I reviewed the data in depth several times during which I coded them into themes, patterns, and categories that reflected the research questions as well as new themes mentioned by the participants. I reviewed and coded each interview several times because additional nuances emerged with the coding of each subsequent reading. In order to facilitate data organization, I placed each transcribed interview into a sortable Microsoft Word table with multiple rows and columns (see Figure 4). Each row contained a distinct question, comment, or phrase. Each column contained either an identifier or a code. After the interviews were coded and placed in individual Microsoft Word tables, I merged them together into a master, sortable Microsoft Word table so that I could group the different codes together. For example, when a participant spoke about medication adherence, that phrase was assigned the code “Adherence”.

Below is a figure that depicts the sortable Microsoft Word Table that I used to organize, code, and sort the data.

Line #	ID #	Comment	Code 1	Code 2
1	2	K: Today is August 13, 2014 and this is the interview with participant		

Line #	ID #	Comment	Code 1	Code 2
		number 2. Okay, so please start off by telling me a little bit about yourself, what you like to do, and what your goals are.		
2	2	2: I like to write poetry and read. My goal is to be a pediatrician.	Likes; 2; poetry & reading	Goals; 2; pediatrician

Figure 4. Sortable Microsoft Word Table used to organize, code, and sort data.

After merging the interviews together into the sortable Microsoft Word table and sorting them by code, all of the phrases that received the code “Adherence” were sorted together and identified by each participant’s identification number (see Figure 5).

Line #	ID #	Comment	Code 1	Code 2
44	2	2: At the beginning I was taking it, it was a lot of struggles to take them but then I forget to take them and I missed a couple of days so I automatically stopped taking them.	Adherence; 2; a struggle at the beginning	Adherence; 2; sometimes forgets & then stops
34	11	11: The hardest part for me is taking it for life. I mean, the doctor who actually went through the process with me and told me that I had to get on the medication said I should feel as if, I should take this as an advantage because, you know... She doesn’t understand. For life?? You have to take this medication for the rest of your life??	Adherence; 11; doctor told her meds are an advantage but doctor doesn’t understand	Adherence; 11; upset about having to take them for life
56	18	18: Ummmm. I don’t feel anything, you know, I just have to take a pill. Some people have to take more, or some people they have to go to the hospital like 3 times a month, you know, so I have to compare myself to other people and I have to make the positive good things for me, you know.	Adherence; 18; trying to be positive because others often take more pills or have worse treatments	

Figure 5. Example of Microsoft Word Table sorted by codes.

During the coding and review process, I collected the phrases that captured the essence of each theme for use in the data presentation section below. I also noted exceptions and alternatives to the patterns I was finding.

Results

Below are two tables that summarize the results of coding the narrative data. I categorized the data into 17 different themes (see Table 5).

Table 5

17 Themes from the Data

Theme #	Name of Theme
#1:	Diagnosis reactions
#2:	Perinatally acquired individuals: learning their status
#3:	Stigma versus acceptance
#4:	Disclosure
#5:	Relationships, marriage, family
#6:	Medication adherence
#7:	Goals pursuit
#8:	Education
#9:	Community education/knowledge level
#10:	Physical health effects
#11:	Mental health effects
#12:	Health Services
#13:	HIV Support Groups
#14:	Support services
#15:	Faith/religion
#16:	Inner resilience & positive attitudes
#17:	Helping others

I then connected each theme with the three research questions and listed the pertinent issues (see Table 6). Each theme is listed vertically in the first column. The issues mentioned for each theme are listed across organized by research question. For example, the theme *Diagnosis reactions* is listed first. In the second column, the issues related to challenges, barriers, and stressors (research question #1) for *Diagnosis reactions* are listed. Column two lists the assets, strengths, and supports (research

question #2) that the participants mentioned for *Diagnosis reactions*. In column three, the needs and suggestion (research question #3) that participants gave for *Diagnosis reactions* are listed.

Table 6

Themes and Issues Organized by Research Question

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
#1: Diagnosis reactions	<p>Intense shock, sadness, depression; some had suicidal thoughts & behaviors at first</p> <p>Many had no one to turn to at first & felt isolated</p> <p>Family members were shocked if told</p> <p>Felt they did not deserve it</p> <p>Some felt they were not participating in risky behaviors or regretted an isolated mistake</p> <p>Feelings of shame & disgust</p> <p>Felt betrayed by partner</p>	<p>Several had a friend or family member who went along, but this was rare</p>	<p>Enhanced mental health services should be available at the time of diagnosis</p>

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
#2: Perinatally acquired individuals: learning their status	<p>Some did not understand at first</p> <p>Some were not told until teens which led to upset feelings & anger</p> <p>Some found out accidentally</p> <p>Parent/caregiver would not discuss it with some</p>		<p>Most wanted to be told at a young age & suggested this for other perinatally acquired children</p>
#3: Stigma versus acceptance	<p>Family did not want them to touch others or use household items</p> <p>Shunned by family & partner's family</p> <p>Verbally abused by family & partner's family</p>	<p>Most had 1 or 2 family members or friends who accepted them and provided support</p>	<p>Participants suggested that more community education might lead to less misinformation and stigma</p>
#4: Disclosure	<p>Fear of rejection by others deterred participants from</p>	<p>Most had received support from a few family</p>	<p>Several wanted a medical or mental health</p>

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
	<p>disclosing their status</p> <p>Some had been rejected by family, friends, partners upon disclosure</p> <p>Several always used condoms or safer sex with others but were afraid to disclose their status</p>	<p>or close friends upon disclosing</p>	<p>professional available when they were ready to disclose to family & friends</p>
#5: Relationships, marriage, family	<p>Afraid they would not be able to find a partner who would accept them; afraid no one would want to marry them</p> <p>Worried that they could not have children or they would pass it on to their children</p>	<p>Several had a partner who supported them & was willing to have children with them</p> <p>Felt that the right person would accept them</p>	
#6: Medication adherence	<p>Many of the perinatally acquired participants were tired of or upset about having to take meds for</p>	<p>Many of the behaviorally acquired participants realized the importance of meds for their</p>	

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
	<p>long periods of time</p> <p>One of the perinatally acquired participant felt guilty about having access to medications because they were not available to her mother who had AIDS years ago and died from it</p>	<p>health & were grateful about taking them</p>	
#7: Goals pursuit	<p>Not able to join the military</p> <p>One participant was having trouble finding a job because of health issues. He also thought the area was violent which was causing him stress.</p>	<p>Several were inspired by having HIV to pursue a health-related career because they wanted to help others with HIV</p> <p>Most did not feel that having HIV was going to get in the way of their school or career goals</p>	<p>One participant suggested that there should be more job programs for individuals his age</p>
#8: Education	<p>Many felt that they had not received adequate health/sex</p>	<p>Several had family members in the health field that helped them to learn about</p>	<p>Many suggested that using motivational speakers who</p>

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
	education in school.	HIV/AIDS after they became positive.	were living with HIV to educate others would be more powerful than giving information. They also suggested that the speaker should be the same age as the group being educated to have the most effect.
	Many felt that the health/sex education they received in school came too late & it should be presented at an earlier age (before puberty) so they could have made more informed choices	Many of them took the initiative to learn about HIV/AIDS on their own after becoming positive by reading information on the internet, in books and brochures, and asking their healthcare workers & others	Many said that schools should offer more in-depth health/sex education starting at a young age
	Many felt that they did not know much about HIV/AIDS before they became positive	Many mentioned that they received information about HIV/AIDS after they become positive from their healthcare professionals &	More parents should be educated about discussing sex with their children

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
		through their HIV support groups	
#9: Community education/knowledge level	Most felt that the level of knowledge about HIV/AIDS in their communities was low and lead to stigma, discrimination, and misunderstandings		Many noted the need for more community education concerning HIV/AIDS
#10: Physical health effects	Several mentioned that they had experienced flu- like symptoms and night sweats after becoming HIV positive Several had experienced HIV- related infections & other conditions	Several noted that they felt they were in excellent health despite being HIV positive	
#11: Mental health effects	Many noted that they had experienced on- going depression related to having HIV	Several of the participants were currently receiving mental health services which helped them cope	Several wanted a medical or mental health professional available when they were ready to disclose their HIV status to family & friends Many mentioned the

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
			need for enhanced mental health services
#12: Health services	Going to an HIV clinic made one participant feel different	Most were satisfied with the HIV-related health services they had received	One participant suggested that HIV services should be integrated with other healthcare services so that individuals living with HIV did not feel like they were being treated differently
#13: HIV support groups		Many had attended HIV support groups and said that the groups helped them to learn from others about coping, to not feel alone, and gave them general information about HIV	Many suggested that there should be more HIV support groups available
#14: Support services		Many mentioned that they were satisfied with the array of support services that were available which included mental	Several wanted to create a drop-in resource center for individuals living with HIV that

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
		health & transportation.	included networking, socializing, support groups, & other services Several suggested that there should be more counseling services for individuals & their families/ friends when they are ready to disclose their HIV status to family/friends
#15: Faith/religion		Several mentioned that their religious faith helped them with coping Several said they felt that getting HIV was a gift from God that made them stronger	
#16: Inner resilience & positive attitudes	Many had worked hard to attain a positive attitude	Many mentioned that having HIV was not going to beat them or get them down	Many wanted other individuals living with HIV to know that they should not give

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
			up because they believed that they could do anything that anyone else could do
		Several felt that having HIV made them strive harder & appreciate life more	Many said that other individuals living with HIV should try to stay around positive people & maintain a positive attitude
		Many expressed an incredibly positive attitude about moving forward with their lives	Several wanted other individuals living with HIV to forgive themselves, realize that everyone makes mistakes, & that life wasn't over just because they were HIV positive
#17: Helping others		Many of the participants wanted to spread awareness & help others yet some were still afraid of disclosing their	Several suggested that more research should be conducted about the challenges, strengths,

Themes	RQ #1: Challenges, Barriers, & Stressors	RQ #2: Assets, Strengths, & Supports	RQ #3: Participants Needs & Suggestions
		<p>HIV status to others</p> <p>Some said that they already had become active by becoming certified HIV testers and by joining HIV activist organizations</p> <p>Several wanted to be speakers for children & other groups</p>	<p>needs, and suggestions of those living with HIV</p>

Results with Interview Excerpts

In this section, I have included verbatim comments made by the participants that represent each theme. Within each theme, I have arranged the comments by research question. For example, under *Diagnosis reactions*, I have listed the challenges, barriers, and stressors (research question #1) that participants mentioned first. This is followed by any strengths, assets, and supports (research question #2) they mentioned related to *Diagnosis reactions*. Finally, I have noted the needs and suggestions they mentioned for the theme *Diagnosis reactions*. The verbatim comments are identified by a randomly selected pseudonym in order to protect the privacy of the participants. These pseudonyms link to the participant descriptions at the beginning of Chapter 4. The following verbatim comments typify the experiences of the participants.

Theme #1: Diagnosis Reactions

Challenges, barriers, and stressors.

Participants mentioned the following challenges, barriers, and stressors when discussing their diagnosis reactions. Most of the participants reported some type of shock, sadness, and depression upon finding out their diagnosis. The degree ranged from depression to suicidal thoughts and behaviors.

At first, it was like a death sentence. I tried to kill myself. I wanted to end it, mainly because before I found out, I was one of those people that you would call HIV phobic. (Jack, personal communication, September 2014)

There were times when I was first diagnosed where I cried for days and some days after I would come home from work I would just sit in the house and watch TV. I was in a dark space like in a room with no lights, just a bad spot. (Nicholas, personal communication, January 2015)

William became so upset after finding out his status that he sped off in his car and had to pull over and compose himself before driving home:

When I found out, oh gosh, I got into my car and tires spinning. I actually had to tell myself to stop, pull over, get out of the car, you're upset, you need to process this before you start driving, and I can imagine other people who can actually lose their life after finding out. (Personal communication, December 2014)

Leo noted that he became so depressed after finding out his status that he turned to drugs and became homeless:

When I found out I was HIV positive, it turned for the worst. That's when I went to using drugs on a daily basis. From January to August, I was homeless and on the streets. I was weighing like 75 lbs. because I did not know where my life was going to go. (personal communication, January 2015)

Several noted that they could not tell anyone about their diagnosis after finding out and had to go home and act as if nothing had happened.

The moment I found out, I just felt so bad and so depressed because I just went by myself and I was not really sure about how to tell anyone including my family. I think I can tell you, it was the worse emotional moment in my life. So, um, I just

go to my house like normal and try to keeping normal because all of my family was there. My mom, my dad, my brother, and stuff like that. And I just tell my mom like 2 days ago because I can't handle the situation by myself. (Jacob, personal communication, September 2014)

Participants reported that family members were usually shocked upon learning their diagnosis.

My mom's reaction? Um, she start crying, she start like screaming so bad, you know, and she asked me a lot of questions, you know, and after that day, she helped in anything, she support me in anything. I think I have more relationship with her right now than before. (Isaac, personal communication, January 2015)

My family's reaction to the HIV? They were kind of stunned, kind of a slap in the face for them, it took them a while to accept it, especially my mom. It took her about a month to a month and a half to come around. She actually went to... works in the medical field so she has connections at major hospitals so she talked to one of the specialists out there about HIV and they reassured my mom that everything's going to be OK because I'm compliant with my meds. (Leo, personal communication, January 2015)

My mom, she cried and she thought I was going to die. And then she called my grandmother and then my grandmother started crying, and then it basically went out to all the family members. They say once you tell your parents, they tell everybody else. (Nathan, personal communication, January 2015)

Most participants reported that they were shocked upon finding out their status and did not feel that they deserved it.

I was born with HIV and that's one of the biggest challenges with me because I feel like I don't deserve it but I have to live with it every day. (Olivia, personal communication, September 2014)

Many of the individuals who acquired HIV behaviorally reported that they did not think their behavior was risky for acquiring HIV.

At this moment in my life, I have too many questions and nobody is ready to give me the answers. And one of my questions is: Why me? Nobody deserves this kind of situation. But, why me? Why, because I never use drugs, I'm not a bad person, I'm not having sex with everybody. I just only have one partner in my life and I guess that's the person who infected me and I think that is not fair. (Jacob, personal communication, September 2014)

William lamented that one mistake cost him his health:

I was in disbelief. I was very shocked. I just couldn't believe it. That one time that I just didn't wear protection. It was that one time that cost me almost everything. Like there's no amount of money that can give me that back. (personal communication, December 2014)

Ava was shocked and felt betrayed that she had acquired HIV from her boyfriend who she thought cared about her:

I caught it from a guy who I thought cared about me enough that he would have told me that but a part of me feels like he probably didn't even know he had it himself so it kind of took me by wind. (personal communication, September 2014)

Some of the participants expressed feelings of shame and disgust about being HIV positive.

I would just think bad things about myself because of the disease. Once you get it, you're a bad person, a horrible disgusting person. (Nicholas, personal communication, January 2015)

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports related to their diagnosis reactions. Several of the participants had family members or friends who came with them to the testing site and supported them when they found they were HIV positive, although this was not the norm.

But I was thankful my great grandmother was there and my mom was there. My family members have always constantly been very supportive of me. Not making me feel like I'm this nasty thing or anything. They still treat me the same way. (Ava, personal communication, September 2014)

I came to (name deleted) Hospital with my (family member: deleted) to get tested. When you get tested you're not allowed to have anybody in the room with you. But when once I found out they told me I could have her come in if I want to and I had them bring her in. That's when I let her know that I was infected. She cried a little bit but said we're going to make it through this. We're going to beat this. It's not going to beat us. (Isaac, personal communication, January 2015)

Needs and suggestions.

Participants mentioned the following needs and suggestions when discussing their experiences related to their diagnosis reactions. Several participants suggested that there should be enhanced mental health services available at the time of diagnosis to help them with the initial shock.

A lot of people need support and help, but also to console and see that they're ok before they leave your building because a lot of incidents can happen after you find out. (William, personal communication, October 2014).

In general, finding out their status was a very traumatic experience for most of the participants as well as their family members. Most of them experienced some type of shock and depression. Several had a limited number of family members or friends who accompanied them for testing, but this was not the norm. Several participants suggested that there should be enhanced mental health services available at the testing site to help individuals with the initial coping situation.

Theme #2: Perinatally Acquired Participants: Learning Their Status

Challenges, barriers, and stressors.

The perinatally acquired participants mentioned the following challenges, barriers, and stressors when learning about their status. Some of the perinatally acquired participants had been told of their diagnosis when they were children but did not understand the ramifications until they were in their teens. Others recounted that they had not been told their diagnosis until their mid to late teens.

My momma had told me at 7 but it really didn't bother me then because I really didn't understand it at all. I really didn't start understanding it until I was like in middle school. My mother said it was about the medicine. I really didn't have a problem with it, I just would never tell anyone about it. (Ella, personal communication, August 2014)

I had HIV since birth. I found out around the age of 14. The people came to me and told me that I have HIV. At first it was a shocker because at first I didn't

know what it was, I was just learning. (Mia, personal communication, October 2014)

Emily found out accidentally while she was at summer camp. When she returned home and asked her mother about it, her mother would not discuss it with her:

I didn't find out until the age of (deleted: mid-teens). It was kind of difficult because I found out on my own. I was at summer camp and went to the nurse's office to get my medicine. Normally, the nurse would cover up the list but I was looking and there was HIV and a positive circled. At first, I kept saying, no, this is not true. I didn't accept it. I came back home and I cried. I asked my mother but she still wouldn't talk with me about it. It was tough for me. (personal communication, November 2014)

Assets, strengths, and supports.

None of the perinatally acquired participants mentioned any assets, strengths, or supports related to learning about their diagnosis.

Needs and suggestions.

When asked about needs and suggestions related to learning about their diagnosis, many of the perinatally acquired participants wished they had been told earlier so they would have had more time to adjust.

The perinatally acquired participants had learned about their status at various ages, some directly and some accidentally. Most of them expressed the desire to have been told at an earlier age so they could adjust before puberty.

Theme #3: Stigma versus Acceptance

Challenges, barriers, and stressors.

When reflecting upon stigma versus acceptance, participants noted the following challenges, barriers, and stressors. Stigma was a big issue for most of the participants. This ranged from being afraid to tell others for fear of rejection, outright rejection, and

the fear of contagion by others. Many of the participants had experienced stigma from their own family members or their partners' family members.

(When asked if she ever had to deal with stigma) From my family, not other people outside but from family members. It was like telling my brother he can't drink after me and stuff like that or I couldn't touch things. It hurt my feelings. (Ella, personal communication, August 2014)

Some of them don't even want to touch you. Some of them don't want to talk to you. Some of them don't want to be around you. I was in the hospital and a lady was nasty toward me. She didn't even want to touch me because I was infected with HIV. It hurts a lot. I'm not going to tell you it's the best thing. But, then you really got to sit there and think who am I living for? I'm living for me. (Isaac, personal communication, January 2015)

I felt like an outcast. Even when I told my aunt about my status. She wouldn't let me shampoo my cousin. (Nathan, personal communication, January 2015)

Mia mentioned that members of her partner's family called her names and said they would never have acquired HIV because they weren't as stupid as her:

It gives me a headache because of the fact my partner's family knows now and they're very mean. They go around telling my business to random people so random people won't be my friend or talk to me. They said they would never be in that predicament because I'm not as stupid as her and they call me all sorts of names and stuff. (personal communication, October 2014)

Lily said that she was picked on when she was a child about her HIV and people were told not to touch her:

I had people along the way when I was younger to pick on me or don't go by her or don't touch her. (personal communication, January 2015)

Olivia said that family members verbally abused her and told her young son that she had AIDS behind her back:

Uh, with my family. They try to verbally, mentally abuse me. One day I had my son over there to watch him. So when I came back they were telling my son that I got AIDS and all that. Why would you even do that or say that to a child that does not have it? My cousin said you're going to die before I am. Just a whole bunch of mental... (personal communication, September 2014)

The participants expressed a great deal of anguish over stigma that was directed towards them from family and friends.

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports related to stigma versus acceptance. Most participants had at least one person in their lives that accepted their situation and provided support. Some only had one or two people in their lives who they had told and who they could rely on for support, while others had a wider network of support. Participants mentioned a variety of friends and family members who were supportive.

I have a select few people that I feel I can be open with and say something about like mom, of course, she's going to always be the first. I have a couple of close aunts and uncles that understands that's also in the medical field. They understand so I feel open more to them but I'm still shut out from a lot of people. (William, personal communication, December 2014)

I also learned that there are friends out there and family that actually accept people like me. (Nicholas, personal communication, January 2015)

My mom and my grandmother and the rest of my family. They are really supportive. They ask me all the time: are you taking your meds? Yes, mom, I'm being compliant. Going to my doctors all the time? Yes, mom. She is really supportive. (Leo, personal communication, January 2015)

Most of the participants had a close family member or friend who they could rely on for support. Their mother was the person most frequently named as a source of support.

Needs and suggestions.

When asked about needs and suggestions related to stigma versus acceptance, most participants felt that the knowledge about HIV/AIDS in their communities was low.

They felt that more community education about HIV/AIDS might lead to more understanding and acceptance.

(When asked her opinion about the level of knowledge about HIV/AIDS in her community) Very low, it's very low, and there are a lot of misunderstandings. Like I say, it's a bad thing. I am not going to sit here and lie and say okay. It's bad, but people make it worse than what it really is. They are not educated. They need more education about it. (Emily, personal communication, November 2014)

Many of the participants had experienced stigma in the form of rejection, taunting, and shunning. In contrast, most also reported that they had a small number of friends or family members who accepted them and supported them. Many noted that knowledge about HIV/AIDS was low in their communities and that more community education might reduce misinformation and stigma.

Theme #4: Disclosure

Challenges, barriers, and stressors.

Participants reported a variety of challenges, barriers, and stressors when asked about their experiences when disclosing their HIV status to others. Many reported that they were reluctant to disclose their HIV status to others for fear of rejection. One young man mentioned that if his friends back home found out he was gay and had HIV, he would be shunned. Some reported that they only disclosed to close friends and family members who they expected would be supportive. Some participants had experienced rejection when disclosing their HIV status to a partner. Several reported that they always disclosed their HIV status to their sexual partners while others reported that they were reluctant to disclose to sexual partners but were very careful to use protection such as condoms so that they would not spread HIV to others.

When I told her (his girlfriend), I got a reaction that really hurt my feelings. She looked at me as though she was beyond disgusted and she didn't have a word to

say to me. She told me to get out. I called her and I tried to tell her I was sorry and stuff but it was no use. So I just moved on. (Jack, personal communication, September 2014)

It's not one of those things you can go on a date and you can talk about over dinner. That's a tough cookie. I've dealt with it. I tried one time to tell someone what was going on with me. We were very close but we broke up because of it. (Ava, personal communication, September 2014)

So if you tell the wrong female she could leak that information and there goes your whole life. And that's when the suicidal thoughts begin to process. (Henry, personal communication, January 2015)

I'm definitely hesitant to telling my siblings because a couple of siblings are judgmental. But I'm definitely going to maybe one day tell but I don't want to tell them right now. (Nicholas, personal community, January 2014)

Most of the participants felt that they had a duty to protect others and to not pass on the virus, but were often afraid to tell their partners that they were HIV positive.

I just tell my partners that I know I'm going to be intimate with. (Mia, personal communication, October 2014)

It kind of has changed that for me so that I'm hesitant with who I tell but when I'm sexually active I do protect myself and them because I don't want anything to happen to somebody like it happened to me. (Emily, personal communication, November 2014)

Even though I'm on meds right now I still use protection because I don't want to hurt nobody else so I don't want anybody to be in the same predicament that I'm in. (Lily, personal communication, January 2015)

As mentioned in the section about diagnosis reactions, many of the participants said that their family members and friends often reacted in shock when they disclosed their HIV diagnosis.

My mom's reaction? Um, she start crying, she started like screaming so bad, you know, and she asked me a lot of questions, you know, and after that day, she helped in anything, she supported me in anything. I think I have more relationship with her right now than before. (Isaac, personal communication, January 2015)

My mom, she cried and she thought I was going to die. And then she called my grandmother and then my grandmother started crying, and then it basically went out to all the family members. They say once you tell your parents, they tell everybody else. (Nathan, personal communication, January 2015)

Most of the participants reported that disclosing their HIV status to others was difficult and they tended to tell those who they felt would be supportive. They experienced a variety of reactions, both positive and negative, when telling others about their HIV status.

Assets, strengths, and supports.

When reflecting on the assets, strengths, and supports that assisted them when disclosing their HIV status to others, most had received support from a few family or close friends upon disclosing.

But I was thankful my great grandmother was there, my mom was there, a lot of people, my family members have always been there and constantly have been very supportive of me. Not making me feel like I'm this nasty thing or anything. They still treat me the same way. (Ava, personal communication, September 2014)

Needs and suggestions.

When asked for suggestions related to disclosing their HIV status to others, several participants suggested that a medical or mental health professional should be in the room to assist them. The professional could answer questions and help with shock and coping.

I think it would be better to have like maybe a doctor to be in there while they are talking to that person and telling them what's going on. So that doctor can answer any questions they might have or if they become a little irate because they're frustrated because of what they've read versus what's really going on. I think that would be a good service to have. (Ava, personal communication, September 2014)

Participants reported a variety of reactions from others when they disclosed their HIV status. Some had experienced rejection and shock, while others had experienced

acceptance and support. Some reported that they were reluctant to tell sexual partners but always used protection such as condoms because they did not want to spread HIV to others. Several of the participants suggested that a health professional should be present when they disclose their HIV status to others in order to assist with questions, shock, coping, etc.

Theme #5: Relationships/Marriage/Family

Challenges, barriers, and stressors.

Participants mentioned the following challenges, barriers, and stressors when discussing relationship, marriage, and family issues. Many of the participants expressed issues related to relationships which included being afraid they would not find a partner who would accept their HIV status. One of the participants mentioned that he was afraid to even kiss a girl because of the consequences and that some women would ask him to get tested for HIV before they would go out with him.

For me, it's most about marriage because at that point I'm going to have to explain a lot and hope that person understands what's going on with me and if they can live with me going through that. That's my only challenges that I really worry about. (Ava, personal communication, September 2014)

I worry about marriage, I worry about having kids, sometimes but then I've done my research on it and there's ways around that so I can still have a baby. (Emily, personal communication, November 2014)

And basically when you realize what you have you've got to depend on your decisions, so you've got to decide, oh I can't kiss this girl, I can't do that with this girl. And, you know you've got to think about the consequences. Oh yeah, if I do this to this girl, then I have to do ten years in prison. Some females will actually ask you sometimes to go get tested and bring your results. (Henry, personal communication, January 2015)

Several were worried that they would never be able to have children because of the fear of transmitting the virus to them.

And it's going to really affect me being young. I don't have kids and someday wanting them. It's going to really take affect later on down the line, especially when I want my own family. (William, personal communication, December 2014)

Most of the participants were worried about finding a partner who would accept them because of their HIV status and were worried about their ability to have children.

Assets, strengths, and supports.

When asked about any assets, strengths, or supports related to relationships, marriage, and family, several of the participants had a partner who supported them. One of the participants had a partner who was willing to have children with him even if it meant becoming HIV positive.

And I've been with this girl for about 6 months. She accepts every part of me. Every bad piece, every flaw, and she loves me and I love her the same so I want to spend my spend my life with her. She told me she would be willing to contract it from me in order to have kids. (Jack, personal communication, September 2014)

Charlotte felt that the right person would accept her.

Relationship-wise, if that person really cared about me regardless of what I have they'll be with me. I met someone who I told and they didn't have a problem with it. I feel like I won't tell everybody, definitely won't, but I will tell that right person. (personal communication, January 2014)

Needs and suggestions.

Participants did not mention any suggestions for dealing with relationship issues in the interviews.

In general, many of the participants were worried about finding a partner who accepted them and were worried about being able to have children. Some of the participants had found a partner who accepted them and were willing to have children

with them in spite of their HIV-positive status. One of the participants felt that the right person would accept her.

Theme #6: Medication Adherence

Challenges, barriers, and stressors.

Participants mentioned the following challenges, barriers, and stressors when discussing HIV medication adherence. Half of the study participants reported that they were taking HIV medications for their HIV. The rest were not taking HIV medications. The participants who had acquired HIV perinatally and had been taking HIV medications off and on since birth were more likely to report being tired of taking HIV medications.

Ella noted that she used to throw her HIV medication away when she was in middle school because she was tired of taking it:

At the beginning, it was a lot of struggles to take them. If I forgot to take them and I missed a couple of days, I automatically stopped taking them. My (family member deleted) was the type to issue out my medicine. I would pretend like I took it but I would stick it in my pocket or something and throw them away when I left. It was because I had been taking it all my life so I just got tired of it. (personal communication, August 2014)

Olivia expressed dismay that she would have to take HIV medications for the rest of her life and felt her doctor did not understand the immensity of the situation:

I had to start back on medication about 2 years ago and that really got to me because before that I wasn't on medication for 9 years. It really took a toll on me especially when they told me that I had to take it forever, for life. I was like, what?? The doctor who actually went through the process for me and told me that I had to get on the medication said I should feel as if, I should take this as an advantage because, you know... She doesn't understand. For life?? You have to take this medication for the rest of your life?? (personal communication, September 2014)

Mia noted that she felt guilty taking HIV medications because they were not available years ago for her mother who ended up dying from AIDS:

I mean, I don't care much about it because I know it will help me but sometimes I don't take it. Sometimes I'll be taking my meds and I get the feeling like I wish my momma would have had these. Maybe she'd still be alive with me. (personal communication, October 2014)

Perinatally acquired participants frequently experienced *medication fatigue* because they had been on HIV medications for long periods of time.

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports related to HIV medication adherence. Of the participants who had acquired HIV behaviorally and had been taking HIV medications for a shorter period of time, most expressed a positive feeling towards taking HIV medications and realized that it was very important to their long-term health and future. One young man noted that he started to have hope about his life after he started taking HIV medications and his viral load became undetectable. Many noted that even though they had experienced some side effects, they realized the importance of taking their HIV medications.

I be ok with taking them because they pretty much are my life right now. So, I'm looking forward to graduating and going to college and being around kids. I have to take it in order to succeed in my goals. (Mia, personal communication, October 2014)

And I just basically lost the will to live life until one day when I was already on medicine and I became undetectable. And I started educating myself more about HIV, learning a lot about it. I started taking medicine and taking care of myself. (Jack, personal communication, September 2014)

I'm taking Stribild. They reassured my mom that I'm not going anywhere soon as long as I've taken my medication. I don't mind it because I take it at night before I go to bed. Occasionally, I'll have some of the symptoms at night that go into the next day, um, but I don't have very many symptoms with it. The medications I was on previously, it was a mess. Now I'm on Stribild and it's four or five pills in one, it's a really good pill. I really enjoy it, I have no complaints on it. Absolutely loving it. (Leo, personal communication, January 2015)

Needs and suggestions.

Participants did not mention any needs and suggestions related to HIV medication adherence in the interviews.

The participants who had acquired HIV perinatally and had been taking HIV medications for long periods of time were more likely to be tired of taking it and had complaints. The behaviorally acquired participants who had recently started taking HIV medications were more grateful for them and more likely to recognize the health benefits.

Theme #7: Goals Pursuit

Challenges, barriers, and stressors.

When asked if they encountered any challenges, barriers, and stressors related to pursuing their goals because they were living with HIV/AIDS, very few of the participants felt that living with HIV would be a challenge or a barrier. Of the few that felt having HIV was a barrier in pursuing their goals, Jack expressed disappointment because having HIV prohibited him from joining the military.

My real primary plan was to go to the military but that's cut off the list now. You know they don't accept people... I wanted to follow my (family member) into the service. Buddy-buddy contract. He's in (deleted) and I'm still over here. He's accomplished a lot and I haven't even started yet. (personal communication, September 2014)

Nathan said that he had recently moved to the area from a smaller town and had experienced some stress because he thought this area was more violent. He was not financially able to move and was having some problems finding a job because of recent health issues.

It can be pretty violent here. Crazy people, violent people, drugged up people, last year a stray bullet went through my window. I want to move. My lease is up at the end of February. I'm trying to get out of there. I feel like I need extra assistance. But because I'm young, they feel like I can do things. I'm dealing

with the fact that I can't be in an environment that I want to be in because of my financial situation. My case manager said that if I wanted to move to these other types of apartments that I've have to pay for the electricity and all that. I'm upset about that part. If I can find me a good job or something, that might help me. I want to have my own place and get a job but some things happened. I've been going in and out of the hospital, and I had a bone infection but now it's clearing up and getting better so now I'm going back on track. (Nathan, personal communication, January 2015)

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports when discussing pursuing their goals. In general, most participants felt that being HIV positive would not interfere with their long-term career goals. Most of the participants were either in school or working. Several were pursuing careers in the health field and mentioned they chose a health career because they wanted to help others due to being HIV positive. None of the participants mentioned that they were having any difficulties pursuing their education or accessing healthcare because of financial issues.

And also to a lot of people who are HIV positive, they should know that they don't have to give up what they want to be or who they want to be because of their status. You can still work and you can still do the things that everyone else still does. And sometimes there's a stigma about that. That's what a lot of people know and don't let anything get you down. (Olivia, personal communication, September 2014)

I don't think it's going to affect my future. (Leo, personal communication, January 2015)

Needs and suggestions.

Participants had a couple of needs and suggestions related to pursuing their goals. One of the participants suggested that there should be more job programs for young adults in general.

(When asked if there were any needs he had or any programs that might help him.) Job programs. (Nathan, personal communication, January 2015)

Most of the participants seemed to be very positive about their future goals and did not seem to think that having HIV was going to interfere with them. One participant was upset because he could not join the military and another was upset because he thought the area was violent, he was not financially able to move, and he could not find a job because of health problems. Even though several of the participants voiced some struggles, I noticed that most of them had a positive attitude and felt that they were going to succeed in spite of having HIV.

Theme #8: Education

Challenges, barriers, and stressors.

Participants mentioned the following challenges, barriers, and stressor related to education. Many of the participants felt that they had not had enough health and sex education in school and did not know much about HIV before they became positive. Most felt that more thorough health and sex education should be taught in the schools at earlier ages.

They don't give too much information about it. Not until 10th grade biology. They should give information earlier. (Nathan, personal communication, January 2015)

Definitely put some programs in school. I would definitely say that we definitely need the programs in our schools. (Nicholas, personal communication, January 2015)

Ava noted that she felt that more information about HIV may have helped her make less risky behavior choices.

They rarely talked about it in school. I felt that they should have talked about it more. Maybe it would have prevented some of the actions that I took or maybe it would have helped me a little more to understand it at that age. This is what's out there and be aware of it. You know, always use protection because you never know. (personal communication, September 2014)

Lily pointed out that it makes sense that if young people are having sex, they should have more thorough information because it's better that they have protected sex rather than unprotected sex.

Florida is in the boat we are because you don't have that knowledge that other places have that are given the knowledge. These kids are having sex – we'd rather you have protected sex rather than unprotected sex. (personal communication, January 2015)

In general, most of the participants felt that more in-depth health and sex education should be offered in the schools starting before puberty so that students are prepared and informed.

Assets, strengths, and supports.

When asked about assets, strengths, and supports when discussing education, participants mentioned the following items. Several participants had family members in the health field who educated them about HIV/AIDS. After learning about their HIV diagnosis, most participants started educating themselves by reading books and articles, looking on the internet, and talking to health professionals and others with HIV. Many felt that they did not know much about HIV before they became HIV positive and felt that educating themselves was extremely important. A lot of the participants had received information from their clinicians and HIV support groups.

I didn't know much about HIV before. I go to the internet for a lot of information. It helps out a lot. I even download apps. They have HIV apps and STD apps that also tell you about the symptoms and tell you what you can do. (Henry, personal communication, January 2015)

I didn't have a lick of sense about HIV before I got it. I've looked at the CDC, I've looked at the AIDS foundation.com, Wikipedia, WebMD, there's been quite a bit. I listen to pod casts from the CDC. There's one called Medscape for HIV which I keep on it daily. I read the Pos magazines. I stay pretty close on track with that because people need to know. (Leo, personal communication, January 2015)

Yea, I got a lot of books about HIV, the infection, and everything. Um, and I search on the internet to educate myself and my mom because she don't know anything about that. And I'm really good right now about the education, about that. (Jacob, personal communication, September 2014)

Jack noted that he had lost the will to live until he started on HIV medication, became undetectable, and then started educating himself about living with HIV.

And I just basically lost the will to live life until one day when I was already on medicine and I became undetectable. And I started educating myself more about HIV, learning a lot about it. I started taking medicine and taking care of myself. (personal communication, September 2014)

Ava mentioned that she had a family member who was in the health field and she had given her a lot of information about HIV:

I do talk to my (family member deleted) because she's an RN so a lot of times when I need information on things she'll give me things and tell me to read up on this or maybe you should take this vitamin because I heard it helps with certain side effects. I have that support with her and going online with those online resources that she gives me. (personal communication, September 2014)

The participants noted that learning about HIV was very important and they had obtained information through a variety of sources which included the internet, brochures, books, health professionals, HIV-related organizations, and family members.

Needs and suggestions.

Participants had the following needs and suggestions related to education. Many of the participants suggested that there should be more in-depth health and sex education in the schools starting at a young age. Several also suggested more health and sex education for parents so that they could talk with their children about it.

I think it needs to be put into the school more. There's the little birds and bees talk that they have. It needs to be more in depth, because as society goes on, HIV and AIDS will keep going, and we don't need that. So they need to incorporate HIV education into schools. People need to be more aware. (Leo, personal communication, January 2015)

It's not only young people who need the education about HIV, I think it is really good to educate the parents to give parents the confidence to talk with every child, you know. I think the support from the family is the best support in life you can have. (Jacob, personal communication, September 2014)

Participants felt that there was a great need for more in-depth health and sex education in the schools at earlier ages. Many also felt that education should be provided to parents so that they could educate their children. Most of the participants did not know much about HIV/AIDS before they became HIV positive and did a great deal of self education after learning about their diagnosis. These findings emphasize the importance of enhancing health literacy so that individuals can make more informed health choices.

Theme #9: Community Education/Knowledge Level

Challenges, barriers, and stressors.

Participants pointed out the following challenges, barriers, and stressors related to community education and knowledge. Several participants pointed out that many people in their community as well as family members were misinformed about HIV. Some of this was already discussed in the section about stigma where there were examples of fear of contagion by casual contact.

Where I live you have a lot of people that don't understand the difference between AIDS and HIV so if they find out that somebody has it they automatically think AIDS and they don't know which one they actually have. (Ella, personal communication, August 2014)

I lived with her before for 4 or 5 years and it was about a money thing because I was getting a check and she was able to claim my son so it's a lot of factors that play a role in it. You never know. And they're uneducated so that plays a major part. Uneducated, don't have a way of thinking, just... (Olivia, personal communication, September 2014)

I think that's what it was for my grandma, no education so she didn't understand. (Ella, personal communication, August 2014)

Assets, strengths, and supports.

None of the participants mentioned any strengths or supports related to community education and knowledge.

Needs and suggestions.

When asked about community education and knowledge, participants noted the following needs and suggestions. Participants felt that more community-level education was an important step in stopping transmission and decreasing stigma.

People, they need more education about this kind of situation, you know, because every second lots of people get infected with this virus, not only in the United States, but every country, and that's very sad because when you have the infection, you have it, you can't turn the time back. (Jacob, personal communication, September 2014)

Participants noted that knowledge about HIV/AIDS was low among members of their community and many members of their family. They suggested that more community education might lead to decreased stigma.

Theme #10: Physical Effects

Challenges, barriers, and stressors.

The following challenges, barriers, and stressor were mentioned by participants when discussing the physical effects of living with HIV/AIDS. Several of the participants mentioned some physical side effects like flu-like symptoms and night sweats. Several had been in the hospital for several related infections.

As far as living with HIV, you might really think something is going on with your body. It comes with soreness of the body. Like I say, the week of my birthday, I got sick probably two days after the encounter. Because it's not a good feeling, you run a fever, your body feels so weak, you have flu-like symptoms, it's not a good feeling. You basically can't move. I slept on the same couch for two days thinking that I could get over this not knowing exactly what it was. I still have night sweats and everything, it's a part of it. (William, personal communication, December 2014)

I just got out of the hospital recently for kidney failure and a bone infection. (Nathan, personal communication, January 2015)

Assets, strengths, and supports.

When asked about assets, strengths, and supports related to the physical effects of living with HIV/AIDS, many of the participants felt that they were fairly healthy in spite of having HIV.

I would say a 10 health-wise. I'm on medication. I had to start on medication about two years ago. (Olivia, personal communication, September 2014)

As far as my health goes right now, I would say that I'm very healthy. (Ella, personal communication, August 2014)

Needs and suggestions.

Participants did not mention any needs or suggestions related to physical health.

Most of the participants felt fairly healthy while several of them had been in the hospital for related issues.

Theme #11: Mental Health Effects

Challenges, barriers, and stressors.

When asked about the mental health effects of living with HIV/AIDS, participants mentioned the following issues. Many of the participants mentioned that mental health was an issue and that they had become depressed since being diagnosed with HIV. Some of these examples were already addressed in the section on diagnosis reactions.

I first got diagnosed last year. I decided to go and take the test one day, just to find out what my status is, and once I went to the doctor and it was confirmed that I had it, mentally I had a break down. I was definitely upset, hurt, stressed, crying, and was wondering how I'd break the news to my partner, and break the news to my mother. (Nicholas, personal communication, January 2014)

Granted it doesn't kill you, but it's not what you want to live with every day. Because you are constantly depressed. I'm on medication for depression, anxiety,

PTSD. I have a cocktail of all kinds of medications. But I want to be an advocate. I want to be a voice for HIV. (Leo, personal communication, January 2015)

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports when discussing mental health effects. Several participants said that they were currently receiving counseling services which was very helpful.

I see my psychologists and mental health counselors at (name deleted). (Leo, personal communication, January 2014)

I haven't gone to any support groups but I have definitely talking to my therapist, my psychologist, and she's been helping me through the riff raffs and how I've been feeling and what's been going on in my head. (Nicholas, personal communication, January 2014)

Needs and suggestions.

Participants had the following needs and suggestions related to the mental health effects of living with HIV/AIDS. Several of the participants said they would like to have a mental health professional available when they were ready to disclose their HIV status to family and friends as noted in the section about disclosure. Many of the participants mentioned the need for enhanced mental health services in general.

Many of the participants experienced a great deal of shock upon learning about their HIV diagnosis and have had ongoing issues with depression which emphasizes the importance of mental health services both at the point of diagnosis and throughout the course of the illness.

Theme #12: Health Services

Challenges, barriers, and stressors.

When asked about challenges, barriers, and stressor related to health services, the only challenge noted by a participant was that going to an infectious disease clinic for her HIV treatment made her feel different.

Why do people have to come to the (name deleted) clinic? Everybody knows what the (name deleted) clinic is. It shouldn't be a stigma about where you go to see the doctor, and if so, why does it have to be the (name deleted) clinic? Like, everybody knows this is an HIV clinic. That's one thing that HIV patients should be treated like anybody else. Like I know they have infection control doctors here who are the best and all that, but they should spread them out and we should be able to go elsewhere. (Olivia, personal communication, September 2014)

Assets, strengths, and supports.

When asked about assets, strengths, and supports related to health services, most of the participants reported that they were very satisfied with the health services they were currently receiving. Many of the behaviorally acquired participants had been coming to the clinic all of their lives and were satisfied with the services.

This is the only place I've come. I'm been coming here for a while. It's pretty good. The doctors are very good at what they do. They are always making sure that my stuff is up to date and if I need to be on medication or not. (Ava, personal communication, September 2014)

I'm very comfortable about coming here. I would never really change to a different doctor. This is what I'm used to. (Ella, personal communication, August 2014)

Needs and suggestions.

The only suggestion mentioned by a participant in relation to health services was mentioned above under challenges. The participant said that health services for individuals living with HIV/AIDS should not be separate but should be integrated with other health services so that they don't feel different.

Participants were generally satisfied with the health services they were receiving and many of the perinatally acquired participants had been receiving services at this particular clinic all of their lives.

Theme #13: HIV Support Groups

Challenges, barriers, and stressors.

Participants did not mention any challenges, barriers, or stressors related to HIV support groups.

Assets, strengths, and supports.

Participants mentioned a variety of assets, strengths, and supports related to HIV support groups. Many of the participants said that they benefited from attending HIV support groups. They said that the HIV support groups helped them meet others like themselves, realize that they were not alone, and helped them to learn from others' experiences.

It was good to meet all these people who were just like me. Some of them went through the same thing I went through and some had other experiences. It was just good to hear their stories. You know, learned how they get through it. It was very interesting to me. And I found it very helpful because at that time I was in high school and I was like this was awesome that they have something like this for kids. (Ava, personal communication, September 2014)

When I found out, they started making me go to this group session for kids like me so I looked around and wow, at least I'm not alone in this situation. So I started getting comfortable with having it and people knowing that I have it so that's ok. (Ella, personal communication, August 2014)

That's still, like, it was basically being around other people who had the same thing, going through the same thing. And not only that, the support group actually helps. It has an impact because when you're in a support group, you find out other things about having HIV, the do's and the don't's, that you really didn't know before, so it's actually a lot helpful – the support group. (Emily, personal communication, November 2014)

Several participants noted that their HIV support groups were their major source of HIV information.

I didn't get much information about HIV in school. I got it mainly from coming to the support group. (Noah, personal communication, January 2015)

Mia mentioned that she was surprised to see others with HIV at the support group who were smiling and happy. It helped her to not look down on herself and to smile more.

I have gone to support groups. I seen a lot of kids that be smiling and like, oh wow. And then there are kids like me and that's why I don't look down upon myself because there are people just like me and they still be smiling regardless of that and I say why can't I smile either and I keep smiling and that's just what I do. (personal communication, October 2014)

Needs and suggestions.

When asked about needs and suggestions related to HIV support groups, many of the participants suggested that there should be more HIV support groups.

I feel like there should be more support groups where we can actually... Where they are not going to be afraid to step up and speak up. Some people just need a little encouragement to get life going. Some people just need a pat on the back, and say, "It's okay, me and you in the same situation."

Many of the participants had gone to an HIV support group and noted the benefits. Participants said that attending an HIV support group helped them feel like they were not alone, gave them information, and helped them to see how others were coping with the condition.

Theme #14: Support Services

Challenges, barriers, and stressors.

Participants did not mention any challenges, barriers, or stressors about support services.

Assets, strengths, and supports.

When asked about assets, strengths, and supports related to support services, participants mentioned a variety of support services including mental health services, transportation services, and general medical care. Participants were satisfied with the services they were receiving.

I've gotten more services here in (city name deleted) that I had in (city name deleted). Bus passes to go to my doctor's appointments, getting rides to go to my doctor's appointments, being able to go knowing where my hospital is, where my clinician is, and just everything is in one central area and it all branches out to different areas. So it's really, really supporting. And the medical staff have been really great with me. (Leo, personal communication, January 2015)

Needs and suggestions.

Suggestions related to support services have already been mentioned in other sections. These included enhancing mental health services, particularly at the time of diagnosis, and having a health professional present at the time of HIV disclosure in order to answer questions and help with coping. Participants were satisfied with the level of support services they were currently receiving.

Theme #15: Faith/Religion**Challenges, barriers, and stressors.**

Participants did not mention any challenges, barriers, or stressors about faith and religion.

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports related to their faith and religion. Several participants mentioned that different aspects of their religious faith helped them to cope with having HIV.

I just listen to some Gospel music. (Nathan, personal communication, January 2015)

I pray in the morning and I pray at night. (Mia, personal communication, October 2014)

Actually, I've been staying in church, a good bible-based church, constantly staying there. I never lost my faith. I just couldn't believe it was me. But I still keep going, I still keep my faith, I still keep going to church. I still keep the word, it keeps me going on a daily basis. (William, personal communication, December 2014)

Emily felt that being HIV positive was a gift from God which she was going to use to help others. She had given the situation over to God and felt that He was her strength.

God makes no mistakes, and that's my biggest strength. To me, personally, I feel like it was a gift from God, and I don't look at it as a bad situation because there's people out there that's actually going through something worse than me. I feel like He gave me something to be a motivator to someone else. When I found out, it was pretty tough, but I went unto the Lord and I told Him, I accept what you gave me and I'm going to use it as a gift. I'm not going to tear myself down. I'm not going to do none of that. Once I gave it to God, I felt relief. Ever since then, He's been taking the wheel for me. That's why I say God works in mysterious ways. (personal communication, November 2014)

Needs and suggestions.

Participants did not have any needs or suggestions about faith and religion.

Several of the participants mentioned that their faith gave them strength and helped them cope with living with HIV. A couple of the participants felt that God was either testing them by giving them HIV or making them stronger.

Theme #16: Inner Resilience and Positive Attitudes

Challenges, barriers, and stressors.

When asked about challenges, barriers, and stressors related to maintaining inner

resilience and a positive attitude, many of the participants mentioned that they had to work hard to have a positive attitude.

I had to learn to pick myself up and not let it beat me. I was fun-loving and outgoing and it definitely pushed me back. I'm trying to get me back to the happy place that I was instead of being sad and depressed. (Nicholas, personal communication, January 2015)

Assets, strengths, and supports.

Participants mentioned the following assets, strengths, and supports related to maintaining inner resilience and a positive attitude. Even though many of the participants said that it was sometimes challenging to keep a positive attitude, many mentioned that being HIV positive was not going to stop them or get in the way of their goals. They mentioned that they gave themselves pep talks and tried to move forward and look on the positive side.

And I was beaten down for so many months and now I'm back on my feet and moving forward. I can't forget or change it, it can only be accepted. That would probably be my motto to anybody. Keep on truckin'; the little train that could. (Leo, personal communication, January 2015)

But as far as my dreams and goals, I don't think it's going to stop me. (William, personal communication, December 2014)

So for me, as far as life, it's plain and simple, you live it, you live life, you don't let life live you, that's my motto. (Jack, personal communication, September 2014)

That's why, when I first found out, I was in that lonely place for a minute, and so I had to get up and tell myself: you're better than this. You're stronger than this. You've got to uplift yourself. (Emily, personal communication, November 2014)

Nathan felt that it made him strive harder for what he wanted:

But the more I live it, it's not a death sentence. It's just... It makes you strive harder for what you really want. It makes you open your eyes. (personal communication, January 2015)

Needs and suggestions.

Participants expressed the following needs and suggestions related to maintaining inner resilience and a positive attitude. Olivia wanted other HIV-positive individuals to know that it should not stop them from pursuing what they wanted to do.

And also to a lot of people who are HIV positive, they should know that they don't have to give up what they want to be or who they want to be because of their status. You can still work and you can still do the things that everyone else still does. (personal communication, September 2014)

Isaac said that he wanted others to hear his story so that they would know they could overcome this type of situation.

I want people to see my story and see that you can overcome this, you can be a better person. You can let other people know in your age group, hey, this isn't.... you have to protect yourself, you have to maintain your health, you have to listen to your body. (personal communication, January 2015)

Many of the participants noted that a positive attitude and staying around positive people was important.

And pretty much, stay around positive people. You don't need anybody that's going to down you or tell you anything negative because you're already living with something negative enough. (Olivia, personal communication, September 2014)

It's good to have positive people around me, the people who do know. It makes me feel good when you have that support because some people they don't have that support and it's a lot of things that they go through that I didn't have to go through. (Ava, personal communication, September 2014)

Many of the participants expressed an inner resilience and positive attitude that they used to help them cope with having HIV. They suggested that people living with HIV/AIDS should not give up, stay around positive people, try to maintain a positive attitude, and to forgive themselves for their part in acquiring HIV.

Theme #17: Helping Others and Activism

Challenges, barriers, and stressors.

Several participants mentioned the following challenges, barriers, and stressors in relation to becoming an HIV/AIDS activist and helping others. Although many of the participants said that they would like to help others and spread awareness about HIV/AIDS, many were also reluctant to do so because they were afraid that disclosing their status might lead to rejection or criticism.

I think that testimonials from people who have it would be good. But I couldn't do it because I don't want to tell others my status. (Henry, personal communication, January 2015)

Assets, strengths, supports, needs, and suggestions.

This sections contains some of the strengths and supports that participants mentioned about helping others as well as suggestions. Many of the participants said that they wanted to help others by spreading awareness and educating others.

I want to make myself an example. I just love to help anyone who needs my help because when I found out, there was no one there for me. (Jacob, personal communication, September 2014)

I thought about becoming a psychologist because I would be able to relate to that individual especially if it was for HIV care. I'm going to the PLWH meetings and starting to become more active in the community like the HIV/AIDS Foundation, any community event dealing with HIV/AIDS because I want to spread the awareness. So that's my goal this year, get with a lot of organizations, build up my knowledge on it, get focused on it, that way I can go out there and tell everybody, teach everybody about it. (Leo, personal communication, January 2015)

I want to be an advocate and an activist for the HIV community especially the young adults. I want to be the voice that's going to be heard because I don't want people my age to go to drug use or get assaulted, and contract HIV. Granted it doesn't kill you, but it's not what you want to live with every day. (Noah, personal communication, January 2015)

Nathan would like to become educated about HIV and then be a speaker at different schools:

I plan on it, I want to get really educated on it, and actually go to schools and hold speaker meetings for 10th grade, 11th grade, 12th grade, and they're the ones who really need it. (personal communication, January 2015)

Emily would like to talk to girls about being themselves and not feeling pressured to grow up too soon:

I always want to talk to young girls and let them know, life is what you make it. You ain't got to be fast, you ain't got to be grown, you ain't got to be none of that. Be yourself. It's nothing out here to rush for. (personal communication, November 2014)

Nicholas mentioned that he would like to talk to teens about the risks:

I would definitely be open to talking with teenagers and telling them the risks and telling them that it's not a joke. It is definitely something serious, like people say you're playing Russian roulette with your life. Like they say, you only get one mother – you only get one life. (personal communication, January 2015)

Leo said that he would like to take a leadership role by helping teens and young adults to be successful:

I want to take a leadership role because I want to be able to help teenagers and young adults. I want them to go to school, go to college, not make the same mistakes I did because I was that young dumb teenager that thought everything revolved around me. Helping people is one of my biggest things because I don't like to see anybody go down the same road I went down. (personal communication, January 2015)

After becoming HIV positive, Nathan became trained as an HIV tester/counselor so that he could help others:

I went to the Health Department in (deleted) and I became an HIV counselor. I do the testing. Give them all the information. Just got it through the course we had to go through. Like a 3 day course. (personal communication, January 2015)

Several individuals felt that motivational speakers who had HIV and were similar to the group they were talking to would be very effective.

Probably have motivational speakers who have been through it. (Nathan, personal communication, January 2015)

I'm really a strong believer in having those who feel comfortable telling their story go out and educate those that don't have it. I think it would be good to have a person walk a day in that person's shoes and see so you won't judge. (Ava, personal communication, September 2014)

So basically having a big old testimony conference with people who have it to give speeches, and invite a bunch of people who don't have it, and who aren't aware of it. And just basically like also, having speeches like that and inviting school kids like you know, elementary or middle school, school kids, who are not aware of it so that way, the people who have it can aware them of it, and let them know it's not a joke. (Henry, personal communication, January 2015)

We just need more young people to step up and try to make it good. We need more of our age range. We need some of the older people because they done live through it a little longer than us, they done experience a lot more, so we can get information from the older person as well, but I feel as if young people need to get together. (Emily, personal communication, November 2014)

Some had personal suggestions for others, such as being more careful about who they trusted and who they were intimate with.

If I would have done it over again, I would have definitely been more aware of who I became intimate with, who I trusted, and who I definitely considered a good person to keep something from me. (Nicholas, personal communication, January 2015)

Jacob said that more research like this study would be helpful:

Doing the same thing that you're doing with me right now, you know, making surveys and research. (personal communication, September 2014)

Many of the participants had an overwhelming desire to help others who were living with HIV and to spread awareness. Many had chosen a career in the health field for this reason. Others wanted to become a teacher or some type of counselor. Many of them felt that it was now their responsibility to help others. Other suggestions included more research studies about living with HIV/AIDS, motivational speakers, and drop-in/resource centers for people living with HIV/AIDS.

Chapter Summary

In this chapter, the study data were organized by themes and research questions. In response to the first research question on challenges, barriers, and stressors, six main issues were raised by participants. These included mental health issues, especially upon learning about their HIV diagnosis, stigma, relationship/marriage/children issues, inadequate health/sex education at school, lack of appropriate HIV/AIDS knowledge in their community, and HIV medication adherence issues, particular for those who had acquired HIV perinatally and had been taking HIV medications for a long time.

The second research question focused on individual, social, structural, and institutional assets, strengths, and supports. In response to this research question, participants mentioned internal resilience and positive attitudes, small support networks of family and friends, HIV support groups, and an array of medical and support services. In general, participants were satisfied with the medical and support services they were currently receiving. Most of the participants were either in school or working and did not feel that having HIV would deter them from reaching their goals.

Participants mentioned the following suggestions in response to the third research question. Suggestions included HIV services that were integrated rather than separated from general medical services in order to decrease stigma, more HIV support groups, more thorough health/sex education in the schools at earlier ages, and more community education about HIV/AIDS to decrease misinformation and stigma. Additional suggestions included services to help individuals disclose their HIV status to family and friends, having motivational speakers who were living with HIV/AIDS and had similar demographic characteristics, drop-in centers for individuals living with HIV/AIDS that

included opportunities for socialization and networking, and more research studies about living with HIV/AIDS. Many of the participants expressed the desire to become HIV advocates, speakers, and leaders in order to educate others and decrease transmission so that others did not have to endure what they have had to endure.

A discussion of the results along with implications for leaders, practice, policy, and future research are presented in Chapter 5.

Chapter 5: Summary, Conclusions, Implications, and Suggestions for Future Research

The purpose of this study was to capture the lived experiences of a group of low income, urban young adults living with HIV/AIDS in order to better understand how factors in their environment presented opportunities and challenges for resilience and coping. I selected this population to study because this age group has the highest rate of new HIV cases. Additionally, young adults living with HIV/AIDS who live in low income, urban areas often encounter additional stressors which can impede their adaptation to their illness as well as their transition to adulthood. These stressors include higher rates of poverty and unemployment, more exposure to gangs and violence, higher high school dropout rates, lower resourced schools, lower resources to access higher education, and less access to quality health care. Therefore, I wanted to study how these young adults were dealing with the normal transitions to adulthood while living with HIV/AIDS as well as the stressors inherent in a low income, urban environment.

This inquiry was warranted because decreasing HIV transmission and HIV health disparities is a top priority of the Office of AIDS Research (NIH Office of Aids Research, n.d.), the National HIV/AIDS Strategy (The White House: Office of National AIDS Policy, n.d.), and Healthy People 2020 (Riegelman & Garr, 2011). A better understanding of how ecological and health factors present opportunities and challenges for resilience and coping among this group may be valuable for educational leaders,

healthcare leaders, policymakers, and other professionals who design and conduct programs, services, and policies for this group.

My research questions included:

1. What are the challenges, barriers, and stressors that serve as vulnerability factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?
2. What are the individual, social, structural, and institutional assets, strengths, and supports that serve as protective factors in the microsystem, mesosystem, exosystem, macrosystem, and chronosystem of young adults living with HIV/AIDS who reside in a selected low income, urban area?
3. What needs and suggestions do young adults living with HIV/AIDS who reside in a selected low income, urban area have for improving programs, services, and policies to help them transition to adulthood, care for themselves, and prevent transmission of the virus to others?

I used a conceptual framework consisting of Bronfenbrenner's (1994) ecological model of human development and the concept of resilience. Bronfenbrenner (1994) proposed that an individual's development was influenced by the interaction between his/her entire ecological environment and the self. He believed that proximal processes, which are the ongoing reciprocal interactions between a developing individual and the objects, people, and symbols in his/her immediate environment, strongly influenced psychological development and behavior.

Resilience can be thought of as the ability to positively adapt to situations of great adversity (Schetter & Dolbier, 2011). Protective factors are those that enhance

resilience. Vulnerability factors are those that detract from the ability to adapt to a serious situation. Resilience can be viewed on a continuum with flourishing or thriving as the most positive outcome, and languishing as the most negative outcome (Fredrickson & Losada, 2005). These two concepts complement each other and enhanced the ability to describe, examine, and interpret the data from this study.

I conducted semi-structured, in-depth interviews with 16 young adults living with HIV/AIDS who lived in a low income, urban area from August 2014 through January 2015. I coded and organized the narrative data by themes and patterns in order to tell their story and respond to the research questions.

Findings

The major findings can be summarized under three broad areas that align with the three research questions, namely major challenges and barriers, major supports and strengths, and participants' needs and suggestions.

Major Challenges and Barriers

Participants mentioned a variety of challenges and barriers categorized under six main areas. The table below depicts these areas.

Table 7

Major Challenges and Barriers

Mental health issues

Stigma

Relationship/marriage/children issues

Inadequate health/sex education at school

Inadequate knowledge about HIV/AIDS among community members

Medication adherence issues

One of the biggest challenges was the internal processing and acceptance of their diagnosis. Most of the participants were in shock and disbelief upon learning that they were HIV positive. This quickly turned into depression and despair in many cases, sometimes even manifesting itself in suicidal behaviors. Many commented that they had to return home and pretend there was nothing wrong because they did not feel comfortable sharing the news with family and friends for fear of stigma and rejection. They had no one to talk to about their feelings or what was going on with them.

Closely linked to these mental health issues were issues related to stigma and disclosure of their status to others. Several had experienced rejection when they told their partner about their status. Some participants mentioned that they were very reluctant to tell their sexual partners but always made sure to use protection such as condoms so that they would not pass on the virus to others. Some of the participants had experienced stigma from family members and friends. Several noted that family members made them use separate eating utensils and would not let the participant care for their children. One young woman experienced extreme discrimination from her partner's family which included one of them telling her he would never end up in her situation because he was not *that stupid*. Many felt that they could not tell certain family members and friends for fear of rejection. However, most of the participants had at least one family member or friend who was supportive. In many cases, this was their mother.

Another disclosure issue that the perinatally acquired participants mentioned was the age and manner at which they learned about their HIV status. Most had been told they were taking medication for a medical reason other than HIV. Several found out they were HIV positive by accident which resulted in a shocking situation for them. Many

noted that they wished they had been told their HIV status at a younger age so they would have had more time to adjust before puberty. One young woman found out her HIV status accidentally while she was at summer camp. When she returned home and tried to talk to her mother about the issue, her mother would not talk to her about it.

Other challenges mentioned by participants were those related to marriage, relationships, and having children. Several of them said that they were afraid they would not find a partner who would accept them. They were worried about explaining their situation and how they acquired HIV to their partner. They were also worried about passing on the virus to their children and were not sure if they could ever have biological children.

Another important finding was that many participants did not feel that they had received adequate health and sex education in school. One young woman mentioned that not much information was given at her school about sex and she thought that might have made better choices if she had been more informed about sex and sexually transmitted infections. Many participants felt that health and sex education should be taught at earlier ages. The teaching of sex education and the age at which to start it is often hotly debated in many school districts. However, the study participants overwhelmingly felt that more information about sex and health should be taught in schools at earlier ages for prevention reasons. Most participants felt that accurate knowledge about HIV/AIDS in their communities was low and more education might result in decreased stigma and discrimination.

Medication adherence was another theme that was discussed by participants. Several of the perinatally acquired participants who had taken HIV medications off and

on throughout their lives were more likely to be tired of taking them. One young woman regularly threw her medications away so she did not have to take them when she was in middle school. The behaviorally acquired participants were more likely to be grateful for having medications available to them. They recognized the health benefits and noted that it gave them hope for the future.

Major Supports and Strengths

The following table lists the major supports and strengths that the participants mentioned in their interviews. The major supports and strengths were categorized into the following four main areas.

Table 8

Major Supports and Strengths

Internal resilience and positive attitudes
 Small support networks of family and friends
 HIV support groups
 An array of medical and support services

A large number of the participants exhibited a great deal of internal resilience and positive attitudes. Many of them indicated that having HIV was not going to stop them and that they were still going to be able to pursue their goals. They noted that a large part of dealing with HIV was mind over matter and they had decided to adopt a positive attitude. When asked where their positive attitude came from, many did not know whereas several related it to how they were raised. One young man said that he learned at home not to carry today's problems into tomorrow. Several of the participants who expressed a positive attitude had come from very turbulent environments which included

a mother who had died of AIDS when they were young or parents who were drug addicts or absent. Several of them relied on their religious faith for support.

Most of the participants had a family member or friend who they could rely on for support. In most cases, this happened to be their mothers who they tended to tell first. Other participants mentioned grandmothers, aunts, and siblings as other sources of family support. A couple of them had a close personal friend who was supportive. However, many participants mentioned that they had only told a few people and were not comfortable about telling a wider range of people in their lives for fear of rejection. Several mentioned specific family members who they thought would not understand or accept their situation.

Many of the participants noted that they had attended HIV support groups which they found beneficial. Several mentioned that it helped them to not feel alone and to find out how others coped with living with HIV/AIDS. A couple of them said that they learned most of their information about HIV from their support groups.

Many participants expressed that they were happy and satisfied with the medical and support services they had received for their HIV. One young man who had recently moved to the area said that he thought the services in this area were better than the area he had moved from. None of the participants mentioned that they had trouble accessing services. It should be noted that all of the participants were covered by the Ryan White HIV/AIDS Program, Medicaid, or private insurance because the clinic where the participants were receiving their HIV medical care did not serve individuals who were not covered by one of those programs. Therefore, individuals who did not have some type of medical coverage were not accessed by this study. For future research, it would

be important to study young adults living with HIV/AIDS not currently engaged in medical care or not receiving medical coverage in order to find out how they are coping.

Participant Suggestions

When asked for suggestions for improving programs, services, and policies for young adults living with HIV/AIDS, the participants mentioned the suggestions listed in the table below.

Table 9

Participant Suggestions

More integrated services
 Disclosure assistance services
 Enhanced mental health services particularly at time of diagnosis
 More thorough health/sex education in the schools at earlier ages
 More community education
 Using motivational speakers to educate young adults about HIV/AIDS
 Drop-in resource/community centers for socialization and networking
 More research studies about living with HIV/AIDS

Participants mentioned that medical services should be more integrated and HIV medical services should not be separate because that makes them feel different. One young woman said that she was hoping for the day when she could go to her regular doctor for her HIV medical care and her HIV would just be another diagnosis on the list of conditions she was being treated for.

Several participants expressed the desire for assistance from a mental health or medical professional when they were ready to share their diagnosis with family and friends. They noted that it would be important for a mental health or medical professional to be there who could answer questions, allay fears, and help with shock and

coping. Participants also suggested that mental health services should be enhanced, particularly at the time of diagnosis.

As noted above, many of the participants felt that health and sex education programs in the schools should be expanded and started at earlier ages. Many noted that they did not know much about HIV before they become positive. Many of the participants had educated themselves about HIV after learning about their diagnosis by reading information on the internet, reading books and brochures, and talking with clinicians and individuals who had HIV.

Participants said that there was a great deal of misinformation about HIV/AIDS in their communities which they thought led to stigma and discrimination. They noted that there should be more programs to educate members in their communities about HIV/AIDS. Many thought that using motivational speakers who were living with HIV and were similar to the group being educated would be an effective way to educate others because it might evoke more empathy and identification. Several of the participants mentioned that they had thought about becoming motivational speakers in order to spread awareness and help others, but were afraid of revealing their HIV status for fear of rejection.

Several participants mentioned that creating more community drop-in centers for individuals living with HIV/AIDS would be a great way to increase support and comradery. A couple of the participants noted that they wanted to create their own centers in order to help others. One young woman wanted to create a support center for young girls who were living in stressful or traumatic situations.

A couple of the participants mentioned that conducting more research studies about living with HIV/AIDS was an important way to help others with HIV, raise awareness, and design better programs and services. Several of them mentioned that they had decided to participate in this research study because they wanted to share their stories about living with HIV/AIDS in the hopes it would help others and raise awareness.

I will relate these findings to the literature in the sections below.

Limitations

There were several issues that served as limitations to the study. One of the limitations of this study involved the recruitment plan. The purpose of this study was to examine the lived experiences of a purposive sample of young adults living with HIV/AIDS who resided in a selected low income, urban area in order to better understand how ecological and health factors presented opportunities and challenges for resilience and coping. My recruitment plan included identifying the zip codes in the area with the lowest household incomes and recruiting individuals between the ages of 18 and 29 who were living with HIV/AIDS and resided in these zip codes.

I planned to recruit these individuals by approaching patients at a local infectious disease clinic, by placing advertisements in local social service agencies that served the study population, and by asking participants to refer family, friends, and acquaintances who met the study criteria. No one responded to the advertisements and none of the participants referred anyone for the study. All of the 16 individuals who enrolled in the study were actively receiving medical care for their HIV at the local infectious disease clinic. Therefore, the study population was limited to individuals who were receiving care at this particular clinic and did not include those who were receiving medical care

for their HIV/AIDS at a different clinic or who were not receiving any medical care at all for their HIV/AIDS. Young adults living with HIV/AIDS who live in low income, urban areas and are not currently receiving medical care for their HIV/AIDS or who are receiving care from a clinic other than the study location may have different lived experiences, challenges, strengths, needs, and suggestions than the individuals who participated in this study. It is therefore important to also study these other individuals. This is a limitation of this study and an important area for future research.

Additionally, recruitment was limited to a small group in one selected urban area. Young adults who live in a different urban area may have different experiences due to factors related to their location of residence. This is another limitation of this study as well as another area for future research.

Another limitation of the study was the self-reported nature of the data that was captured through the interviewing process. With self-reported data, there is often no way of knowing if the respondent is answering truthfully or accurately. He or she may respond in an untruthful or inaccurate manner for a number of reasons, especially in response to sensitive or personal questions. He or she may have left out or embellished some information because of its sensitive nature due to fear of embarrassment or rejection. In order to make the participants feel comfortable about disclosing information, I tried to maintain an accepting and non-judgmental attitude during the interviews. Additionally, I promised the participants that their identities would not be linked with their responses in any reports. This may or may not have made the participants feel comfortable about disclosing sensitive information, however I noticed that many participants spoke freely during the interviews and disclosed a great deal of

sensitive information. Therefore, I believe that I established an atmosphere that encouraged the participants to feel safe about disclosing sensitive information.

Also, only five participants returned for a second visit which was meant as a review of the responses from the first interview for clarity of meaning. I was not able to conduct a second visit with the other 11 participants. Because I noticed this trend early in the process, I offset this limitation by reviewing responses at the end of each first interview in case I was not able to arrange a second visit with the participant.

Additionally, researchers have noted that the results and conclusions of single-investigator, qualitative studies can be influenced by the skills and attitudes of the single investigator because s/he is the only collector and interpreter of the data (Creswell, 2007; Patton, 2002). Therefore, I took great care to follow accepted research principles, maintain an unbiased and open attitude, and fully disclosed my educational training, perspectives, skills, connoisseurship, and schemas of understanding in Chapter 3 in order to minimize this limitation.

Implications for Theory Development

The Ecological Model of Human Development

One of the theories in my conceptual framework was Bronfenbrenner's ecological model of human development (1994, 2000, 2005). This theory proposes that an individual's development and socialization is strongly influenced by interacting factors in his/her environment which were termed proximal processes by Bronfenbrenner. In this study, participants discussed the impact of these ecological factors on their lives. Upon reviewing the influence of factors in the microsystem, most of them had a few close family or friends that they could rely on for support. However, many also recounted

stories of discrimination and rejection from close family members and friends. This seemed to be more prevalent among the participants who had acquired HIV perinatally and had been living with HIV/AIDS all of their lives. Most of the participants were worried about disclosing their HIV status to individuals in their microsystem for fear of rejection. This carried over to current and prospective intimate partners. A few noted that they usually disclosed their HIV status to intimate partners, however many of them mentioned that although they did not disclose their statuses outright, they *always* practiced safer sex because they did not want to pass on the virus to others.

Many mentioned that they were satisfied with the services they were receiving at the clinic and did not feel they had issues accessing medical care. This is an important factor for these individuals because they all resided in the lowest income zip codes in the area. As noted previously, the participants were individuals who were actively receiving medical care and therefore were covered by some type of health coverage because this was required by the study clinic to receive services. Therefore, accessing medical care for their HIV was not an issue for these individuals even though they lived in a low income area. The quality of these services was not explored by this study or compared to services by other types of HIV care providers. This is an important area for future research.

Other parts of the microsystem included religious institutions, the schools, and the workplace. Several participants noted that their church and their religious faith were sources of support. Many of the participants mentioned that they did not feel they had received an adequate amount of sex/health education from their schools. Several said that more information may have helped them to avoid risky behaviors. Many said that

they felt that earlier and more in-depth sex/health education in the schools was important in order to help young people make more informed choices about risky behaviors. None of the participants mentioned discrimination in the workplace, but since most of them noted that they had only disclosed their status to a few select people in their lives, their status was probably not known to work colleagues. Most of the participants felt that being HIV positive would not impede their educational or career goals.

It is difficult to determine the influence of factors in the mesosystem, which are the interactions between parts of the microsystem, because participants often did not disclose their HIV status to many people in their lives. Therefore, individuals outside of their close circle of friends and family such as schoolmates and work colleagues, often did not know they were HIV positive. There was one instance where family members of one the participant's partner said negative things about her to people in her neighborhood, but in general, factors in the mesosystem did not play a part in the lives of the participants.

Upon reviewing the influence of factors in the exosystem, federal policies such as the Ryan White HIV/AIDS Program, Medicaid, and the Affordable Care Act influence the access to HIV medical and support services for individuals living with HIV/AIDS. The Ryan White HIV/AIDS Program is a large, federal program administered by the USDHHS that pays for medical care, mental health care, and a variety of support services for low income individuals with HIV/AIDS (USDHHS, n.d.i.). In FY 2011, 13% of all federal dollars spent on HIV/AIDS services were covered by the Ryan White HIV/AIDS Program. Medicaid is actually the largest payer of HIV/AIDS services at 51% of all federal dollars expended on those services in FY 2011 (The Henry J. Kaiser Family

Foundation, 2011). The Affordable Care Act prohibits most private health insurance companies from denying insurance coverage to individuals living with HIV/AIDS (The Henry J. Kaiser Family Foundation, n.d.).

Thus, individuals living with HIV/AIDS in the United States are able to receive healthcare coverage through these programs. All of the participants in this study were covered by the Ryan White HIV/AIDS Program, Medicaid, or private insurance. None of the participants noted any difficulties accessing healthcare because of their healthcare coverage under these programs. Several important areas for future research would be to explore the quality of care being received and why some low income young adults living with HIV/AIDS are not engaged in care even with the availability of programs like Medicaid and the Ryan White HIV/AIDS Program.

Another element of the exosystem that was a theme among participants was school practices and policies regarding the teaching of sex education. The school system is a major socializing agent whose major purpose is to transmit information, skills, and the elements of culture in a society (Berns, 2012). It has a great impact on people's lives. The transmission of information and skills about health and sex often collides with another important socializing agent in society, religious institutions. Many of the participants mentioned that schools should start in-depth health and sex education at an early age so that young people are more informed and prepared. However, some religious institutions have strict moral laws governing sexual behavior that conflict with passing on information to young people. This often creates a conflict regarding health and sex education curriculum in the schools.

From a theory perspective, the participants in this study thought that teaching in-depth health and sex education at early ages would serve a practical and preventive purpose. Additionally, several large studies have indicated that young adults who received sex education were more likely to start sex at an older age and use birth control or protection (Bourke, Boduszek, Kelleher, McBride, & Morgan, 2014) and teens who had sex education were less likely to have sex and become pregnant (Kohler, Manhart, & Lafferty, 2008). Still, there is a controversy in the school systems about when to begin health/sex education and how much information to offer. This is an issue that educational leaders need to be aware of and will have to struggle with. Perhaps they can present research results along with suggestions from evidence-based prevention programs to parents to reach a feasible compromise.

Ecological factors in the macrosystem that impacted the lives of the participants included cultural norms and beliefs such as those that precipitated stigma and discrimination. Many of the participants reiterated the pervasive belief that people who contracted HIV had participated in immoral behaviors, were *disgusting* or *stupid*, and were going to die. Many noted that accurate information about HIV/AIDS was low and misinformation was high within their families and communities. Several participants said that family members expressed a fear of contagion over casual behaviors such as touching or eating off the same dishes. This indicates the need for more community-level education to help increase knowledge and decrease stigma.

The influence of the chronosystem, or changes over time, were most evident for the participants who had acquired HIV perinatally at birth. One of the major issues that they were dealing with was the fatigue that comes with long-term medication use.

Several noted that it had been difficult for them to have to take HIV medications all of those years and some reported that they had skipped or thrown away medication along the way. They also discussed the experience of finding out their HIV status. Most had been told they had another condition other than HIV when they were a child. Some had been told their HIV status outright as an older child or young teen, while several had found out on their own. One young woman found out when she saw her condition circled next to her name on a medication list at camp. The perinatally acquired participants noted that HIV-positive children should be told before puberty so that they have time to adjust to the situation.

Another life transition issue that participants mentioned was getting married and having children. Several were worried that it was going to be difficult to find someone who would accept them as a life partner because of their HIV status. This included uneasiness about explaining to them how they had acquired HIV, the fear of rejection, and the fear of passing on the virus. Additionally, some of the participants were afraid that they would not be able to have biological children because of their HIV status. They were afraid that they would pass on the virus to their children.

There is a new and successful HIV medication regimen called PrEP (pre-exposure prophylaxis) which consists of giving certain HIV medications to partners of HIV-positive individuals in order to prevent transition (Celum, Hallett, & Baeten, 2013). Additionally, there have been HIV medications available since the mid-1990s that are given to HIV-positive pregnant women. This reduces the chances of transmitting the virus to their babies to less than 1% (Rollins et al., 2014). The CDC has published a set of recommendations that includes offering family planning services to patients living

with HIV/AIDS. The purpose of this information is to help HIV-positive individuals to be aware of their options, making sure that pregnant women find out their status early in pregnancy and receive treatment, and counseling women living with HIV/AIDS to avoid breastfeeding which is a source of transmission to infants (CDC, n.d.b.). This information is important for this population because the CDC report noted that low levels of income and education present challenges to reducing perinatal transmission. Since there are new advances in preventing HIV transmission on a regular basis, it is important that patients remain engaged in care, receive regular treatment, and receive ongoing health education so that they are aware of these new advances.

Resilience

The other concept in my conceptual framework was the concept of resilience. Resilience is the ability to positively adapt and cope with adverse life situations (Hakansson, 2010; Luthar & Cicchetti, 2000; Schetter & Dolbier, 2011). Resilience falls on a continuum which includes flourishing at the positive end and languishing at the negative end (Fredrickson & Losada, 2005). Protective factors are those that enhance resilience while vulnerability factors are those that present challenges. Most of the participants in this study seemed to lie in the middle of the continuum and slightly towards the flourishing end. They were either working or pursuing a degree in school. Their protective factors included a few supportive family members or friends, being covered by the Ryan White HIV/AIDS Program or Medicaid so that they could access health care services, and the comprehensive nature of the services that were being provided by the clinic where the study was located. However, many of them were dealing with anguish or depression related to living with HIV/AIDS.

Additionally, I noticed that many of the participants displayed positive personality, dispositional and other self-related factors such as optimism, a positive attitude, personal agency, and persistence in the face of adversity. Several mentioned that they becoming HIV positive was a wake-up call and motivated them to appreciate life more. A couple of the participants said that it stimulated a return to their religious faith as support. This was very similar to the results of Siegel and Schrimshaw (2000) who found parallel results among a group of women living with HIV in New York.

Several of the participants noted that their condition was not going to stop them and they were on a mission to succeed. They were working hard to move forward and stay positive. Many had actively educated themselves about HIV/AIDS by reading information on the internet, in brochures and books, and talking with their healthcare providers. Additionally, several mentioned that their strong spirituality played a role in their positive coping ability.

Research has shown that individuals with chronic diseases who actively participate in maintaining their health by monitoring their symptoms and actively pursuing treatment, medications, and positive health behaviors are more likely to have positive health outcomes than those who don't (Clark, Gong, & Kaciroti, 2014; Giarelli, Bernhardt, Mack, & Pyeritz, 2008, Préau et al., 2005). Marks and Allegrante (2005) and Marks, Allegrante, and Lorig (2004) noted the importance of enhancing self-efficacy and responsibility through ongoing patient education for individuals with chronic diseases in their review articles. Additionally, there is a positive correlation between health literacy, which is the ability to understand medical information and instructions, and positive health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Paasche-Orlow

& Wolf, 2007). These are important implications for educational leadership and health education because it emphasizes the importance of education in enhancing health outcomes.

It is important to note that the participants in this study were actively pursuing healthcare services, adhering to their medications for the most part, and educating themselves about HIV/AIDS. This may have set them apart from those young adults living with HIV/AIDS who were not actively pursuing healthcare. These other individuals, for some reason, were not taking the responsibility for maintaining their health. It is important to investigate these other individuals in order to find out why they were not engaged in care and how to encourage them to engage in care and take responsibility for their own health.

The vulnerability factors that were mentioned most often by the participants included stigma, discrimination, and rejection from family members, friends, and acquaintances, and the depression that resulted from having to come to terms with a serious, chronic, highly stigmatized illness. As mentioned above, many of the participants displayed a positive attitude and were trying to move forward with their lives, but many were still experiencing depression and downheartedness related to the enormity of their situation. It is curious to note that most of the participants did not mention economic reasons as challenges even though they all resided in the lowest income zip codes in the area. One young man was having challenges finding acceptable housing and employment. However, most of the participants were able to find jobs, secure money to pursue school, and access healthcare. Therefore, I suspect that these young adults were probably more motivated and were better problem solvers than the low

income, young adults living with HIV/AIDS in this area who were not engaged in healthcare and therefore not accessed by this study. Investigating these other young adults is an extremely important area for future research.

Another vulnerability factor mentioned by participants was the lack of thorough sex education in the schools and the low level of knowledge about HIV/AIDS among individuals in their communities. These issues were noted earlier in the section on implications regarding the ecological model of human development, but deserve revisiting because of their importance to educational leadership and health education. Several participants noted that if they had more information about HIV/AIDS at an earlier age, they might have been able to make a more informed choice that included avoiding risky behaviors. Many of them mentioned that more thorough sex and health education should be offered in the schools at an earlier age, at least before puberty. Many participants said that the amount of misinformation about HIV/AIDS, especially about transmission, was high in their communities and more community education was needed. This is a practice and policy issue that should be noted by the educational and public health community.

The Developmental Aspects of Young Adults and the Millennial Generation

The participants in this study were 18-29 years of age which categorizes them as young adults and places them in the Millennial generation. They displayed many of the characteristics of young adults in their interviews including being in the career/school exploration phase, focusing on finding a long-term relationship, being optimistic about the future, and feeling invincible about their susceptibility to acquiring HIV. All of the participants started off their interviews by telling me about their career/school goals.

Many of the participants were currently in school. Most of them were optimistic about their future career goals and did not feel that being HIV positive was going to impede their plans. Many displayed an optimistic attitude about dealing with being HIV positive in general. Several of them mentioned that they were worried about their ability to find a life-long partner and to have children because of their status.

Additionally, many of them mentioned that they were shocked and surprised when they tested positive for HIV because they did not believe they were participating in risky behaviors. This last factor has implications for treatment, prevention, and health education programs. The health belief model proposes that people who do not believe they are susceptible to a certain condition are not as likely to employ prevention behaviors (Champion & Skinner, 2008). A recent study by Rao, Kekwaletswe, Hosek, Martinez, and Rodriguez (2007) found that feelings of invincibility coupled with stigma were related to poor medication adherence among young people living with HIV/AIDS.

Many of the participants said that they began to educate themselves when they found out they were HIV positive and they often used the internet to obtain information. This relates to the study by Johnson (2006) which indicated that most members of the Millennial generation are technologically savvy because they have lived with computers most of their lives. Therefore, another important program implication is to teach young adults how to access health information on the internet and how to evaluate the quality and validity of the internet sites that they use.

It is important for educational and healthcare leaders to keep factors about being a young adult in mind when designing health education and treatment programs for this age group.

Implications of Living in a Low Income, Urban Area

All of the study participants resided in one of the nine lowest income zip codes in the urban area where study recruitment took place. One of the participants felt that the area was more violent than the smaller town he had moved from. He had experienced a bullet going through his window. He wanted to move but was unable to do so for financial reasons. He was looking for a job but had not been able to work due to health issues related to his HIV. All of the other participants were employed or in school. They were hopeful about their futures and did not express any feelings of hopelessness regarding their economic situation. None of them noted having any issues accessing health care because they were covered by Medicaid, the Ryan White HIV/AIDS Program, or private insurance. Because of the general nature of this study, it is possible that participants did not mention any financial or environmental challenges because they were not the foremost items on their minds. These challenges might come out in greater detail in a study that focuses on that specific issue. Therefore, an important area for future research would be to look specifically at financial and environmental challenges that this group is facing.

Implications of Living with HIV/AIDS

There are many physical/biological, social, and psychological aspects to living with any illness. Saylor (2004) noted that the prognosis, physical and cognitive disability level, and disruption of daily activities were major factors related to living with an illness. In the case of the study participants, the prognosis for them was positive because of new medications and there was little chance of physical and cognitive disability for those whose HIV status had not progressed to AIDS. One of the participants commented that

he felt ill when he first became HIV positive and that he was still experiencing some night sweats. Another participant had recently been in the hospital with some infections. However, the rest of the participants noted that they were currently healthy. Some of the participants noted that pill taking interfered with their daily activities, especially when they were trying to not disclose their status. Additionally, several individuals had experienced stigma and rejection related to relationship issues. However, most of the participants did not feel that being HIV positive was going to impede their future career and school goals.

Falvo (2014) noted that there were many psychological effects related to having an illness such as depression, denial, stress, and shame. Radcliffe et al. (2007) found that 93% of the young adults living with HIV/AIDS felt that finding out their diagnosis was a traumatic event. Most of the participants mentioned that they had experienced these psychological effects and many were still dealing with depression. Many noted that these psychological effects were most pronounced at the moment they found out their positive status. One young man mentioned that he tried to commit suicide shortly after finding out his status but was saved by a family member. Another participant mentioned that he drove away from the testing center at a dangerously high speed after finding out his HIV status and had to pull over and calm himself down. Several of the participants noted that they had been receiving mental health services to help them deal with these feelings.

Freund, McGuire, and Podhurst (2003) noted that an illness sometimes serves as a disruption to one's goals, identity, and developmental process. Some of the participants were worried that living with HIV/AIDS was going to make it difficult for them to find a

life partner and to have children. However, most of the participants felt that living with HIV/AIDS was not going to impede their future career and school plans.

Stigma was a major issue for most of the participants and many had experienced it to some degree. Several had been rejected upon disclosing their HIV status to an intimate partner. Some had experienced stigma and discrimination from family members which included not being allowed to babysit a relative, having to use separate dishes and glasses, and being taunted. One young woman was regularly taunted by her boyfriend's family who also disclosed her status to others in the neighborhood in a negative manner. This was often related to the manner in which they or their mother (if perinatally acquired) had acquired HIV. Many of the participants had experienced some of the challenges related to stigma mentioned by Catalozzi and Futterman (2005) which included the decision to disclose their status to others, related depression, and coming to terms with it in general.

The perinatally acquired participants expressed some of the same issues that Szlag (2011) found when she interviewed a group of perinatally acquired young adults, their mothers, and their clinicians. One of my study participants noted that she found out she was HIV positive while away at camp and tried to discuss the situation with her mother who would not talk to her about it. Szlag found that the mothers she interviewed expressed a need for assistance when talking to their HIV-positive children about their status due to embarrassment, denial, anxiety, and other factors. Szlag suggested that status disclosure for perinatally acquired individuals should happen at a young age and that mothers need support when disclosing their status to their children. The perinatally acquired participants in this study had the same suggestions.

Some of the participants mentioned that they had experienced cumulative stigma and discrimination because they were both gay or bisexual and HIV positive. One of the male participants mentioned that he would be shunned by his friends in his hometown if they found out he was both gay and HIV positive. This correlates to some of the studies mentioned in the literature review that found that MSMs who were HIV positive experienced high rates of depression and stigma (Dowshen, Binns, & Garofalo, 2009; Jeffries, Marks, Lauby, Murrill, & Millett, 2013; Voisin, Bird, Shiu & Krieger, 2013). Delving more into this issue would be an interesting area for future research.

Given that 14 of the 16 participants were African American, it was interesting to note that none of the participants mentioned the influence of racial discrimination, mistrust in the healthcare system, or conspiracy theories about the origins of HIV which have been issues among the African American community (Bogart & Thorburn, 2005; Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Jeffries, Marks, Lauby, Murrill, & Millett, 2013; Voisin, Bird, Shiu, & Krieger, 2013; Warren, Williams, & Wilson, 2012.) However, I did not specifically probe about racial discrimination so it is not possible to comment on its influence. Probing on the influence of these issues would also be an interesting area for future research. Likewise, I did not specifically investigate the relationship between continuing risky behaviors and being HIV positive which is mentioned in the literature review (Hsin, 2011; Stock, Gibbons, Peterson, & Gerrard, 2013). These are all important areas for future research.

In summary, many of the themes expressed by the participants confirmed and added to the previous research conducted in the areas of the ecological model of human development, resilience, young adulthood, and living with HIV/AIDS. The results of this

study continues to add to the literature because it investigated the influence of the combination of these theories on the lives of young adults living with HIV/AIDS in a low income, urban environment and provided additional rich description about their lives.

Implications Related to Practice and Policy

One of the important findings related to practice included those related to mental health services. Many of the participants mentioned that they experienced severe shock and depression upon learning of their diagnosis. One young man tried to commit suicide immediately after finding out his diagnosis but was rescued by a family member.

Another participant sped away in his car because he was very upset after learning his diagnosis and had to pull over and compose himself before continuing his drive home. Many of them had to return home and pretend that everything was normal because they were either afraid to tell family or friends, or they did not know how to tell them. This is similar to findings by Radcliffe et al. (2007) who found that 93% of the 30 young adults they surveyed felt that finding out they were HIV positive was a traumatic event in their lives.

Testing for HIV can be obtained at many clinics, public health departments, hospitals, Title X Family Planning Clinics, community health centers, health fairs, some pharmacies, specialized mobile vans, and other public locations (USDHHS, n.d.h.). Most health departments offer a short training course for individuals to become HIV counselors and testers. For example, in the state of Florida, the minimum standards for becoming an HIV tester/counselor is a 2 ½ day course run by the Florida Department of Health (Florida Department of Health, n.d.). Any adult can take the testing/counseling course to become a certified tester/counselor. My practice recommendation is to have a certified

mental health counselor or psychologist available at all testing sites in addition to regular testing/counseling staff to immediately counsel individuals who test positive before they leave. This may be a budget issue, however the data captured in this study along with other research such as Radcliffe et al. (2007) indicates that the moment an individual receives a positive HIV diagnosis can be extremely traumatic and warrants additional mental health services.

In addition, individuals who test positive should be offered an immediate referral for mental health counseling if they choose to in addition to a referral for medical treatment. Several of the study participants were participating in mental health counseling at the clinic whereas several of them were not aware that mental health counseling was available. The ones that were participating in mental health counseling mentioned that they learned about the availability of counseling after they started coming to the clinic for their medical care. Currently, the emphasis for HIV treatment is on getting positive individuals into medical care as soon as possible (CDC, 2006a). I believe that the same emphasis should be placed on getting HIV-positive individuals into mental health counseling.

Many of the participants said that they would like to help other young people who have HIV/AIDS and become active in spreading awareness to young people who are at risk of acquiring HIV. However, most of them were afraid to disclose their status to others because of fear of stigma, rejection, and discrimination, and were therefore reluctant to take leadership roles. Many of them had very positive attitudes about moving forward with their lives in spite of being HIV positive. Another practice recommendation would be to harness this enthusiasm among these young adults by providing leadership

seminars, counseling, and opportunities to help them overcome their fears of rejection and stigma, take leadership roles, and help others.

Another issue related to practice is the suggestion by several participants for assistance from a clinician or mental health counselor when they are ready to disclose their status to family or friends. Participants suggested that they would like a clinician or counselor to be present when they disclosed their HIV status to family or friends so that the professional could help answer questions and help those involved deal with feelings and issues that came up. The clinic where study recruitment took place offers this type of mental health services however not all of the participants were aware of this service. My practice recommendation is to offer this service to all individuals living with HIV/AIDS and increase awareness among patients when this service exists.

Another practice and policy issue is the offering of health and sex education in the schools. As mentioned above, most participants did not feel that the level of sex education they had received in school was adequate and thought that more in-depth sex education should be taught at earlier ages. The content, depth, and age of starting sex education in the schools have been controversial issues because of overlaying social and religious beliefs. However, several large studies have indicated that young adults who received sex education were more likely to start sex at an older age and to use birth control or other protections against pregnancy (Bourke, Boduszek, Kelleher, McBride, & Morgan, 2014). Kohler, Manhart, and Lafferty (2008) found that teens that had sex education were less likely to have sex and become pregnant.

Additionally, several studies have also shown that sex education and information about contraception and safer sex does not increase rates of sexual activity among teens

as some people who oppose sex education have proposed (Bennett & Assefi, 2005; Smoak, Scott-Sheldon, Johnson, Carey, & SHARP Research Team, 2006). Federal funding of sex education programs in the K-12 system between 1998 and 2010 was limited to abstinence-only education (Santelli et al., 2006; Schalet et al., 2014). It is interesting to note that many of the study participants were in middle and high school during this period of time which meant that the sex education they received would have been influenced by this policy. Since then, schools can apply for federal funding through the Office of Adolescent Health's Teen Pregnancy Prevention Initiative to use one of 35 approved evidence-based pregnancy intervention programs (Schalet et al., 2014). Schalet et al. (2014) further noted that even though this is a step in the right direction, these programs do not address sexual orientation and various cultural and economic diversity issues that influence adolescent sexual behavior. Given that the highest rates of new HIV cases are among young men who have sex with men and young low income, minorities (CDC, n.d.c.), these factors should be part of any sex education program. Additionally, the Division of Adolescent and School Health at the CDC has a wealth of evidence-based information about different programs and curricula on their website (CDC, n.d.c.) that may be helpful to educational leaders when assessing their own school's current health and sex education program or looking for a new one.

Another issue related to education is to enhance the development of health literacy in the Pre K-20 school system. The development of general literacy skills, critical thinking skills, and the information learned in health and sex education classes have a direct impact on the development of health literacy which is the ability to obtain, understand, and use health information (Nielsen-Bohlman, Panzer, & Kindig, 2004;

Ratzan & Parker, 2000). Research has shown a close correlation between health literacy, health behaviors, and health outcomes (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Norman & Skinner, 2006; Zarcadoolas, Pleasant, & Greer, 2005). It is important for educational leaders, policy makers, and teachers to be aware of this link and to enhance school curriculum in order to foster the development of health literacy.

Another implication for practice and policy is increasing community education programs about HIV/AIDS. Many of the participants mentioned that there was a great deal of misinformation about HIV/AIDS in their communities which they felt fueled stigma. The USDHHS sponsors a website that lists resources and funding opportunities for community organizations to develop educational programs about HIV/AIDS (USDHHS, n.d.b.). This is another area where educational and healthcare leaders can collaborate in order to enhance the health education of their communities.

In summary, the results of this study have several important implications for practice and policy including enhancing mental health services, providing more in-depth health and sex education in the schools at earlier ages, enriching school programming to develop better health literacy skills, developing more community-based education programs, and creating leadership opportunities for young adults living with HIV/AIDS so that they can help others.

Implications for Education and Educational Leadership

This document is full of examples of the important links between education and health. The USDHHS's health goals for the nation for the next decade, *Healthy People 2020*, has a component called *Education for Health* (Riegelman & Garr, 2011). This component was developed by the *Healthy People Curriculum Task Force*, a group of

experts from eight educational associations related to health, and proposed vertically integrating progressive health education in the Pre K-20 school system. It also proposed the horizontal integration of health education by public health professionals, educators, and clinicians.

Because of the close relationship between education and health, many experts are advocating for more coordinated program and policy efforts between the educational system and the health system. Low and Low (2006) advocated for enhanced early childhood development and educational policies as an avenue for improving the health of the overall population. They proposed that educational policies are one of the social determinants of health and are among the many researchers who believe that education policy is synonymous with health policy (Low, Low, Baumer, & Huynh, 2005). Therefore, it is important for both educational leaders and healthcare leaders to understand and appreciate the close relationship between education and health so that more coordinated programs and policies can be developed and implemented. This includes more in-depth and age-appropriate health and sex education classes, and efforts at enhancing health literacy.

Another important implication for educational leadership that I experienced through this study was the close interaction with the participants to learn their stories and experiences. That helped me as a leader to better understand them and their needs. I believe it is important for educational leaders to interact closely with all the stakeholders in their environment in order to understand their needs, stories, and experiences. Northouse (2007) noted that leadership involves motivating a group to accomplish a shared objective. Jones, Lefoe, Harvey and Ryland (2012) stated that current leadership

theories focus on employing collective collaboration methods instead of using different forms of power and control. Levi (2007) noted that the positive aspects of using collaborative leadership methods included the pooling of resources, skills, new ideas, and knowledge. He also noted that when decisions were made by a group rather than one leader, the decisions resulted in a better understanding of the people, processes, and ideas. Therefore, leadership should not occur in isolation and leaders need to interact with and understand their constituents in order to lead them in the most effective manner.

Listening to stakeholder's stories, experiences, and needs is an excellent way for leaders to use collective collaboration methods of leadership. Stephen Covey (2004) discusses this in his book *The 8th Habit: From Effectiveness to Greatness*. His 8th habit is *Find Your Voice and Inspire Others to Find Theirs*. He talked about finding the voice of the human spirit which he said is the heart and soul of all organizations. He said that the human spirit is innately good and resilient, and will drive an organization to thrive. It combines talent, passion, need, and conscience. He suggested that leaders should take the worm's-eye view, which involves talking with and interacting with their stakeholders to find out their stories, experiences, and needs, rather than the bird's-eye view from above. I found that taking the worm's-eye view by interacting with these young adults and listening to their stories helped me to understand their challenges, supports, and needs at a very deep level. I believe that if leaders get to know their stakeholders at a deep level, a greater degree of collaborative leadership is possible.

The participants in this study noted that the knowledge level about HIV/AIDS in their communities was low. They felt that this led to misinformation and stigma. Enhancing community learning in this area is an important implication for educational

leaders. Educational leaders can benefit from the theories of constructing learning communities and community-based participatory research. Learning communities have grown out of the work by Senge (2006) who proposed learning organizations where the entire organization establishes a culture of cooperative learning. This theory can be used by educational leaders at the community level to collaborate with members of a particular community to establish cooperative learning communities about HIV/AIDS.

Another concept that educational leaders should be aware of is community-based participatory research which moves beyond general research to the goal of transforming communities (Hacker, 2013; Wallerstein, & Duran, 2006). It involves establishing close partnerships with members of the community, educating community members about research methods, involving community members in all stages of conducting research projects, and the philosophy that the research must benefit both the researchers and the community. It is often used in disparities research. Educational leaders can use community-based participatory research as the basis for designing evidence-based programs in collaboration with communities to enhance collaborative learning about HIV/AIDS.

Therefore, I believe that this study has strong implications for educational leaders, particularly in terms of the importance of the links between education and health, and the importance of learning about the lives of ones' stakeholders in order to design more effective and collaborative educational programs.

Reflexivity

It is difficult to explain the exhilaration and sheer terror that I felt after my proposal was accepted by my committee, I received the IRB approvals, and now I

actually had to recruit participants and collect data on my own. I had decided to conduct one-on-one, in-depth interviews with a population that was very different from me. Even though I had graduate level training in anthropology, educational leadership, and public health along with several years of experience managing research projects, I experienced what I can only describe as *stage fright*. Would I be able to find individuals who were willing to participate in my study? Would I be able to establish rapport and trust with my participants? Would they be willing to open up to me, someone who was very different from them? Would I ask the right questions? Would I be able to explore their responses appropriately without it sounding like an interrogation?

I was pleasantly surprised when most of the individuals who I approached were very willing and eager to share their stories with me. They were grateful that someone wanted to listen to them. One young man mentioned that he felt that research like the study I was conducting was very important for improving services for individuals living with HIV/AIDS. Several participants contacted me after they saw one of the flyers in the clinic because they wanted to share their story in order to help others. I was very surprised at how open and forthright most of the participants were during the interviews.

Most of the time, I only had to ask a few short introductory questions and the participants willingly shared their stories about their experiences with HIV. I learned that it worked best if I let them talk without any additional comments or questions. If I interjected with comments or questions, it often stopped the flow of the conversation. Invariably, they all told me the same type of story without much prompting: how they got it, what their reaction was, how they felt about having it, who they told, how they were coping with it, and how they thought it was going to affect their future.

Additionally, every interview was an eye-opening and emotional experience for me because I was amazed at the deep level at which the participants bared their souls. I felt extremely privileged that they shared this deeply personal and heart-felt information with me. It was a different experience than the quantitative-driven studies I had participated in the past. I was astounded at the richness of the data that resulted from the interviews. I felt that I connected at a deeply personal level with each participant and learned far more about the meanings they attached to their experiences than I could have ever learned from a survey.

Some additional lessons I learned from this experience included the importance of assessing the availability of the study population. My original recruitment plan included recruiting 18-24 year olds living with HIV/AIDS from nine of the lowest income zip code areas in the county. I was only successful in enrolling eight individuals during the first five months of data collection. The main barriers included the small size of the population along with the fact the patients in this age group had a very high *no show* rate for their appointments at the clinic where I was conducting the study. In order to enhance enrollment, I decided to increase the age range to 29. This was warranted because 25-29 year olds have the second highest rate of new HIV cases among all age groups so they are also an important group to study (CDC, n.d.c.). During the sixth month of data collection, I conducted interviews on an additional eight interviews of which three were in the 25-29 year old age group. Therefore, investigators should take the availability of the study population into serious consideration when designing a study in order to complete the study in a reasonable period of time.

Finally, before conducting this study, I had only participated in fielding several small qualitative studies. I had many years of experiences conducting quantitative studies such as fielding surveys and analyzing quantitative datasets while working in institutional/educational research and healthcare research. Therefore, I was originally thinking in the direction of conducting a quantitative study for my dissertation. However, the nature of the research questions and the type of data needed to answer them required me to do a paradigm shift. With some trepidation mixed with a great deal of excitement about moving into a new area, I forged ahead with valuable assistance from my dissertation chair, Dr. Francis Godwyll.

I was handsomely rewarded by the extremely rich and descriptive data that I was able to capture in the interviews along with a strong personal connection with the participants that helped me to relive their stories with them. As mentioned above, the experience was extremely powerful and emotional. I also experienced firsthand how important deep, rich qualitative data adds to the understanding of the lives of the participants. This validated the importance of qualitative research for me. I feel like I have made that paradigm shift as a researcher and I now understand the importance of both qualitative and quantitative research to scientific inquiry.

I have presented preliminary results of this study at four meetings, including being selected to represent the University of North Florida Graduate School at the Statewide Graduate Student Research Symposium at the University of Central Florida. A poster presentation of this study has been accepted at the American Public Health Association's Annual Meeting and Expo in the fall of 2015 and a case study of my

dissertation research experience has been accepted for publication in Sage Research Methods Cases which will be published in January 2016.

All of these experiences have helped me to grow as a writer, thinker, researcher, scholar, social scientist, and person. I am certain that I will be able to use this valuable learning experience in my future professional and personal life.

Suggestions for Future Research

I believe that one of the most important suggestions for future research would be to investigate why some young adults living with HIV/AIDS are engaged in healthcare and some are not. This is important given the current research on the HIV care cascade model which showed that there is a troubling drop-off that occurs as individuals move from testing positive, becoming engaged in care, staying in care, going on HAART therapy, and staying on HAART therapy so that the virus is suppressed to very low or undetectable levels (MacCarthy et al., 2015). Recent data from the CDC indicated that of the approximately 1.2 million Americans living with HIV, 86% have been diagnosed, 40% are engaged in care, 37% are taking HAART, and 30% have suppressed viral loads (USDHHS, n.d.g.). Individuals with an undetectable viral load have fewer medical issues related to being HIV positive and are less likely to transmit the virus (Montaner et al., 2014).

Therefore, the ideal scenario is to get all individuals living with HIV/AIDS engaged in care and receiving HAART. The participants in this study were all currently receiving care at the clinic where study recruitment took place. These individuals were also covered by Medicaid, the Ryan White HIV/AIDS Program, or private insurance because the clinic does not see uninsured individuals. It would be extremely informative

to investigate the reasons why these young people chose to engage themselves in care from their perspective. It would also be important to investigate the reasons why other young adults living with HIV/AIDS were not engaged in care and/or were not covered by any health insurance and how their lived experiences differed. These are extremely important areas for future research.

Since stigma is an important challenge for young adults living with HIV/AIDS, additional research into programs to combat stigma is important. This includes the development of more community-based education programs to educate and inform people about HIV/AIDS in order to decrease misinformation. Conducting research into related topics such as the impact of homophobia and racial discrimination on living with HIV/AIDS might help to combat stigma. Investigating strategies to help individuals living with HIV/AIDS who are LGBTQ and/or members of a minority group cope with their condition is also important.

Another important area for future research would be to conduct further investigation into the attitudes of educational leaders, policy makers, teachers, parents, and students about the age at which to start health/sex education in the schools and the depth of this education. The young adults in this study clearly felt that they did not receive enough sex education in school and that it should be started at an earlier age. One participant mentioned that earlier sex education may have prevented some of the risky behaviors that she took because she was not informed. As mentioned previously, this is a controversial issue that is influenced by different moral and religious beliefs. Therefore, it is important to conduct additional research with all the stakeholders in this area in order to inform practice and policy.

An important area for future investigation related to education is the issue of health literacy among young adults living with HIV/AIDS. There has been a great deal of research that has linked health literacy with positive health outcomes, increased medication adherence, decreased risky behaviors, and more engagement in treatment (Berkman, Sheridan, Donahue, Halpern, & Crotty, 2011; Norman & Skinner, 2006; Zarcadoolas, Pleasant, & Greer, 2005). Individuals with higher levels of health literacy are better able to understand the course of their illness, different treatment options, prevention factors, and the effects of health behaviors in general. Enhanced health literacy involves the development of general literacy skills, critical thinking skills, and the information learned in health and sex education classes. Therefore, it is important to understand the level of health literacy in these young adults living with HIV/AIDS and the role of the educational system and other avenues for developing and enhancing their health literacy.

Another area for future research would be to specifically investigate financial and environmental challenges that young adults living with HIV/AIDS from low income, urban areas experience. As mentioned above, one young man thought that the area was violent and had experienced a bullet going through his window. He could not move because of financial difficulties and was having problems finding a job because of HIV-related health problems. Most of the other participants were employed or going to school and did not mention any environmental or financial challenges. However, more nuanced issues related to financial and environmental challenges might emerge if that was the focus of the study.

It would be informative to investigate different socioeconomic classes to study the impact of these differences on the lived experiences of young adults living with HIV/AIDS. Ramjohn (2012) found that socioeconomic status and the availability of supportive resources influenced coping strategies among a group of African American and Hispanic females 16-24 years of age living with HIV/AIDS in the New York City area. It would also be informative to study this topic in different regions of the United States.

Other timely issues that would be interesting areas for future research include quality of care issues among the different types of healthcare programs and insurance providers for young adults living with HIV/AIDS. Also, issues related to medication adherence among young adults would be very timely given the new USDHHS treatment guidelines that all individuals living with HIV should be taking HAART (USDHHS Panel on Antiretroviral Guidelines for Adults and Adolescents, 2014) and the availability of PrEP (pre-exposure prophylaxis) for young adults in high risk groups who are not currently HIV positive (Karim & Karim, 2012).

The data collected in this study generated a series of themes that were important in the lives of the study participants. Each of these themes represents an area for future research. A separate qualitative study could easily be conducted on each one of these themes and the different subthemes within them as noted above. It is important to conduct similar types of studies in different age groups and in different locations in order to capture how these different groups experience living with HIV/AIDS.

Conclusions

Young adults face many challenges while transitioning to adulthood. Those who are living with HIV/AIDS and live in low income, urban environments often experience additional stressors related to their environment. It is important for educational leaders, healthcare leaders, policymakers, and other professionals who serve this population to take the worm's-eye view and attempt to understand their lived experiences as well as their challenges, strengths, supports, needs, and suggestions for better programs and policies. Throughout this study, I endeavored to give voice to a vulnerable population. The data indicated the need for enhanced mental health services, more in-depth health and sex education in the schools, more community-level education about HIV/AIDS, and HIV services that are more integrated and accessible.

It is important for educational and healthcare leaders to be aware of the important link between education and health. The development of general literacy skills, critical thinking skills, and content information learned in health and sex education classes may have a direct impact on the development of health literacy. This may ultimately impact health outcomes. It is also important to take the cultural norms and the social context into consideration when designing health education programs in order to maximize effectiveness, appropriateness, and receptivity. Godwyll and Ngumbi (2009) proposed that culturally sensitive health promotion messages about HIV/AIDS were generally more effective than top-down, authoritative messages. Using culturally sensitive and community-based participatory research methods are an important way for educational leaders to connect with their stakeholders and enhance the appropriateness of their programs.

The story of HIV/AIDS shows the influence of behaviors, social norms and attitudes, and socioeconomic status on the epidemiology of an illness. The demographics of the individuals impacted by this condition in the United States have changed dramatically over the last 30 years. At the beginning of the epidemic, it was most prevalent among Caucasian males who had sex with men. It is still very prevalent among men who have sex with men, however, it is much more prevalent among low income, minority groups of both genders than Caucasian males. Anderson, Scrimshaw, Fullilove, Fielding, and the Task Force on Community Preventive Services (2003) said that social justice and equity within a population is a direct reflection of how resources are distributed within that group. They noted how societal and ecological resources interact with other factors such as social cohesion, education, norms, health promotion efforts, opportunities for learning, living conditions, and employment opportunities to influence health outcomes. I believe that these factors have influenced the course of HIV/AIDS in the United States. Therefore, I believe it is important for educational and healthcare leaders to examine how these factors continue to influence this health disparity, to understand the lives of the populations who are affected, and to develop evidenced-based programs grounded in cultural sensitivity to combat this issue.

Qualitative research puts a face to the story and presents the data in a more personal way. The legitimacy and acceptability of various social, educational, and health programs that assist individuals who have low amounts of resources such as the participants in this study have frequently been debated in our country. Will (1993) noted that public opinion normally favors social programs for individuals who they feel are deserving of them. Therefore, understanding the lived experiences of individuals such as

the low income, young adults living with HIV/AIDS that participated in this study through reading their stories might give educational leaders, healthcare leaders, policymakers, lawmakers, and other professionals who do not directly interact with them an intimate peak into their lives that numerical data cannot. It might help them to understand why those different programs are extremely helpful to the quality of their lives. Therefore, it is important to understand the lived experiences of these individuals because it may directly benefit the quality of their lives and may also indirectly benefit the rest of society by enhancing the knowledge about coordinating education and healthcare efforts from a culturally-sensitive perspective to improve the health of all individuals.

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Appendix A: Interview Guide

The following document is a guide that I used for the interview process. The goal of the interview process was to examine the lived experiences of young adults living with HIV/AIDS who lived in a low income urban area. I explored their challenges, barriers, strengths, assets, and needs, and collected their suggestions for improving programs, services, and policies.

The following key connects the purpose, research questions, and components of the conceptual framework to each interview question.

Key	Concept, question or component
K1	Lived experiences
K2	Research question 1: challenges, barriers, stressors Resilience: vulnerability factors
K3	Research question 2: assets and strengths Resilience: protective factors
K4	Research question 3: needs and suggestions
K5	Ecological model of human development: microsystem (family, peers, school, workplace)
K6	Ecological model of human development: Mesosystem (interactions between parts of the microsystem)
K7	Ecological model of human development: Exosystem (neighborhood, community)
K8	Ecological model of human development: Macrosystem (general social norms, beliefs, etc.)
K9	Ecological model of human development: Chronosystem (changes over time)

- Ice breaker: Please tell me a little bit about yourself: What do you like to do and what are some of your goals?

Probes (collect some basic demographic information): Do you work or go to school?

What is your highest level of education? Are you married or in a relationship? Do you have children?

- (K1) Let's talk about HIV and your life. Tell me about when you became HIV positive and how you found out about it. Probes: How did you feel when you found out you were HIV positive? Did you tell anyone and who were they? How did it go when you told them? How did you decide who you were going to tell? Who have you told in your life since then? How did it go when you told them? What has worked for you and what hasn't when disclosing your status?
- (K1) What did you know about HIV at the time you became positive? Probes: What have you learned since then about HIV and from where/whom? Did you seek out info about HIV on your own and from where/whom? What have been the best and worst sources of information for you?
- (K1, K2, K3, K5) Let's talk about your current health. Has having HIV affected your health in any way? Probes: Has your health been any different since you acquired HIV? When you found out you were HIV positive, how soon did you go for treatment? Have you had a recent ER visits, hospitalizations and illnesses (if yes, please describe)? How often do you see a doctor about your HIV and how do you feel about this? What is your relationship with your health care providers like? Are you taking any medications for HIV and how do you feel about that? What do you do to stay healthy? How do you think that having HIV might affect your future health? What do you think you have to do to maintain optimal health?
- (K1, K2, K3, K5) What it is like for you to live with HIV on a daily basis? Probes: What are some of the pros and cons? How does it affect your personal identity? Has being HIV positive affected your mood? How do you feel you have been coping with being HIV positive? Has it effected being able to work or go to school? What are

- your future goals and how do you think it might affect your future goals? If you were to describe what it is like to have HIV to someone who doesn't have it, what would you tell them? What has worked for you and what hasn't in dealing with being HIV positive in your daily life? What would an ideal day look like for you?
- (K1, K2, K3, K5, K6,) How do your family and friends play a role in how you live with it? Probes: What do you think your family and friends think about HIV and how does this affect you? Do you have family and friends that help you? Hinder you? Anybody else that helps or hinder you? Have you experienced any stigma/discrimination from family or friends, and what was that like? What have you already attempted in order to deal with stigma/discrimination and what has helped you?
 - (K1, K2, K3, K4) When you look back now, do you think there is anything you could have done differently that would have prevented you from acquiring HIV? Are you doing anything now to prevent transmitting the virus to others?
 - (K1, K2, K3, K7, K8) What do the people in your community or neighborhood think about HIV and how does this affect you? How do you think that society feels about HIV in general and how does this affect you? Have you experienced any stigma/discrimination from people in your community or from society in general, and what was that like? What have you already attempted in order to deal with this type of stigma/discrimination and what has helped you?
 - (K1, K9) If you have been HIV positive for more than a year, has your experiences changed at all over time? Have the reactions of others towards you changed over

- time? Has your ability to cope changed over time? What has worked well for you and what hasn't?
- (K1, K2, K3, K7) Do you feel that you have enough resources to deal with your condition, like income, health insurance, access to health care, enough information, enough support, etc.? Probes: Are there places in your community that you can go for help or assistance? Do you feel that you have access to the health care that you need? How do you feel about navigating the health care system? How do you feel about the type of insurance or medical assistance that you have? Which places have helped you or worked well for you? What other type of resources would you like to have?
 - (K1, K2, K7, K8) What is your personal level of trust with the healthcare system, the government, and the pharmaceutical industry when it comes to information about HIV and fighting the epidemic?
 - (K2, K3, K4) Do you feel that you have the information you need to manage your condition? What else would you like to know about?
 - (K2) What would you say are the top challenges that you are facing right now because you are HIV positive? How would you like things to be different?
 - (K3) What are some of the strengths and assets that you have personally or in your life that help you deal with your HIV?
 - (K2, K4) Do you have any needs in regards to having HIV that are not being met? What are your most important needs? What would your preferred future be like?
 - (K4) What do you need personally to reach your goals? To stay healthy?

- (K3, K4) What suggestions do you have about better programs to help young people like yourself who are living with HIV/AIDS (probe: in schools, doctor's offices, churches, community agencies, etc.)?
- (K3, K4) What suggestions do you have about better programs to teach/inform young people like yourself about HIV prevention and risky behaviors (probe: in schools, doctor's offices, churches, community agencies, etc.)?
- (K3, K4) What do you think might be some effective ways to teach/inform other young adults like yourself about HIV and prevention? Probes: What do you think about different type of "instructors" such as health care professionals, professors/teachers, community members, peers, etc.? What do you think about: lectures, classes, brochures, web sites, support groups, motivational speakers? What other suggestions do you have?
- (K1-K9) If you were to think of something that someone else who was in the same situation as you might benefit from, what would it be? Suppose you were able to change something or someone to make your life better – what would that be and how would that make your life different?
- (K1) How has your life changed because of your positive status? What are some of the key moments, turning points or critical incidents connected with being HIV positive?
- What else do you think people should know about living with HIV/AIDS?

**Appendix B: Initial Telephone Script for Approaching Potential Participants
about Study Participation: Current (clinic name deleted) Patients**

Study: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from a Low income, urban Area

Eligibility: HIV-1 infected young adults 18-24 years of age who live in the following zip codes: (deleted to protect participant confidentiality)

Potential participant's name: _____ DOB: ___/___/___

Phone number(s): _____

Dates of calls: Result: (no answer, left message, disconnected, moved, not interested, interested, other)

___/___/___ _____

___/___/___ _____

Hello. May I speak with <potential participant's name>?

If potential participant is not available: Would you please ask <potential participant's first name> to call Kathy Thoma at (phone number deleted) (*do not mention (clinic name deleted) for confidentiality reasons*)?

If potential participant is available: Hello, <potential participant's first name>. My name is Kathy Thoma and I'm calling from your doctor's office about a voluntary research study that I am conducting. I was wondering if I could speak with you about it for a few minutes.

If potential participant agrees to hear more about the study: For confidentiality reasons, would you please verify your date of birth and social security number? (*Check birth date and social security number given at top of script.*) I am conducting a research study at (deleted) with young adults (*HIV is not mentioned as an additional protection of their confidentiality*). The study will include a private 60-90 minute interview about your life and a return visit to review the interview transcripts. If this is something you might be interested in, I'd like to meet with you at (clinic name deleted) to have you review the consent form and possibly enroll into the study. (*If potential participant has any additional questions, please try to answer them from the study protocol*). If you are not comfortable meeting at (clinic name deleted), is there another location where you would feel more comfortable meeting?

Date scheduled: _____ Time: _____ Location: _____

If potential participant is not interested in the study: Thank you very much for your time and we look forward to seeing you at your next clinic visit.



Appendix C: Initial Telephone Script for Approaching Potential Participants about Study Participation Individuals Who Learned about the Study from the Flyer or Another Individual/Agency

Study: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from a Low income, urban Area

Eligibility: HIV-1 infected young adults 18-29 years of age who live in the following zip codes: (deleted to protect participant confidentiality)

Potential participant's name: _____

Phone number(s): _____

Dates of calls: Result: (no answer, left message, disconnected, moved, not interested, interested, other)

____/____/____ _____

____/____/____ _____

Hello. May I speak with <potential participant's name>?

If potential participant is not available: Would you please ask <potential participant's first name> to call Kathy Thoma at (phone number deleted) (*do not mention [clinic name deleted] for confidentiality reasons*)?

If potential participant is available: Hello, <potential participant's first name>. My name is Kathy Thoma and I'm returning your call because you left a message on my answering machine indicating that you are interested in possibly participating in a research study that I'm conducting. I was wondering if I could speak with you about it for a few minutes.

If potential participant agrees to hear more about the study: I am conducting a research study about young adults (*HIV is not mentioned as an additional protection of their confidentiality*). The study will include a private 60-90 minute interview about your life and a return visit to review the interview transcripts. If this is something you might be interested in, I'd like to meet with you to have you review the consent form and possibly enroll into the study. (*If potential participant has any additional questions, please try to answer them from the study protocol*). Would you be agreeable to meeting me at (clinic name deleted)? If not, is there another location where you would feel more comfortable meeting?

Date scheduled: _____ Time: _____

If potential participant is not interested in the study: Thank you very much for your time.



Appendix D: Revised Telephone Script for Approaching Potential Participants about Study

Approved: 07/03/2014 Expires: 06/18/2015

Participation:

Current (clinic name deleted) Patients

Study: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from a Low income, urban Area

Eligibility: HIV-1 infected young adults 18-29 years of age who live in the following zip codes: (deleted to protect participant confidentiality)

Potential participant's name: _____ DOB: ___/___/___

Phone number(s): _____

Dates of calls: Result: (no answer, left message, disconnected, moved, not interested, interested, other)

___/___/___ _____

___/___/___ _____

Hello. May I speak with <potential participant's name>?

If potential participant is not available: Would you please ask <potential participant's first name> to call Kathy Thoma at (phone number deleted) (*do not mention (clinic name deleted) for confidentiality reasons*)?

If potential participant is available: Hello, <potential participant's first name>. My name is Kathy Thoma and I'm calling from your doctor's office about a voluntary research study that I am conducting. I was wondering if I could speak with you about it for a few minutes.

If potential participant agrees to hear more about the study: For confidentiality reasons, would you please verify your date of birth? (*Check birth date given at top of script.*) I am conducting a research study at (deleted) with young adults (*HIV is not mentioned as an additional protection of their confidentiality*). The study will include a private 60-90 minute interview about your life and a return visit to review the interview transcripts. If this is something you might be interested in, I'd like to meet with you at (clinic name deleted) to have you review the consent form and possibly enroll into the study. (*If potential participant has any additional questions, please try to answer them from the study protocol*). If you are not comfortable meeting at (clinic name deleted), is there another location where you would feel more comfortable meeting?

Date scheduled: _____ Time: _____ Location: _____

If potential participant is not interested in the study: Thank you very much for your time and we look forward to seeing you at your next clinic visit.



Approved: 11/25/2014 Expires: 06/18/2015

Appendix E: **Revised**
Telephone Script for Approaching Potential Participants about Study Participation
Individuals Who Learned about the Study from the Flyer
or Another Individual/Agency

Study: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from a Low income, urban Area

Eligibility: HIV-1 infected young adults 18-29 years of age who live in the following zip codes: (deleted to protect participant confidentiality)

Potential participant's name: _____

Phone number(s): _____

Dates of calls: Result: (no answer, left message, disconnected, moved, not interested, interested, other)

____/____/____ _____

____/____/____ _____

Hello. May I speak with <potential participant's name>?

If potential participant is not available: Would you please ask <potential participant's first name> to call Kathy Thoma at (phone number deleted) (*do not mention [clinic name deleted] for confidentiality reasons*)?

If potential participant is available: Hello, <potential participant's first name>. My name is Kathy Thoma and I'm returning your call because you left a message on my answering machine indicating that you are interested in possibly participating in a research study that I'm conducting. I was wondering if I could speak with you about it for a few minutes.

If potential participant agrees to hear more about the study: I am conducting a research study about young adults (*HIV is not mentioned as an additional protection of their confidentiality*). The study will include a private 60-90 minute interview about your life and a return visit to review the interview transcripts. If this is something you might be interested in, I'd like to meet with you to have you review the consent form and possibly enroll into the study. (*If potential participant has any additional questions, please try to answer them from the study protocol*). Would you be agreeable to meeting me at (clinic name deleted)? If not, is there another location where you would feel more comfortable meeting?

Date scheduled: _____ Time: _____

If potential participant is not interested in the study: Thank you very much for your time.



Approved: 11/25/2014 Expires: 06/18/2015

Appendix G: Revised Recruitment Flyer



Appendix H: Initial Consent Form

IRB Study# 2014-112

Informed Consent to Participate in Research



You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your protected health information necessary for the study. The Principal Investigator (the person in charge of this research) will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary. If you choose not to take part in this study, you will not be penalized or lose any benefits to which you would otherwise be entitled.

1. Name of Study Participant:

Date of Birth (for identification reasons): _____/_____/_____

2. Title of Research Study: What is Your Story?

3. Principal Investigator Name, Address, and Telephone Number(s)

Kathleen Thoma
 University of Florida
 Department of Pediatrics

(phone number deleted)

University of North Florida
 College of Education and Human Services
 Department of Leadership, School Counseling & Sport Management
 Building 57
 1 UNF Drive
 Jacksonville, FL 32224

4. Source of Funding or Other Material Support

The University of Florida and the University of North Florida are providing material support only.

5. What is the purpose of this research study?

The purpose of this study is to collect information about the lived experiences of HIV-infected young adults so that educational and healthcare leaders can design better programs, services and policies to help them.

6. What will be done if you take part in this research study?

You are being asked to participate in this study because you are infected with the HIV virus, are between 18 and 24 years of age, live in one of the zip codes in or around (deleted) in (deleted) County, and speak English. You will participate in an interview that will last 60-90 minutes. During the interview, you will be asked about yourself and to describe what it is like for you to live with HIV infection. The interview will be digitally recorded so that the Principal Investigator can easily review it later. You must consent to the digital recording of the interview in order to participate in the study.

Shortly after your study visit, the Principal Investigator will listen to the interview recording and write up a transcript and interpretation of the interview. She will contact you to set up a time to meet with you to review the transcript and interpretation. During that visit, the Principal Investigator may ask you to clarify some of the information you gave during the interview. After that, your participation in the study will be complete.

6a. What procedures would be done as part of your normal clinical care (even if you did not take part in this research)?

If you are a patient at (deleted), you will continue to receive the same medical treatment at (deleted) as usual as part of your normal clinical care. If you are not a patient at (deleted), this does not apply to you.

6b. What procedures will be done only because you are taking part in this research study?

As described above, you will participate in an interview, and meet with the Principal Investigator 2-3 weeks later to review a transcript and interpretation of the interview.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed on the front page of this form.

7. If you choose to take part in this study, how long will you be expected to take part in the Research?

You will meet with the Principal Investigator twice: once to complete the 60-90 minute interview and 2-3 weeks later to review a transcript and interpretation of the interview. After that, you will be done with the study.

8. How many people are expected to take part in this research?

Approximately 15-25 young adults will take part in this research.

9. What are the possible discomforts and risks?

One of the risks of the study could be accidental disclosure of your HIV status to someone other than the Principal Investigator. Great care will be taken to prevent this from happening and to protect your confidentiality. You will be identified by a unique identification number and only this number will be recorded during the interview, written on the interview transcripts, and study notes. The interviews will be uploaded to a computer with security passwords and then will be erased from the recorder. All consent forms, interviews, interview transcripts, and other study documents will be kept in a locked file cabinet in the Principal Investigator's office or on a computer with security passwords. Your name or the names of your family or friends will not be used during the recording of the interview. You will be asked to refer to your family and friends by their relationship only, not their names in order to protect confidentiality.

There may be questions which you find unpleasant or difficult to answer. You may refuse to answer any question. The Principal Investigator will try to answer any questions you have and discuss any concerns you may have about answering a question. If you are not sure of any questions, you may ask the interviewer to explain them. During the interview, you may remember sensitive and emotional experiences. The Principal Investigator will give you the space to pause or discontinue the interview if it becomes too emotional for you. If you need immediate psychological assistance, the Principal Investigator will contact the clinic psychologist or the (deleted) Emergency Department. Additionally, you will be given contact information for the clinic psychologist and the (deleted) Emergency Department in case you need psychological assistance any time after the study visit.

If you present any homicidal or suicidal thoughts, the Principal Investigator must report this to (deleted) clinical staff where you will be counseled to determine if you are of harm to yourself or others.

Any information regarding incidences of child abuse may require the Principal Investigator to report the information to the (deleted) Department of Children and Families.

This study may include risks that are unknown at this time. Taking part in more than one research study or project may further increase the risks to you. If you are currently enrolled or have recently taken part in another research study, you must tell the person reviewing this consent form with you.

Throughout the study, the Principal Investigator will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

10. What are the possible benefits to you?

Even though you may not directly benefit from taking part in this study, some participants might find it beneficial to discuss and reflect on their experiences. You may or may not personally benefit from taking part in this study.

11. What are the possible benefits to others?

If you choose to take part in this study, you will be helping researchers and other people who work with HIV-infected young adults to learn more about them so that they can develop better programs, policies, and services for them. This may benefit HIV-infected young adults in the future.

12. If you choose to take part in this research study, will it cost you anything?

Any medical services provided to you during your participation in this study would have been provided to you if you were not in this study. These medical services will be billed to you or your insurance company. You will be responsible for paying any deductible, co-insurance, or co-payments for those services, and any non-covered or out-of-network services. Please contact your insurance company for additional information.

You will not be responsible for any study-related costs.

13. Will you receive compensation for taking part in this research study?

After completing the interview, you will receive a \$10 gift card to compensate you for your time and travel. If you return for the second visit to review the interview transcript, you will receive an additional \$10 gift card to compensate you for your time and travel for that visit.

14. What if you are injured because of the study?

If you are injured as a direct result of your participation in this study, only professional care that you receive at the (deleted) will be provided without charge. Hospital expenses will be billed to you or your insurance. You will be responsible for any deductible, co-insurance, or co-payments. Some insurance companies may not cover costs associated with research studies. Please contact your insurance company for additional information.

No additional compensation is routinely offered.

The Principal Investigator and others involved in this study may be (deleted) employees. As employees of (deleted), they are protected under state law, which limits financial recovery for negligence.

Please contact Kathleen Thoma at (deleted) (Monday-Friday, 8:30 am – 5 pm) if you experience an injury or have questions about any discomforts that you experience while participating in this study. If you experience a life-threatening injury related to the study at any other time, please call 911 or proceed to the (deleted) Emergency Department or the nearest emergency facility immediately.

15. What other options or treatments are available if you do not want to be in this study?

This is not a treatment study. Your alternative is to not participate in the study without risk of penalty. You may still receive services at (deleted) if you are a patient there.

16. Can you withdraw from this research study?

You are free to stop taking part in this research study at any time without penalty and without losing any benefits to which you are entitled.

If you decide to stop taking part in this research study for any reason, you should contact Kathleen Thoma at (deleted) (Monday-Friday, 8:30 am – 5 pm).

If you have any questions regarding your rights as a research participant, you may call the University of Florida Institutional Review Board (IRB) office at (904) 244-9427 or the University of North Florida Institutional Review Board (IRB) office at (904) 620-2498.

17. If you withdraw from this study, can information about you still be used and/or collected?

If you stop taking part in this study, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete and protect the validity of the research. You can revoke this authorization by giving a written request with your signature on it to the Principal Investigator.

18. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

- You do not qualify to be in the study, because you do not meet the study requirements.
- You do not want your interview to be digitally recorded.
- You do not want to answer the interview questions.
- The investigator decides that continuing in the study would be harmful to you.
- You are unable to keep appointments.
- The study is cancelled and/or other administrative reasons.

19. If you agree to take part in this research study, the Principal Investigator will create, collect, and use private information about you and your health. Once this information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected about you will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the legal right to review these research records, and they will protect the secrecy (confidentiality) of these records as much as the law allows. These people include researchers for this study, certain

University of Florida and University of North Florida officials, and the Institutional Review Boards at the University of Florida and the University of North Florida (IRB; an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research). Otherwise, your research records will not be released without your permission unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

20. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator or other researchers may benefit if the results of this study are presented at scientific meetings or published in scientific journals. In this case, the Principal Investigator is conducting this study to complete the dissertation portion of her doctoral degree in Educational Leadership at the University of North Florida.

21. Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Printed Name of Person Obtaining Consent and Authorization

Signature of Person Obtaining Consent and Authorization Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You will receive a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Printed Name of Person Consenting and Authorizing

Signature of Person Consenting and Authorizing Date



Appendix I: Revised Consent Form*IRB Study# 2014-112****Informed Consent to Participate in Research***

You are being asked to take part in a research study. This form provides you with information about the study and seeks your authorization for the collection, use and disclosure of your protected health information necessary for the study. The Principal Investigator (the person in charge of this research) will also describe this study to you and answer all of your questions. Before you decide whether or not to take part, read the information below and ask questions about anything you do not understand. Your participation is entirely voluntary. If you choose not to take part in this study, you will not be penalized or lose any benefits to which you would otherwise be entitled.

1. Name of Study Participant:

Date of Birth (for identification reasons): _____/_____/_____

2. Title of Research Study: What is Your Story?**4. Principal Investigator Name, Address, and Telephone Number(s)**

Kathleen Thoma
University of Florida
Department of Pediatrics

(phone number deleted)

University of North Florida
College of Education and Human Services
Department of Leadership, School Counseling & Sport Management
Building 57
1 UNF Drive
Jacksonville, FL 32224

4. Source of Funding or Other Material Support

The University of Florida and the University of North Florida are providing material support only.

5. What is the purpose of this research study?

The purpose of this study is to collect information about the lived experiences of HIV-infected young adults so that educational and healthcare leaders can design better programs, services and policies to help them.

6. What will be done if you take part in this research study?

You are being asked to participate in this study because you are infected with the HIV virus, are between 18 and 29 years of age, live in one of the zip codes in or around (deleted) in (deleted) County, and speak English. You will participate in an interview that will last 60-90 minutes. During the interview, you will be asked about yourself and to describe what it is like for you to live with HIV infection. The interview will be digitally recorded so that the Principal Investigator can easily review it later. You must consent to the digital recording of the interview in order to participate in the study.

Shortly after your study visit, the Principal Investigator will listen to the interview recording and write up a transcript and interpretation of the interview. She will contact you to set up a time to meet with you to review the transcript and interpretation. During that visit, the Principal Investigator may ask you to clarify some of the information you gave during the interview. After that, your participation in the study will be complete.

6a. What procedures would be done as part of your normal clinical care (even if you did not take part in this research)?

If you are a patient at (deleted), you will continue to receive the same medical treatment at (deleted) as usual as part of your normal clinical care. If you are not a patient at (deleted), this does not apply to you.

6b. What procedures will be done only because you are taking part in this research study?

As described above, you will participate in an interview, and meet with the Principal Investigator 2-3 weeks later to review a transcript and interpretation of the interview.

If you have any questions now or at any time during the study, you may contact the Principal Investigator listed on the front page of this form.

7. If you choose to take part in this study, how long will you be expected to take part in the Research?

You will meet with the Principal Investigator twice: once to complete the 60-90 minute interview and 2-3 weeks later to review a transcript and interpretation of the interview. After that, you will be done with the study.

8. How many people are expected to take part in this research?

Approximately 15-25 young adults will take part in this research.

9. What are the possible discomforts and risks?

One of the risks of the study could be accidental disclosure of your HIV status to someone other than the Principal Investigator. Great care will be taken to prevent this from happening and to protect your confidentiality. You will be identified by a unique identification number and only this number will be recorded during the interview, written on the interview transcripts, and study notes. The interviews will be uploaded to a computer with security passwords and then will be erased from the recorder. All consent forms, interviews, interview transcripts, and other study documents will be kept in a locked file cabinet in the Principal Investigator's office or on a computer with security passwords. Your name or the names of your family or friends will not be used during the recording of the interview. You will be asked to refer to your family and friends by their relationship only, not their names in order to protect confidentiality.

There may be questions which you find unpleasant or difficult to answer. You may refuse to answer any question. The Principal Investigator will try to answer any questions you have and discuss any concerns you may have about answering a question. If you are not sure of any questions, you may ask the interviewer to explain them. During the interview, you may remember sensitive and emotional experiences. The Principal Investigator will give you the space to pause or discontinue the interview if it becomes too emotional for you. If you need immediate psychological assistance, the Principal Investigator will contact the clinic psychologist or the (deleted) Emergency Department. Additionally, you will be given contact information for the clinic psychologist and the (deleted) Emergency Department in case you need psychological assistance any time after the study visit.

If you present any homicidal or suicidal thoughts, the Principal Investigator must report this to (deleted) clinical staff where you will be counseled to determine if you are of harm to yourself or others.

Any information regarding incidences of child abuse may require the Principal Investigator to report the information to the (deleted) Department of Children and Families.

This study may include risks that are unknown at this time. Taking part in more than one research study or project may further increase the risks to you. If you are currently enrolled or have recently taken part in another research study, you must tell the person reviewing this consent form with you.

Throughout the study, the Principal Investigator will notify you of new information that may become available and might affect your decision to remain in the study.

If you wish to discuss the information above or any discomforts you may experience, you may ask questions now or call the Principal Investigator listed on the front page of this form.

10. What are the possible benefits to you?

Even though you may not directly benefit from taking part in this study, some participants might find it beneficial to discuss and reflect on their experiences. You may or may not personally benefit from taking part in this study.

11. What are the possible benefits to others?

If you choose to take part in this study, you will be helping researchers and other people who work with HIV-infected young adults to learn more about them so that they can develop better programs, policies, and services for them. This may benefit HIV-infected young adults in the future.

12. If you choose to take part in this research study, will it cost you anything?

Any medical services provided to you during your participation in this study would have been provided to you if you were not in this study. These medical services will be billed to you or your insurance company. You will be responsible for paying any deductible, co-insurance, or co-payments for those services, and any non-covered or out-of-network services. Please contact your insurance company for additional information.

You will not be responsible for any study-related costs.

13. Will you receive compensation for taking part in this research study?

After completing the interview, you will receive \$10 (gift card or cash) to compensate you for your time and travel. If you return for the second visit to review the interview transcript, you will receive an additional \$10 (gift card or cash) to compensate you for your time and travel for that visit.

14. What if you are injured because of the study?

If you are injured as a direct result of your participation in this study, only professional care that you receive at the (deleted) will be provided without charge. Hospital expenses will be billed to you or your insurance. You will be responsible for any deductible, co-insurance, or co-payments. Some insurance companies may not cover costs associated with research studies. Please contact your insurance company for additional information.

No additional compensation is routinely offered.

The Principal Investigator and others involved in this study may be (deleted) employees. As employees of (deleted), they are protected under state law, which limits financial recovery for negligence.

Please contact Kathleen Thoma at (deleted) (Monday-Friday, 8:30 am – 5 pm) if you experience an injury or have questions about any discomforts that you experience while participating in this study. If you experience a life-threatening injury related to the study at any other time, please call 911 or proceed to the (deleted) Emergency Department or the nearest emergency facility immediately.

15. What other options or treatments are available if you do not want to be in this study?

This is not a treatment study. Your alternative is to not participate in the study without risk of penalty. You may still receive services at (deleted) if you are a patient there.

16. Can you withdraw from this research study?

You are free to stop taking part in this research study at any time without penalty and without losing any benefits to which you are entitled.

If you decide to stop taking part in this research study for any reason, you should contact Kathleen Thoma at (deleted) (Monday-Friday, 8:30 am – 5 pm).

If you have any questions regarding your rights as a research participant, you may call the University of Florida Institutional Review Board (IRB) office at (904) 244-9427 or the University of North Florida Institutional Review Board (IRB) office at (904) 620-2498.

17. If you withdraw from this study, can information about you still be used and/or collected?

If you stop taking part in this study, no new information will be collected about you. However, information that was already collected may still be used and shared with others if the researchers have relied on it to complete and protect the validity of the research. You can revoke this authorization by giving a written request with your signature on it to the Principal Investigator.

18. Can the Principal Investigator withdraw you from this research study?

You may be withdrawn from the study without your consent for the following reasons:

- You do not qualify to be in the study, because you do not meet the study requirements.
- You do not want your interview to be digitally recorded.
- You do not want to answer the interview questions.
- The investigator decides that continuing in the study would be harmful to you.
- You are unable to keep appointments.
- The study is cancelled and/or other administrative reasons.

19. If you agree to take part in this research study, the Principal Investigator will create, collect, and use private information about you and your health. Once this information is collected, how will it be kept secret (confidential) in order to protect your privacy?

Information collected about you will be stored in locked filing cabinets or in computers with security passwords. Only certain people have the legal right to review these research records, and they will protect the secrecy (confidentiality) of these records as much as the law allows. These people include researchers for this study, certain

University of Florida and University of North Florida officials, and the Institutional Review Boards at the University of Florida and the University of North Florida (IRB; an IRB is a group of people who are responsible for looking after the rights and welfare of people taking part in research). Otherwise, your research records will not be released without your permission unless required by law or a court order.

If the results of this research are published or presented at scientific meetings, your identity will not be disclosed.

20. How will the researcher(s) benefit from your being in this study?

In general, presenting research results helps the career of a scientist. Therefore, the Principal Investigator or other researchers may benefit if the results of this study are presented at scientific meetings or published in scientific journals. In this case, the Principal Investigator is conducting this study to complete the dissertation portion of her doctoral degree in Educational Leadership at the University of North Florida.

21. Signatures

As a representative of this study, I have explained to the participant the purpose, the procedures, the possible benefits, and the risks of this research study; the alternatives to being in the study; and how privacy will be protected:

Printed Name of Person Obtaining Consent and Authorization

Signature of Person Obtaining Consent and Authorization Date

You have been informed about this study's purpose, procedures, possible benefits, and risks; the alternatives to being in the study; and how your privacy will be protected. You will receive a copy of this Form. You have been given the opportunity to ask questions before you sign, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By signing this form, you are not waiving any of your legal rights.

Printed Name of Person Consenting and Authorizing

Signature of Person Consenting and Authorizing Date



Appendix J: University of Florida IRB Approval Letter

UF Institutional Review Board
UNIVERSITY of FLORIDA

Health Science Center / Jacksonville
College of Medicine
Institutional Review Board
FWA00005790

500 West Eighth Street
Tower II, 9th Floor, Suite 9015
Jacksonville, FL 32209
(904) 244-9478
(fax) (904) 244-9035

MEMORANDUM

DATE: July 3, 2014

TO: Kathleen Thoma, *SKT*

FROM: Sheila M. Austin, CIP
Coordinator, Institutional Review Board for
Alan Hilderin, MD
Chair, Institutional Review Board

SUBJECT: Expedited Review of UFJ 2014-112

TITLE: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience Among HIV-Infected Emerging Young Adults from an Impoverished Urban Area

Your request for approval of the above study under the classification of expedited was reviewed in the IRB office and as IRB Chair I am pleased to inform you that your study was approved on 7/3/2014 under the following expedited category(s):

- ___ 1. Clinical studies of drugs and devices only when:
 - a. An investigational new drug application (IND) or investigational device exemption (IDE) is not required, and there is no significant increase in risk or decrease in acceptability of risk, or
 - b. The device is cleared or approved for marketing and is being used in accordance with its labeling.
- ___ 2. Collection of blood samples by finger, heel, or ear stick, or venipuncture no more than twice weekly as follows:
 - a. From healthy non-pregnant adults weighing at least 110 pounds, in amounts less than 550 ml per 8 weeks.
 - b. From other adults and children, considering the health and habits of the subjects, in amounts less than 50 ml or 3 ml per kg (whichever is less) per 8 weeks.
- ___ 3. Prospective collection of biological specimens for research purposes by noninvasive means. Examples:
 - a. Hair and nail clippings (non-disfiguring)
 - b. Deciduous teeth at exfoliation or indicated extraction
 - c. Permanent teeth excreta at indicated extraction
 - d. Excreta and external secretions including sweat
 - e. Uncannulated saliva
 - f. Placenta removed at delivery
 - g. Amniotic fluid at the time of rupture of the membrane prior to or during labor
 - h. Supra- and sub-gingival dental plaque during routine prophylactic scaling
 - i. Mucosal and skin cells by buccal scraping or swab, skin swab, or mouth washings.
 - j. Sputum after saline mist nebulization

SUBJECT: Expedited Review of UFJ 2014-112

TITLE: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience Among HIV-Infected Emerging Young Adults from an Impoverished Urban Area

___ 4. Collection of data through noninvasive procedures (not involving general anesthesia or sedation) routinely employed in clinical practice, excluding procedures involving x-rays or microwaves. Examples:
 a. Physical sensors that do not involve input of significant amounts of energy or invasion of privacy.
 b. Weighing or testing sensory acuity.
 c. Electro-cardiography, electro-encephalography, thermography, detection of naturally-occurring radioactivity, electroretinography, ultrasound, diagnostic infrared imaging, doppler blood flow, and echocardiography.
 d. Moderate exercise, muscular strength testing, body composition assessment and flexibility testing where appropriate for age, weight and health.

___ 5. Research involving materials (data, documents, records, specimens) that have been or will be collected solely for non-research purposes (such as medical treatment or diagnosis).

6. Collection of data from voice, video, digital, or image recordings made for research purposes.

7. Research on individual or group characteristics or behavior (such as studies of perception, cognition, motivation, identity, language, communication, cultural beliefs and practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Research records (data collection sheets, records of clinical, educational, behavioral intervention, signed Informed Consent forms, and IRB correspondence) must be kept for at least 3 years following the completion of the research. Holding onto these documents for three (3) years allows for authentication of research activities and findings. In addition, investigators may need to make these records available for review by various agencies that oversee human subject protections.

The new HIPAA rule mandates that all Authorizations given by research participants to use their protected health information for research purposes be maintained by six (6) years following completion of the research project. That means that all separate HIPAA Authorizations and all Informed Consent forms that include HIPAA Authorization must be kept for an additional 3 years over the other research records.

You must inform the Board of any modifications or changes to this research (protocol or consent changes) since they could affect its expedited status.

Please note the category of informed consent listed below that has been approved for this study:

You have been granted approval to conduct this study using the enclosed stamped, IRB-approved consent form. This consent must be photocopied and used when enrolling subjects into this project.

OR

___ You have been granted a waiver of documentation of informed consent, in lieu of a verbal consent.

OR

___ You have been granted a waiver of informed consent.

SUBJECT: Expedited Review of UF12014-112

TITLE: What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience Among HIV-Infected Emerging Young Adults from an Impoverished Urban Area

Your protocol is approved until 6/18/2015 at which time you will need to submit a regular continuing review report in order to continue the study. This study has been approved for enrollment of 40 subjects. If you find the need to increase this number, please submit a Revision to the IRB office immediately.

Thank you for informing the Board of your proposal.

Appendix K: University of North Florida IRB Approval Letter

Click on Sign to add text and place signatures on a PDF file.



UNF
UNIVERSITY of
NORTH FLORIDA

Office of Research and Sponsored Programs
1 UNF Drive
Jacksonville, FL 32224-3603
904-670-2415 FAX 904-670-2457
Equal Opportunity/Equal Access/Affirmative Action Institution

MEMORANDUM

DATE: July 30, 2014

TO: Ms. Kathleen Thoma, MA

VIA: Dr. Francis Godwyll
LSCSM

FROM: Dr. Jennifer Wesely, Chairperson
On behalf of the UNF Institutional Review Board

RE: Review of New Project by the UNF Institutional Review Board IRB# 602785-1:
"What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from an Impoverished Area"

UNF IRB Number: 602785-1
 Approval Date: 07-30-2014
 Expiration Date: 07-30-2015
 Processed on behalf of UNF's IRB *KLC*

This is to advise you that your project, "What is Your Story? A Phenomenological Study of the Impact of Ecological Factors on Resilience among HIV-Infected Emerging Young Adults from an Impoverished Area" underwent "Expedited" Categories 6 & 7 review on behalf of the UNF Institutional Review Board. Your reviewer recommended approval without modifications.

This approval applies to your project in the form and content as submitted to the IRB for review. All participants must receive a stamped and dated copy of the approved informed consent document when possible. Any variations or modifications to the approved procedures or documents must be cleared with the IRB prior to implementing such changes. For example, if you plan to make changes to your stamped and dated informed consent form, it will be necessary to submit a copy of the revised form via an amendment so that it can be reviewed and approved prior to use. Once approved, a new stamp and date will be included on the revised consent form so that it can be used. Any unanticipated problems involving risk and any occurrence of serious harm to subjects and others shall be reported promptly to the IRB within 3 business days.

Your study has been approved for a period of 12 months as of 07/30/2014. If you would like your project to continue for more than one year, you will be required to provide a completed Status Report and applicable continuing review documentation to the UNF IRB prior to 06/30/2015. An extension will be necessary if your study will be continuing past the 1-year anniversary of the approval date. *We suggest you submit your status report 11 months from the date of your approval date as noted above to allow time for review and processing.* When you are ready to close your project, please complete a Closing Report Form which can also be found in the documents library called "Forms and Templates" in IRBNet. Please note that it will be necessary to create a

Appendix K: University of North Florida IRB Approval Letter (continued)

new package in IRBNet in order to submit amendments, status reports, or closing reports in the future. All applicable records relating to this research shall be retained for at least 3 years after completion of the research. Data containing protected health information are to be retained for 6 years.

CITI Course Completion Reports are valid for 3 years. Your Human Subjects Protection CITI completion report is valid through 4/17/2016 and Dr. Godvill's completion report is valid through 4/10/2015. The CITI training for renewal will become available 90 days before your CITI training expires. Please renew your CITI training within that time period by following this link: <http://www.citiprogram.org>. Should you have questions regarding your project or any other IRB issues, please contact the research integrity unit of the Office of Research and Sponsored Programs by emailing IRB@unf.edu or calling (904) 620-2455.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within UNF's records. All records shall be accessible for inspection and copying by authorized representatives of the department or agency at reasonable times and in a reasonable manner. A copy of this approval may also be sent to the dean and/or chair of your department.

UNF IRB Number: 60785-1
Approval Date: 07-30-2014
Expiration Date: 07-30-2015
Processed on behalf of UNF's IRB *KLC*

CURRICULUM VITAE
KATHLEEN A. THOMA, M.A., C.C.R.P.

EDUCATION & CERTIFICATIONS

- Doctoral Candidate • University of North Florida • Educational Leadership with Public Health Cognate • Expected completion date: 12/2015
- Certificated Clinical Research Professional (CCRP) • Society of Clinical Research Associates (SOCRA) • 2011-2017
- Masters of Arts • University of Illinois at Chicago • Anthropology (medical/public health focus) • 1987
- Bachelor of Arts • University of Illinois at Chicago • Anthropology • 1981

FELLOWSHIPS

- 2013 Health Disparities Research Fellow Mentoring Program, The People's Scientific Conference to Promote Health and Eliminate Health Disparities, University of Florida College of Medicine, June 14 & 15, 2013

GRANTS

- 2015 • University of North Florida Graduate Research Grant • \$500

PROFESSIONAL EXPERIENCE

- 2012-Present • Clinical Research Specialist • University of Florida Center for HIV/AIDS Research, Education and Services (UF CARES)
- 2007-2012 • Director of Research • University of Florida Center for HIV/AIDS Research, Education and Services (UF CARES)
- 2005-2007 • Resource Development Officer and Director of Educational Research • Florida State College at Jacksonville
- 2001-2005 • Research Project Manager • American Academy of Pediatrics • Pediatrics Research In Office Settings (PROS) Network
- 2000-2001 • Assistant Director of Institutional Research and Planning • DeVry, Inc.
- 1994-2000 • Research Assistant • National-Louis University, Office of Institutional Research and Planning
- 1994 • Adjunct Faculty • Roosevelt University, Department of Social Sciences •

Taught Sociology courses

- 1993-1994 • Adjunct Faculty • Elgin Community College, Department of Social Sciences • Taught Anthropology and Sociology courses
- 1990-1995 • Adjunct Faculty • Oakton Community College, Department of Social Sciences • Taught Anthropology and Sociology courses
- 1989-1992 • Coordinator of Research and Planning • Oakton Community College, Office of Institutional Research and Planning
- 1987-89 • Project Coordinator/ Research Specialist • University of Illinois at Chicago, College of Medicine and School of Public Health

PUBLICATIONS

- Thoma, K. Tips and tangles when conducting the qualitative dissertation: The lived experiences of young adults living with HIV/AIDS in a low-income, urban area. Accepted for publication in SAGE Research Methods Cases. Expected publication date January 2016.
- Schwartz, R. P., Hamre, R. A., Dietz, W. H., Wasserman, R. C., Slora, E. J., Myers, E. F., Sullivan, S. A., Rockett, H. A., Thoma, K. A., Dumitru, G., & Resnicow, K. A. (2007). Office-based motivational interviewing to prevent childhood obesity: A feasibility study. *Archives of Pediatric and Adolescent Medicine*, 161, 495-501.
- Serwint, J. R., Thoma, K. A., Dabrow, S. M., Hunt, L. E., Barratt, M. S., Shope, T. R., & Darden, P. M. (2006). Comparing patients seen in Pediatric Resident Continuity Clinics and the National Ambulatory Medical Care Survey (NAMCS): A study from the CORNET Network. *Pediatrics*, 118; e849–e858.
- Slora, E. J., Thoma, K. A., Wasserman, R. C., Pedlow, S. E., & Bocian, A. B. (2006). Patient visits to a national practice-based research network: Comparing Pediatric Research in Office Settings (PROS) to the National Ambulatory Medical Care Survey (NAMCS). *Pediatrics*, 118; e228-e234.
- Mohr, J. J., Lannon, C. M., Thoma, K. A., Woods, D. M., Slora, E. J., Wasserman, R. C., Kleckner, D., & Uhring, L. (2004). Learning from Errors in Ambulatory Pediatrics (LEAP). *Advances in Patient Safety: From Research to Implementation*, 1, 355-368.

PRESENTATIONS

- Thoma, K. Stories of challenge and resilience: The lived experiences of low income, urban young adults living with HIV/AIDS. Accepted as a poster presentation at the American Public Health Association's Annual Meeting and Expo, Chicago, IL, October 31-November 4, 2015
- Cook, R. L., Hu, X., Weber, K. M., Mai, D., Karki, M., Thoma, K., . . . & Cohen, M. Pharmacotherapy for hazardous drinking in HIV-infected women: A pilot randomized clinical trial. Presented as a poster presentation at the 38th Annual Research Society on Alcoholism Meeting, San Antonio, TX, June 20-24, 2015
- Thoma, K. A. What is your story? A phenomenological study of the impact of ecological factors on resilience among HIV-infected emerging young adults from an impoverished urban area. Presented as a poster presentation at the HIV Prevention Trials Network and International Maternal Pediatric Adolescents AIDS Clinical Trials Network 2015 Annual Meeting, Arlington, VA, June 12-18, 2015
- Thoma, K. A. What is your story? The lived experiences of HIV-infected, low income, urban young adults. Presented as a poster presentation at the Statewide Graduate Student Research Symposium, University of Central Florida, Orlando, FL, April 24, 2015
- Thoma, K. A. What is Your Story? The lived experiences of HIV-infected, low income, urban young adults. Presented as an oral presentation at the University of North Florida's Graduate Student Research Spotlight, 14th Annual Showcase of Osprey Advancements in Research and Scholarship, Jacksonville, FL, April 17, 2015
- Thoma, K.A. What is your story? A phenomenological study of the impact of ecological factors on resilience among HIV-infected emerging young adults from an impoverished urban area. Presented as a poster presentation at the University of Florida Health's Research Day, Jacksonville, FL, May 21, 2015
- Thoma, K. A., Thomas, G. L., Usitalo, A. M., Ravi, M. S., Cook, R. L., & Rathore, M. H. Pharmacotherapy for hazardous drinking in HIV-infected women: The University of Florida Center for HIV/AIDS Research, Education and Service's (UF CARES) Experience. Presented as a poster presentation at the 2013 People's Scientific Conference to Promote Health and Eliminate Health Disparities, University of Florida College of Medicine, Gainesville, FL, June 14 & 15, 2013.
- Hu, X, Karki, M., Cohen, M., Young, M., Weber, K. M., Thoma, K. A., Thomas, G., Rathore, M., Mai, D., & Cook, R. A pilot study of pharmacotherapy (Naltrexone) for hazardous drinking among women infected with HIV. Present as a poster presentation at the 18th Annual International Meeting for the International Society of Pharmacoeconomics and Outcomes Research, New Orleans, LA, May 18-22, 2013.

- Thoma, K. A., Thomas, G. L., Usitalo, A. M., Ravi, M. S., Cook, R. L., & Rathore, M. H. Pharmacotherapy for Hazardous Drinking in HIV-Infected Women: The University of Florida Center for HIV/AIDS Research, Education and Service's (UF CARES) Experience. Presented as a poster presentation at the University of Florida Health Science Center's Research Day, Jacksonville, FL, May 17, 2012.
- Thoma, K. A. START Study (Strategic Timing of AntiRetroviral Treatment). Presented at Research, Yesterday and Today; Dispelling the Myths about Clinical Trials, University of Florida Health Science Center, Jacksonville, FL, June 25, 2011.
- Thoma, K. A. Discriminant Analysis: A Type of Canonical Correlation. Presented as part of a Symposium on The Multivariate General Linear Model: Using Canonical Correlation as a Frame of Reference for Understanding Other Multivariate Statistical Models, Mid-South Educational Research Association Annual Meeting, Baton Rouge, LA, November 4-6, 2009.
- Renninger, P., Nichols, C., Peterson, J., & Thoma, K. Why Write a Grant? Presented as a workshop at the 18th International Conference on College Teaching and Learning, Ponte Vedra, FL, April 2-5, 2007.
- Schwartz, R., Resnicow, K., Hamre, R., Dietz, W., Slora, E., Myers, E., Sullivan, S., Thoma, K., & Wasserman, R. The Healthy Lifestyles pilot study. Presented as a platform presentation at the 2006 Pediatric Academic Societies' Annual Meeting, San Francisco, CA, April 29-May 2, 2006.
- Pascoe, J., Little, D., Slora, E., Thoma, K., & Wasserman, R. Patient visits to a midwestern primary care practice-based research network: A comparison to two national data sets. Presented as a poster presentation at the 2005 Pediatric Academic Societies' Annual Meeting, Washington D.C., May 14-17, 2005.
- Slora, E. J., Thoma, K. A., Wasserman, R. C., Pedlow, S. E., & Bocian, A. B. Representativeness of patient visits to a national practice-based research network: A comparison of Pediatric Research in Office Settings (PROS) and National Ambulatory Medical Care Survey (NAMCS) data. Presented as a presidential plenary presentation at the 2004 Pediatric Academic Societies Meeting, San Francisco, CA, May 1-4, 2004.
- Serwint, J. R., Thoma, K. A., Dabrow, S. M., Hunt, L. E., Barratt, M. S., Shope, T. R., & Darden, P. M., Comparing patients seen in continuity clinics and the National Ambulatory Medical Care Survey (NAMCS): A study from the Continuity Research Network (CORNET). Presented as a presidential plenary presentation at the 2004 Pediatric Academic Societies Meeting, San Francisco, CA, May 1-4, 2004.
- Mohr, J. J., Lannon, . CM., Slora, E. J., Wasserman, R. C., Thoma, K. A., Kleckner, D., Uhring, L., & Woods, D. Learning from Errors in Ambulatory Pediatrics (LEAP). Presented as a poster presentation at the Chicago Patient Safety Forum,

2003 Showcase of Patient Safety Improvements, Institute of Medicine of Chicago, Chicago, IL, October 16, 2003.

ADVISORY BOARD MEMBERSHIPS

- 2011-2015 • Biomedical Sciences Advisory Board • Florida State College at Jacksonville

PROFESSIONAL MEMBERSHIPS

- American Educational Research Association (AERA)
- American Public Health Association (APHA)
- Society of Clinical Research Associates (SOCRA)

HONOR SOCIETIES

- Pi Lambda Theta