THE CATHOLIC UNIVERSITY OF AMERICA

Growing Up with HIV: The Lived Experience of Perinatally Infected Young Adults

A DISSERTATION
 Submitted to the Faculty of the School of Nursing Of The Catholic University of America In Partial Fulfillment of the Requirements For the Degree Doctor of Philosophy © Copyright All Rights Reserved By Elaine F. Williams Washington, D.C. 2014
In the United States, access to antiretroviral therapy is the primary factor changing perinatal HIV infection from a life-threatening childhood illness into a life-long chronic condition. The surviving perinatally infected children are now young adults. There are limited publications about how these young adults describe growing up with HIV and there are many unknowns about how best to help these youths make successful transitions into healthy adulthood. The purpose of this phenomenological study was to interpret the study participants’ perceived journeys, lived experiences, learning experiences, recent events and situations that affected growing up with HIV. The application of Van Manen’s (1997; 1990) interpretative framework enabled exploration of the phenomenon of the lived experience of young adults growing up with HIV. The study was conducted at a large metropolitan area pediatric hospital. A total of 17 young adults (9 males, and 8 females) 18–24 years of age, participated in the study. Upon receiving the required IRB approvals and a Certificate of Confidentiality from the National Institute of Health (NIH), the interviews were conducted and transcribed verbatim. Themes were developed and the four fundamental lifeworld themes used as a guide to describe the responses. Five essential themes offered a fuller description of the overarching elements of *A Secretive Uncertain, Harsh and life*. The four lifeworld existentials described by Van Manen namely, lived
space (spatiality), lived body (corporeality), lived time (temporality), and lived relation (relationality) provided the components for interpretation and discussion of growing up with perinatal HIV. The findings demonstrated a range of social and emotional factors affecting growing up with HIV for the study population. Future research is needed to describe the support needs of young adults growing up with perinatal HIV. Future research is also needed to describe how the young adults’ are transitioning to adulthood. This study suggested the need for improvements in the delivery of family-centered health care services and implementing an environment to continue a conversational relationship with the participants.
This dissertation by Elaine F. Williams fulfills the dissertation requirement for the doctoral degree in Nursing approved by Janice Agazio, Ph.D., CRNP, FAANP, FAAN, as Director, and by Janet Merritt, Ph.D., R.N., CNS-BC, and Natella Y. Rakhmanina, MD, PhD FAAP, AAHIVS, as Readers.

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Dedication

This dissertation is dedicated to all young adults growing up infected with perinatal HIV. My heartfelt gratitude and sincere thanks go to the young adults who generously shared their stories growing up with perinatal HIV. The young adults told their stories and it was my pleasure to publish the findings. My most sincere hope is that their experiences are adequately reflected in this work.

This dissertation is also dedicated to my family. I thank my dear husband, Roland, for his love, friendship, support and patience. Your wisdom and inspiration will always be priceless to me. I also thank my son, Allard for the ray of sunshine he brings to my life each day. My wish for Allard is for him to be healthy, always happy and loved. Lastly, I dedicate this work to my parents, Pearl and Cecil, who have always believed in me and encouraged me to pursue my dreams.
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Acknowledgements

I wish to acknowledge my dissertation committee for their guidance in assisting me to give voices of the lived experience of young adults growing up with perinatal HIV. I am indebted to my former major advisor Sister Rosemary Donnelly, PhD, RN, FAAN, for offering expertise, encouragement and guidance as I developed my proposal. I also would like to thank my siblings, Pamela, Winston, Patrick and Joy and my nieces and nephews for years of love and encouragement.

I am especially thankful for the efforts of my major advisor, Janice Agazio, PhD, RN, CRNP for her steadfast support, patience, encouragement, qualitative method expertise, and interest in my success. I would like to thank Janet Merritt, Ph.D., R.N., CNS-BC and Natella Y. Rakhmamina, MD, PhD, FAAP, AAHIVS, my committee members for their expertise, encouragement, feedback and guidance. I would like to thank Pamela Hinds, PhD, RN, Susan Feethan, PhD, RN and Kathy Kelly PhD, RN for their leadership in nursing research and encouragement leading to my success.

I would like to thank John van den Anker, for averting obstacles that could be perceived as barriers to my success. To my dear friend Marlene Lee, your friendship is precious. You participated in this study generously sharing your time and eloquently sharing your insights. To Ruby Daniels, you make each day very special. I would also like to thank Kathy Ferrer and Keetra Williams for their interest in this project. To my friends Donna and Janelle thank you for your friendships and encouragement. To Victoria, Syamala and Micky, Grace and Danielle, you have made a lasting impression in my life and I wish you the very best in life.
I would like to thank my Catholic University of America (CUA) classmates and members of the doctoral support group, my colleagues in the Children’s Research Center (Brenda, Von, Ianka Leesa, Vera, Nicole and Jayna) and the Special Immunology Services and Adolescent Clinic colleagues (Kimberly, Jean, Keith and the social workers) for their support throughout my doctoral program. Lastly, I would like to acknowledge the support of the Nursing Research Advisory Committee (NRAC) and the Sigma Theta Tau International, Kappa Chapter.
Chapter 1

The Problem

In developed countries such as the United States, children infected with perinatal human immunodeficiency virus (HIV) (the transfer of HIV from mother to child) have normal life expectancy despite their complex health care needs (Chiappini et al., 2009; Fernet et al., 2011; Fielden et al., 2006). The Centers for Disease Control (CDC) (2010a) reported that 69% of all new perinatal HIV infections in the United States were among African Americans.

African Americans face a number of issues that contribute to the higher rates of HIV infection. Lack of awareness of their HIV status and higher rates of other sexually transmitted infections (STIs) can significantly increase the chance of getting infected or transmitting the HIV illness. The socioeconomic issues associated with poverty, limited access to health care, housing, stigma, fear, discrimination, homophobia, and negative perceptions about HIV testing also place African Americans at higher risk. Many at risk for HIV may be more afraid of being discriminated against than the HIV infection test and may choose not to seek testing (CDC, 2014).

Pediatric acquired immune deficiency syndrome (AIDS) in the District of Columbia in Washington, D.C., ranks 11th in the nation. AIDS is the final stage of the perinatal HIV disease, which causes severe damage to the immune system (CDC, 2012a). This is relevant because the percentage of new perinatal HIV infections has been consistently higher among African Americans than that of any other race or ethnicity because the women diagnosed with HIV late in pregnancy had no treatment with antiretroviral (ARV) medications, or had low CD4 cell counts at the time of delivery (Whitmore et al., 2012).
Over twenty years ago, perinatally HIV-infected young adults were children who most likely spent less time in school, and as a result, today are frequently unemployed or underemployed as adults (Bush-Parker, 2000; Souza, Santos, Valentini, Silva, & Falbo, 2010). Unemployment or job instability is also prevalent among individuals living with HIV, and a majority of the HIV infected population in the United States (US) is unemployed (CDC, 2010b).

As young adults with perinatally acquired HIV live into mature adulthood, they continue to cope with HIV-related stigma, discrimination, isolation, racism, unemployment, inadequate education, limited social support, and the need to be taking medications for the rest of their lives (Brown, Lourie, & Pao, 2000). Today many individuals living with HIV continue to face challenging employment decisions that have personal, financial, and health impacts on their lives, lives of their partners and children (Cho & Chan, 2013; Glenn, Ford, Moore & Hollar, 2003).

**Background of the Problem**

In spite of the significant advances in highly active antiretroviral treatment (HAART) in the prevention of perinatal transmission in the 1990s, each year the CDC continues to report perinatal HIV births in the (U.S). In addition, children worldwide are being born with HIV because resources and the recommended HAART may not be available to prevent transmission of the infection. Qualitative research is needed to better explain the barriers to the zero new HIV infections vision (UNAIDS, 2012). Pregnant women may not have access to HIV testing or HAART to eliminate the anticipated lifelong health challenges of their children growing up with HIV (CDC, 2011).
Few qualitative studies have examined the process of growing into young adulthood with perinatal HIV. Growing up with HIV and living longer only became possible in the last decade; hence, a phenomenological research approach needs to be used to describe the aspirations, feelings, and actions of perinatally HIV-positive young adults.

The Panel on Antiretroviral Guidelines for Adults and Adolescents (2012) describes the cluster of differentiation 4 (CD4), lymphocyte cell count as a major indicator in assessing the immune function in patients with HIV and the factor in whether to initiate HAART. The fewer functioning CD4 cells due to untreated HIV, the weaker is the immune system. A CD4 cell count of 600-1200 cells/ml is considered to be within the normal reference range, and the percentage of CD4 cells of 31–57% corresponds to normal immune function. A CD4 count below 200 cells/ml, or 14%, is used define profound immune suppression or AIDS (CDC, 2008a; Cotran et al., 1999).

The factors affecting the progression of HIV include the HIV co-receptor modules, HIV viral load, and HAART. Most strains of HIV use co-receptor molecules. The C-C chemokine receptor type 5 (CCR5) and the CD4 co-receptor molecules infect a cell, and the Chemokine receptor type 4. (CXCR4) molecule attacks cells. The receptors enable the virus to enter a cell during the initial stage of HIV infection, creating a cycle of viral replication, or the amount of HIV in a person’s blood. People with high viral loads are more likely to advance to AIDS or become clinically ill faster than people with lower levels of the virus. In addition, HAART, a potent combination of three or more antiretroviral drugs belonging to different antiretroviral drug classes, is capable of lowering the viral load and suppressing viral replication (Gulick, et al.,
1997). For many perinatally HIV-infected young people, HAART delays and prevents the progression to AIDS (Department of Health and Human Services, National Institutes of Health, 2010).

**Perinatal HIV**

Perinatal HIV transmission is the primary cause of pediatric HIV in the United States and worldwide (UNAIDS, 2010; 2012). During pregnancy, labor, delivery and breastfeeding the maternal HIV viral load determines the transmission of the disease to the child (Taha et al., 2003). Fortunately, perinatal HIV transmission declined in the United States since the 1990’s (McKenna & Hu, 2007). The reduction in transmission was primarily due to HIV policies, ARVs prophylaxis during labor, delivery and breastfeeding (CDC, 2012a). Since the start of the HIV epidemic in the United States, there have been 17,000 cases of perinatal HIV, which represents 91% of all pediatric cases. Due to the subsequent introduction of HAART, it is estimated that there are 9,898 survivors of perinatally acquired HIV living in the United States Lindgren, et al 1999).

Perinatally or vertically acquired HIV is usually identified in infancy and the introduction to the HAART regime starts at a much younger age than in the horizontally HIV-infected adult (Bush-Parker, 2000). The horizontal HIV infection occurs usually in adolescence due to high risk behaviors. A major concern today is the use of HAART over a period of years from the time of birth (Hazra, Siberry, & Mofenson, 2010). The differences between the horizontally infected (high risk) and the perinatally HIV-infected adolescent is that perinatally infected HIV youth might present with delays in growth and physical development, due to abnormal growth patterns if HIV was left untreated early in life (N. Y. Rakhmanina, personal communication, 2012).
In a review article, Brown, Laurie, and Pao (2000) reported that abnormal developmental milestones in perinatally infected children many create major concerns. In the review, five studies detailed below, reported significant psychological implications for children growing up with HIV. Mintz et al. (1996) wrote that HIV-infected children and adolescents develop neurocognitive deficits resulting from progressive encephalopathy (PE). A triad of symptoms characterizes HIV-associated PE: (1) impaired brain growth, (2) progressive motor dysfunction, and (3) abnormal developmental milestones. Lobato, Cadwell, Ng, and Oxtoby (1995) suggested that infants and young children are most vulnerable at the time of HIV infection during the development of the brain and reported the prevalence of PE at 13–23% among perinatally infected HIV children. Papola, Alverez, and Cohen (1994) reported that 48% of 86 HIV-infected school-age children were functioning in the below-average to average range of intelligence and 56% demonstrated language impairments. Another study, by Wolters, Brouwers, Moss, and Pizzo (1995), reported that abnormal computed tomography (CT) scans of HIV-infected children under age of 10 years of age with pediatric HIV were associated with changes in receptive and expressive language functioning, in which expressive language was significantly more impaired compared to the receptive language. Bachanas et al. (2001) and Brackis-Cott et al (2009) reported that the school-age HIV-infected children had lower results on the Wechsler Intelligence Scale for Children (WISC-111) testing for reading or writing skills, and indicated that the academic achievements and physical functioning were below average in the HIV-related cohort compared to non-infected children.

As they grow older, perinatally infected children experience a significant amount of non-HIV-related stress caused by socio-economic conditions such as poverty, inadequate access to
the medical services, and limited social support (Brown, Lourie, & Pao, 2000). The chronic anxiety over the HIV diagnosis can make it difficult for the young adults to initiate conversation about their illness.

**Medication Adherence**

HAART reduces the viral load and transmission of the virus from one person to another (Panel on Antiretroviral Guidelines for Adults and Adolescents, 2012). A well-documented challenge to the effectiveness of HAART is non-adherence to the medications (Murphy, et al 2010). For younger patients, the adherence problems are mostly associated with the taste of the medicine. Growing independence, peer pressure, and increased risk-taking behaviors are among several adolescent adherence challenges (Rakhnamina & Phelps, 2012).

Currently, pharmaceutical companies produce several classes of anti-HIV medications. Currently, the majority of ARV medications are FDA approved for pediatric use in formulations of liquid, powder, tablet, or capsule suitable for pediatric HIV patients (Maron, Gaur, & Flynn 2010). Several authors reported that since pediatric HAART became available, the survival period for perinatally HIV-infected children has doubled (Chiappini et al., 2006), though they continue to experience and endure the unpleasant effects of or adverse events from the HAART regimens (Lee et al., 2006). Adherence is important to decrease the viral load and prevent the development of viral resistance (Horberg, et al., 1964)

There are varied causes of medication non-adherence among perinatally infected adolescents, including the scenario when parents directly involved in the medical plan protect them from knowing about their HIV status (N. Y. Rakhmanina, personal communication, 2012).
In order to hide the child’s HIV status, some parents re-label or hide the prescribed medications, avoid filling the antiretroviral prescriptions at a local pharmacy, or miss doses when the child is not at home to be able to take the medication privately (Belzer, Fuchs, Tucker, & Slonimsky, 1998; Buchanan, et al., 2011).

Young children have particular difficulty taking medication because of the taste or the inability to swallow tablets (Best et al., 2011). Adolescents, on the other hand, may refuse to take medication as a manifestation of rebellious behavior (Martinez et al., 2000; Reddington et al., 2000). Healthy guardians may be best able to manage the care of the perinatally HIV-infected child. HIV-positive mothers struggle with stress, pain, and a sense of failure, especially if they have challenges in meeting their own health care needs (Desmond, 2009; Melvin & Sher, 1993). HIV-infected mothers usually report being sick and overwhelmed with their own illness, which requires as much care as their infected child (N. Y. Rakhmanina, personal communication, 2012). Over time, when the health of the parent or custodial guardian fails, a guardian will be court appointed because perinatally HIV-infected children require dedicated resources for custodial and routine care (Mok & Cooper, 1997). In the 1990s, perinatally infected children were more likely than other chronically ill children to miss many days of school, medical appointments, and routine doses of prescribed HAART (Buchanan, et al., 2011).

Today case management research reports an increase in medication adherence by combining the efforts of a pharmacist, nurse coordinator, and primary care provider (Horberg et al., 2012). As perinatally infected HIV children grow up, they require more than just medical
care and flexible scheduling. The young adult may be isolated from a support system; case management can address those needs and reinforce treatment adherence and retention of medical care and treatment (Johnson et al., 2003).

As children continue to live longer with perinatal HIV and a HAART regimen, adherence to lifelong therapy becomes critically important. Drug resistance in multi-drug-experienced children complicates care when there is limited availability of pediatric formulations of antiretroviral regimes. Pediatric HIV therapy now focuses on morbidity related to long-term HIV infection and children’s treatment as they grow up (Hazra, Siberry, & Mofenson, 2010), treatment that enables children to develop normally and improve chances of survival (Lee et al., 2006; Nachman et al., 2005).

**HAART**

Currently, there are approximately 32 ARVs approved by the FDA to treat HIV infection (National Institute of Health (NIH, 2013). Five FDA-approved ARVs (Maraviroc, Delavirdine, Rilpivirine, Indinavir, and Saquinavir) are approved for adults only, but many of them are currently being investigated in pediatric clinical trials for FDA approval (Clinical Trials, 2013). The ARV treatments do not cure people with HIV; rather, the treatments suppress the virus to lower levels, which are undetectable, but not completely eliminated from the body. Although the viral load may be low, transmission of the virus is still possible. From a young age, perinatally infected young adults must take ARVs for the rest of their lives to stay healthy (United States Department of Health and Human Services, [U.S. DHHS.] 2012).

Antiretroviral therapy (ART) falls into five major classes: entry and fusion inhibitors: (Enfuvirtide); CCR5 inhibitors(Maraviroc); integrase inhibitor; (Raltegravir); non-nucleoside
reverse transcriptase inhibitors (NNRTIs): (Delavirdine, Efavirenz, Etravirine, Nevirapine, Rilpivirine); nucleoside reverse transcriptase inhibitors (NRTIs): (Abacavir, Lamivudine, Stavudine, Tenofovir, Disoproxil, Fumarate, Zidovudine); and protease inhibitors (PI): (Atazanavir, Darunavir, Fosamprenavir, Indinavir, Lopinavir, Nelfinavir, Ritonavir, Saquinavir, Tipranavir) (NIH, 2013).

Fusion inhibitors block HIV’s ability to merge with and infect healthy cells; entry inhibitors block integrase; NNRTIs and NRTIs, bind to and block HIV reverse transcriptase, an HIV enzyme that facilitates the HIV replication and increases the amount of HIV in the blood; and PIs block HIV replication by binding to their proteases (NIH, 2013).

Over several decades, HAART has helped children live longer with HIV, but has a spectrum of side effects (Connor et al., 1994). Side effects from the HAART regimen forces the young adults to manage the illness for a longer time since their life expectancy is significantly extended (Hazra et al., 2010). The resulting HAART toxicities may be acute or delayed in their manifestation after drug administration, and such effects may vary from mild to severe (Murphy et al., 2001).

Concerns exist about the effects of antiretroviral drugs on several major body systems exposed to HAART, such as the central nervous system (Shanbhag et al., 2005); endocrine and cardiovascular systems (Fisher, Miller, & Lipshultz, 2006; Vigano, Pattarino, Cerini, & Zuccotti, 2009); the skeleto-muscular system (Basu, Kumar, & Bhatia, 2011; McComsey et al., 2011; Mora et al., 2001; the renal and urinary system (McCulloch & Ray, 2008). Perinatally infected persons are also more likely to complain of fatigue, which affects their ability to function (Lerdal, Gay, Aouizerat, Portilloand, & Lee, 2011; McElhiney, Rabkin, Van Gorp, & Rabkin,
Unlike children with other chronic illnesses, perinatally HIV-infected children usually have parents living with HIV or have lost one or two parent to the illness (CDC, 2009; Fielden et al., 2006). It has been reported that children affected by HIV do not anticipate a family life or romantic relationships (Fernet et al., 2011).

Brown, Laurie & Pao (2000) and Lindegren, Steinber, and Byers (2000) reported increased longevity among perinatally infected children receiving HAART. However, there are few qualitative phenomenological articles specific to the lived experience of young adults with perinatal HIV in the United States. The qualitative approach to research explored the issues and answer questions regarding the perinatal HIV phenomenon. The qualitative approach involves the analysis of literature reviews, unstructured data analysis, open-ended survey responses, audio recordings leading to content analysis, and the identification of themes to explore living with HIV from the young adults’ perspectives.

**HIV/AIDS**

Four major routes of HIV transmission resulted from unsafe sex, contaminated intravenous (IV) needles, perinatal (mother-to-child transfer), blood transfusions and medical procedures. When antiretroviral therapy is administered ante-partum, intra-partum and post-partum, only a few women transmit the HIV infection to their children (American College of Obstetricians and Gynecologists, 2004; Wade et al., 1998).

HIV-1 (which accounts for more than 90% of HIV infections) and HIV-2 are the types of infections discussed in this study (Plantier et al., 2009). HIV-1 group M was the first HIV strain which infected more than 31 million people worldwide (Plantier et al., 2009). The HIV-1 M group subtypes are phylogenetically associated groups or classes of HIV-1 sequences, and are
labeled A1, A2, B, C, D, F1, F2, G, H, J and K (World Health Organization [WHO], 2011). HIV-1 is more virulent and infectious and causes most HIV infections (Gilbert et al., 2007). While HIV-2 is confined to West Africa because it is not easily transmitted, HIV-1 easily spread worldwide (Reeves & Doms, 2002). The HIV-1 virus was detected in the Congo area of West Africa during the period of 1959–1960 (Sharp et al., 2001). Several authors (Gilbert et al., 2007; Worobey et al., 2008) have reported that a strain of HIV-1 subtype B transferred from Africa to Haiti in 1966 and entered the United States and other countries around 1969.

Fauquet and Fargette (2005) referred to HIV as genus lentivirus (a member of the retrovirus family); Douek, Roederer, and Koup (2009) and Weiss (1993) found that HIV causes AIDS. When infected with the lentivirus, the human host experiences long-lasting episodes of illness and incubation (Lévy, 1993). This results in immune system failure, affecting several major organs and systems in the body. In addition, the HIV-1 infection spread for many years among the U.S. population before the recognition of AIDS in 1981 (Gilbert et al., 2007).

**Global HIV/AIDS**

There are about 34 million people worldwide living with HIV, many of whom are unaware of their HIV status and may be transmitting the disease to others (UNAIDS, 2012). Worldwide, 15 million children have been orphaned by the epidemic, and approximately 2.5 million children are living with HIV contracted through perinatal infection (UNAIDS, 2010; WHO, 2011). Areas of the world most infected by HIV include Sub-Saharan Africa with greater than 28 million infected individuals living with HIV (UNAIDS, 2012).

The majority of perinatally infected children with AIDS in the United States are Black. Black immigrants come from several countries in the Caribbean and Africa. The data on foreign
Blacks growing up with HIV in the United States have not been published, but foreign-born individuals make up a growing segment of the U.S. Black population. Between 1970 and 2000, the foreign-born Black population in the United States rose 6.5%. In Washington, DC, nearly 8% of the Black population was foreign-born, an increase from 1% in 1970 (U.S. Census 1970, 2000, 2010).

**HIV statistics in the United States**

In the United States, approximately one million people live with HIV/AIDS (CDC, 2012b). In 2009 (the most recent year that data are available), there were an estimated 48,100 new HIV infections, with a 21% increase in people ages 19 to 21 years of age. Much like the rest of the world, one-quarter of those with HIV in the United States do not know they are carrying the virus, which should be of significant concern to women of childbearing age (CDC, 2008b; CDC, 2010b; UNAIDS, 2010).

In 2009, 46% of people living with HIV in the United States were Black. The data also show that 44% of new infections occurred among Black people (CDC, 2012a; Prejean et al., 2011), which is relatively unchanged from the last census (CDC, 2007a). The HIV diagnosis rate for Black women is 15 times that of White women (CDC, 2011). The most recent HIV report, in 2009, showed 66% of HIV positive Black Americans, excluding Hispanic or Latino, were perinatally infected (CDC/HIV fact sheet, 2011). Over time and during the HIV epidemic, the research results of Black people showed that they die sooner than White people simultaneously diagnosed (CDC, 2007b; CDC, 2007c; Losina, 2009). The rate of persons living with HIV/AIDS is listed as 9.1 per 100,000 population, but the rates are highest in New York (20.6./100,000),
Florida (19.1/100,000), Puerto Rico (20.0/100,000), New Jersey (19.1/100,000), Maryland (22.1/100,000) and the District of Columbia (112.1/100,000) (CDC, 2012a).

In the United States, 9,898 perinatally infected children younger than 13 years are living with AIDS throughout the nation. The 11 states with the highest number of pediatric AIDS cases are as follows: New York, 2,437; Florida, 1,570; New Jersey, 811; California, 703; Texas, 398; Pennsylvania, 378; Maryland, 338; Illinois, 290; Georgia, 252; Massachusetts, 231 in the District of Columbia, 190 (CDC, 2012b).

**HIV statistics in the District of Columbia**

In the District of Columbia, 16,087 people, which is approximately 2.7% of the population, live with HIV/AIDS (CDC, 2012a). Also, more than 1,500 HIV positive youth (ages 13 – 24 years) live in Washington, DC and many of them are unaware that they are infected with HIV (Children’s National, 2013). Since the beginning of the epidemic, the District’s HIV and AIDS surveillance system reported the following: a total of 349 pediatric HIV and AIDS cases; 68.0% of pediatric HIV/AIDS cases were over the age of 13 at the end of 2008 (Census, 2010). The approximate percent of youths with HIV 18-24 years of age living in Washington, D. C. are as follows: Blacks, 81.4%; White, 8.5% and Hispanic 8.5% (Washington, DC, Department of Health, 2007).

Empirical evidence shows an increased number of HIV infections among women of childbearing age in Washington (Washington, DC, Department of Health, 2011). The District of Columbia accounts for 6% of perinatal HIV infections and 9% of perinatal AIDS cases in the United States. Four in 10 of the perinatally infected children were HIV negative until two years of age. Fowler, Gable, Lampe, Etima, and Owor (2010) suggested that perinatal infection with
HIV-1 can occur during pregnancy, particularly in the third trimester, during the intrapartum and lactation periods. The response to the perinatal HIV epidemic resulted in numerous successes in which the number of new perinatal HIV infections decreased from its peak in the 1980s, but challenges remain because there are new perinatal HIV births recorded annually.

The primary factor enabling perinatally infected children to reach adulthood has been the introduction of HAART. Little is known about what it is like to grow up being perinatally HIV infected; young adults’ descriptions of living and maturing with HIV will be invaluable to health-care providers as they work with perinatally HIV-infected young adults.

**National HIV goals**

The national goals for HIV-infected people in the United States are as follows: (1) reduce the number of HIV infections; (2) increase access to care and improve health outcomes for people living with HIV; and (3) minimize HIV-related health disparities (U.S. DHHS., 2012). The anticipated outcome of the use of HAART in HIV-infected infants is a plan of care associated with increased survival (Viani, Araneta, Deville, & Spector, 2004). The use of HAART results in the following positive outcomes: a reduction in opportunistic infections (Gona et al., 2006); improved growth and development (Nachman et al., 2005); and improved quality of life (Skevington, Norweg, Standage, & WHOQOL HIV Group, 2010).

However, in a review of literature about adherence to HAART, Steele and Grauer (2003) revealed that administering HAART from very early in the infant’s life is a health and medical challenge for the child, family, and medical team. The goal of HAART is “to achieve viral suppression, protect the immunologic system, prevent disease development and minimize the side effects of the medications” (Maron, Gaur & Flynn, 2010, p. 360). Hazra, Siberry &
Mofenson (2010) reported that HAART used over time causes several side effects significant to perinatal young adults growing up with HIV. Salehian, Bilas, Bazargan, and Abbasian (2005) reported that protease inhibitors caused diabetes in older African American participants infected with HIV. These patients who used HAART reported hyperglycemia or the onset of diabetes. In similar studies, patients reported severe adverse reactions, such as liver toxicity, liver failure, pancreatitis, and neuropathy (Ammassari et al., 2001). Individually or combined, the adverse reactions mentioned above may affect people growing up with HIV.

There are many challenges in accurately documenting adherence to HAART medications (Chesney, 2006; Williams, P.L. et al., 2006). There are barriers to medication adherence even though laws exist to facilitate access to antiretroviral therapy for children. Public Law 107-109 amended the Federal Food, Drug, and Cosmetic Act. The purpose of PL 107-109 was to improve the safety and efficacy of pharmaceuticals for children. Another law, the (Pediatric Research Equity Act, 2003) was enacted for the same purpose. The Congress proposed and implemented this legislation to increase the number of drugs tested and labeled for use with children and suggested that immediately after the diagnosis of HIV, children need medications that are designed, prepared, and manufactured specifically for them (The Best Pharmaceuticals for Children Act, 2002).

**Neurocognitive development in children living with HIV**

Side effects of the HAART regimen can become physical and psychological burdens, which may vary among individuals (Ammassari, 2001). Approximately 10% of HIV-infected infants develop HIV encephalopathy, which, although decreased by HAART when administered early in life, leaves residual cognitive and motor deficits that can interfere with mobility and the
activities of daily living (Foster et al., 2006). The Paediatric European Network for the treatment of AIDS (PENTA) (PENTA Network, 2009). WHO (2010) recommend that all HIV-infected infants receive treatment early in life to prevent any adverse effects in neurodevelopment. Some subtle cognitive abnormalities include expressive language delay and behavioral difficulties (Coplan et al., 1998). In addition, when young adults with perinatal HIV infection are compared with a group of adults diagnosed with the HIV infection for more than 15 years, the young adults demonstrated higher rates of asymptomatic neurocognitive impairment (Paramesparan et al., 2010). The interpretation of the findings is often unclear and limited by the multifaceted etiology of neurological disease (PENTA Network, 2009).

Foster et al. (2006) reported that peer support groups described perinatal HIV adolescents as having cognitive limitations. These limitations may cause them to engage in risky adolescent behaviors similar to that of healthy and horizontally infected teens, without awareness of the risk (New York Department of health, AIDS, 2010). In the case of the perinatally infected child, the possibility of developmental disabilities and cognitive deficits exists from birth in ways different from horizontally infected youth.

The HIV Perspective for Healthy People 2020

Some researchers have explored the relationship between physical determinants of health and perinatally acquired HIV. The Healthy People 2020 publication provides science-based national health-promotion and disease-prevention objectives for all Americans established by the United Department of Health and Human Services (U.S. DHHS). The goals were created in 1979, then subsequently updated every ten years for Healthy People 2000, Healthy People 2010, and Healthy People 2020 (U.S. DHHS, 2012). Healthy People says that everyone should have
the chance to live long healthy lives. Healthy People identifies physical examples of health determinants such as (1) natural environment, such as plants, weather, or climate change; (2) atmosphere and environments, such as buildings or transportation; (3) employment locations, schools, and recreational settings; (4) accommodation, residences, and neighborhoods; (5) limitation of contact with contaminated substances and other environmental hazards; (6) limitation of physical hardships, especially for people with disabilities; and (7) aesthetic environments, such as good lighting, trees, and benches (2020 (U.S. DHHS., 2012). Could there be a relationship between limited physical determinants in health and overall success for young adults growing up with HIV? Some authors suggested that educational opportunity, career development, and future plans for perinatally HIV infected children require more thorough investigation (Battles & Wiener, 2002; Wiener et al., 2007).

**Young Adult HIV Risk Experiences**

HIV-infected young adults have the usual adolescent problems as they grow up, such as acting out, experimenting or risk-taking behaviors. HIV-infected adolescents interact with their peers in the community who are infected with HIV through high risk, potentially increasing the chances for the ongoing transmission of HIV in the community (Cederbaum, Marcus, & Hutchinson, 2008).

The majority of young adults with HIV are represented by Black people of American descent who are living in a high-risk environment. In a review article on perinatally infected adolescents, Rodrigo & Rajapakse (2010) reported that the impact of poverty on females living with HIV is associated with the unemployed, uneducated, unmarried, and financially strained, with all these factors affecting the family. This is especially true when the family consists of a
single parent as a result of divorce, death, or incarceration of the partner/husband (N. Y. Rakhmanina, personal communication, 2012). In addition, perinatally infected young adults may demonstrate behavior that limits their ability to form positive close relationships, thus leaving them vulnerable to negative peer pressure (LaRue & Herrman, 2008).

**Foster care**

Perinatally infected children orphaned by AIDS are most vulnerable and require custodial care. In addition to assuring the presence of a parent or family member, foster care can provide social support for children growing up with HIV. The adoption and foster care analysis and reporting system (AFCARS) Report U.S. Department of Health and Human resources (2011), estimated that 408,000 children lived in foster care. In addition in Washington, DC, approximately 5% of the foster care placement results from medical neglect (Child Welfare Bureau, 2011). In the 1990s, when HIV mortality was very high and treatment was limited, perinatally HIV infected newborns were eight times more likely to be placed in foster care at the time of hospital discharge (Nicholas, 1994).

Foster care children with HIV often live in underserved areas, and many are in foster care because of parental abuse, neglect, or parental incarceration (Cohen & Nehring, 1994). HIV-infected children enter the foster care system in a variety of ways: parents abandon them or relinquish custody; parents become disabled themselves or die from AIDS (N. Y. Rakhmanina, personal communication, 2012).

Furthermore, perinatally infected adolescents who have experienced the death of a peer or face the impending death of a parent require sensitive bereavement counseling (Rosenheim & Reicher, 1985; Siegel & Gorey, 1994).
**Stigma**

Stigmatization describes the experiences of vertically and horizontally infected HIV young adults. HIV is presented in youth transmission in two major groups of horizontally and vertically (or perinatally) infected individuals. According to Foster, Waeblbrouck, and Peltier (2007), perinatally HIV-infected young adults have different pasts and health-care needs, compared to their horizontally infected peers. Perinatally infected young adults live with a chronic illness and receive medical care from a pediatric medical team, while the horizontally infected group is usually sexually active and receives care in an adult medical setting. Perinatally HIV-infected young adults and their horizontally infected peers, both face the same stigma associated with HIV (Scambler, 2009). Medical treatment and the use of HAART have made it possible to live long and well with HIV, thus, concealment of HIV status due to fear stigmatic reactions only create the possibility of transmitting HIV to others (Bundock et al., 2011).

**Disclosure**

When a family is available to provide care, disclosure of HIV status to children is a sensitive matter (Letteney & LaPorte, 2004). Disclosure may occur at any point in the child’s life, as described in the disclosure literature by Murphy (2008) and Reyland, Higgins-D’Alessandro, and McMahon (2002). Sowell et al. (1997) and Wiener et al, (1996) reported that the decision to disclose and when to do so is the responsibility of the parent. The parents of the perinatally infected child usually do not disclose the HIV status to the child and frequently cite the uncertainty and insecurity about disclosure, being the primary reason for their unwillingness to disclose. In another report, parents firmly demanded that the medical staff not inform young children of their HIV status, though many infected children often learn about their condition.

In a qualitative report, Woodring, Cancelli, Ponterotto & Keitel (2005) described adolescents’ experiences with perinatal HIV in terms of themes such as parental loss, transition in care, HIV disclosure, coping in school, and support networks. There are many publications on variables associated with HIV HAART (Besch, 1995; Chesney, 2000; Chesney, Ickovics, Hecht, Sikipa, & Rabkin, 1999; Chiappini et al., 2006; Holzemer et al., 1999; Lerner, 1977; Williams & Friedland, 1997). Several authors mention self-advocacy, self-efficacy, perceived stigma, and family resiliency as measured through coping, as significant factors affecting adherence and the disclosure process (Tschoop, Frain, & Bishop, 2009). Other authors, Rudy, Murphy, Harris, Muenz, and Ellen (2010); Rowland et al., (2000); Sherman, Bonanno, Wiener, and Battles (2000); and Wiener, Mellins, Marhefka, and Battles (2007) described the HIV disclosure process which does not include all of the life experiences of growing up with HIV.

**Financial Considerations**

Soanes and Timmons (2004) reported that care-time for the chronically ill child compared to the HIV-ill child is 7.8 hours and 3.9 hours per day, respectively. The comparative cost of care for the chronically ill child is approximately $25,900 and $9,300 for the HIV-positive child, resulting in approximately $86.5 million annually for HIV-positive children and $155 to $279 billion for chronically ill children.

**Nursing Case-Management**

Nursing case management provides ongoing assessment to address barriers such as housing instability, substance abuse, access to medical care for HAART adherence, insurance
access, ARV drugs, illnesses, and referral for counseling or family therapy (Harberer & Mellins, 2009). The strategies include measures to reduce pill burdens, such as home visits not just for intensive periods, since good adherence is a concept that must be maintained for a lifetime (Harberer & Mellins, 2009; Williams, et al 2006). Nursing involvement in HIV case management results in a greater ability to increase the quality of patient care and reduce cost. Multiple issues such as medication adherence, coordinator of services, motivation and development of an individual plan of care for perinatally HIV-infected young adults require a multidisciplinary team of medical providers to assure uninterrupted ART therapy (Rakhmanina & Phelps, 2012).

There is a gap in the literature which suggests a dearth of phenomenological studies that describe the challenges faced by the perinatally HIV-infected young adult growing up with the disease. Understanding the phenomenon of growing up with HIV from the young adult’s perspective can enhance nursing case management practice related to the education, health, and counseling of patients who will live with HIV for all of their lives.

**Relevant Dissertation on Disclosures**

Aiges’s (2008) dissertation on factors related to caregivers’ disclosure of the diagnosis to HIV-infected children ages 5–20 years of age reported on the disclosure process and reasons for the disclosure decisions. The overall goal of the study was to gain an understanding of how caregivers communicate with children about the illness. The caregivers who supported disclosure wanted the children to be aware of their diagnosis by providing honest and effective communication with their children, while being able to preserve the trust and bonding. The families who took a position against disclosure felt that children would be
incapable of keeping the stigmatizing diagnosis a secret.

More qualitative reports are needed to describe the adolescents’ lived experiences with HIV, especially on the disclosure of HIV status at various ages. Qualitative research provides an opportunity for the participants to describe their thoughts and feelings in the process (Lofland & Loftland, 1984).

**Purpose**

The purpose of this phenomenological study was to interpret the study participants’ perceived journeys, lived experiences, learning experiences, recent events, and situations that affected growing up with HIV after the disclosure process. The application of Van Manen’s (1997) interpretative framework enabled exploration of the phenomenon of the lived experience of young adults growing up with HIV.

**Research Questions**

The researcher’s aim answered the following core questions: 1) What are the experiences of perinatally HIV-infected young adults growing up with HIV? and 2) What meanings do perinatally HIV-infected young adults ascribe to their experiences? The following sub-questions were pursued: 1) How is living with HIV expressed by young adults? (2) How do young adults growing up with HIV describe available social support? (3) How does HIV affect a typical day in the life of young adults who have grown up with HIV? (4) How does the HIV condition affect the relationship with family and friends in young adults who have grown up with HIV? (5) What are the expectations of young adults living with HIV over time? (6) How were the young adults who have grown up with HIV told they have the disease? (7) Do the young adults who have grown up with HIV think often of HIV often? and (8) How are health concerns expressed by
young adults who have grown up with HIV?

**Definition of Terms**

For the purpose of this study, the following theoretical and operational definitions of terms were formulated:

*Young Adult*: The theoretical definition of young adult is one who is in the sub-stage period between adolescence and adulthood (Erikson, 1998). Operationally, young adult is defined as an individual age 18–24.

*Antiretroviral*: The theoretical definition of an antiretroviral is a medication that suppresses the replication of HIV (Fischl, et al., 1987). Operationally, antiretroviral is the medication used and reported by the participants.

*Highly Active Antiretroviral Therapy (HAART)*: The theoretical definition of HAART is a combination of chemotherapeutic drugs used to suppress replication of HIV, thereby preventing progression to AIDS (Gulick, 1998a & Gulick, 1998b). The usual HAART regimen combines three or more different drugs, such as two nucleoside reverse transcriptase inhibitors (NRTIs); a protease inhibitor (PI): two NRTIs, and a non-nucleoside reverse transcriptase inhibitor (NNRTI); or Fusion and entry and integrase inhibitors. Operationally, HAART referred to the medication regimen used by the participants.

*Perinatal*: The theoretical definition of perinatal describes the time period shortly before and after birth (NIH, 2013). Operationally, perinatal HIV infection could have occurred during pregnancy, labor, delivery, breast-feeding, or from pre-chewing food to feeding children under one year of age.
**Perinatal transmission:** The theoretical definition of perinatal transmission is the passage of HIV from an HIV-infected mother to her infant. The infant may become infected while in the womb, during labor and delivery, or through breast-feeding (CDC, 2007d). Operationally, perinatal transmission refers to children who grew up with HIV from birth.

**Growing up with HIV:** The theoretical definition of growing up with HIV describes children living with the disease (Hazra, Siberry, & Mofenson, 2010). Operationally, growing up with HIV describes how children with HIV cope with the illness as they transition into adulthood.

**Disclosure:** The theoretical definition of disclosure is the method of informing the child of his or her HIV status (Wiener, Mellins, Marhefka, & Battles, 2007). Operationally, disclosure is when and under what circumstances young adults were told by the parent or guardian about their HIV diagnosis.

**Pediatric HIV/AIDS:** The theoretical definition of pediatric HIV/AIDS is concerned with the development, care, and treatment of HIV children from birth through adolescence (NIH, 2013). Operationally, pediatric HIV/AIDS is the name of children living with HIV.

**Acquired Immunodeficiency Syndrome (AIDS):** The theoretical definition of AIDS is a syndrome characterized by opportunistic infections, which develops under the immunosuppressive conditions caused by HIV (NIH, 2013). Operationally, AIDS may be a diagnosis listed in the participant’s medical records.

**CD4 cells:** The theoretical definition of a CD4 cell count at or below 200 cells/mm³ is considered an AIDS-defining condition (CDC, 2008a). Operationally, CD4 cell count result and documented along with the participant’s diagnosis.
Blacks: African American refers to people who indicate their race as Black, African American, or Negro, or provide written entries such as African American, Afro American, and African (U.S. Census, 2010a). Operationally, Black refers to all people of the Black race regardless of nationality and ethnicity.

Social Support: Social support is defined as the “the individual’s feeling of belonging or being included, loved, or valued, not for what the sufferer can do for others” (Moss, 1973, p. 27). Operationally, social support refers to the people receiving emotional and physical care as participants in the study.

Isolation: Isolation refers to living apart from the community, which is deleterious to health (Harris & Larson, 2007). Operationally, isolation refers to people describing their detachment from the community based on stigma.

Limitations of this Study

As this study is limited to mostly Black young adults living with HIV in the Washington, DC, area including Maryland, the findings may not be generalized to young adults of all races/ethnic background living in a rural setting or other cities. Bias may occur as a result of enrolling an identified selection of young adults who are willing to participate in the research.

Significance of this Study

The significance of this study for nurses is that perinatally HIV-infected young adults are now living with the infection as a chronic illness, and the District of Columbia, ranks 11th in the nation in pediatric AIDS. Young adults who were infected at birth through no fault of their own may become detached from the seriousness of HIV health consequences (Ferrer et al., 2012), and
nurses must be able to provide the needed medical and psychological guidance to encourage medication adherence and faithfulness to the medical regimes which are inherent in the challenge of living with HIV.

Creating an overview of the young adult growing up with HIV requires combining different views of the disease, such as memories and experiences, just as is done from the perspective of a child or adolescent with cancer (Peterson & Bredow, 2004; Spinetta & Maloney, 1975, 1978). Therefore, this research shows what it is like growing up with HIV, learning about the diagnosis, and becoming an adult with perinatally acquired HIV in the Washington, DC, area. In addition, this study will be important in providing insight into the health concerns of perinatal young adults growing up with HIV.

The primary focus is on the young adult’s experience growing up with HIV as part of a family or social group. Van Manen’s framework helps describe how the young adult endures the intense accumulation of demands often associated with chronic illness. In the future, nurses caring for young adults with perinatal HIV will have additional practical information from the self-reported qualitative information obtained from narratives (Burns & Grove, 1997). Moreover, this research will support the ongoing proposals to assist children born with HIV. The reflection and knowledge gained from this study may generate new hypotheses and implications for future studies related to perinatally infected HIV young adults living in the United States and the world.

Assumptions

The assumptions of this study included the following:

1. The response received from the perinatally HIV infected young adult will be reflective of the memories of the young adult after disclosure.
2. The young adult growing up with HIV may have similar experience as described in the chronic illness literature.

3. The young adults who participate in this study will accurately describe their experiences growing up with HIV.

Summary

Perinatally HIV-infected young adults are growing up with this chronic illness affecting their growth and development. When perinatally infected children grow up, the transition program should be similar to the process used for other chronic illnesses, including social support (Foster, Waeblbrouck, & Peltier, 2007). The existing literature on young adults reveals limited information about children growing into adulthood with HIV. Most of the empirical evidence of lived experience is derived from international studies describing the perils of growing up with HIV. In developing countries, this research can either support the findings or add to the perinatal HIV body of literature.

HIV-positive individuals should expect to receive at a minimum antiretroviral therapy and support interventions. In fact, medication and medical access have become the key to quality of care for patients from all health-care providers and institutions. Despite these requirements, adherence to medical care and medications for infants, children, and adolescents remains an unresolved challenge (U.S. DHHS., 2012).

HAARTs’ effectiveness keeps children alive so they can become adults (Horberg et al., 2012). An understanding of how these young adults perceive growing up with HIV is lacking. However, Healthy People 2020 promotes creating a society in which everyone has an opportunity to live a long, healthy life. In spite of the benefits of HAART, the adverse effects of
therapeutic doses of the HAART regimen given at a very young age may rob young adults living with perinatally acquired HIV of a healthy life.

While, HAART brings great benefit to perinatally HIV-infected children, chronic intake of HAART medications add a significant burden to the patient, including side effects and adherence challenges. The pediatric literature contains numerous qualitative and quantitative studies on specific aspects of the HIV epidemic, but those studies do not adequately describe the experience of young adults growing up with HIV. The new descriptions of living and maturing with HIV will be invaluable to health-care providers as they work with perinatally HIV-infected young adults. This research also has the potential to identify strategies that support case management with the goal of improving health outcomes for the Perinatally infected patient and families. An understanding of this experience is significant for the development and implementation of strategies necessary to encourage a positive experience for HIV-affected children as they grow up.
Chapter II

Literature Review

Several authors described the challenges faced by HIV-positive youths horizontally infected and who participated in high-risk sexual behaviors (Koenig, Espinoza, Hodge, & Ruffo, 2007; Lightfoot, Swendeman, Rotheram-Borus, Comulada, & Weiss, 2005; Murphy et al., 2001; Naar-King, et al., 2006). Up to now, these data on adolescents with horizontally infected HIV may be the only guide useful enough to explain the behavior patterns of perinatally infected youth.

Many young adults growing up with a chronic illness (asthma, cystic fibrosis, or diabetes mellitus) graduate from high school and become employed. However, young adults growing up with HIV seldom realize educational and vocational milestones and are more likely than their healthy peers to be unemployed (Maslow, Haydon, Ford, & Halpern, 2011). In addition, overwhelming events such as isolation, HIV-diagnosis secrecy and parental death negatively affect other relationships. The literature on HIV-infected young adults also suggests that usually adolescents with HIV socialize with friends who have similar attitudes about life but may demonstrate dissimilar behaviors in the ways they process information, possibly due to decreased cognitive ability (New York Department of Health, 2010). There is also a concern that the perinatally HIV-infected youth may be prone to rush into risky sexual behavior at an early age, assuming they might not have a normal life span (Kang, Mellins, Ng, Robinson, & Abrahams, 2008). In summary, very little is reported about peer relationships and their influence on perinatally HIV-infected young adults.

As anticipated, when a responsible caregiver is available, perinatally HIV-infected adolescents may have some support from family and caregivers. Abramowitz et al. (2009) reported that 60%
of perinatally infected adolescents had someone to remind them of clinic appointments; 53% had supportive family members; and 4% had friends who were supportive and knew they had HIV. Specifically, families infrequently provide the health care for youth with horizontally acquired HIV (Valenzuela et al., 2009). Additionally, caregivers, especially birth parents of perinatally HIV-infected youth may have shielded the child over several years from the concerns of daily life, thus reducing their abilities to succeed with social opportunities (Havens & Mellins, 2008). Accordingly, many perinatally infected young adults must accept living with all the consequences of a stigmatizing illness that may force them to withdraw from social circles into isolation (Henry, Schoeny, Deptula, & Slavick, 2007). The research indicates a gap in the literature on the life challenges facing perinatally HIV-infected young adults, especially regarding when to tell children they will be living with HIV for the rest of their lives (Wiener, Mellins, Marhefka, Haven, & Battle, 2007).

This literature review begins with a general overview of HIV health care, nursing, pediatrics, and young adults as the major points of review. These variables were associated with the initial keywords search for “perinatal HIV” and “lived experience.” Six hundred and ninety references were identified in the keywords search. This larger area of literature was subdivided to consider the issues related to perinatal HIV. “Perinatal”, “vertical HIV transmission” and “young adults” were then searched in the following databases: the Cumulative Index to Nursing and Allied Health Literature (CINAHL®), Ref Works, Comprehensive Resource for Nursing and Allied Health Literature. AIDSline for African American Studies, Academic Research Elite, Medline, Pub Med and Psychology & Behavioral Sciences. The Catholic University of America (CUA) Dissertations Database was also included in this search.
The databases found to be most useful were PubMed, CINAHL for nursing, the current CDC statistics, and AIDSline search for international studies. The American research publications on perinatal HIV were minimal; AIDSline provided many African and other international studies. This literature search produced several articles describing perinatal HIV in children, but very few on growing up with HIV.

This general discussion follows a more detailed analysis of literature concerning the lived experience of HIV from childhood to young adulthood, as many of the articles were from international studies. The selected review includes specific areas supporting the research question under investigation in perinatal HIV. The purpose of this literature review is to provide pertinent background information about young adults growing up with perinatal HIV. This current literature review is divided into five sections: (1) the social support of young adults growing up with perinatal HIV; (2) health-related concerns of young adults growing up with perinatal HIV; (3) peer relationships of young adults growing up with perinatal HIV; (4) economic and education status of young adults growing up with perinatal HIV; and (5) disclosure in young adults growing up with HIV. Based on the literature search, the five areas listed above are the most relevant variables for young adults, especially minorities, growing up with HIV.

It is not surprising that the CDC data represent minorities in the young adult HIV population, since the majority of the perinatal HIV-infected young adults are Black people. Twenty years ago, the majority of perinatal HIV-infected young adults grew up with parents living with HIV (CDC, 2008a), or parents who later died (Mellins and Ehrhardt, 1994; Melvin & Sherr, 1993). The literature on parental absence or death due to HIV while caring for young children with HIV is relatively new. Some of the social interaction and family life issues evolve
from trying to cope with HIV infection, low income, poverty, or urban environments. The literature on young adults with HIV describes social support networks as an important factor in growing up the number of people available to assist when necessary and the frequency of human contact from this social support system (DuBois & Silverthorn, 2005; Thoits, 1995).

In the 1990s, Mason, Cauce, Gonzalez, & Hiraga (1994) examined the effect of peer problem behavior caused by the absence of a male in the home. In a sample of 112 African American adolescents perinatally and horizontally HIV infected, there were two important findings: (a) the male or father’s absence in the child’s life created the negative impact of peer influence, and a strong mother-adolescent relationship served to protect adolescents in father-absent homes; and (b) male caregivers can provide positive social support for this group.

Negative social support exacerbates a chronic illness, and it complicates the way patients cope with the difficult conditions (Dalgard et al., 2006). Some of the adversity, when linked to poverty, intensifies the HIV condition. Health-care professionals, especially nurses, must consider the challenges and special needs faced by this group when providing care (Lee, Detels, Rotheram-Borus, Duan, & Lord, 2007; Rotheram-Borus, Murphy, Kennedy, Stanton, & Kukliniski, 2001).

**Social Support**

Social support enables people to negotiate life’s crises. The guidelines of social support among adolescents are very similar to those of adults of any gender and age (Eckenrode, 1983; Tolsdorf, 1976). Cohen, Gottlieb, and Underwood (2001) stated that the empirical research on social support among adolescents is relatively new. People with low levels of social support experience negative life events and illness because of a weaker social support environment (Sarason, Sarason, Potter, Antoni, 1985). Hays, Turner, and Coates (1992) described social
support as (a) the available resource for people during tense situations; (b) the amount of social support given that has a positive or negative impact on stressful situations; and (c) the access to comfort and assistance provided informally by friends and families during a crisis.

Social support is an important HIV issue because of how potentially devastating the effects of stigma associated with the illness can be on the individual. The literature review on the young adult’s inner circle characterizes the individual’s support in three categories: (1) emotional, (2) instrumental, and (3) informational (Norbeck, Lindsey, & Careri, 1983). The first category, emotional support, provides self-esteem and stronger relationships (Norbeck, Lindsey & Carrie, 1983).

Frank, Blount, and Brown (1997) suggested that coping, attribution style, and social ability predict the capacity to adjust to emotional problems, the first category described above. The second category, instrumental support, includes economic or housing assistance (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001). The third, informational support provides advice and information on social, health, or employment issues (Turner, Hays, & Coates, 1993).

In a recent study, Giannattasio et al. (2011) described the psychosocial issues in adolescents with HIV. A total of 41 families of children with HIV participated in this study. The children were 6–20 years of age and most were perinatally infected. The participants were from two pediatric HIV infection clinics, located in Naples in southern Italy and Brescia in northern Italy. Children with biological parents, foster parents, and second-degree relatives (uncles, aunts, or grandparents) completed the questionnaires. The following major findings were reported: (1) limited availability of antiretroviral therapy due to poverty and unemployment; (2) psychosocial issues in children with HIV; (3) a high prevalence of children of low socioeconomic status and orphans; and (4) major impairments of body structures related to the immune system (32%),
lipodystrophy-caused skin problems (27%); vision (17%); and the gastrointestinal tract (15%). Although this study enrolled Italian participants, similar illustrations and findings for children living with HIV would be anticipated in the United States.

Lee et al. (2007) reported that there is a need for positive social support among HIV-infected young adults. The authors suggested that a small number of positive people is more effective in the lives of adolescents than a large support network or greater frequency of contact. The study recruited 413 HIV-affected adolescents to examine their depression as a function of their social support using the Brief Symptom Inventory (BSI). The number of people providing social support determined the size of social support. Depression, although not being researched in this project, is important to note. Also reported by Thoits (1995), the frequency of contact refers to the number of times per month young adults were in contact with social support providers. Such positive social support was associated with optimistic influences. In the study, the adolescents participated in a two-hour home interview. African American or Latino adolescents made up a majority of the participants (62%). The findings highlighted the relationships between social support and the behavior of the HIV-affected adolescents. The behaviors related to negative social support from the family systems were as follows: (a) illegal drug use, (b) alcohol abuse, (c) unprotected sex, and (d) illegal activities.

Bal, Crombez, Van Oost, and Debourdeaudhuij (2003) described the importance of social support in a group of adolescents experiencing stressful issues associated with HIV that affected the needs for social intervention. Eight hundred and twenty adolescents between 12 and 18 years of age filled out several questionnaires assessing social support, including a Social Support Questionnaire (Sarason, Shearin, Pierce, & Sarason, 1987). A total of 42% of the adolescents reported stressful experiences. This finding suggests that almost half of the participants needed
social support, especially the subjects who experienced abusive or stressful events.

Reyland, Higgins-D'Alessandro, and McMahon (2002) analyzed parental involvement in qualitative and quantitative responses of 60 minority teens whose mothers were living with HIV. The participants, 11 to 16 years of age, were from the Bronx and Queens boroughs of New York. The relationships between adolescents and mothers were described as: (1) feeling different, (2) having secrets, (3) worrying, and (4) caretaking. The authors reported using content analysis from the qualitative data. The six themes reflected how HIV affected these adolescents: (1) concept of life, (2) apprehension of death, (3) shame and segregation, (4) loss of significant others, (5) concern about being cared for, and 6) worry about financial assets. The findings in this study illustrate many stress-related factors experienced by adolescents whose parents may be dying from AIDS.

Reported in the 1990s when perinatally infected young adults were growing up with HIV, Aspinwall and Taylor (1993) found positive social support corresponded to a better quality of life, even if the individual is under stress. Although the support was significant within the family structure, individuals found positive support outside the family as well (Barrow, Armstrong, Vargo, & Boothroyd, 2007). An essential family system theory includes a code of belief of both ecological and social network theories. Bronfenbrenner (2005) described The Ecological Systems Theory (microsystem, the mesosystem, the exosystem, and the macrosystem) that shapes the growth and development of an individual.

The Microsystem describes the family, school, peer group, neighborhood, and childcare environments. This theory is much more than social support and is used describe how the family support is structured. This is also when a child’s parents may affect his beliefs and behavior and similarly, the child will affect the behavior and beliefs of the parent (Bronfenbrenner, 2005).
When observing the HIV family as an ecological unit, a community exists that allows the family to participate individually or as part of the group so that a change in one unit affects other units or the entire community. Since the literature on growing up with HIV is relatively new, studies on chronic illnesses such as asthma, sickle cell, and cancer described in research studies conducted by Gallant (2003) and King et al. (2003) were used as a guide to show how support groups and family are essential components in promoting the management of chronic disease.

**Sexual relationships**

In a recent abstract, Ferrer et al. (2012) reported that 77 perinatally infected young adults enrolled in a study to evaluate their sexual behavior. The sample enrolled 13- to 21-year-old male and female subjects, median age 16 years, 43.2% female, and 90.5% Black. One-third of the sample reported being sexually active, and the mean age of sexual debut was 16. All sexually active youths were aware of their HIV status, and only 9% disclosed their HIV status to the partner. Those with virological suppression < 1,000 copies/ml reported consistent use of condoms. The sexually active perinatally infected young adults were more likely to have a history of marijuana and alcohol abuse.

The four studies below described HIV-infected adolescents’ perceptions of sexual relationships. Adolescents discussing HIV described the stigmatizing circumstances when they overheard teasing conversation about their HIV status. Colbert, Kim, Sereika, and Erlen's (2010) description in secondary analysis using Goffman’s (1963) model of stigma to examine the relationship of social support, health status and HIV stigma found the three different types of stigma relevant to the concerns of the HIV-infected adolescent: (a) “abominations of the body,” such as the skin infections or physical deformities associated with HIV at a time when adolescents value their physical appearance; (b) “blemishes of individual character,” if the
adolescent was viewed as homosexual or sexually active because of the mode of disease transmission; and (c) “tribal stigma of race, nation,” where the majority of HIV transmission occurred through lineages and infected all members of the family.

Teitelman, Bohinski, and Boente (2009) explored girls’ reactions, conflicts, and challenges regarding their sexual health. The participants consisted of 33 African American and European American female teens; 15 African Americans, 15 White Americans, and 3 biracial individuals whose ages ranged from 14 to 18 in grades 9–12. The interview consisted of semi-structured and open-ended interview questions. The two major groups (African American and European American) included similar numbers of lower income teens (51%) and higher income teens (48%). Thirteen of the adolescent girls lived with a single parent, nine of them lived with both parents, four were living with a stepparent, and the remaining seven lived with grandparents, foster parents, or guardians. This study described how adolescent girls learn about sexuality, relationships, and social support. The participants listed family, friends, peers, partners, school, and the media as the most common sources for learning about sexual health. The authors reported the information given to the adolescent girls about their sexual health needed clarity to help the girls cope with the stress in their daily lives.

Varied expectations of social support and stigma exist in the literature for sexually active men and women living with HIV. Several researchers (Dowshen, Binns, & Garofalo, 2009; Galvan, Davis, Banks, & Bing, 2008; Smith, Rossetto, & Peterson, 2008) suggested that women experience the stigma and shame of HIV in greater proportion than men, and that available social support does not exist to help women with the embarrassment and other factors they experienced.
Janson and Sloan (1991) suggested older patients who lived for a long period with HIV provided reliable outcome data showing the importance of extended family social support. In the event of a parent’s death, many grandmothers raise their grandchildren. Children with HIV may lose a parent, experience grief over their loss and significant disruptions to their home and family life, such as living in foster care or the care of another relative. The current study is important because patients with pediatric HIV have not lived long enough to saturate the literature and provide sufficient information and outcome data for a thorough analysis.

**Foster Care and HIV**

Foster care is an important aspect of the young adults’ social support experience. Kools, Paul, Norbeck, and Robbins (2009) described the health and illness of adolescents in foster care. The authors used descriptive analyses to show the dimensions of health of 105 adolescents in foster care. In this study, 38% of the adolescents lived in long-term foster care. The significance is that those children grew up away from a conventional home and experienced interrupted periods of family living. Gramkowsk et al. (2009) reported on adolescent health problems experienced by troubled youth. The authors reported a reduced amount of risk behavior problems among younger adolescents placed in alternative care with supervision. In the study, as the children grew older they reported experiencing poor health, physical abuse, attempting suicide, or parental death.

Mellins and Ehrhardt (1994) conducted semi-structured interviews on the psychosocial impact of HIV on 25 family members guardians and children infected with HIV. African Americans and Latinos from low socioeconomic backgrounds participated in the study. The majority of the caregivers were women who were single heads of the households, including birth mother, grandmother, and foster-care or adoptive parent. The single-parent caregivers, especially
the HIV mothers, reported being overwhelmed with the responsibilities of caring for the HIV-positive child. The HIV-positive children reported helplessness and vulnerability when a parent died. The authors reported that the caregivers required many services, such as time away from administering care to lessen stress and at the same time fill the needs of the HIV-positive child.

In an Italian study, Melvin and Sherr (1993) reported that disclosure of the children’s HIV infection to preschool centers is not a usual practice, and nondisclosure still occurs in the United States. The study examined the psychosocial needs of 18 Italian children with AIDS and HIV. Eight boys and 10 girls up to 12 years old participated in the study. Nine of the children were under two; five were in the two- to five-year age range; three in the six- to nine-year category, and one child was over 12. As reported in most studies, the majority of perinatally infected children were living with one HIV-positive parent (CDC, 2008a). Fifteen of the children in this study lived with their mothers, of whom 60% were single mothers. For 77% of children, the mothers were HIV positive; 44% of the fathers were also HIV positive; and 55% of children had siblings. The authors reported that many mothers had periods when they could not care for the children. These difficulties affecting parenting activities are reported in other studies as well (Abada’A-Barrero, 2002; Reyland, Higgins-D’Alessandro, & McMahon 2002) . Thus, the effects of HIV and its associated illnesses is a primary reason for placement in care outside of the home.

**Adolescents’ Health**

Studies have reported HIV diagnosis as a chronic illness. King et al. (2003) in a qualitative study described participants’ resilience in chronic disabilities. A total of 15 people with disabilities described the obstacles they faced living with a chronic illness. The triggers, turning points, barriers, and solutions to the problems provoked many emotional responses from the group. Meaningful and vivid emotions were experienced when the turning points or
exacerbations of the HIV illnesses occurred. This study supports the findings in the literature that protective factors such as social support and family involvement determined the individual’s ability to adapt to HIV as a chronic illness.

In a qualitative study, Baumgartner (2007) reported three important occasions when people disclose HIV illness: (1) when a combination of surprise, panic, denial, and liberation of the disclosure to significant others occur; (2) when there is a need for public disclosure; and (3) when a reason to disclose exists. The author also reported that the timing of all three points, and when significant events occurred was an important factor, which allowed them to incorporate HIV concerns; but poor health forced the infected person to instantly disclose HIV.

In a retrospective (52 weeks) cohort study conducted at a pediatric medical center in Washington, D. C., data from 127 HIV-infected children (60 boys and 67 girls; mean age 9.9 years) were collected to measure medication adherence. The information collected from clinical and research databases revealed that 24% of patients had 100% adherence and 40% of patients rarely or never achieved complete adherence (Khan et al., 2009). Steele and Grauer (2003) compared and evaluated 13 empirical studies of children's adherence to HAART and summarized that the use of HAART in children and adolescents appeared to be less than optimal, since very few investigations identified the causes of poor adherence.

Secrecy in families prevails and encourages children infected with HIV and their families to live apart from the community. Often and within the family structure, adolescent support may be absent, especially when the family needs help adjusting to living with HIV. Therefore, outside support, such as the community, becomes the primary support when living with HIV (Abada’A-Barrero, 2002).
Battles and Wiener (2002) reported findings similar to previous adolescent studies. Cohen, Gottlieb, and Underwood (2001) suggested social support was negatively correlated with problem behavior in HIV-infected children who are more likely to survive to adolescence and beyond. Their psychosocial needs resulting from HIV appeared similar to the needs of a child with a chronic infection, as opposed to one who is mortally ill. The authors also suggested families of HIV-infected children should help them plan for living longer, which included preparing adolescents for independent living.

Barbarin, Whitten, and Bonds (1994) conducted case reviews and focus groups to develop clinical profiles of 327 poorly adjusted children with sickle cell anemia in a comprehensive sickle cell clinic in a predominantly poor and urban population. In describing risk and resilience in adjustment to sickle cell disease, the authors used clinical profiles and quantitative data to report the findings on the social environment, emotional behavior, academic achievements and failures. They also collected family adjustment data from a plurality of parents. In the study, 20% of the children had problems related to behavior and scholastic ability.

Cancer is another serious illness that can be compared with a chronic disease such as HIV. Claflin and Barbarin (1991) observed that parents tell young children less about the disease progression of cancer than is told to older children and adolescents, in a desire to prevent information overload or worry, but parents reported similar levels of distress related to disclosure in both groups. In the study, there were 43 children diagnosed with cancer who reported the information given to them and the reason they were told of their health status. Consistent with parental reports, children under nine (42%) were told less about HIV than children 9–14 years of age (35%) and adolescents (23%). In summary, parents felt more comfortable disclosing to older children and adolescents.
Transition

Transition from pediatric care to adult care is a major challenge and there is very little empirical research published about the perinatally infected HIV adolescent transition (Soanes & Timmons, 2004). Vijayan, Benin, Wagner, Romano, and Andiman (2009) used qualitative methods to collect data from open-ended interviews to describe transitioning the medical care of children with perinatally acquired HIV from pediatric care to internal medicine. The challenges described in caring for adolescents were poor adherence to medication regimens and adolescent sexuality. The majority (80%) of adolescents reported pressure to engage in sexual activity, and less than 3% had sex without disclosure of their illness to the partner. Many participants were unsure about feelings about sex and dating because many of them lived in unstable or temporary homes. The majority of adolescents in the study (80%) lived with adoptive parents. The study listed barriers to transition: (1) families’ negative perceptions of the new medical providers; (2) an impractical expectations of the adolescents’ abilities; and (3) difficulty letting go of old relationships (Vijayan, Benin, Wagner, Romano, & Andiman, 2009). The adolescents, guardians, and providers described a familial relationship and fear about ending the old relationships and developing a new relationship with a new caregiver.

Although stigmatic barriers (Goffman, 1963) are among the challenges people with HIV experience during transitioning, the environmental barriers described by Glenn and Wilson (2008) can inform health-care providers on how to construct successful transition programs. This study, through its focus group format in an African American church, provided information about the strengths and weaknesses in order to plan culturally appropriate interventions.
Peer Relationships

The articles in this section provide a general overview of peer relationships of adolescents with HIV. In order to understand the role of peers in assisting the young adult living with HIV, Harris and Larson (2007) reported that peer counselors fostered hope in HIV-infected young adults. Peer counseling provided the means to combat stigma and isolation. The authors stated that a consensus often occurred between peer counselors and client. The study enrolled 12 HIV-infected participants living with the HIV virus for at least two years. The majority held roles as peer counselors (75%), and 91% of them had received the benefit of peer counseling following diagnosis. According to the authors, the findings suggested that peer counseling and peer relationships facilitate hope for people living with HIV.

Over the years, many studies have reported similar factors related to HIV relationships. Bastardo and Kimberlin (2000) compared the relationship between health-related quality of life (HRQL), social support, and disease-related factors in HIV infection. In this exploratory study, the authors conducted a survey using a paper-and-pencil questionnaire about social support with 118 HIV-infected people living in Caracas, Venezuela. The study indicated social support is important to individuals growing up with HIV.

Villarruel, Jemmolt, Howard, Taylor, and Bush (1998) administered a paper-and-pencil questionnaire and focus-group interviews on the understanding, attitude, and sexual behaviors of inner-city adolescents and their peer educators. The sample included 33 African American adolescents (42% female, 58% male, 55% adolescent, 45% peer educators) 14–24 years of age. The participants had exceptional knowledge of how HIV affects their lives which included condom use, and attitudes regarding condom use. They also reported low perceptions of their susceptibility to HIV infection. Education reduced high-risk sexual behavior especially with the
peer educators. In comparison to individuals in the above sample, Friedland, Renwick, and McColl (1996) reported lower levels of social support in a similar HIV-infected sample of Canadians, a sign that the ambivalent attitudes of family and friends were similar to those of individuals in the Venezuelan sample. The findings supported previous research showing there is a relationship between how people living with HIV describe HRQL and social support (Friedland, Renwick, & McColl, 1996).

**Summary**

Despite the increased availability of HAART and its effectiveness against HIV, mothers with AIDS continue to deliver perinatally infected babies, and the epidemic continues to increase in some parts of the world, such as Russia. Perinatal HIV remains a concern, particularly with African American young adults in the District of Columbia. The goal of this HIV perinatal literature review was to summarize, describe, and explain the findings on social support, health, peer relationships, education and employment among young adults living with HIV since birth.

The empirical research on social support among HIV-infected young adults is scant (Lee et al., 2007). Studies have examined specific characteristics of support, such as the size of social support networks (Thoits, 1995). Not surprisingly, negative social support results in negative outcomes (Dalgard et al., 2006), and positive social support contributes to positive outcomes (Cohen, Gottlieb, & Underwood, 2001). Social support and peer relationships are both essential to young adults living with HIV; therefore, additional information is required about the experience of the years of living with HIV. When there is a transition from a parent-dependent child to a fully autonomous adult, peers take on a major role in influencing the young adult’s actions. Although the peer influences are not always helpful or positive, there is hope that young adults will resist negative peer influences and risky behaviors.
Thirty-three years ago, it was inconceivable that perinatally infected newborns would become productive members of society with access to education and economic preparation. HIV is a chronic illness against which HAART has been used successfully.

The HIV disclosure literature has examined some concern about how much information about the disease is necessary to share with the child growing up with HIV. When parents die, children are most vulnerable and experience much anxiety from stigma. The highest rates of functional difficulties were found in boys (Dowdney, 2000). The death of a parent is the most distressing event in a child’s life, and children may demonstrate behavioral patterns of violating the rights of others and poor school performance (West, Sandler, Pillow, Boca, & Gersten, 1991). Some authors disagree about the benefits, disadvantages, or proper timing of disclosure, but at this point the information about the disclosure process with children or adolescents infected perinatally is only a guide for practitioners.
Chapter III

Methodology

Very little is known about young adults growing up with HIV, and many questions remain unanswered about what this chronic illness means to this unique population. The central question in this phenomenological research is, “What is the meaning, structure, and essence of this lived experience?” Thus, the hermeneutic phenomenological inquiry method was selected for the current investigation (Van Manen, 1990, p.66-67). The approach developed by Max Van Manen was used to explore the young adults’ perceptions of their lifeworlds as experienced growing up. This chapter focuses on the methodology of the study, which included the philosophical orientation of phenomenological design, reflections of the researcher, assumptions, sample size, setting, participants, protection of human subjects, instrumentation, data collection procedure, and analysis plan.

Phenomenology: Philosophical Orientation

Philosophical hermeneutics refers to” the theory of knowledge” initiated by Martin Heidegger (Grondin, 1994, p2). The term “phenomenology” is described in the 18th century text of Immanuel Kant (Cohen, 1987). The phenomenological tradition has made strong contributions to the discipline of philosophy. Phenomenology grew out of “a critique of positivism when applied to human concerns” (Cohen, 1987, p. 31).
To prepare for this investigation, it was essential for the investigator to understand how phenomenology is used. Phenomenology is an accepted term used in multiple fields of studies and described differently. Van Manen (1990) stated, “phenomenology asks for the very nature of a phenomenon for that which makes some-‘thing’ what it is” (p. 10). Husserl (1970) described phenomenology as a philosophy. Denzin and Lincoln (2000) described it as an inquiry paradigm, an interpretive theory. Moustakas (1994) used phenomenology as a research method framework. Polkinghorne (1989) explored the structures of consciousness in human experiences using phenomenology.

Van Manen (1990) emphasized the experiential aspects of the concept of “lifeworld” (p. 184). Husserl (1964), a preeminent philosopher, and Dowling (2007) also suggested that “lifeworld” is how the person understands an experience. Prior to the phenomena, the individual encounters seeing, clarifying, determining the meaning and distinguishing meaning” of the event (Husserl, 1964, p. 58). Phenomenological research seeks to describe rather than explain, starting from a perception free of hypotheses and presumption (Husserl, 1970).

Max van Manen was born in 1942 in the Netherlands and migrated to Canada in 1967. He taught for several years in Edmonton Public Schools, completed an MEd (1971) and a PhD (1973) at the University of Alberta, Edmonton. He was a professor of secondary education in research methods, pedagogy, and curriculum studies. He is presently professor emeritus at the University of Alberta and adjunct professor at the University of Victoria, where he conducts summer seminars in ongoing inquiry in phenomenology and pedagogy (Van Manen, 2013). Van Manen provided a phenomenological approach to research that is frequently used by nurses (Dowling, 2007; Munhall, 2007).
For Van Manen (1990), the experience provided by the individual is, “the description of the lived experience” (p.54), and this method was used to describe the experience of the young adult living with HIV. The description of experience in this study focused on young adults living with HIV without the researcher’s personal biases affecting the interpretation of the personal experiences provided by the participants.

To produce lived-experience descriptions, Van Manen (1990) suggested the following: “(1) describe the experience the subjects lived in; (2) engage in the phenomenological reflection which involves conducting thematic analysis; (3) describe personal experiences and emotions; (4) explore the phenomenon and generate data; (5) focus on a precise and truthful account of the phenomena; and (6) avoid fancy phrases to explain the phenomenon” (pp. 64–65).

Van Manen (1990) suggested that there are several ways to structure phenomenological research: “thematically, analytically, exemplificatively, exegetically, existentially, and inventing” (pp. 168–173). This research used thematic description. In addition, Van Manen proposed four fundamental lifeworld themes that are helpful guides: “(1) lived space (spatiality), is felt space; (2) lived time (temporality), is when we are happy and enjoying life; (3) lived body (corporeality), is knowledge of our body and our relationships; and (4) lived human relations (relationality or communality)” (p. 101). While these four themes can be identified, they cannot be separated in the lived world of experience; they are all related to the human experience (Van Manen, 1990).

**Study Design**

Phenomenology is a deeper understanding of the meaning of everyday life, and the purpose of this phenomenological study interpreted the study participants’ journeys, lived experiences, learning experiences, recent events, people, and situations that affected the young
adult growing up with perinatally transmitted HIV. This research investigated the phenomenon of living with HIV in each of these areas. With human subjects, this normally means gathering information and perceptions through qualitative methods such as interviews, discussions, observation, and representing the data from the perspective of the research participants. Investigating the lived experience involves “searching the lifeworld for lived experience materials that, upon reflective examination, might suggest a fundamental nature” (Van Manen, 1990, p. 53). For the current study, the primary form of data collection was the hermeneutic interview. In phenomenology, the interview serves as a means of exploring and gathering information for the narrative, and it can be used as a process to develop a “conversational relation with the participant about the meaning of the experience” (Van Manen, 1990, p. 66).

A semi-structured lifeworld interview attempts to elicit the themes of everyday lived experiences from the participants’ own perspectives. Kvale and Brinkmann (2009) proposed that the aim of the interview is to seek a description of the lived experience, including specific situations and events, with the interviewer exhibiting openness to new and unexpected phenomena. For the current study, a hermeneutic semi-structured interview guide (see Appendix C) provided open-ended questions to facilitate the interview process. Several experts on HIV reviewed the interview questions for relevance and face validity (Anastasi, 1988). Using the phenomenological research method, the participant’s responses guided the research project (Van Manen, 1990). The young adult provided personal knowledge, perceptions, and interpretations of the phenomena of growing up with HIV.
Setting and participants

The study was conducted in a private office at Children’s National Medical Center in a large metropolitan area. The setting provided a comfortable atmosphere for the participant and privacy for conducting the 60 90-minutes interview.

Participants and sample formation.

Following approvals by the Institutional Review Boards (IRBs) of Catholic University of America and Children’s National in Washington, DC, a purposive sample of adolescents and young adults with perinatal HIV were recruited from the Special Immunology Services (SIS) at Children’s National Center in Washington, D.C. Once a week, the SIS team members identified and contacted participants who met the study criteria and introduced them to the study. The nurse researcher contacted the participants who were agreeable and scheduled a convenient time to enroll them in the study.

The SIS clinic provides specialty medical services to children and adolescents perinatally infected with HIV up to 24 years of age. The SIS Clinic is staffed with attending physicians, residents and nurses. The clinic hours are Monday through Wednesday and patients are scheduled quarterly or as needed for physical examinations and laboratory assessments. All patients and families are eligible to receive childcare, emergency financial assistance, food vouchers, case management, transportation, mental health services, substance abuse services, and treatment adherence. In the main clinic, there are approximately 175 perinatally infected children and adolescents, of whom approximately 20 young adults met the criteria for the study. Of the sample, 90% were African American/non-Hispanic; 5% White/Hispanic; and 5% other or mixed ethnicity.
A purposive sample is commonly used in phenomenological inquiry. The power of purposive sampling provides theoretical saturation when the participants no longer generate new information (Higginbottom, 2004). Purposive sampling seeks detailed information from the well-informed participants (Patton, 2002). This method enrolled a sample of individuals with the experiential knowledge of a phenomenon for the purposes of telling their lived experience (Speziale & Carpenter, 2007).

Participants met the following inclusion criteria: (a) had a documented diagnosis of perinatal HIV; (b) expressed a willingness to participate in an interview in the clinic setting at Children’s National and follow-up data clarification phone calls if necessary; (c) were able to read and speak English; and (d) were between the ages of 18 and 24. An invitation (see Appendix D) to participate in the study was disseminated at the Special Immunology clinics throughout the Children’s National main campus by the Director of the Special Immunology Services.

**Sample size with justification**

Seventeen (17) young adults who met the criteria of the study were enrolled. Van Manen (1990) did not indicate a specific sample size for his phenomenological method; others suggested the sample should be 6–12 participants (Haase, 1987). To determine an appropriate sample size, the plan was to collect a great deal of information from a small number of participants ($n = 17$). The data were obtained from responses to interviews and questionnaires (see Appendix B).

**Protection of human subjects**

To protect human subjects, the following are essential: ethical principles of autonomy, beneficence, and justice (Orb, Eisenhauer, & Wynaden, 2001). The following concerns are addressed in this section: informed consent, benefits and risks, and confidentiality. Written
informed consent is an essential document in the conduct of ethical research (U.S. DHHS, 2001). The investigation consent form (see Appendix A) includes the requirements for informed consent in research as outlined by the Code of Federal Regulations 45, Section 46.116 (U.S. DHHS, 2001): a statement that the study involves research; an explanation of the purpose of the research; a description of the procedures in the study; the expected duration of the study; a description of any foreseeable risks or discomforts; a description of the benefits to the subjects; a statement describing confidentiality of records and identifying the subject; information that the data collected were secured by using passwords and encryption; audio and/or video recordings of subjects were transcribed and then destroyed to eliminate audible and visible identification of subjects; and information about the Health Insurance Portability and Accountability Act (HIPAA), the privacy law that protects individually identifiable health information (protected health information, or PHI). This privacy law requires the participant to sign an agreement permitting researchers to use or share the PHI for research purposes. This section described how information may be used or shared in the research study. Included in the consent form was information about the individual the participant should call in an emergency and the participant’s right to terminate the interview or request that the audio recorder be turned off. Finally, the collection of sensitive information about subjects was limited to the amount necessary to achieve the aims of the research, so that no irrelevant sensitive information is collected.

Prior to the start of this investigation, the IRBs of Catholic University of America and Children’s National reviewed the research procedures. IRB approval was necessary to facilitate research subject recruitment and enrollment. The participant was contacted in person by the attending physicians or medical staff of the Special Immunology Services at Children’s National and informed about the study. A convenient time to enroll in the study was discussed. If the
participant agrees, the consent form was made available for review followed by a verbal explanation of the study by the nurse researcher. In addition, the participants were given enough time to have their questions answered prior to the actual participation in the study. A private area was used for this study to assure confidentiality. The consent stated that the participant could withdraw at any time without reprisal.

The completed demographic questionnaires and transcribed interviews were assigned codes, kept in a locked cabinet in the investigator’s office and separated from the consent documents to assure anonymity. The computer containing the study data was password protected, and electronic databases with patient identifier data was user-access protected. All information regarding the subjects remained confidential and access to the database was restricted to the research staff.

There were no immediate risks anticipated for participation in this study. However, if a participant exhibited signs suggesting emotional distress during the interview, the interview would have been stopped if requested, but there were no young adults exhibiting emotional distress during the study. The investigator planned to provide emotional support and refer the individual to an appropriate source after consultation with the director of Special Immunology services. Potential benefits of participation in this investigation include offering the participant an opportunity to talk about their experiences and concerns in a confidential environment and potentially gain personal insights into the participant’s life growing up with HIV.

**Instrumentation**

In phenomenological research, the interview serves as the primary instrument. An interview guide was used to structure the interview (see Appendix C). The second instrument was the demographic questionnaire (see Appendix B) to collect information about the
participant’s gender, age, race, employment status, (type of occupation), marital status, siblings, education level, children in the home, activities in the home, description of health, adherence, risk exposure, and access to health care. The participant’s diagnosis and viral load were confirmed by the Special Immunology staff.

The nurse researcher conducted the semi-structured interview to ensure a similar interview style throughout the research. The researcher had a list of questions (see Appendix C) that covered specific topics listed on the interview guide and allowed the interviewee a great deal of leeway in the response. Every attempt was made to ask the questions and prompts were used exactly as outlined on the schedule. Questions that are not included in the guide may have been asked based on how the interviewees respond. Introductory questions, follow-up questions, and probing questions were asked throughout the interview. Specific questions and direct questions, such as “Are you happy?” were asked toward the end of the interview, in order to not influence the direction of the interview. Kvale (1996) recommended that interviewers be clear, knowledgeable, and sensitive and allow periods of silence.

**Procedure for Data Collection**

One questionnaire was collected from each participant. The procedures for data collection were as follows:

1. At the time of initial contact between the investigator and the prospective participant, the information about the study was provided, and the participant was interviewed to confirm the eligibility criteria.

2. If the participant met the criteria and agreed to participate, an interview was scheduled in the clinic.
3. In preparing for and prior to each interview, the investigator reflected on personal beliefs, preconceptions, intuitions, motive, and biases to achieve a state of “openness.” These thoughts were recorded in a personal journal when describing emotional experiences of the researcher, like field notes.

4. At the beginning of the interview, the investigator obtained an informed consent, and the participant completed the demographic questionnaire.

5. The investigator assigned a code or number to the demographic questionnaire and then placed it in a sealed envelope. The coded completed questionnaires were stored by the investigator in a secured facility separate from the interview tapes and transcripts.

6. Two digital audio recorders were placed on a convenient surface so that the investigator could control the devices at all times. Two recorders were used to ensure recording in the event of mechanical failure of one of the recorders. Participants were reminded that at any time during the interview they could request the recording devices be turned off for any reason.

7. Consent for audio-taping was verbally acknowledged at the beginning of the tape-recorded interview. The lead question was presented, and the interviewer interjected probe questions during the interview. The interview lasted about 60-90 minutes. When complete, or upon the request of the participant, the tape recorders were turned off. The code number was verbally noted at the beginning and end of each taped interview.

8. The investigator requested permission from all of the participants to contact them by phone if clarification of the narrative material was needed.
9. The audio recordings, consents, and demographic questionnaires were secured in separate locked drawers. The recordings were deleted after the completion of the dissertation defense and in compliance with IRB rules.

10. A professional service, Franklin Square Services Inc. was used to transcribe the interview tapes. Upon receiving the transcribed records, the investigator listened to each recording to detect and correct transcription errors. The de-identified information was shared with the research advisors.

11. Written transcripts, consents and other materials will be preserved for three years upon completion of data analyses and then shredded in compliance with IRB rules.

12. In responding to the study questions, the participant could share sensitive HIV information with the researcher. To further protect the participants’ privacy, the nurse researcher obtained a Certificate of Confidentiality from the National Institutes of Health. With this certificate, the researcher cannot be forced to disclose any information that may identify the participant, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceeding.

**Data Analysis Procedures**

The data derived from the demographic questionnaire were analyzed to obtain descriptive information about the participants. A qualitative analysis approach was used to organize the narrative transcript data and the thematic notes. The two sources of data collection strengthen the study and give different perspectives.

Franklin Square Services Inc., Chapel Hill, N.C. a qualitative transcription company, transcribed the interview. The field notes were collected in the form of field experience logs or diaries and notes on themes of the study. The analysis consisted of looking for patterns that
might emerge, creating relationships (Lincoln & Guba, 1985). The researcher condensed raw data into codes and established links between the research questions and the findings. A thematic analysis of the data was created to describe the lived experiences of growing up with HIV. The data were summarized and linked to the lifeworld themes from the participants’ responses under the following headings of the interview: (1) family life and HIV social support, (2) health concerns, (3) peer relationships, (4) economic and educational status, and (5) HIV disclosure. The information gathered was sorted into themes on lived space, lived time, lived body, and lived human relations (van Manen, 1990). Additional researchers double-checked the codes and themes for accuracy. Research Electronic Data Capture (REDCap) was used to analyze the descriptive data.

**Techniques for Establishing Credibility, Transferability, Dependability, and Conformability**

Unstructured interviews are the mode of choice when the interviewer does not know the answers to the questions and must therefore rely on the respondent to determine the trustworthiness of qualitative inquiry. The criteria for determining the trustworthiness of qualitative inquiry, namely credibility (Denzin & Lincoln, 2000; & Koch & Harrington, 1998) and transferability, dependability, and conformability are discussed below.

The techniques for establishing credibility were as follows: (1) engagement in which sufficient time was spent in the interview creating relationships and rapport with members of the culture; (2) persistent observation during the interview providing additional meaning to the interview; (3) peer debriefing examined and support the emergent hypotheses; 4) negative case analysis involved searching for and discussing elements of the data that contradicted patterns
anticipated; (5) referential adequacy or a portion of data was archived, but not analyzed; and (6) member-checking (Lincoln & Guba, 1985).

The researcher gained the participants’ trust by having of the Special Immunology staff introduce her and establishing rapport with the participants. This gave the participants the comfort and freedom to discuss their views and experiences, increasing the rigor and trustworthiness of the research findings (Lincoln & Guba, 2000).

In establishing credibility, the development of rapport and trust facilitates understanding. The investigator established credibility through peer debriefing of the categories, interpretations, and conclusions and member checking with participants from whom the data were originally collected. Through this process of debriefing, the researcher could become aware of the participants’ attitudes toward the data and the analysis. In qualitative research, rigor is needed to show the credibility of the research (Lincoln & Guba, 1985). Credibility allows for the vividness and faithfulness of the interpretation of the phenomena (Koch & Harrington, 1998).

The use of member checking is also useful for establishing the validity of qualitative research. Member checking relies on the assumption that there is a fixed truth of reality that can be accounted for by a researcher and confirmed by a respondent. The members and researchers in a scholarly project may recall the interview differently. These perceptions could result in different findings reported in the data. It is also possible that the information obtained in the interview could make the members feel embarrassed. Also, the members may have poor memory. They may forget the important details of the interview, or have different views of the same data (Sandelowski, 1993).

Transferability means describing a phenomenon in vivid detail and is the responsibility of the investigators, who must engage in continuous data analysis so that all pertinent
information is reported from the research. Transferability is the degree to which the results of qualitative data can be generalized or transferred to other settings. The investigator has the responsibility to provide a database that makes transferability judgments possible for new researchers and to describe the research assumptions and findings that were central to the research (Lincoln & Guba, 1985). Thus, transferability of the research findings to other settings is also very important in qualitative research (Hammersley, 1992).

Audit inquiry is a technique used to establish dependability. External audits promote the accuracy or validity of a research study. They also provide an opportunity for an independent person to challenge the process and findings and to adequately assess preliminary results and final data leading to more strongly articulated findings. The drawbacks to external audits share many of the same problems as member checking. An external auditor may disagree with researchers’ interpretations, and then the question of whose interpretation should stand becomes an issue (Lincoln and Guba, 1985).

Quantitative research gives several examples of reliability: (1) the degree to which a measurement, given repeatedly, remains the same; (2) the stability of a measurement over time; and (3) the similarity of measurements within a given time period. Qualitative research describes dependability and examines both the process and the product of the research for consistency, which enhances dependability. Since there can be no credibility without dependability, a demonstration of the former is sufficient to establish the latter (Lincoln and Guba, 1985).

Confirmability is “the degree to which the researcher can demonstrate an unbiased interpretation of the results through a confirmability audit (Lincoln and Guba, 1985, p321)” An audit trail may consist of any of the following: 1) raw data, 2) analysis notes, (3)
reconstruction and synthesis products, (4) process notes, (5) personal notes, and (6) preliminary developmental information (Lincoln and Guba, 1985). In the current study, notes were listed as field notes and all of the above were carefully examined with the dissertation committee to allow for a vigorous report on the findings of the study.

**Limitations**

The investigator adhered to strategies for protection of research participants while preserving the integrity of qualitative investigation. Qualitative research produces many ethical problems about which researchers must ask the gatekeepers for permission to interview the participants, with the assurance that the person in charge holds the power to permit the research activity (Holloway & Wheeler, 1995). In this study, the IRBs and the Director of Special Immunology at Children’s National granted permission to conduct this research. Researchers often recognize the conflict between recognition of the rights of the research participants and conducting the research (Sim, 1991), or they may experience problems being a researcher or a professional caregiver (Fowler, 1988).

In qualitative methods, the researcher repeats the consenting process several times during the interview. As the study began, the participant’s knowledge of the specific focus of the research was limited and the ideas expressed from the collection of the data during the interviews focused mainly on the meaning and interpretations expressed by the participants. Ramos (1989) suggested empathic association between the researcher and the participant decreased anxiety and concern while allowing the research to continue.

Ramos (1989) wrote that the design, the researcher’s interpretation of the subjective data, and the researcher-participant relationship can present three types of problems that may
Weaken qualitative studies. This is because qualitative findings of the research are not tested to determine statistical significance (Leininger, 1994). In addition, the findings in qualitative approaches cannot be generalized to the same degree as quantitative analyses.

**Summary**

This chapter provided a description of the philosophical orientation, design, setting, sampling, human subjects’ considerations, instrumentation, and general steps for data collection and analysis for the current study. This research is feasible and was conducted using the phenomenological approach informed by the work of Van Manen (1990). The method consisted of semi-structured interviews, questionnaires, and several types of field notes. All interviews were transcribed verbatim, and these transcriptions of the audio recordings, observations, and all written documents collected from the participants were the text used for the data analysis. Rigor and credibility were the criteria used to ensure quality in this research. The phenomenological approach suggested by Van Manen (1990) was used as the study design to reveal the experiences of young adults growing up with HIV.
Chapter IV  
Presentation of Findings

The purpose of this phenomenological study was to describe the essential themes of the participants’ perceived journeys, lived experiences, learning experiences, recent events and situations that affected growing up with HIV. The investigator grouped essential themes to determine the phenomenon (Van Manen 1990).

The application of Van Manen’s (1990) interpretative framework allowed the researcher to explore the phenomenon of the lived experience of young adults growing up with HIV. To present the findings of this investigation, the chapter is organized as follows: (a) the study aims: (b) the hermeneutic semistructured interview; (c) a description of the participants; (d) an overview of the essential themes; and (e) a description of the participants’ experiential lifeworld situations growing up with HIV.

The Aim

Aim #1: What are the experiences of perinatally HIV-infected young adults growing up with HIV?

Aim #2: What meanings do perinatally HIV-infected young adults ascribe to their experiences?

The following sub-questions were pursued: (1) How is living with HIV expressed by young adults? (2) How do young adults growing up with HIV describe available social support? (3) How does HIV affect a typical day in the life of young adults who have grown up with HIV? (4) How does the HIV condition affect the relationship with family and friends in young adults who have grown up with HIV? (5) What are the expectations of young adults living with HIV.
over time? (6) How were the young adults who have grown up with HIV told they have the disease? (7) Do the young adults who have grown up with HIV think often of HIV? and (8) How are health concerns expressed by young adults who have grown up with HIV?

**Hermeneutic semi-structured interview**

During the interview, the participants provided a vivid description of the lived experience, including specific situations and events, with the interviewer exhibiting openness to the participants’ responses. For the current study, a hermeneutic semi-structured interview guide (see Appendix C) provided open-ended questions to facilitate the interview process. Several experts on HIV reviewed the interview questions for relevance and face validity as suggested by Anastasi (1988). Using the phenomenological research method, the participants’ responses guided the research project. Phenomenology research does not problem-solve. The phenomena required novel questioning which is considered unique in that the questions cannot be positively solved (Van Manen, 1990).

The study employed the hermeneutic phenomenological inquiry approach described by Max van Manen to explore the young adult’s lifeworld as experienced in everyday life. In order to provide a more in-depth description of Van Manen’s methodological research activities, the young adults provided personal knowledge, perceptions, and interpretations of the phenomena of growing up with HIV.

Van Manen (1990) suggested that all phenomenological human science research efforts “are really explorations into the structure of the human lifeworld - the lived world as experienced in everyday situations and relations” (p. 101). These existentials will be used as an interpretive guide for a discussion of the themes in Chapter V.
Van Manen’s themes include: “turning to the nature of the lived experience, investigating the experience as we live it, reflecting on essential themes, the art of writing and rewriting, maintaining a strong and oriented relation and balancing the research context by considering parts and whole” (p. 31).

The study procedure

For the current study, experiential data were gathered from seventeen young adults who receive medical care from the SIS and Burgess clinics at a large urban children’s hospital on the East Coast. The study activities lasted approximately 90 minutes and consisted of the consenting process, the demographic questionnaire and the interview.

A purposeful and convenient sample was recruited for this study. Recruitment lasted three months. The study was introduced to the participants by nurses, social workers and physicians in the SIS and Burgess clinics at a large urban children’s hospital on the East Coast. A total of 10 participants declined the invitation to participate because of conflicts with their busy schedule or lack of access to transportation after participating in the study activities or inability to return for the interview. Twelve participants were willing to participate in the study after their scheduled clinic visits and five participants scheduled appointments at a convenient time and honored those commitments. The consenting process was considered complete after all questions were asked and answered and a signed copy of the consent given to the participant. The demographic questionnaire was completed verbally by the researcher followed by the interview. The interviews were tape recorded with permission from each of the participants. The researcher assigned a number code (A001, B002…) and a pseudo-name (Alvin, Bea, Cassi, Donita, Ella, faith…) to each participant to preserve anonymity.
All data were stored in locked cabinets on a password protected flash drive and computer. All of the study activities were conducted in a private and quiet room located in the CRC at a large urban children’s hospital on the East Coast. The interview room environment had a comfortable temperature, adequate lighting, two chairs and a table. The door was locked and a notice was posted indicating the use of the facility, thus discouraging interruption. Bottled water and facial tissues were readily available on the table for the convenience of the participants. All of the participants were asked to turn off their cell phones.

All interviews were guided by one main question “please tell me what it is like growing up with HIV”. From the literature review, the five areas listed below were the most relevant variables for young adults, especially minorities growing up with HIV and they were used throughout the interview: (1) social support of young adults growing up with perinatal HIV; (2) health-related concerns of young adults growing up with perinatal HIV; (3) peer relationships of young adults growing up with perinatal HIV; (4) economic and education status of young adults growing up with perinatal HIV; and (5) disclosure in young adults growing up with HIV were introduced throughout the interview. Upon completion of the interview, the participants were given a $25.00 gift certificate to the Target department store. The investigator recorded field notes that detailed the young adults’ appearance and gestures during the interviews. Following the interview, the investigator’s personal impressions and the participant’s responses were written in a journal.

Generally, the participants most willingly told their stories with a minimum amount of emotional distress. Tears were noticeable when the participants were recalling events surrounding the death of a mother. The female participants reached for tissues to wipe away tears and usually did not drink the water provided; unlike most of the male participants who drank oor
more 4 ounces bottles of water. The male participants also attempted to hold back tears by wiping their eyes occasionally with their hands.

From the phenomenological perspective, Van Manen’s (1990, p. 10) interpretation is “less interested in the factual status of particular instances” that is, whether something happened, how often it tends to happen or the presence of other conditions and events”. For example, this phenomenological research questioned, “What is the essence of the experience of growing up with HIV” to better understand what this experience is like for the young adults growing up with HIV. In this research three areas were important to learn. The researcher wanted to find out what meaning young adults make of their reality in terms of the phenomenon of growing up with HIV; what meanings did the young adults make about their experiences of being infected with HIV; and what was the subject matter of the phenomenon, that is, what was it really like?

Although each individual experience is different, the participants were coping with an equivalent stigmatizing illness. The researcher’s assumption is that there is a shared understanding among young adults growing up with HIV and that there is an essence that holds a phenomenon or experiences together.

**Van Manen’s Thematic Investigation Guide**

A qualitative method, phenomenology, was used to interpret the data. Detailed understanding of the information was required to gain an in-depth exposure to the young adults’ experiences and interaction with the phenomenon of growing up with HIV. The researcher provided the participants with an advance review of the interview questions. The review helped the participants describe the lived experience when asked open-ended questions. In this phenomenological study, Van Manen’s (1990) theme, turning to the nature of the lived experience, the researcher started with one question, “*tell me what it is like growing up with*
HIV” and continued the interview encouraging the participants’ responses with prompts to guide a description of the essence of the lived experience. After transcribing the participants’ interviews, the researcher then searched for essence within the themes.

Van Manen (1990) explained essence in phenomenology “as a universal which can be described through a study of the structure that governs the instances or particular manifestations of the essence of that phenomenon” (p. 10). To explain what was meant by themes in phenomenology Van Manen (1990) used metaphors to describe everyday-life and his words also have semantic meanings. He suggested words such “a mother’s love” and “parenting” are “more telling about the way we account for certain affectionate interactions than about the deep meanings of those interactions” (p. 49). Patton (2002) also suggested that metaphors communicate findings in a single powerful phrase chiefly as a tool for revealing the event. The researcher formed a likely description for the participants enrolled in this study as “a passing cloud over the brightness of a sunny tomorrow”. In other words, the young adult’s narratives described various forms of uncertainty growing up with HIV that puts a veil on their existence.

This phenomenological study followed the general inductive data analysis format (coding, categorizing and thematizing) in addition to intuiting, analyzing and describing. The researcher engaged intuiting, when the researcher became totally immersed in the process avoiding criticism, evaluation or opinion of the data being collected (Van Manen, 1990; Spiegelberg, 1975). The researcher bracketed all preconceived notions about the phenomenon at hand to the greatest extent possible. This allowed the researcher to understand the experience from the participants’ own point of view. In intuiting, the researcher was responsible for listening to the individual describing the phenomena of growing up with HIV.
Analysis of the data included repeated reading of the transcripts throughout the data collection and transcription periods of the study. Van Manen’s (1990) theme, reflecting on essential themes in this study refers to the process of recovering the themes when the researcher lists every significant statement which is relevant to the topic. As the researcher listened to the data, common themes emerged from the narratives. The process involves identifying the essence of the phenomena (Spiegelberg, 1975). Each statement relevant to the phenomena was valuable. Finally, the researcher wrote a description of the experience.

Describing the data had several verbal and written explanations of the phenomenon. The description was based on grouping statements made by the participants about the phenomena (Spiegelberg, 1975). In the describing process, the researcher groups the statements into clusters of similar meaning units, or themes. The ultimate goal of this phenomenological research was to reveal the essence of the experience of growing up with HIV.

Van Manen’s (1990) method, the art of writing and rewriting is described once the themes were developed. In Van Manen’s (1990) method of thematic description the researcher engaged in phenomenological writing. The process of writing and rewriting is the art of the method used in the study. In this process, common themes were written to capture the essence of their meaning allowing the researcher to develop and describe the narrative text of the lived experience of growing up with HIV.

Van Manen’s (1990) method of maintaining a strong and oriented relation is to remain true to the data research. In this process, the researcher is absorbed in the phenomenon and does not become distracted. During this stage, the researcher is engaging in thoughtful analysis of the themes, staying focused on the lived experience of the participants. This stage does not permit premature speculations or “narcissistic reflections” (p. 33).
The method balancing the research context explained how parts and whole common themes from the interviews were extracted from the data analysis. In the final thematic description, the researcher used Van Manen’s four fundamental lifeworld themes “(1) lived space (spatiality), is felt space; (2) lived time (temporality), is when we are happy and enjoying life; (3) lived body (corporeality), is knowledge of our body and our relationships); and (4) lived human relations (relationality or communality)” (p. 101). According to Van Manen, these four themes were identified in the lived world of human experience (Van Manen, 1990).

**Descriptions of the participants**

Seventeen perinatally HIV infected young adults 18 to 24 years old (male 8, 47.1%, female 9, and 52.9%) participated and were enrolled from the HIV outpatient clinics at a large urban children’s hospital on the East Coast. Sixteen participants were infected with HIV through mother to infant transmission at birth and one female participant was infected with HIV from a blood transfusion at birth. A majority of the participants were African American (15, 88.2%) followed by White (1, 5.9%), mixed race (1, 5.9%) with ethnicity reflecting Hispanic (2, 11.8%), and Non-Hispanic (15, 88.2%). Most were unemployed. The employment status included full-time (1, 5.9%) part-time (5, 29.4%) and unemployed (11, 64.7%), The salaries ranged from less than $9,000 to $20,000; only two participants (18%) reported income levels between $10,000 and $20,000. Marital status was single (11, 64.7%), partner, (5, 29.4%), and divorced and head of household (1, 5.9%). The educational level or the highest levels of education reported were some high school (4, 23.5%), high school graduate (10, 58.8%), and some college (4, 23.5%). A total of 2 participants 29.4% had 5 persons living in the household. Three participants 41.2% had 7 persons living in the household. Four participants, 23.5% had 4 persons living in the household and 1 participant, 5.9% had 6+ living in the household. The parental/ guardian involvement
was mother (8, 47.1%), father (1, 5.9%), grandparent (3, 17.6%), mother deceased (8, 47.1%), no parental or guardian involvement (3, 17.6%), aunt (1, 5.9%), and other (3, 17.6%). One participant, 5.9% had three children. All of the participants (n-17) were prescribed ARV medications. The percentage of time the participants took RVs was 0% of the time (1, 5.9%), 50% of the time (2, 11.8%) and 100% of the time (14, 82.4%). See table 1.
Table 1
Demographic Table of Young Adults Growing up with Perinatal HIV

<table>
<thead>
<tr>
<th>Variables</th>
<th>Young Adults (n)</th>
<th>Young Adults (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All</td>
<td>17</td>
<td>100</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8</td>
<td>47.9</td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
<td>52.9</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>African American</td>
<td>13</td>
<td>76.4</td>
</tr>
<tr>
<td>Mixed Race</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Hispanic</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>Employment Status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-Time</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Part-Time</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>Unemployed</td>
<td>11</td>
<td>64.7</td>
</tr>
<tr>
<td>Salary</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤$9,000</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>$10,00-$20,000</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>Marital Status:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>11</td>
<td>64.7</td>
</tr>
<tr>
<td>Partner</td>
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<td>29.3</td>
</tr>
<tr>
<td>Divorced</td>
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<td>5.9</td>
</tr>
<tr>
<td>Highest Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some High School</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>High School Graduate</td>
<td>5</td>
<td>29.4</td>
</tr>
<tr>
<td>Some College</td>
<td>4</td>
<td>23.5</td>
</tr>
<tr>
<td>2-year College</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>4-year College-Enrolled</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>Parent/Guardian</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mother alive</td>
<td>9</td>
<td>52.9</td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Mother Deceased</td>
<td>8</td>
<td>47.0</td>
</tr>
<tr>
<td>No Parental Involvement</td>
<td>3</td>
<td>17.6</td>
</tr>
<tr>
<td>Aunt</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Other</td>
<td>3</td>
<td>17.6</td>
</tr>
<tr>
<td>Participants with children</td>
<td>1</td>
<td>5.9</td>
</tr>
<tr>
<td>Percentage of time took ARVs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>0%</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>50%</td>
<td>2</td>
<td>11.8</td>
</tr>
<tr>
<td>100%</td>
<td>14</td>
<td>82.4</td>
</tr>
</tbody>
</table>
In the study fifteen participants’ mothers were African American and non-Hispanic, one mother of African descent, while another mother was of African American and Hispanic heritage. One mother was white and Hispanic. Eight of the mothers who were the primary guardian of the young adults died from HIV/AIDS related illnesses. The mean age of the participants was 20.47 years and the mode was 19 years of age.

Although, one of the college enrolled participants recently experienced the death of his mother, he is continuing his college education and lives away from home in a college dormitory. The other college participants lived at home. Of the seven students who did not graduate from high school, one male participant is attending night school to obtain his high school diploma. None of the remaining six participants have been involved in academic activities since their eighteenth birthday.

Five participants were employed or earning less than $20,000/year. One participant had fulltime employment (two part-time jobs) and the others had part-time employment. The job titles included cashier, bar-assistant, waiter, sales associates, food servers and patient care assistants. Five of the participants had a close relationship with a significant other, described as male/male partner (n=1) heterosexual partner (n=3), and a female/female partner (n=1). One participant was divorced, pregnant and mother of three children ages three months, twelve months and four years of age. Her children were all HIV negative. Two of the 3 children are living in relative-foster-care homes and the participant provides care and lives in a homeless shelter with the youngest child.

The participants in the study were living with a birth mother, father, adopted mother, grandmother, siblings, independent or in homeless shelters. Eight of the participants
were orphaned at various ages and four of them lived in many foster care settings. A female participant lives with an older sister who was infected with HIV in her youth and a male participant lives with a non-HIV infected older brother. One participant is living independently with roommates in an apartment style dwelling. Two participants in the study are homeless and live in a shelter or receive temporary accommodations from family and friends. All 17 (100%) of the participants have been prescribed ARV medications. The medication adherence mean was 88.24. Only one female participant is currently refusing to take any HIV medications; two participants reported having a very high viral load.

Participants reported significant health concerns, such as, shingles, asthma, fatigue, cerebrovascular accident (CVA), flu symptoms, cancer, non-Hodgkin’s lymphoma, coughing episodes, fever, recurrent pneumonia, transient ischemic attack (TIA), seizures, kidney failure, thrush, hot flashes, stomach ache, gout, urinary tract infection, diarrhea, and anal warts.

The essential themes below described the essence of the meaning of “the lived experience of perinatally infected young adults growing up with HIV” who participated in this study.

**Overview if the Essential Themes**

The stories told by the young adults were noteworthy in terms of the serious concerns they had about their future. At a very young age the perinatally infected HIV young adults were being forced to take liquid medications that had an unpleasant taste and if they refused to take the medication, they were told they would die. Many of them threw the medication away or vomited immediately after the dose. Mothers died and when that happened, the young adults wondered if they too would die soon. For the young adults there was no consistent age level of HIV disclosure. The age of HIV disclosure ranged from 5-18 years of age. A consistent story
told by the young adults was that they were required to keep their HIV status secret, but if they were under 12 years of age, they did not understand what it meant to be infected with HIV. Their illness was not discussed in the home and the young adults described not knowing anyone diagnosed with perinatal HIV. They expressed the desire for someone to discuss their HIV infection with them.

Very few stories told by the young adults, revealed enjoyment of life or any degree of happiness. The sentiments verbalized seem typical of young adults living a harsh life. One participant said “I did not have a childhood, I had perinatal HIV”.

These young adults whose mothers were diseased did not have concerned and compassionate guardians to provide the needed social support involving major teenager concerns, such as driving lessons, picture taking and graduation activities which precede and are part of college preparation activities.

While listening to the young adults describe their expectations of growing up with HIV it was evident that there was a void in several developmental areas, such as: (a) academic development, which was needed in as many as seven of the young adults did not graduate from high school; (b) physical development of those young adults, of whom many were observed to be short stature or otherwise physically underdeveloped, also documented by Hirschfeld (1996) and Isanaka, Duggan & Fawzi (2009) who noted that prenatally HIV-infected youth have decreased growth; (c) social development stemming from those young adults who were reluctant to disclose their HIV status because of the stigma and fear of telling the HIV secret.

In addition, friendships and romance were not priority needs. Most of the young adults were not currently sexually active. Two male participants stated they never engaged in sexual
activities. Emotional relationships were void when some of the young adults reported not having a caring parent or guardian who would absorb their displaced anger. One participant reported risky behaviors such as smoking marijuana and drinking alcohol; and (e) spiritual development, that is, four young adults discussed religious beliefs and practices that help them cope with the emotional concerns and fear growing up with HIV. One young adult disclosed his HIV to his pastor and reported being very surprised when his pastor responded, “honey you will be fine, my daughter has that too”, referring to HIV.

The analysis of the interview text revealed one overarching theme and five essential themes that emerged as representations of growing up with HIV, the lived experience of young adults growing up with HIV. The overarching themes for the young adults telling their stories were of a Secretive, Uncertain and Harsh life. From the overarching theme, the five essential themes emerged that offer a fuller description to the essential theme. The essential themes are:

- A life of uncertainty
- Wishing for a purposeful life
- Longing for a future
- Managing emotions
- Hoping for better health

These five essential themes, shown in Table 1, offer a description of the young adults experiencing growing up with HIV, since it was not expected the young adults would survive the HIV illness and grow up to be young adults. With each essential theme, there are several sub-themes or thematic elements that further express the phenomena of growing up with HIV.
**Overarching Theme**

An overarching theme, a “Secretive Uncertain and Harsh” life was revealed in the stories told by the young adults growing up with HIV who participated in the study. The participants described being very uncomfortable telling others of their HIV status. For most, only one life-long friend or family members living in the household was aware of the participants’ HIV status. Many of the participants asked “why did this happen to me”. The participants spoke of living a life of HIV in the shadow of fear of rejection. The use of the metaphor “living in the shadows” suggests a “Secretive” life. Many of the participants talked about feeling angry when parents did not disclose the participant’s HIV status to them until it was necessary. They talked about the expectation that they will keep their parents HIV status secret and the vulnerability in disclosing their HIV status to others. In another narrative the metaphor “pray for a miracle” suggests “Uncertainty” in life.

Most of the participants living with their birth mother or a maternal grand-mother were able to state achievable goals without a completion or graduation date. One participant stated:

> I love doing schoolwork. I love challenging myself. I’m a theater major, so I love theater and I love what they’re doing. I just always had a passion to just be in the arts. Either singing, acting, or just all that”. While another stated, “I would like to be a Photographer.

The young adults in this study reported delaying intimate relationships. The young adult asked about marriage and family reported:

> Like now, I’m focusing on myself and me getting my life together before I be a partner with somebody else ‘cause then that’s more stuff added to me and then, like I might sometimes fall off, get off the track ‘cause of that person. So, I’m basically just working on myself.

A current theme among the orphan participants was that life changed drastically after the mother died. One young adult stated:
I was six years old when my mother died. My mom loved me but when she died my cousin took care of me but she did she ever take that anger out on me for my -- you know, that frustration -- out on me for my mom? Because sometimes she would just torture me and I felt like she would hit me, punch me, like I was somebody on the street, hurting me physically and put burns on me and everything. Hit me with those orange thick extension cords, all of that kind of stuff.

In the narrative, the use of the metaphor “tough” suggests a “Harsh” life. The young adults who were orphaned very young in life also reported relatives placed them in foster care and never checked to make sure they were receiving safe care.

One time I got put out, way out, Chesapeake Beach, and my family is here in DC. So I had to stay out there where nothing is. I had to depend on a ride to go see my family. This isn’t right.

Nevertheless, the young adults independently managed their health care with a daily routine of maintaining the regimen of medication administration and quarterly physician appointments. The participants were asked to describe growing up with HIV and answer the probe questions. Table 2, lists the essential and thematic elements.
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A life of uncertainty

In responding to the questions asked: (1) How is living with HIV expressed by young adults?, (2) How do young adults growing up with HIV describe available social support?; and (3) How does HIV affect a typical day in the life of young adults who have grown up with HIV?, the participants provided vivid descriptions of the experiential lifeworld situations growing up with HIV. The essential theme living a life of uncertainty revealed the thematic elements growing up unprotected, relative foster-care living arrangements, stranger foster-care living arrangements, my father is who he is, being different, being orphaned, an unstable household, limited social support and unhappy tears are described through several stories told by the participants.

Growing Up with Unprotected

Henrietta described being bullied as a major reason for not completing high school. She described being bullied throughout the day and labeled her school as “violent” She suggested she was not protected by the school officials and being too short may have been the reason she was bullied.

I’ve been bullied at a High School, which make me not want to go. And because I informed the principal, I informed teachers, they’ve done nothing about it, so I just left high school, and that was it. It’s like a violent school. So from down to like the gang members to people that just think they can overpower smaller people, but it wasn’t like bullying to the point of hands on activity with me, it was just the typical bullies, from down to like the gross and nasty stuff to the name calling. And I don’t really like that, like if I don’t bother you, don’t bother me. And, yeah, so when I first started the high school I dealt with the bullying, I was in the classroom with the boys, they went from plucking boogers to putting stuff in my food, and I’m like, “Oh my God,” like I wanted to get mad and rage out, but I’ve like gotten older and more mature. So I dealt with it for two years, and it got to my third year and I switched classes and those boys just come to school and just talk about me all day long, and pick on me all day and I completed the 9th Grade because that’s just a lot of distractions.
Karen described living with her mother’s cousin after her mother died and suggested the experience made her “tough.” The use of the metaphor “tough” suggests a “harsh” life. Karen described her experiences living with a relative after her mother died:

I remember getting like -- she would make me look ugly. She’d dress me like a boy. What I had looks all the same. She would beat me. I remember sitting on the steps and, “Can I make this?” She just walk up there and slap me in my face. It's just certain things that she did to me. I think because her and my mother didn't get along. I think that's why I'm so tough and defensive with people because all my life, I had to defend myself. I was the only person to defend me because she always hurt our kids. They used to bully me. Even at my mom's funeral, they locked me in the bathroom, so I have this phobia of being closed in places. I refuse to close the door anywhere. So, certain things that they did to me, even her and her kids, it just sticks on me until today. I'm trying to get over the fear of being by myself in closed places and stuff like that.

Lori was asked, if she felt safe and protected when she was younger and she described being raped by someone she knows and felt helpless because the rape and abuse continued for several years.

My mother’s best friend’s boyfriend raped me when I was nine all the way to thirteen – all that time. It was like he would just touch and feel on me, come in my room and ask me could he get in or say “hey chocolate” or try to grab on me and grab on my butt.

Oden described how it made him feel to live with HIV:

I don’t have a right to be frustrated? And all people can say is, “Oh Oden, just take your medicine. Oh Oden, just do this.” It’s much easier said than done and that’s what people really don’t understand. This is not a cancer. This is not high blood pressure. This is not something else that I have to take medicine for. This is something that -- me taking my medicine is dependent whether I’m going to live or not. What 19-year old wants to have that type of control? You want to just live life and hope that nothing bad happens to you. You don’t want to have to worry about, “Oh, well, if I don’t take my medicine then I’m making that choice to take my life.” You don’t want that on your conscience but at the same time, you don’t want to have to keep dealing with that everyday. I am so tired. I’m tired. I don’t think I can get any more tired.
Relative Foster care settings

Karen’s paternal grandmother was afraid of her HIV illness. The grandmother was afraid she would be infected with HIV by touching her. When Karen was younger, as a punishment she was given a bath in her own urine if she had a bed wetting incident.

Several participants told many stories of hardship, isolation and stigma in relative foster care. Oden described the circumstance that caused him to be placed in foster care:

We were all grieving from my mom and my aunt’s death. My grandmother only had two daughters. Both of them passed away within a month apart. Now being kids, we didn’t really behave well. My problem was she would always get calls from school because I’m doing something I’m not supposed to be doing. My brother and my sister they was doing their own thing and she just kind of got fed up and she called CFSA and we ended up in care.

Qual’s grandmother was the custodial parent for most of his youth but he had a strong desire for a relationship with his mother, so, without permission, he moved into the home with his mother just before she died:

It already makes me feel bad enough that my mom gave me away to my grandmother at a young age, and she kept my brother and sister. And then on top of that, I’m the one who was infected and not them. So it made me not feel a part of them. And actually, when I moved out of my mom -- I lived with my mom for like the last five years of her life, like when I was 13. I forced myself to move with her, because I wanted to have a mother. I wanted to have that relationship. While my mother was still alive I didn’t understand why I couldn’t have that. My grandma had guardianship of me, but I actually forced myself to move over there. And we were developing a relationship, but we still never talked about this issue. Ever. And I just always said we were going to have it one day. I just always pushed it to a side. But then it was too late and I was just that.

Stranger foster care

Karen provided examples of living in both stranger and relative foster care after her mother died. She described feeling very unhappy when placed in a foster-care home with strangers and described her behavior as “impossible” to cope with. “Impossible” as a metaphor suggests living a harsh life.
In my head, if I didn't like a place, I was going to terrorize it, just so I could leave. No, that's how I was as a younger, so I was in a lot of foster homes growing up. But it was just because some of them people, I knew that they were just -- I didn't want to be there. They didn't make me feel like I was a part of their family, so I terrorize the foster home. It wasn't like I did anything -- I just would like disobey them, what they said. I did what I wanted to do because I know that they couldn't put their hands on me and I took advantage of that. So, I did whatever I wanted to do and then, they call the people to come and get me and everything like that.

Karen also stated she was deserted without a family and described the living conditions in the foster home after her mother died. She was asked to describe her relationship with foster care family:

To be honest, first it was rocky because we were getting -- fought a lot, towards the end, because they had it with it. They wanted me to go to independent living so that could prepare me for the real world. Basically but, then I came with them when I was what, 17? I think 16 or 17 and with me now, I realize I think it was just for the money. I really feel like it was just for the money. I hate to say it, but it's just like with me, I observe certain things and I'm just sitting back. I'm like -- since I was working with them, I was always working. They had an allowance that they was supposed to give me. I never asked my allowance. I knew I was supposed to get it, but I never asked for it, so I'm thinking maybe they were saving it up for me until I leave, until I emancipate and go onto independent living. When I left there, I never got the money. I didn't make a penny. I didn't talk to my social worker about it. I didn't tell anybody about it. I just said, "Okay, whatever." I noticed that and then, last year, before I got my apartment, I was staying with friends because I asked them. I was like, "Can I stay with you guys until I can get on my feet because I don't have nowhere to go?" They did not let me stay with them.

Oden is currently emancipated and homeless. He and his boyfriend have exhausted most of his available living accommodations. On the night of the interview, he said, his aunt will allow both of them to spend the night, but he admits neither he nor his male friend have future housing accommodations. He was asked to describe his experiences living in foster care:

This home that I was just in, that would have been my 12th home since 2004. That’s ridiculous. I’ve never been in a group home before. I’ve only been in foster homes. I’ve been in something like a group home. It was residential, a residential placement. It was out in Pennsylvania and I stayed there for about a year and a half. Outside of that, I’ve been hospitalized, put on the adolescent unit. I’ve had therapy pretty much all my life. It’s just too much. It really is., like I didn’t really stay in the home no more than what? Two to three months. It got to a point where I was moving too many places and
they just got to a point where, “Well, we tried to put you in DC but this is all we have.” One time I got put out, way out, miles away from home and my family is here in DC. So I had to stay out there where nothing is. I had to depend on a ride to go see my family and I wasn’t allowed that only once a month and I’m like, This isn’t right.

My Father is who he is

Some participants who were in contact with their fathers spoke of the absence of a father in their lives. In the study, the father was not usually the primary caregiver. Alvin parents are alive and living with HIV. After his parents separated, the mother moved away with his sister and the father and Alvin remained in the townhouse. Alvin was asked what it is like living with one parent:

The household’s financial are limited. My father sold the townhouse because we could not afford to keep it. Now we live in an apartment and I was asked to work to help with the family expenses.

Most of the young adults have limited or no relationships with their fathers. Jake knows his father is alive. He was asked whether he would discuss his HIV status with his father:

I haven’t had a chance to talk to him about this yet because I’ve only seen him once in person, and majority of the time I’ve talked to him is via text message, over the phone, and what I want to say, I don’t think it’s really over the phone appropriate. I prefer to ask him about this face-to-face. I would Just try to find out where this came from because it just didn’t come from out of the blue like you just don’t get it walking down the street, you know.

Karen’s father is alive and she speaks openly about him. She stated her father is an irresponsible parent. She was asked to describe her relationship with her father:

He signed me over because they gave him the choice to take me in. He signed me over. My dad isn’t quite -- he's on drugs. He's not right in the head, so I wouldn't even have wanted to live with him if I had the choice because he was sleeping with girls really young. That would have scared me, so he always -- like the girl right now that he's so-called engaged or married, she's my age. So, I don't want no part because that's embarrassing to me. Seriously, two of my friends, I invited them to my birthday dinner. That was the -- I was like -- I don't judge anyone, but it was like really embarrassing to me.
Mark lived with both parents as they struggled with AIDS and finally died. Mark was asked about his experience living with his father and he said:

My father passed away from HIV a year after my mother in 2009. He died after my mother. I think he just gave up..

Nepal lives with his mother and maternal grandmother. As an adult, he is developing a relationship with his father. He was asked to describe getting to know his father:

Dad, he doesn’t work. He’s still recovering from a stroke. He took out a benefits claim on me, but he wasn’t hardly in my life as much. He would have come to my birthday on days of my birthday and call, but he was never around to actually teach me how to ride a bike. I learned from my cousins. He wasn’t there to see me take my first steps and all of that, not that I can recall. He’s doing good right now. We’re talking now because he usually texts me every now and then and make sure it’s a Monday. If it’s a Monday, he usually texts me because we watch wrestling even though he’s not with me, we catch up on the wrestling on the WWE, and we predict what will the outcome of the event will be or the football game. We talk trash and stuff like that. So he’s starting to get that bond again, but I wish it was kind of sooner in my life and not just now.

Oden’s father is alive and has limited contact with him. He was asked to describe his relationship with his father or whether his father would contact him:

When he wants something or when he think he can get something out of me. One time I was working at Six Flags and he had a car ticket that he had to pay. It was about $150. He asked me for it. I had no problem with giving it to him. I took him right to the ATM, gave him the money. Never seen it again. Never seen it again. Same thing with my brother. I had a summer job, he asked me for $90. I gave him the $90. Never seen it again. So I’m getting hoodwinked by all these people in my life and these crazy situations keep coming up on top of me having to live with this everyday.

Paul’s father died years ago and he cannot recall living with him. He said, “He is deceased. He had been deceased a long time ago”.

Qual’s father has been in jail in a foreign country for over ten years and described their relationship below:

He is incarcerated in Costa Rica. He’s been locked up for about ten years. So when I was about nine he went to jail. I don’t have a relationship with him. I don’t really -- I don’t want to seem harsh, but I don’t really like my father. So, I would want to know how is doing, now that my mom is gone. He contacts us. I don’t write him back. I don’t really have anything really positive to say. I just have -- I would just want to know answers.
And that’s about it. I don’t really want to have a relationship. I just feel like he has to earn his way back into my life. And he hasn’t done that, yet. I don’t know if he’s changed.

**Being different**

Many of the young adults with siblings mused, “Why only me, and not my siblings have HIV”. Although, in the clinic there are siblings diagnosed with perinatal HIV, none of them participated in this research. Several participants stated, “my mother made sure my siblings do not have HIV, but she was not as careful with me. Also my friends do not have HIV”

Alvin was asked to describe what it is like spending time with his friends after he told them he had HIV:

I told my best friend like three, four months ago and he was like, “Really? I did not know that.” All he did is just give me a hug and everything and like, “I’m here for you whenever you need me.” And I was like, “It doesn’t really matter because it’s just a thing right now to me. I deal with it. I live with it and everything.” One time he was sleeping over at my house and he saw me take the meds. He was like, “Why do you take meds all the time whenever I come over -- spend the night, whenever I can.” I was like, “Because I have this virus called HIV,” and he just kept on asking me questions like, “How’d you get it? When did you find out?” The same usual things that when people don’t know about it. And then I just educated him more and more about it. He’s sticking with me ever since that day.

HIV stigma has negative attitudes or maltreatment directed at people living with HIV. The consequences of stigma are wide-ranging such as being shunned by family and peers. Gretta was asked to describe an experience when she was treated differently by a family member

There was one of my aunt’s house, she lived in New York, I went to, and I saw that they were having dinner and she gave me a plastic plate and a plastic cup, and she gave my sister and my little brother a glass plate and a glass cup and utensils that were silver, and my utensils were plastic. And I felt different in a kind of way, “So why are you treating me like this? Like you know I have this problem. We gave you pamphlets; we talked to you about it. Why are you treating me this way?” So that’s the way I feel, that they’re not -- they don’t treat me right when I go over their house”

Henrietta was asked if anyone else in her family was born with HIV and she replied:

“why can’t I just be normal like my brother and sister”? 
Oden was described a similar story living with HIV and verbalized why me:

And I’m thinking, “Why me?” And I’m going through stuff “Why me? What did I do to deserve this? I didn’t ask for this? Should I or should I not be mad at my mother for this?” All of this is going through my head, all of this. But I’m not allowed to be upset or be frustrated or get tired. And all people can say is, “Just do it. Just take it.” No, how about you take it every day of your life. And if you don’t take it, your life is pretty much done. How about you have all of that on your conscience and see don’t you be frustrated.

Qual has two younger brothers who are not infected. He said, “She took the medicine during her pregnancy with them two.” During the interview he discussed how he felt being told his mother did not take medications while she was pregnant with him.

The counselor said it. I don’t remember the counselor’s name. She said it. And we had confidentiality; you know, they talk about how no one would find out and you could talk to certain people, and she’d let me know what the disease was. And how, if I take my medicine, I can keep my viral load down and I could be healthy -- I could live a long, healthy life. And then she brung my grandmother into the room, and she did like a review of what we talked about. And my grandmother told her that I couldn’t talk to everyone in the family because everyone didn’t know. And then I was kind of throw off, like I wanted to know who knew. But at that age I didn’t ask that many questions. It was a lot for a 13-year old to really sink in. She told me I had HIV. But I still didn’t understand what it meant. I was -- okay. Like, I didn’t understand until -- like I understand now. Even though it’s not that big of a stigma and it doesn’t necessarily I’m just going to die. But it’s just still serious. And I didn’t know how serious it was then. And then she told me afterwards, she was like, “Yeah; your mom didn’t take medicine when she was pregnant with you.” And she said, “She took it when she was pregnant with your brother and sister.” And, “She need to take her medicine.” Because my mom always struggled with taking medicine. Always. So she needed to get back taking her medicine.

Qual provided another example of being different

It’s hard for me, personally, to grow up with it because my family, we don’t talk about it. I know that I was given it -- I was diagnosed through birth, so it was nothing I had any control over. It’s nothing I could have did differently, but be born.” My siblings weren’t diagnosed. It was just me. I’m the oldest child. And none of -- I don’t know who in my family knows and who doesn’t know, so I don’t know who to talk to about it and who not to talk to about it. Because I don’t want to just throw this burden on other people about my life. So I tend to stay quiet about it a lot. So it’s something that I dealt with personally, within myself. And something I had to overcome without no one helping me overcome it, in a way.

An Orphan’s life

Bea knew she was adopted and was asked to describe growing up with HIV without
her birth mother at such a young age.

It was kind of hard because I don’t remember if my mom even telling, -- I think I knew I was adopted, but I didn’t know. I kind of had a feeling because my mom, I will always have like a social worker. We always had to go places, go to the court, sign papers. So it’s like as a young child I kind of already knew, but when I was five, I want to say I didn’t really know about being adopted when I was five. So I would say I think they told me about the HIV first then told me about being adopted. Mom adopted me and one of my other siblings, my sister, and one of my other brothers. She adopted us three because she wanted us three to be together not separated. So she adopted us three, and I know my grandmother. I know my little sister. I know my other brothers, and I know my aunt, and I know my nieces and nephews. My birth mom and foster mom had a relationship, and my adopted mom knew my grandmother, too. She knew my real family, but my mom told me that she had a good reason to give us up, and she just kept telling me not to blame her.

Karen gave a vivid account of life after the death of her mother. She was asked to describe living with her mother’s cousin:

I would say, even one time the Make-a-Wish Foundation took me to Disneyworld. She was doing all kinds of stuff like -- it was supposed to be my time to have fun. That was my once-in-a-lifetime kind of thing and it was horrible because of her. She made the trip horrible. I didn't get to have that experience that I was supposed to have for myself. So, certain things like that, she ruined and it's just everything. Her, I'm glad, I thank god I got out of there and got foster care. I didn't get to have that experience that I was supposed to have for myself. So, certain things like that, she ruined and it's just everything. Her, I'm glad, I thank god I got out of there and got foster care. I used to have to be afraid to take my shoes off because I had holes in my socks and everything. I used to have to wash my underwear and she got a check for me. She never bought me clothes or anything like that, so when I got to the foster care and these people started doing things for me, get for me all these things that I needed and stuff like that, I realized that people, like I said, they do care. My cousin, she was just in it for the money. She was not right in the head, either. She was getting locked up and things like that.

Qual described being the supportive older brother for his siblings since their mother died.

He described wanting the pain taken away and not his mother:

I felt stronger than I thought I would be. I was strong for my siblings, of course. Because when I found out she passed I didn’t cry at that moment. It didn’t really hit me then, because I know I had to be -- my little brother; I had to be strong for him, mostly. So I made sure that I was there for him. And I didn’t want to let him see me really weak at that point. But the funeral is when it really did hit me. I was strong enough to actually sing a song at the funeral, because I wanted to honor my mother in that way. But it did hit me then that that was the end. And I didn’t want my mother to be in pain anymore, because I saw -- I had to call the ambulance myself in the summertime, when she was really in pain and she was crying and stuff. And I didn’t want that anymore. But as well
as me not wanting -- I didn’t want my mother to leave. I just wanted it to be taken away; the pain to be taken away, not her.

An unstable household

Alvin reported that although his mother is not dead, she left him to live with his father. He described the living conditions in his home:

Recently, my parents separated for, I don't why. I like they supposedly drifted apart or something like that. So my sister lives with my mom. I just stayed with my dad in the townhouse. We had to sell the townhouse, because my father could not afford the mortgage.

Lori listed the number of people who died and was asked to describe the people who were available to take care of her over the years,

I was four when my mom died. She died from AIDS. I was seven when my dad died in a car accident. I was ten when my grandmother died and I was fourteen when my other grandmother died. So after mom died I’ve been going from house to house. Like my grandmother had me and then my other grandmother had me. My mother’s best friend kept me and my cousin kept me and then when I was fourteen I went to foster care. I was sexually abused from nine to thirteen.

Mark’s parents are separated and he is not fully aware of the HIV status of his father. He described his relationship with his parents:

My mother and father was together most of my life but then they broke up or got a divorce. My mother was diagnosed with HIV so that’s how I became HIV positive. That’s how I became HIV positive but that’s it.

Limited Social Support

Social support may come from a variety of different sources, but for the young adults growing up with HIV, the birth mother provided the major source of social support, followed by friends, family relationships and support groups. Ella was asked if she felt supported by family and friends:

No. It’s stressful sometimes, depressed. Sometimes I feel like everybody is against me. To me, I feel like everybody is against me.

Gretta provided a different perspective and valued support groups. She was asked if
people in the support groups care about, value, and love her:

   I lived in California for a few years ….I feel in California I had a lot of support in California, as here in Maryland, I feel like here in Maryland people that are HIV positive are quiet, of course I’m quiet about it, too, but like in support groups, in camps, in things like that, I feel like people are just like quiet about it.  As in California, I had all these support people my age, people older than us, people just supporting us so much; we had support groups and we were open to talk about it and we had camps where you feel like you’re flying because everybody knew what you had and you didn’t have to feel different from anybody else, so I feel like in California I was more supported by more people in California.

   Gretta also suggested that the support group helped her to manage the HIV obstacles in her life:

   Support groups are helpful. Managing HIV is a big challenge to me because you have all these different obstacles you have to get to in your day, unlike I person without HIV, they don’t have to go through all these obstacles like I do. When I say obstacles I mean like in a regular day like when I get up until I go to sleep, my thoughts are, “I have to make sure I have to drink my medicine; make sure I'm in good health; make sure I’m eating well,” just making sure my health is good throughout my whole day

   Ian had the contrasting response and cannot see the value in support groups. He was asked to describe his experience in a support group:

   See, I don't think I could take that.  See, if it’s just me and you, we could talk about it, but if it’s like a whole group and we just talking about it like so, “How you feel about having HIV?” I can't do that. And everybody just listening.

   Nepal described receiving social support from his mother and probably will not seek support from others. He was asked to describe a typical day in his life:

   A typical day of my life. Well, I am very quiet, shy, just don’t want to really go out or adventure out, you know, meet new friends or meet new people or do stuff on my own because I know how the society and the world is now. I’m still trying to grow up and get accustomed to it.

   Nepal received a car as a gift for graduation and he described the support he received from this mother after failing the Department of Motor Vehicle driver’s road test several times:
I didn’t know, come to find out I had a car since my 18th birthday, but it was moved from location to location. My mom was getting it customized. I got a spoiler. She got tinted windows. She put, -- I’m a huge Philadelphia Eagles fan. She put Philadelphia Eagles car mats and headrests all in the car and everything. So I was totally surprised and happy. Me and her had a talk when I failed the driver’s test the second time, I would always get emotional and mad at myself for failing, and my mom was saying, well, you need a car or something to go to school because I don’t feel comfortable with me taking the Metro or the bus to school every day now that everything is happening now, and I just sucked it up and just, once after I got that car, it was because I was actually practicing in her low car, and it was a sports car. She has a Eclipse, and I couldn’t really see out the side and back windows so the cone, but when I got my car and took the test, I could see perfectly and passed it with flying colors.

Oden was asked to think about his life experiences and whether would it would be different if his mother were alive and able to provide care for him while he was a child:

It seemed to me that when my aunt and my mom died, I would go around everybody and it just seemed like everybody had their mom. But everybody had their dad. Everybody had all their aunts and great grandmothers and I’m like, “Well, I’m left with nothing.

Paul lives at home with his birth mother in a three bedroom house and views that relationship as the source of his support. The young adults experienced uncertainty very early in life. The use of the metaphor “pray for a miracle” suggests “Uncertainty” in life. Below he describes his relationship with his mother

We get along, we do great. She said, don’t give up, pray for a miracle. Most families when they are with their mom, they don’t have bonding, I guess. I guess I have real good bonding. Like whatever she want to tell me, she would tell me. What I have to tell her, I tell her. Like when I was 18, that’s when I started smoking, so my friends were like, don’t tell her, and I was like I am not listening to you all, and I went up to her and I said mom, I smoke, and she was like, okay because she smoke too and she knows her son and stuff.

Paul’s aunt is the only other source of support. Although his dialysis diet is limited, he looks forward to occasionally dining with her;

My aunt Windy is here, she is very nice, sweet, funny. She takes people out when she has a day off.: For fun, normally I like to go out to eat, maybe Tuesday. Fridays, to Carolina Kitchen.

Qual’s existing support is limited and he described being overwhelmed with the
information he was given about his mother’s health and the decisions made while she was dying.

I’m pretty strong in the sense that I don’t even want people to tell me it’s okay when I know it’s not okay. I know my mom passed in a way that wasn’t okay. I know that nothing the doctors said even made sense to me at that point. I was so confused during those last days, about what was going on and the decisions they were making by taking my mother off of the machines and there’s no such thing as a liver transplant, when I knew there was. And I was just confused.

Qual has two younger brothers. He described his current relationship with his siblings and explained why the relationship between the two of them will always be stronger than his with them.

I’m trying to make it better, because I never felt like an older brother to them. I felt like -- I used to only come over on the weekends. And now I try to make myself move over there with them. But their relationship will always be stronger than mine with them. So it’s like I don’t have a really serious relationship with them. It started to develop during the death. I really had to be a big brother then. Because of them. But it’s not as strong as I would want it to be. Just like I will always say about my mother -- me and my mother’s relationship -- it’s not where I want it to be, but we’re working on it. I would always say that.

During the interview, Qual was one of the four participants who described religious activities as a source of social support.

I was actually introduced to church through my best friend in ninth grade. And I was introduced to her pastor. She has a youth pastor, and then the pastor would take a group of kids to church all the time. She would take them out to eat, and stuff like that. And then I got involved and I got baptized. So I always went to church separate from anyone in my family. No one in my family really went consistently but me. Then I started going all the time and I got really involved, and I started dancing and singing, and doing all these different productions in church. And now I’m at school. I try to go to different churches because I can’t really have a consistent one because I’m not going to always be there. And then I have to work some Sundays, but, I still try my best to attend.

Unhappy Tears

Although, some of the birth mothers are still alive, participants had several stories to tell or questions to ask, such as, why am I your only child with HIV and why me? When they told the stories, it was apparent that they were holding back the tears and managing their
emotions. One participant simply said “I have no more tears”.

Alvin repeatedly asked his parents why he was infected with HIV, and he said:

My mom cried a lot as I was questioning them, “How did this happen and why? Who did this and blah, blah, blah.” And they just told me straightforward it was from young mistakes and everything else. I was like, “All right, it happened. It happened. It doesn’t matter. I can just move on from it.” Then over time, I just lived a normal life.

Bea was asked to describe what she was able to recall about her birth mother:

My birth mom, she is dead. She died when I was ten years old. I only saw her twice, and I always wanted to ask her why she did, -- I always wanted to ask her the two biggest questions. Why she gave me up for adoption, and why do I have HIV, and why she didn’t take care of herself when she knew she had it and when she knew she was pregnant with me. And those are the things that I wanted to ask her, but it’s just like when I first met her, I didn’t know what to say to her. I was scared to even open up my mouth because that was my first time meeting her, and then my second time meeting her, she was in the hospital, and I definitely didn’t want to say anything about it then. Those are the only two times I got to see her, and I went to her funeral, and it was kind of hard to even be there because I didn’t want to go, but I went because all my other siblings wanted me to go with them and go to the funeral.

Donita reported not being angry with her birth mother at the time of the interview and discussed their mother and daughter relationship. Donita’s mother is alive and states she is “too strict”. Donita uses a walker and complained of pain in both legs. She also described neglect from her mother and not receiving the care she needed to recover fully from a stroke.

My mom is alive, she’s just strict. I mean, she’s not like the mean person, she’s just strict. She just likes to talk a lot, so I usually try to stay away from any kind of conflict with her. I do what she asks me to do, and I love my mom to death, but she just likes to talk a lot. She’s just strict. She’s just a strict person. She could be a nice person too but, I broke my foot last year and I never had physical therapy ever when I had the stroke. That was the big mistake my mom made. She never took me to physical therapy, she was always working. She was a single mom, and I never learned how to walk the right way.

Conversely, Ella believes she would be happier if her mother was still alive and has many questions to ask her.

Like how did she deal with it for so long. That’s all I want to know, how she dealt with it. Although my mom died, my life really didn’t change since my aunt got incarcerated. I miss your mom every day. I actually think about her, like where will my life be if she was still here every day sometimes. I think it will be much better a little bit. I’d be more
happier. I guess that’s what I think it’s going to be. I won’t be that lonely either. I mean, I’ll always have somebody right there.

Gretta also had a similar feeling of loss and was asked to describe what she was able to recall about her birth mother:

I feel a little left out. I’m not going to lie about it. I feel sort of left out, even though I talk to my mom about it, she goes, “I’m here with you,” but it’s not the same, but she, I feel like she had her younger days, she got to do certain things. I’m not going to say that even because I have HIV that I’m limited to doing stuff, but it’s not -- it’s just not the same when you’re born with it, instead of you getting it later in life. I believe that when you get it later in life you had your childhood, like you had your time that you didn’t have to worry about so much stuff. Me, being born with HIV, I had to make sure I was drinking my medicine, I had to go to the doctor’s like literally every single week getting poked and blood and this and just a lot. I believe I was confused. I was confused. And I lookup to my sister, and my sister’s negative, so every time I look confused I would look at my sister and my sister would just be asking questions, like, “Why does she have this? Why this? Why that?” but I was seven years old, so I just was feeling really confused.

Henrietta was also asked to recall what she remembered discussing with her birth mother about growing up with the illness:

Like why do I have to live with this illness? And like I rarely ask her, because back then it was hard times and it wasn’t her fault, but at times I -- like when I’m mad I say it’s her fault, but I know for sure it’s not her fault. And I asked her how does she feel about it, and she says it’s not really that hard, but she doesn’t like it, but it’s not that hard. But it’s hard for me, because I never really got that chance to live without it, you know, I was just born with it.

Ian had a similar response about how he felt:

There’s been times that I just -- it’s like, “Why me? Why I got to be the one?” And you know, somebody like, people used to be like -- people say, “I would rather for it to happen to me then to happen to you.” But I will not rather for it to happen to me or anyone else.

Ian also wished he had the opportunity to spend some more time with his mother before she died. He verbalized wishing to have a final conversation with her:

If I can speak to my mom, I’d tell her I love her. I would pretty much tell her to come back if she can. And save me a spot next to her in heaven.

Jake had a similar request for a conversation with his mother if she was still
living.

My mother passed away when I was a baby. She died from AIDS related complications. Just hope she’s proud of me is the main thing I’d ask her.

Karen said “Mommy spoiled me. I think she felt sorry. I think she felt bad, so she felt like she had to make it up, but before she was like getting really sick, she always spoiled me, even my siblings, my older sibling always told me, "Mommy always made sure that you had anything you wanted." When she asked what she remembered about living with her mother, she replied:

So, it's just like sometimes I wonder why she did that or whatever. I see the ways that I was spoiled by her sometimes and I'm like no, but I just feel like she wasn't there for me in my life, but I heard and from what I've seen, I remember being a little girl and living with her. She had a cat. Also, at her funeral, I remember her funeral. I remember the day.

Karen further explained the relationship she had with her mother and was asked if her mother were alive today what would she ask her about her HIV diagnosis:

If your mom was alive today, I would say to her, “I love you and I forgive you because I know that she would probably feel -- I love her because if it wasn't for her, I wouldn't be here. I thank her for giving me life. I thank you. Actually the virus makes me stronger person because not everyone can live and deal with what I can deal with. Not everybody can do that. So, at the end-of-the-day, I'm just grateful just to be alive and living. I appreciate life. We all make mistakes. I make mistakes. Everybody makes mistakes, so at the end-of-the-day, even though you made a mistake, you still gave birth to me.

In the midst of grieving for his mother, Mark had to find a job which was not necessary when his mother was alive.

My mother died in 2008. I did not know she was dying. I dropped out after my mother passed away. We had to work when I wasn’t working at first. I had to work. Now that she was passed away, I had to start to work so that’s how it changed. I had to take a job in housekeeping. I felt sad when mom died. I think she would be proud of me today.

Oden lamented he did not have enough time with his mother before she died. He described what he remembered about living with his mother.
I can't really say that there was much good times with her because I had such little time with her, of knowledge, of knowing who she was and even having a good time because such little time and she got sick. I only knew her for about, wow -- I only knew my mom for about two or three years. That’s sad. I’ve always lived with her but like I said, the knowledge of knowing who she was and the type of person -- just getting used to a person period, there wasn’t enough time. I didn’t have enough time with my mom and that’s, I think a lot of times, what really makes me sad is that I wish I had more time with her.

Qual described the events surrounding his mother’s illness the day he found out his mother died. He described the day he received the call informing him of his mother’s death: Grandmother found out that my mother, along with the HIV had Hepatitis B and pneumonia. She told me that over the phone. It’s like she started the thing about being secretive; some things are just taboo to talk about. So I guess that was one of the things. And when I asked my grandmother, it was the weekend before my mom went into the coma. I asked my grandmother, “How is my mom doing?” And she told me to stay focused on school; your mom is going to be okay. And I was just like, “But she hasn’t called me.” It had been like a week since my mom had called me, and usually I talked to her on the phone. I’d call the hospital and stuff. But she wasn’t calling me. And my grandma was like she was being transferred to these different hospitals and she was getting tubes down her throat, but she was snatching them out and stuff. So at this point I’m worried, because this is my mom. Regardless if you tell me to focus on school, this is my mom. But when I did get a call, it wasn’t the call that I was expecting. So my grandmother kind of waited until the last minute, in my opinion. To let me know.

Qual suggested the relationship with his mother should have been better and had many questions for her:

I loved her. Well, I love her. And I wish that our relationship could have been stronger. Because I’m her first child. I was her first. I would think that it would be the strongest, because I was her first. And I was the oldest, and I understood the most. And I knew the most. I knew when my mom was being abused by my dad. I was there. And I remember. And she knows I was there and she knows I remember. And she knows that’s why I don’t like him. So I just would expect me and her relationship to be so strong. I never expected her to give me away to my grandmother. And I would ask her why. And everything about the disease. And I don’t know. I don’t want to just question her. But there are a lot of questions I wanted to ask my mother.

Wishing for a purposeful life

In responding to the questions asked: How does the HIV condition affect the relationship with family and friends in young adults who have grown up with HIV?, the participants provided
vivid descriptions of the experiential lifeworld situations growing up with HIV. The essential theme wishing for a purposeful life revealed the thematic themes, relationships, marriage and family and helping peers understand HIV are listed below.

**Relationships**

The participants enrolled in this study were 18-24 years of age and at this stage of development relationships should be important, but many described having very few friends or significant relationships. The themes of relationships, marriage and family and helping peers understand HIV are described below in the stories told by the study participants.

Many of the young adults in this study disclosed a limited expectation of significant love relationships. Cassi prefers not to have too many friends at this time and she was asked to discuss her romantic relationship:

> My ex-partner was female and I don't do boys. Right now. Like now, I'm focusing on myself and me getting my life together before I'd be a partner with somebody else 'cause then that's more stuff added to me and then, like I might sometimes fall off, get off the track 'cause of that person. So, I'm basically just working on myself.

Peer support should occur when the young adults provided emotional, social and practical help to each other. Only one participant described knowing another perinatally infected young adult. The participants who attended a HIV camp stated the other campers did not disclose their status as perinatally or horizontally transmitted and none of the participants are currently part of a HIV support group. The participants below provided a description of peer relationships while living with HIV.

Most of the young adults may disclose to one peer. Ella described the peer she told of her HIV status:
My god-sister, and you can say one of my sandbox best friends. That means we’ve known each other for like 15 years now. And she’s my best friend. She’s my new best friend. I met her in middle school when she’d been there.

Donita was asked how she feels about getting involved in a romantic relationship at this time:

My age right now, a lot of boys try to talk to me. I don’t really focus on it. I have friends, and I have people, like I said, boys who try to talk to me. I have to finish what I’m doing like focus on making my life a little bit better before I jump into a real, real relationship.

Gretta was asked if she keeps in touch with her non-HIV infected peers:

I would say it no. It has to do with like your peers sort of, in a way. You have friends that are not HIV positive, and you don’t see them that they have to like go inside early because they have to take their medicine or they get tired too quickly because of the side effects of the medicines, so you have to go to sleep earlier than them. Now when you’re older, you really just don’t have time for it now, you just know, you just take it because you have to take it, it’s part of your life and it’s not going to go away and you just live with it. And you just instead of having negative thoughts, you just have to have positive thoughts throughout your day when you’re going to take your medicine.

Jake described what his peers say in a routine conversation about HIV:

There are a lot of things, like what get’s on my nerves a lot of times when people do movies about people with HIV, they use the term full blown AIDS which isn’t a real thing because no one has full blown AIDS because that’s like saying at one point you had half blown AIDS, and that doesn’t exist. I still think it’s, -- maybe it’s just in our community a lot of people think it’s still like a primarily gay disease. Not as bad as it used to be of course, but you know just things people don’t know. It’s like people don’t die from AIDS. They die from AIDS-related illnesses due to weakened immune system. I don’t know. It’s just things like that. People just don’t understand.

Oden is one of the younger participants in the study. His partner is male and he was asked to describe his partner and how he disclosed his HIV status:

I kind of told him my story and he got it through that. I didn’t just come right out and say, Hey, I have HIV.” He had to kind of pull it out of me, but it came out itself by me just telling my story. When I got to the part about my mom, he automatically knew. So then after I was done venting then he said, “Okay, so now my question to you is, do you have HIV?” And I said, “Yes.” And he said, “All right.” He said, “I don’t care.” He said that drew him closer to me actually. And he said I’m actually his third or fourth relationship with somebody that has HIV.
Marriage and family

Of the sample, one participant had children and was divorced. In the midst of grief, a clear desire emerged, uncontestable: The young adults either wanted children or did not wish to impose such a harsh life on a child. This was a clear decision that was answered without hesitation. Below, several participants described what they hope for in a marriage and family:

Alvin was asked if he plans to marry and have children:

I’ve been thinking about that. I would love to have a nice, happy family, nice, stable relationship. If that were to happen, I’d probably tell her first, just straight off the bat. Just tell her that I had the HIV and if she wanted to still start a family with me, we’d be talking more about how we can do it and everything without me transferring it to her and transferring it to the other kids. So I would just be like, “All right, let’s go to the doctor and explain our little so-called problem or little challenge in the future.” So that’s probably what I would do. Just talk to her first and tell her that I have it and then go from there.

Donita had a similar response regarding marriage and family, She is optimistic and suggests if she married someone also diagnosed with HIV there would be less disapproving conversations between them:

I used to think that if I found like a handsome husband and he has it, it will feel like perfect, like we both have it and wouldn’t be able to judge each other. That’s what I would think a lot. I was like, even if I find one without it, the HIV, it’s fine too as long as he doesn’t judge me because of less educated about it. I always think it would be a lot simpler if I find one that just has it and we like each other. I don’t know if that’s even possible because everybody’s hiding it.

Ella did not oppose getting married but has a strong opinion against having children:

I don’t want any children because I don’t want my children to have this. I don’t want to bring nobody in the world with this. I don’t want any children.

Gretta plans to have a husband and children. She was asked about her plans to tell the children, if she has any, about her HIV status:

What am I going to tell my kids, “Yeah, your mom is HIV positive.” I know it’s going to be hard, but I feel like they would understand, they would have a little bit of understanding, like understand what I’ve been through, and they’ll probably even look for that, you know, there actually are infections, diseases out there that we have to be
careful with. That’s how my mom feels right now with my sister; she feels like my sister’s more preventive of getting an STD and things like that, because she sees what me and mom, what we have, and she protects herself even more, when she’s out there and stuff.

Henrietta is currently unemployed and for the past six months refused to take any HIV medications, but she is hopeful for a marriage and a family and described her plans for a Family:

I want a girl and a boy, but most likely a boy, but, you know, whatever comes to me. But I would want to be like a working mom and be able to provide for my kids, I don’t want to be like, “I don’t have no money. What we going to do?” you know, to take care of my kids, stuff like that. I would jump on my medicine. I mean, if I was pregnant I would take my medicine and be able to help the baby grow and be healthy and stuff. I mean, I ain’t going to let the baby die just because I’m dying, no. It ain’t going to work like that. If I’m like lying in a hospital bed on my way to death, I just turn all that off, just, “Well, that ain’t happening for me.” Yeah. But for right now, since I don’t feel sick and down, I’m still planning on that.

Jake may get married, but his family will not include children:

I don’t know if I want a family because of my condition, I really don’t. I know there are things they can do to like make sure that the kid doesn’t get it, but I couldn’t imagine passing this on to a kid which is why I really don’t want kids is the main priority.

Deciding to disclose and thinking ahead about reasons for telling, or not telling is one of the best ways to prepare for disclosure. Jake was asked about the circumstances under which he disclosed his HIV status:

I told some yes, some no. And just only ones I got through school with, but other ones I didn’t even do anything with. I just kind of explained to the best of my knowledge what I had at the time. I always used protection so that’s a plus, and just let them know that I’m letting you know that this is what I have because, -- I mean they were, I won’t say all right with it, but they understood. Sometimes it causes a strain on the relationship, because you just don’t know how the person’s going to reac

Karen described how she disclosed her HIV status to her boyfriend:

I really love him and I told him. To be honest, he’s the best thing. Just being around him, I found myself just wanting to be around him. After that, we were always around each other and then it got to a point where it was just like, I said, "I want to be with you. I want to be with you. I just want to be all yours," and I never felt like social. I just never felt like that before. I'm 100% sure. I don't want to be with nobody else. He told me the
same thing. Then, it was just like that. We just grew a bond. He likes to say, "It's not an argument. It's a disagreement," so I never say we argue. I just say we have disagreements because he doesn't stay mad at me for long. It's like three minutes and then he's back smiling and laughing. He's really supportive of me. "Did you take your medicine?" Even this morning, "Did you take your medicine last night?" Things like that, I really appreciate because that lets me know that he cares about me.

Mark was asked if he wanted to have children in the future and he said, “definitely Yes” as he smiled:

I want to have children, Yeah. Someday. I would say to them, I have HIV and here’s the ways you can prevent yourself from having HIV.

Nepal was also asked if he wanted to have children in the future and he had similar response:

Yes, I want to have children, the conversation I would have before you had sex with a girl. Well, I would first do as my mom wants me to tell her is to sit down and tell her, okay, mom and/or grandma, I’m thinking about having sex, and they give me guidance to how to put the condom on and what to do and how to approach her, and then with the girl, I would tell her well, I’m, you know, can I talk with you? I’m HIV positive. I was born with it from birth, and as long as we use condoms, everything should be good as long as we don’t take it over the limit.

Paul described having a family and stated he is “hopeful” for a nice wife. During the interview he described what a family means to him:

Hopefully, I have a family and get a good wonderful job and a nice wife that don’t put up with drama. I have seen in reality shows and stuff where they gossip about everything, but that’s not necessary, this day to you and the next day to them. Well for one, they are not like these other people where they hang out in the streets and stuff like that, they actually educate you on being successful and learn and stuff. They will guide you to the right path. I only say that children may be too much work because you got to buy pampers, food, and then when they grow up you got to go to the schools, you got to go to their meetings and stuff, that’s too much. Then you got to have money for prom and all of that.

Some of the young adults are looking forward to marriage and a family. Over time, Qual has a positive response to having a family which includes children.
But when I first was told I was just like, “I don’t want a family.” I just didn’t want to affect anyone else. I just am going to be alone. But as my life goes on I find that there are maybe ways to get around certain things. There are still some things about it I don’t even know. So. But I do feel like I do want a family.

**Helping peers understand HIV:**

Bea was the only participant who states she knew other young adults with perinatal HIV. She was asked to describe her experience at the HIV camp:

I have lots of friends with it. I met them all at camp this camp for kids living with HIV and AIDS. I met them all at camp, and I know they told some of their stories about telling other people, telling their other friends, and that’s how I started to come out because one of my friends that I was really close to there, she was telling me, oh, why you don’t tell people. Don’t you think they should have a choice to make their own decision whether if they want to do this or do that, and she just really made me think about that, and it really got to me. So that’s why I’m more open about it now because I, -

when you go to that, when you go to them camps, it feels like you already know the people there. You already feel close to them even though you don’t know them, but you know why they’re there. It’s like you’re, I want to say be kind with people who you know you can talk about it with other than talking to somebody who really doesn’t know what you’re feeling.

Donita was asked to describe how she feels about the way HIV is discussed:

The rest of the world is ignorant about it. As soon as they hear HIV they automatically think, oh, you have AIDS, and that’s not the case. I hear a lot of smart comments about it, and I try to keep myself from saying anything, but I always end up saying something. I will be in class and somebody talks about, oh, he has AIDS. I’m like, no, it’s HIV, stuff like that. And they automatically think HIV is AIDS. HIV is AIDS but only if you don’t have any more T-cells fighting to keep your body alive. HIV is different. You’re alive with HIV, but AIDS you have little time to live. That’s how I see it.

Gretta described how she explained her HIV illness to younger family members:

this is extra work to teach others about HIV:

My other little cousins, they don’t really educate themselves enough. So they still think like those machines we use to clean our faces, I was using one of them and I told them, “Oh, here, you can use mine, it’s fine.” She’s goes, “No, because you have that and I might get it.” I’m like, “No, you can’t get it that way.” So it’s like they’re not educated well enough to know how cannot get it, so I have to like show them or like go on a computer and actually like tell them about it and things like that. It is extra work. I feel like sometimes I do feel down about it, but now that I’m older, I’m just like, “Let me get
the time and actually educate them, let me get the time and actually teach them about it, because if I don’t do it, who else is going to do it?

Gretta elaborated further that HIV information was limited and inaccurate. She was asked about the HIV information discussed in her classes in school:

They didn’t really talk about HIV in school, and in like health class I feel like they didn’t have the right material to talk about -- the right research to talk about HIV and AIDS, because the way they put it -- the way they were educating us as students, were, “If you get HIV you get sick and then you die.” That’s the way they were teaching us about HIV, and I couldn’t say anything, of course, because then I knew if I said something then everybody would look at me in kind of a weird way, “Oh, so then you’re HIV positive cause you know all this stuff,” and things like that.

Jake had a similar response when asked about HIV information in the classes. He was asked about the HIV information discussed in his classes:

It would have been helpful to hear a little more about HIV in the classroom because I have it, and I’ve been coming here since I was so young, and I’ve been involved in groups and stuff, and I went to camps that were like Camp Heartland and Camp Safe Haven with kids who are infected and affected with HIV, and they taught so much to me about it, I have a good understanding about it, but I understand the next person in my class might not know anything about it. They might still think it’s a gay disease or whatever the case is as sad as that is. So I do think that there should be some general knowledge taught to people about it, but unfortunately right now, it doesn’t seem like HIV’s the big thing right now. Everyone’s focused on cancer right now which it’s sad that we can’t fight both, but it seems like well, AIDS, that was ‘80’s, ‘90’s. Now we’re focused on cancer.

When Paul was 20 years old, he disclosed his HIV status to his friends. He described how he told them he had HIV:

Well, actually I gathered them up as a group and told them that I have HIV and stuff like that and they were like, okay. It was on my mind a long time ago, so I just had to blurt it out. Hey everybody now look, I have it but you can’t catch it, unless you do drugs or needles and stuff like that. Eventually, I told them. I had a carrier, I had to tell them, they were like, oh, it was no need to hide it, we are all friends and stuff like that.

Qual and his caseworker are discussing disclosing his HIV status to his sibling. He suggested to the case worker several important reasons why he would like to tell his siblings about his HIV infection:
I feel like they should know. I feel like they should know because my mom passed away and it was too late for me to talk to her about it. And I feel like I want to break that cycle, in a sense. Because I don’t want it to be like that for our kids, and just a secret about everything. Why should it be a secret? I know some things can hurt each other, but if anything it could also help. Because I know it would have helped them a lot. And I think the reason I can deal with my mom’s passing is because I knew how sick she was. They don’t know how sick -- they didn’t know how sick she was. They didn’t know what she dealt with every day. I knew what she felt. And I knew that I wouldn’t want anyone to feel what she felt. And that helped me a lot, to accept that it was better that she would pass than to have to struggle and be in pain. So I would want them to know that I have it. But I’m not in pain. My numbers are good; I’m undetectable. And make them knowledgeable. Because I’m sure they hear a lot about the disease. And I’m sure their ignorance can just make them say anything about it and not really care about it. But when I actually tell them and they see how close to home it hits, and they can get a respect for it and then they can know that it’s still real, it’s still prevalent. And it still can be defeated. It doesn’t have to take over a person.

Longing for a future

In responding to the question, what are the expectations of young adults living with HIV over time? The participants provided vivid descriptions of the experiential lifeworld situations growing up with HIV. The essential theme longing for a future revealed, out of work, elusive and unplanned education, transition to adult responsibilities and acceptance of life’s circumstance.

Little is published about the cognitive functioning of perinatally infected HIV young adults (Brackis-Cott, KanG, Dolezal, Abrams & Mellins (2009). The young adults in the study were over 18 years of age and it was expected that they would begin assuming their financial responsibilities through employment, but an estimated 80% of the participants were not adequately prepared for employment. As many as 41% of the participants did not graduate from high school and 100% of the participants reported income less than $20,000 annually. Only one participant had a home where she was responsible for paying rent. The themes out-of-work,
unqualified, transitioned to adult responsibilities and acceptances of life’s circumstance are described below.

**Out-of-work**

Just like so many of the young adults in the study, Donita is unemployed, but she is trying to develop a small business. She suggested her physical status is the primary reasons employers will not hire her:

I apply for jobs. I can’t do a standing up job so I try to do office jobs. Some will not take me because I can’t do a lot of stuff. Usually I just clean, and I do my own private job is just building an I-phone or a computer.

Henrietta is not employed and stated she has poor coping skills. She lost a good friend when she dropped out of school. Finishing her education, taking her medicine and working are all very important to the friend that she lost:

But like I told her, it’s not that easy to just go out and get a job, or like I don’t have like good coping skills, so I don’t really associate with other people as much. So school is not really an option for me. But see like for the past year I started high school, I’ve been bullied at High School, which make me not want to go.

Ian said “I never had a job” and he is seeking employment although not a specific about the type of employment. He was trained in school for carpentry and as a barber. He was asked what he is doing to find a job:

I think social workers are good. I think social workers is like a brother or a sister, you probably just don’t know and you all got each other’s best interests like I was telling you and that’s it. I’ve never had a job. I’m probably doing half of what it takes as far as asking and going to stores and asking people if they hiring but far as keep pushing myself and really pushing myself, I don't think I push myself enough and I think that’s one of the problems. I don't think like, if I be like, “Okay, today I’m going to go out and look for me a job.” I don't think I’ll be like, “Okay, all day I’m going to just be looking for a job. That’s all I’m going to be doing all day is job searching, job searching.” And if I do that, eventually something might just cross my mind. No. See, I just basically want to take the jobs that I studied in school. That’s where I got a little bit of skill in, as far as carpenter and cut hair.

**An Elusive and Unplanned Education**

Alvin has been moving around to different schools and he described his
experiences in school:

I was in a special needs program, like the Special Eds. Also my program kept on switching me to different schools because I had trouble reading, dyslexia and sometimes trouble writing and so they just kept on switching me to schools from time to time. At start of junior year I moved back to my old school where I was originally supposed to go because first year of high school was in Northwest. So I was only there for two years and then moved back because I wanted to be back with my old friends from kindergarten and everything else.

Bea had a 3.4 grade point average in high school and told a story of not being able to attend a four year college because financial aid information was not given to her. She described the events around applying to a four-year college.

My mom could not afford to send me to a four-year school. Information wasn’t shared in school. It happened with most everybody in my class, and I didn’t know nothing about no financial aid, and that’s weird because they’re supposed to tell you, but they was telling us about grants and loans. I had to get them, and my mom was like, don’t get no loans, and I applied for a whole bunch of grants and stuff. I was just like, well, I might just do this financial, -- well, when I heard about financial aid it was from my brother when he came back from Job Corps, and he told me about it. So that’s how I knew about financial aid.

Cassi described the events that led up to not continuing her education beyond high school.

I didn't you go onto college right out of high school. 'cause I was sick, so and I was in the hospital, so I couldn't do school and get my health together, so I had to take a break. So, then I started going to like a little bit of classes, but then I got sick again, so now I want to go back. But I applied for schools and everything and I think I'm about to be in this class with the Connect program through school. If I get sick and have to go into the hospital again I will have to stop school.

Ella graduated from high school, but was sick and missed many days. Upon graduation, she was ready to go to college, but her sister, the guardian told her there wasn’t enough money to send her to a four-year college. Ella described her disappointment in learning she couldn’t to go to college:

In my 9th and 10th grade, yeah. I believe in my whole high school, I missed a lot. Sometime I kept getting hospitalized or I was sick, but I graduated. My aunt is my guardian, but she is in Jail, so I am living with my sister for now. My sister we had a fuss.
They’re sending me to the college I don’t want to go to. The college I want to go to was in Ohio. She had a fuss to send me there. Like she had a fuss to send me, pay for everything, for my tuition. There is not enough money. I had for tuition. But to get me there, she had no way to get me to the college. If mom was alive she would’ve found a way. She would’ve found a way to get me there, will get me to that college. I just believe my sister didn’t want to do it for me, I guess. I don’t know.

Gretta was not prepared for college after high school and recalled her experience of cancer and finishing her last round of chemotherapy.

I was not prepared for college when I graduated high school. I wanted a break, because I just finished with chemotherapy and things like that. So I told myself, “I want a little break before I can actually go to school, and just put myself through all the stuff that you need to do in school, and I guess from doing that break, the cancer came back. So it was just me registering and then not going, registering and then not going, and to finally know that I’m 21 and I’m registered and I’m actually in, I feel like great because I’ve been waiting for this day for a long time.

An Individualized Learning Program (IEP) is mandated by the Individuals with Disabilities Education Act (IDEA) for individuals with educational disabilities. The interview revealed Henrietta had an IEP until the 10th grade and because the IEP was discontinued, she did not graduate from high school. She described her experiences in high school and her future educational plans.

I had an IEP until the 10th grade. Like one on one, like a teacher was able to walk around the classroom and help you one on one, and then there was a teacher that helped the kids that were more ahead. Yeah. I think about attending, cosmetology, veterinarian, graphic design or culinary arts programs. There’s a whole lot of stuff, to like soccer and swimming and basketball, football and daycare. And, no, I am not enrolled in a program. Actually, today I’m trying to gather up all my information to go to Job Corps, which I can complete my education for high school and I can go into a trade or maybe more than one trade. I’m just trying to move on.

Ian had several opportunities at career choices in high school and was asked if high school prepared him for a career:

I was becoming an adult and that I wasn’t no longer at a little kid’s school so, I took barber. I took carpenter. And I was going to take childcare. Take a math class, reading and auto mechanic. I did not finish the courses.
Jake entered in a four-year college after he graduated from high school and explained that he was not given adequate guidance to complete college. He lamented, “I went to college, but did not graduate”. Currently, Jake is employed in two minimum wage part time jobs.

I went to Westwood which is in Virginia which is like a career oriented school. So you pick a program, and they give you classes based on that career. It’s about three years. I didn’t complete it though. I didn’t complete college.

Mark also was in a special education program and he was asked, what that experience was like:

Different. I mean I was sick sometimes and sometimes I wasn’t well enough to go to school. I was in Special Education and I don’t think that that was helpful. Well I mean they had me in the wrong classes so I didn’t really get what I needed out of that. I was in a class with children who had special needs. In high school, they had me placed in a mentally retarded class for most of the three years that I was there. Yeah. I definitely needed it but I don’t think I needed that particular class. About twenty to sixteen students and one teacher. Well, she was trying to teach. I dropped out in the 10th grade”.

Nepal attended a” progressive school” that is a special needs school. He was asked, to describe that experience:

I had fond memories of his school teachers. My teachers, they were pretty cool except for one that gave me a hard time, but as I recall on it now, I can see why because he pushed me to do good to make sure I’m good and all of that, to make me strive for excellence. My other teacher, we were real cool. I’d go in his classroom, and we’d just talk about the football games and sports. A real cool person. My college summit teacher/yearbook teacher, she was real good. I had her for three years. She wrote my letter of recommendation. She basically just guided me towards the right way to college.

Oden was asked to describe the type of high school he attended:

I did not attend regular school. Mm-hm, no, well, my high school years, I graduated from a transitional school. It was called The Foundation School. It was out in Largo, Maryland. And I was in there from about 8th or 9th grade all the way up until 12th. They didn’t see fit for me to be in a regular school so they thought that this is something more therapeutic. Something else therapeutic that they thought would help and so they put me in there.

Qual missed several school days during his youth for various illness and described this time as a rebellious period in his life.
I did not want to go to school. A part of me rebelling for some reason. I guess my grandmother. I just would wake up one day and say, “I don’t want to go to school today.” But she would make me. She would say you have to go. But I wouldn’t go; I would go outside and just walk around. And I would spend days not going to school out of rebelling because I just found out I had this disease. I’m just lost, to why I’m not living with my mother, and just all these things on a child -- I didn’t want to go to school. I didn’t feel like I should have to go. I also would not want to come here, for check-ups. I always say why do I even have to come here? But I knew why I had to come here. But it was a way of reintroducing the conversation. But the conversation still didn’t happen. I don’t want to go to the doctors. I don’t want to go to school. Anything they wanted me to do, I just didn’t want to do it.

In describing their future goals, Qual was the only participant who described his educational goals and plans and expected a successful career. He attends a four-year college and hope to be a role model for his siblings:

I like school. I’m big in academics. I love doing schoolwork. I love challenging myself. I’m a theater major, so I love theater and I love what they’re doing. But I’m thinking about changing schools, now. I just always had a passion to just be in the arts. Either singing, acting, or just all that. Dancing. All that. And I just was never driven away from that, for some reason. Even when people tell me how it’s hard to get a job, you’re going to struggle, and all the negatives. It’s just my passion never really let that get in the way of what I was there for. I always remember why I was there. And it’s like when my mom passed -- it really let me know that’s what I want to do. I should just focus on that, because my life really isn’t promised here. And I should go for what I need, what I want, what I desire. I never really had a real big role model in my life who I can -- I never had like a mentor or anything like that. In some ways my grandmother used to always be my role model because of her strength, I guess. And my mom, because of her strength. And even on her last days I saw how strong she was.

**Transition to adult responsibilities**

No differences in transition were reported by the participants who attended regular high school or a special education high school program. Alvin, Karen, Mark and Oden attended special education high school and reported that more attention and time was devoted to skill development such as carpentry, beauty school and barber skills. None of these participants completed any of the training programs nor had a plan of action for achievable goals. Transition
was not different for Casi and Oden who were of a sexual minority or are gay; or for Bea, Oden or Paul whose diagnoses are medically complex.

Bea recalled the discussion she had with her social worker; she recalled:

At the age of 30, I expect to have my own house, to be driving, married, have a good education, and be financially stable, have, I guess, have a child, one, have one child, and that’s it. Be a full grown, responsible woman.

Several participants also reported the experiences of finding employment as too difficult. Cassi was recently hired as part time cashier. Her salary is less than $9,000 annually and she was asked how she felt about her new job.

I work every-day about 30 hours a week as a cashier. I am happy to have this job. I am not sure anyone else will hire me because I don’t have a skill.

Faith graduated from high school, has not attended job training and is unemployed. Faith was asked about future goals:

From the time I graduated from high school until now, I have done nothing. I’ve been going out looking for jobs. I’ve been signing up for jobs but it’s like, they never called me back so I went down there and signed up for some new jobs and they still didn’t call me back.

Henrietta told a story of being forced to grow up. While growing up her mother met all of her needs. Enabling behavior was initiated by her mother. Most importantly, she never learned to independently take her ARVs. On her 18th birthday she stated “all of a sudden I am expected to take care of myself”. Henrietta is unemployed and has no income. She was asked to describe what is expected of her as an adult:

My mom was like babying me all the way, like she would get my medicines, give me my medicines, cook dinner, breakfast, you know, make sure I’m taking my medicines constantly, constantly, constantly, and now she feel like I got older of doing it, then it’s like I can do it myself. But it’s not that easy, like when you’re so used to help all the time and then it just stops, it’s not that easy to regain yourself. No, it’s just that I’m not used to doing it myself. I’m not used to filling up my own sandwiches, cooking my own food, supplying myself with my medicine. She would buy me like shoes and outfits and
little knickknack toy stuff that I would want, like she would have my phone bill, like pay it and stuff, and now it’s like nothing. Ever since 18 it’s been nothing.

Social workers are currently assigned to assist in resource acquisition for young adults with HIV transitioning to adult care (Wiener et al., 2007). Jake was transitioned to an adult HIV health center and was having difficulty obtaining his ARVs:

I was really worried, not really worried, but when I went to the pharmacy maybe months ago, and they said that they didn’t take my insurance or something like that, and I was trying to find out what was going on. I’ve been coming here all these years. You’re just telling me now you don’t take my insurance, and I have to find out what’s going on, and I’m not at my pediatric center any more. So usually if that happened when I was here, I could call a social worker and say, I’m having trouble getting my medicine. What can I do? This I had to do on my own. I had to call the insurance people and find out this and that. I think they led me to kind of a primary adult care program or something that will pay for my medicine because the county did not approve. It will be $3,000. It’s like, oh, yes, I got that. Let me pay for that right now. That’s fine. I don’t have that money on me. They just say that so calmly like it wasn’t paid for right. I don’t have that.

Jake said “At Children’s hospital, if you ever need help with something, there’s somebody to help you. ‘You can call them” Jake described the differences he experienced in the transition from the adolescent clinic at his old pediatric center to the adult health center:

There, I guess it’s more adult primary, adult oriented so I guess they kind of feel, unless it’s an emergency, you’ve got to get through it on your own. You’re responsible for your appointments. They may call you one day, oh, you have an appointment next week at this time, but they’re not going to be like, the day of the appointment, hey, where are you? You’ve got an appointment. You missed your appointment. You missed your appointment. Hopefully you’ll be able to see the doctor you have to within the next week or so.

Nepal’s transition plans included living in the family home with his mother for the remainder of his life. He attends community college and is unemployed. He was asked about a potential salary that would be enough to pay for his living expenses:

Probably, well, my career, I wouldn’t expect for it to be up there like $20,000 or something like that. Maybe about $5,000 a year or something like that because my mom already told me that the condo that we live in it will already be paid off when I’m 32, so I don’t really have to worry about that unless something goes wrong between now and then.
Qual lives in the college dormitory and is responsible for his care. He described “being 19 years old” and making adult decisions that affect his life and the lives of others.

Right now I’m just coming as a college student. I’m not saying a visitor, but in a sense maybe a visitor. Because I spend most of my time at school, and this is the first time where we have actually been living with my grandmother. I feel like now I’m 19, I’m about to be 20 years old. I clearly -- well, not clearly. But I basically make all the decisions in my life. Regarding school. I have to do everything on my own, now, because my mom has passed away. And I was doing that towards the end, anyway. I was very independent; I found my own jobs and stuff like that. So I feel like if I choose to make that decision I don’t think she would really be upset. Maybe she would question it, and I would tell her why. But I have recently just had to tell my father’s father -- my grandfather. He didn’t know. And I didn’t know he didn’t know. Because he was so close to me as a child. He is the closest thing I have to a father, basically. I thought he would have known. But he never talked about it. But, again, I thought it was because you don’t talk about it; that’s just something you don’t talk about. But in actuality he didn’t know. So it was a bomb on him. And it hurt his feelings that no one had told him. And I hated to be the one that told him, but I figured it was better to tell him now than I guess never.

Acceptance of life’s circumstance

Donita described HIV as a condition she has to live with and growing” bitter” won't change the inevitable. Donita described living with HIV below:

Living with it is it’s normal for me. At first I thought it was going to be the worst like most people would think, like, oh, it’s something that you’re going to give to somebody instantly or somebody who’s near you is going to get it. It’s hard to think that you’re alone, because you are alone sometimes. Most people wouldn’t tell somebody, oh, I have it. So mostly I’m just looking, I catch myself trying to find people who’s like me even though everybody’s hiding it, like me. So for me I just do what I have to do. I take my medicine when I have to take it, and I try not to miss it, and my family don’t remind me about my medicine. I do it on my own way. I remind myself to take it. I have the pill box near my bed so I know I always go there before I go to sleep so I don’t forget. That’s another thing. And then on top of it is so many medicines it’s very annoying, but I have to take it so I don’t get more medicine added to it. So that’s mostly my motivation to stay well and not have more medicine added to what I have to talk already.

Henrietta’s medication compliance is 0% and stated “I may die” but I need help to take my medicine. In describing the lack of support from her mother, Henrietta described how she feels about probably dying due to not taking her medication:
I feel like I have things worth living for, like I think about the times like my family they’re going to miss me, my friends, they’re going to miss me, I ain’t going to be able to complete my goals or what I want to do in life or whatever. But it’s like now, I feel like much better not taking the medicine than taking it, but I know my insides are like, “Ugh, give me some medicine.” I mean, I don’t know. It’s just I have -- like I have had help from my mother from a really long time, and for her to stop at 18 is like, “Ugh, where am I supposed to go from here.

Most of these young adults have accepted HIV as a life long illness and have discussed the willingness to accept the circumstances with which they are confronted. Ian described how he feels about growing up with HIV:

It’s kind of hard but then again it’s not because I didn’t really know I had it, but after I knew it’s a disease. I guess I kind of figure I had no choice but to get used to it. But it’s not no different because if I have it or don’t have it, I still feel like any other normal kid. it’s like a best friend you got to get used to. It’s like having an inside best friend that you don’t know about and over the years you all relationship get bigger as you all know about each other. So I’m good. I’m doing fine.

Ian is unemployed and also participating in a job training program. He hopes the training will help him find a job. He described what he is learning in the program:

The program that is reinforcing filling out applications and proper dressing and do well where you shake --the proper way to shake someone’s hand and eye contact and things like that.

In describing his life overall, Jake perceived his life’s circumstances as fortunate when compared to others living with HIV.

My life’s been pretty average over the, -- HIV is a small part of my life compared to other things. I’m lucky enough that my condition isn’t as bad as other people’s. I’m able to get around on my own. I don’t need help with anything for the most part. So, and I’ve probably only been hospitalized maybe less than six or seven times in my life, and it’s small stuff. So, I do have friends who are HIV positive who they’re always in the hospital, or they’re always sick, and they’re not feeling good, and so to some aspect I do feel lucky that mine’s isn’t as bad as theirs.

Karen described struggling to cope with the idea that she has to live with HIV and learning to accept the illness as a part of her reality for the rest of her life:

To me, I don't look at it as like a death sentence or anything. Like I said, I guess being born with it, I'm able to cope with it differently. I've been taking the medicine all my life,
so basically I'm comfortable with it. Some days I have my down days where I'm like --
but I think I'm past that stage, but I was blaming, "Why did my mom do that?" you know,
and upset with her because I'm like, "Why do I have to suffer from her mistakes she
made?" but it's life and as I'm getting older, I'm learning from that. But taking the
medication sometimes can be frustrating on a day-to-day basis, every day, you having to
do that. That's part of my daily agenda, but sometimes it can be frustrating because you
forget and you've got to keep reminding yourself about it. It just can become a lot
sometimes, but like I said, once it's part of your life style, there's nothing you can do. I
always say I have HIV. HIV doesn't have me. This is something that I can control. It
can't control me. It can control me if I let it, but I'm not going to allow it to. It's just all
in how you look at whatever perspective you have of it. Some people let it take them
down, but I'm a fighter. I wouldn't dare ever let this take me down.

In accepting his life's circumstance, Mark explained not being able to participate fully in
school because of his illness.

You take what life can give you and you just make do with it. Growing up with HIV for
me has been more or less about HIV and more about the things I missed out on in life or
in school.

Qual accepted accepting the fact that his mother is dead and she will not be around in the
future to help him cope with living with HIV:

When my mom first passed I really didn’t see my life getting any better. It just scared me,
because I am also living with it. And it’s like it’s unpredictable. They can tell me my
numbers are undetectable, but I’m still afraid. I’m afraid that I don’t have my mom here,
who also was dealing with it and that we couldn’t ever deal with it together. We all had to
go in our separate corners and deal with our own things, like … I’m not the child and I’m
not hurting because of something maybe she did, maybe she didn’t. I don’t know. I don’t
know she retrieved it. But I just know I should have been told something. I should have
been supported. Helped. So the future. I think now, seeing what my mom had to go
through -- the thing clicked in my head a long time ago, when it came to taking my
medicine. When I knew I had to. Because I couldn’t dwell on wow; this happened to me,
my life is over. I couldn’t dwell on that any longer. I couldn’t cry about it any longer. I
had to make the best of what I have. Because nothing in my life has been really
tremendously affected by this. It’s not in control of my life. The only time I’m reminded
is when I come here for my three-month’s checkups. I mean, I have to take my medicine.
But now I’m only on once a day, so it’s not even that big of a deal to me; it has just
become a part of my life.

Paul has Cerebral Palsy, is wheelchair dependent and has dialysis treatments three
times week. He was asked about living with HIV in addition to other medical complications and
he replied, “Well, first it was difficult, but as I grew up, I had to deal with it, I learned how to deal with it”

Managing emotions

In responding to the questions asked, how were the young adults who have grown up with HIV told they have the disease? And do the young adults who have grown up with HIV think of HIV often? The participants provided vivid descriptions of the experiential lifeworld situations growing up with HIV. The essential theme managing emotions revealed, anger loneliness, stigma, secrets, fear, surviving and Sex and HIV.

Anger

Several participants reported feelings of anger when they found out they had HIV. Alvin was 19 years of age at the time of the interview and he described his feelings when he was told he had HIV:

I knew I had sick medicine. I thought it was for like something to help me sleep or something like that. That’s what they always told me, but over time they took me to this special psychologist that told me about the stuff and everything else. And out of nowhere she hit me with the bomb that I had it and I was very, very devastated. A kid does not want to know that he has a virus at such a young age. For me, it would have been fine if they’d told me sooner instead of telling me many years later. I believe it was when I was in 7th grade, 12. The first couple of years I was just all down and depressed. I feel different now than I did before like the first couple of days of school. I sort of felt like an outcast because supposedly if I told anyone they’d probably judge me and everything like that and say, “Oh, stay away from him.” He has some sort of disease that you don’t want or something like that.” But then I kept on doing some more research on it from health class and just normal day research. So then after that, I just kept on getting used to it and used to it and just lived with it. After that, it just went away. It’s like, “I’m healthy. It doesn’t really matter. It’s a part of me now so I can just stick with it.”

Bea shared a similar story when she found out she had HIV since birth and blamed her mother for transmitting HIV to her:

When they told me, it was like, oh, that hurt because I just blamed on my mother, and my birth, I blamed it on my birth mother for her not doing what she was supposed to do, and I always have felt like it was her fault, and I just have so much anger and just want to do
bad things because it just makes you mad because she done put you through so much, and
then put you to adoption, and then being born with HIV, then having to take medicine,
then having to hide it. I want to say that she made my life hard, but she just made it a
little bit more complicated, and having to take on it at a young age is like really hard
especially at the age of five years old. So I’m just thankful that my mom was there, and
my therapist helped me get through it.

Cassi described the circumstances under which she found out she had HIV and how
she felt the day she found out she had the illness:

I felt like I was not gonna' make it because when they kept asking me, "What school I go
to?" I was trying to say it, but it wouldn't come out and after that, that's when it all went
down and I woke up, I was in ICU and they didn't know if I was gonna' survive, the way
the seizure and the stroke at the same time, 'cause I end up on the floor, the hospital floor.
I guess I fell off the bed when I was shaking or whatever. I really don't know 'cause I just
blacked out and when I woke up, I was in a whole different room. There's no arguments
or anything between me and my mom. Our relationship is good.

Faith also shared similar story when she said, “I was angry because she didn’t tell me
until I turned like seventeen”.

Oden described being frustrated because he is forced to live with HIV through no
fault of his own.

My whole life I’ve been back and forth between pills and liquids trying to get
comfortable with it and I just can’t. At this point, I’m kind of tired of taking medicine.
I’m kind of tired of living with it period. People don’t know what I go through everyday.
Waking up, having to just know that I’m living with this and it’s not my fault. It’s really
annoying and it’s sad. I don't know. It's frustrating. It really is.

Paul was 18 years old when his mother told his he as HIV. Paul described the
conversation between them:

She was like, you know we have HIV, whatever happens, nothing can -- what did she
say, there is nothing that we can do about it except for take our medicine. I was not okay
with it actually. I was like why do I have it and my brother do not. That’s not fair. So, I
just thought, you know what, God do stuff for a reason.

Just like other participants in the study. Qual described not discussing his HIV status
with his mother before she died:

Me and my mom never talked about it, ever, before she passed. So it’s something that I
was battling with because I didn’t know. I wanted answers. I wanted to know why it was
me. I wanted to ask my mom -- I want to know how my mom got it. I don’t know if that was any of my business, but I do want to know that. And I wanted to know why she didn’t take the medicine when she knew she had it, in order to prevent me from having it. I want to know.

**Loneliness**

Loneliness is a chronic emotion described by the young adults enrolled in this study due to isolation or lack of companionship. Most of the participants agreed that they attributed loneliness to HIV. Alvin described loneliness as not being able to share his HIV experience with his friends.

Sometimes, I am lonely. yeah, sometimes, no. It’s like an in between thing for me because most of the time either if I’m alone I’m just why is this -- I know I have a lot of friends but most of the times it’s that feeling that you’re alone, like no one wants to be with you or around you. Sometimes I feel sometimes but I know I’m really not. It’s just something in the back of my mind it’s like, “You’re alone. No one wants to be with you. You don’t have any friends or anything like that” but then after that, I just regain my consciousness and be like, “That’s not true. I have my friends. I have my family. They’re all supportive of me. They’ve been there thick and thin for me every step of the way.” It’s sometimes like that. Sometimes I feel alone but then in reality, I know I’m not.

Cassi had a cheerful smile throughout the interview. She described loneliness as having few friends and keeping to herself:

I really don’t talk. I mean. I don't really talk about my health issues to everybody. Like my friend, like I don't do that. Like I talk, but I just don't talk about my health-wise because the only person I really talk to is my best friend when I feel that type of way of talking about my health. Other than that, I'm just joyful and playful and I keep a smile on my face.

Donita chooses to remain lonely and has to live a secretive life. She has very few friends and does not want them to accidentally find out she has HIV:

Friends, um, I don’t have a lot of friends. I have a couple of friends, but I don’t tell them anything because you don’t know your friends your whole life. You don’t know, I mean, I love my friends, but you don’t know, just everybody have a dark side. Some day you might do something that gets on your nerves and then they might just shout it out. That’s what I’m scared of. Like some people might do it without even thinking, so I know a lot
of our people’s personalities. They will do it when they get mad, and they don’t even mean it. So that’s one of the things that keeps me from telling any or my friends.

Gretta’s loneliness is from feeling she is the only person in her circle of friends and family living with perinatal HIV:

I feel to this day now with my family I’m the only one that’s HIV positive. I mean, my mom is HIV positive, too, of course, but she’s more -- I look at her as an adult. I’m saying like my peers, like my peers and my family, immediate family, like cousins a bunch of girls, when we all hang out, they sort of push me, not like push me like, “You’re nasty,” push me, but push me in a way like you’re never going to understand this because you’ve never gone through this. Things like that, that’s when I feel lonely.

Ian has conflicted feeling about being lonely and feeling abandoned. He described how he feels when lonely.

At times I might feel like I don’t got nobody but that’s all the devil wants you to think. That’s what the devil wants you to think. I have good support.

Jake no longer feels lonely. He is now focused on stabilizing his financial status:

I used to feel lonely a lot. I don’t really know what changed. It’s just like I said, my focus has diverted from trying to establish relationships with the opposite sex to trying to make sure I’m financially secure and have my own place. So, I’m trying to focus on one thing at a time.

Nepal’s friends have moved on or moved away and he has very few peers around to share his experiences of growing up with HIV

To be honest, I’m part in the middle of loneliness because back then I used to have many people who I would talk to, text, talk on the phone, text, go outside with. Now it’s just like everybody just ventured out and just gone their separate ways. So I just keep everything to myself and just do me, stay on my path.

Oden was asked to discuss if he feel lonely and what events or situations makes him feel lonely:

I don’t really live anywhere right now. I’m back and forth between my best friend and my great aunt And I just live from day to day and hope that I’ll be okay. I am lonely in a sense -- lonely like I’m really in this by myself. None of my family members have it that I know of. Nobody else in my family has it. I really feel like an outsider because of this. Everybody may seem lovey dovey and like they don’t care and all this other stuff.
That’s fine, but I still feel -- I know I’m not the only one in the world with this but in my circle I feel alone with it

Qual mother died a few months ago and was asked to describe if he felt lonely:

I think when I was away at school and dealing with my mother’s death, I think I was lonely. I think maybe still I am. I think now I’m just worrying about my brother and sister and stuff, and it’s easier to not slip into that. But when I was at school I may have had friends, but I felt like I was dealing with losing my mother all by myself.

Stigma

For Bea, the responsibility for keeping the HIV secretive behavior of not telling others she has HIV changed over time. She is less concerned about the stigma attached to others finding out she has HIV. Now she is older and more willing to tell others she has HIV instead of saying “I take medications for Asthma”.

Keeping it a secret or having to keep it a secret, I know when I was little I was scared to tell anybody. I would never tell anybody about what I had, and now that I’m getting older, it’s like I’m more open with it, with telling people, and getting their reactions. When I was young, having to keep it a secret was really hard because people would ask, oh, why do you take medicine, and why do you do this, and I would have to tell them I take medicine, I would have to say because my asthma. I couldn’t tell them why I had to really take it so I just told them I had to take medicine because of my asthma.

Conversely, Donita’s HIV status remains hidden. She described how she perceives others as they judge her HIV status:

When I go over to a sleepover I have to hide it. I have some friends who are doing nursing school, and I don’t want them to judge me automatically because they see the medicine, and these medicines they show it to like every health class. I’ve been in the health class and the teacher’s showing us what it looks like, and that’s the reason why I stopped taking my medicine from the people. They have special marks on them that will automatically tell people it’s HIV medicine. People would think that as soon as you get it you’re dead, you’re like completely dead. I’m like, I live normally. Nobody would ever know I have it unless I tell them, well, except my nurses and doctors.

When others joke about Magic Johnson’s HIV recovery, Donita described remaining silent in fear of others finding out she has HIV.

It’s like a little secret you’re not supposed to tell people, but when it gets out you’re screwed. To this day I’m looking at people making fun of Magic Johnson, and it gets me
upset like, why does that have to affect you? What he has is not going to come to you. All over the internet people talk about it. They have a joke, they said something about something being useless like Magic Johnson giving blood. That got me really upset, like this ignorant people thingy need to be educated a lot better than what they think of it now. They think it’s something that you’re going to catch instantly by touching someone.

Henrietta described being scorned by her peers when they found out she had HIV. In her experience it was best never to disclose her to others in fear of rejection:

Through the lifetime, yeah, a lot of people pushed me away. I would let them know and it’s like it’s straight cut off, and they got their number changed or blocked me or whatever. Or, you know, some like -- when I was in middle school, some kids were like, “Eww, don’t touch me. I don’t want your cooties,” and this was like from girls and boys. And it’s hard for me for like people to ask me, “Why do you have to take medication?” and I would say, I don’t want to tell you, I just do.

Ian described the stigma of HIV as, “It sucks having it. Besides that, I don’t know what else to tell you”

The stigma of HIV is still a concern. Jake described his perception of HIV stigma.

There’s still a lot of stigma about it. You can tell one person, I’m HIV positive, and they’d be like, oh, what’s that, and this and that. You can explain it to them. Another person be like, oh, I’m HIV positive, and they be like, oh my god. I can’t believe this. So it’s hard to gauge reactions. I mean most reactions I’ve had have been, I won’t say positive, but not too negative.

Oden also described the stigma of HIV. He described his experiences of HIV stigma in the foster home.

I’ve been in homes where I’ve been criticized for having HIV. I’ve been in so many homes it just doesn’t make sense. You come across so many different people in life. Some people accept you. Some people don’t. Some people turn up their nose at you. I’ve been in homes where I’ve had to use plastic everything. I couldn’t wash my clothes with the rest of everybody else because they thought something was going to happen. It was terrible. It really was. And now I’m at a place in my life where I can just say, “If you don’t like it, you don’t have to be around me” because at the end of the day, I’m the one that has to live with this whether I live or die.

Secrets

For of the participants, it took time for them to adjust to being told they were HIV positive. Alvin described how he responded to his parents when he was told he was living with
HIV:

Both parents kept their secret from me for a long time. It was actually right across the room from over here at the hospital when I was told. It was like three or four rooms down. I forget what the doctor’s name was. They both came in. They started coming out with tears and I was just pissed, extremely pissed at them. I was cursing at them all the time, the whole time and they were just staring at me crying. I was like, “Why didn’t you tell me? Why did you keep it a secret from me all these times? Why couldn’t you tell me when I was studying these, in the middle of 5th grade when I was in the normal health classes doing projects on these when I could have known back then?” And they were like, “You wouldn’t understand.” I was like, “I don’t care, you should have told me back then.” And I just kept on babbling and babbling and babbling at them. And after that, I was like, “All right, I’ve got to stop.

Bea knew she had HIV at a young age and blamed her birth mother for transmitting HIV to her. She was told not to tell anyone including members of the family fearing a stigmatic reaction.

When they told me, it was like, oh, that hurt because I just blamed on my mother, and my birth, I blamed it on my birth mother for her not doing what she was supposed to do, and I always have felt like it was her fault, and I just have so much anger and just want to do bad things because it just makes you mad because she done put you through so much, and then put you to adoption, and then being born with HIV, then having to take medicine, then having to hide it. I want to say that she made my life hard, but she just made it a little bit more complicated, and having to take on it at a young age is like really hard especially at the age of five years old. So I’m just thankful that my mom was there, and my therapist helped me get through it.

Cassi found out she had perinatal HIV when she was fifteen years old and her mother is not willing to answer any questions.

I asked, "How did I get it?" She said, "Obviously it's from me." And I asked, "How did you get it?" She said, "I don't want to talk about that." That was that. She didn't tell me until after the doctors 'cause I guess I got it from her because she has it 'cause she takes the same medicine I take now. Well, she's taking the medicine that I'm taking now, so obviously I didn't know until after the fact and I kind of got -- me and her kind of got into it because she could of told me, but she didn't know that I was going to get it 'cause I guess, she didn't know until the doctor said something. I was 15 years old when I knew I had HIV. I guess I was never sick like she was and I guess it was already in my blood, but I never knew until I really got sick 'cause she had been taking medicine since I was little, so I didn't know she -- that it passed onto me 'cause I know she has diabetes. I thought that was the only medicine she was taking, but obviously I was wrong. But now
we both take the same medicine. But only medicine that I don’t take is for diabetes. That’s it.

Donita was born in Africa and was infected with HIV via a blood transfusion. At the age of seven, she found out she had HIV.

I never got sick. I never ever got sick until I came to the United States. I came here when I was about seven, and the first thing that hit me was the flu. That’s the first time I came to this hospital. They took my blood, that’s the first time they took my blood. Then they called my mom for an appointment. When I came for the appointment they sat my mom in a different room. I don’t know what they told her. They told me to stay in the waiting room. She came in and she was crying. I was like, are you okay? She was like [God, she’s one? Then they took me aside and then they told me. The first thing that came to mind was it’s really, really bad. I was crying too because I saw my mom cry. I didn’t know what it was, but I knew it was bad. I heard people talk about it. I still didn’t know what it is but I still cried, and they gave me medicine. So that’s how come I didn’t take it seriously, the medicine, because I didn’t know what it was. That was what I knew when I was seven years old. So between seven to twelve years old I didn’t take my medicine a hundred percent of the time. I was in this hospital so many times for everything, everything in the book, everything you can catch from people. Ask my mom how I got HIV and she never really answered that question for me. She never answers questions. It’s like it’s hard for her to talk about it too.

Ella recalled being told she has HIV.

I was so messed up and, hey, I was lost. It was like when she died, a couple of months later that’s when I got diagnosed so I thought I was going to die. That day, I came in the hospital. My doctor, she called me back. It was like she called my aunt. I need to come back to the hospital. I came to the hospital. It was me, my aunt, my doctor, and the social worker. She was telling me, I just burst out in tears like I’m going to die. And then they kept telling me I’m not. I’m yelling. And then I kept telling them my mother had it and so I’m going to die because she died before me. Sometimes I do, and then sometimes I don’t still feel like I’m going to die from it.

Faith told a similar story when she found out she had HIV.

I wasn’t talking to her for a minute – like awhile because that upset me until she told me don’t be mad because that wasn’t her fault. It was my father’s fault. She didn’t tell me until I turned like seventeen not fifteen. She didn’t tell me until I turned like fifteen or seventeen. She should have told me at the age of twelve before I start having sex and all that.

Gretta was told she had HIV when she was seven years old and for some time believed she had a secret monster living inside her body.
I kept asking my mom why I have to come in the doctor’s every month, “Why do I have to take this medicine? Why do I have to get poked every time I come to the doctor?” I just kept asking my mom, “Why? Why? Why? Why?” So that’s when she chose to just tell the doctor that it was time to tell me. I was confused. I didn’t know what was going on. I was seven, so I don’t really think about it too much. All I knew was I had a monster, they told me, “You have a monster inside of you and this monster, it’s a secret monster, you can’t tell certain people about this monster because sometimes they’re not going to treat you the same as people that don’t have a monster inside of you.” And so all I knew is that they kept telling me, “This monster needs to get stronger; so the way it gets stronger, you take this medicine,” that’s how they explained it to me when I was little. Basically there was like a monster inside of me, and basically the monster needed to get stronger so I would have to take my medicine every day. If I didn’t take my medicine every day, then the monster wouldn’t get strong, so it would make me sick. So that’s how they explained it to me.

Henrietta recalled the conversation she had with her mother explaining how she was infected at birth with HIV

I was told when I was six and now I am nineteen. And she said she was on drugs and it came out to be this way, but she was telling me the story about that when I didn’t first have it for the first six months of the pregnancy, but she went out and was with some other guy that didn’t tell her his situation, and that’s how I got it. And she didn’t know I had it until a year after I was born, but she was telling me that if she was on medications then, I would’ve grew out of it, but I didn’t because she didn’t know until a year after I was born.

Karen described the day she found out she had HIV and how she feels today.

On that day “I wasn't depressed. Even still, now I'm not sad. That's not me, to me, having that HIV doesn't scare me at all”.

Nepal described when he was told he had HIV.

I do not remember when I was told I have HIV. I know I was young. I want to say about six or seven. We had somebody from Children’s Hospital come to our house and sit down and have a meeting with me, just me, and explain to me what the HIV was and everything.

When Qual was 13 years old he was told of his HIV diagnosis and longed for someone to teach him how to cope with living with HIV. He revealed like so many others do that HIV is not discussed in the home.
My grandmother, she raised me. She is the reason I actually found out, but we never -- we talked about it once, and we talked about -- She made me take my medicine, but she never told me why. So I had stopped, and I said I’m not going to take my medicine anymore until I found out why I have to take medicine. I was about 13 when I told her that. And she told the doctors here at Children’s, and they set me up with a counselor. And the counselor told me. She didn’t tell me, but the counselor told me. And then that’s when I found out. And we never talked about it after that day. She told me not everyone in the family knew, and that my mom refused to take medicine when she was pregnant with me, so therefore I was infected. And I was just like but where do we go from here? How am I supposed to feel better about having it? How am I supposed to cope with it? But no one ever reached out a hand and tried to teach me how to, still.

Qual described secretive events surrounding his mother’s death and the vital information kept from him. He was not told she was dying and was surprised at the news of her death:

I’m not sure. How secretive she was about the disease and -- When she was in the hospital and I was away at college, she went in the hospital in the summer. In the beginning of the summer. And she always had those times when she would go in the hospital, and she would come out. She would be sick for a while but she would get nursed back to health. And we would move on with life. No one knew how serious this was. She was in about seven different hospitals. I was working, and I was trying to make sure my brothers and sisters were okay at school. And then I had to get ready to go to school in the fall, for my sophomore year. But then they called me to tell me my mom was almost gone. It was too late. Everyone else had saw her, and talked to her up until. But they waited until she couldn’t even talk anymore to call me. And I was just -- I didn’t know what to think. So I spent the last three days. And she passed the 19th. No one -- I didn’t know. I can say that. I don’t know if anyone else knew, if anyone else isn’t saying anything. But I didn’t know, personally.

Fear

Bea is fearful of passing on HIV to future children:

The thing I’m concerned about is passing it. That’s my biggest fear I have”. I found out I had HIV when I was five years old, and I was seeing a therapist here at Children’s who told me that I was positive, and we talked, me and my mom talked about it, and she told me what it was, and she was like, don’t tell nobody because people’s going to start acting weird, and so I just lived my life like it was no big deal, and I really haven’t told everybody in my family. Just like people that I’m close with or I feel like needs to know, and with school, having HIV and going to school is like you’re an only kid going to school except people don’t know what you have so it’s like you got to try to, I don’t know, like choose your friends wisely because a lot of people don’t know how to act when you tell them that you have HIV
Karen described being fearful in the past of others finding out she has HIV and gained confidence to disclose after telling a boyfriend she has HIV.

Even now talking about it to people is easy for me now. I've had an experience where I was afraid to tell one of my boyfriends. That situation made it very easy for me after that to talk about it to anybody after that because it was so hard. I just went through so much with it and I thought if I disclosed my HIV that I would never have a boyfriend or they won't like me. So, I finally gained the knowledge if they don't love me for who I am, then I don't need to be with that person.

Lori experienced losing her job when her co-workers refused to work with her because she had HIV.

People are judgmental all the time. I lost my job because my boss told me she was going to let me go because I had HIV and she said “I can’t let you work here because you have this and other people are saying they’re not going to work here as long as you still be here so I have to let you go.” Well I told one person and then it spread around the whole school. Other people in my school knew so they told my boss and she told me she had to let me go.

Nepal shared his mother’s fear about others finding out he has HIV.

It is kind of difficult because you have to watch, I have to watch the people I am with or associated with. I can’t just tell every single body every detail about my status. I told family members, my mother, my dad’s girlfriend, ex-girlfriend. I told her because I trusted her, and she kept her word. She’s trustworthy. I haven’t told any friends or anybody. The only people that knows is my parents and family members and her. My mom’s biggest fear for me about the HIV is she wouldn’t know how people would react had I told them.

Surviving

Karen described the event surrounding her 19th Birthday after she left foster care. During the interview she again as she recalled the event to tell the story:

Him or his wife did not want to celebrate my birthday with me. So then, I texted him yesterday and told him how I felt. It actually made me cry because I'm like, "You guys told me that you guys loved me," but I don't get that no more. I don't feel that way no more about them. That made me feel really sad, anyway. I already felt like I don't have any family because my biological family's is not there for me. They're not in the picture. So, I thought that they were my family, but it doesn't look like that anymore. It just looks like it's just me, my best friend and my boyfriend.
Mark did not complete high school and was asked what was his expectations for his future your life:

It’s been two years and this is not what I expected, but you take what life can give you and then you just make do with it.

Nepal also described problems he currently has in college. He believes he is doing the best he can. He does not understand how to study and fails the class as a result:

I didn’t know anything about the advanced government type stuff so I was all confused and everything and just kept quiet in my seat while I hear everybody else get the idea or get the lesson, and me, it’s just I didn’t speak up, or say I’m confused. And, I’m still the same person. I still don’t speak up or ask for help not unless I actually fail a test or something. I don’t study. I just don’t find it in my viewpoint, I just don’t like studying. I lose interest when I’m studying. I just rather just go off memory and just say multiple choice process of elimination and see what fits right. See if that makes sense in my head. Make sure that fits the line, paragraph, whatever.

Qual described how his friends reacted when he disclosed his HIV status to them and his unchanged relationship with them today:

When I first found out I told my friends. Who I thought were my friends. Because I didn’t have anyone else to tell. I couldn’t talk to my family. So I thought someone needs to know what I’m going through. Because I’m like -- I’m hurting and no one is coming to me; as a child no one is coming to me and saying, “How are you feeling today?” “I know you just found out. How are you feeling?” Or just anything like that. I didn’t ever get that. So I was just telling my friends, “Yeah, I just found out I have something.” I didn’t even know the seriousness of it, so I was just throwing it around. And I don’t regret it, because I was young and I was just trying to find a way to express and vent, I guess. But now I told some of my friends and they understand the seriousness of it. And I can have a serious conversation with them when I tell them. And I feel good about it because they never changed towards me; they never judged me and never treated me differently because of it. Like, I’m just the same person. And I never wanted sympathy.

Sex and HIV

Faith is not currently sexually active and talked about a conversation on the issue of sex with her first boyfriend and other partners

He just had to make sure it was okay with his mother. He was my first boyfriend. I may have had unprotected sex, but I do not have a current relationship now because they are cheaters, liars and thieves. That’s what I call them. I hate liars, cheaters and thieves. I would be like I’ve got to tell you something. Sometimes I get nervous to tell people so I’d just tell them yeah I was born with HIV, would you still be with me and stuff like
that. I don’t get mad if they say no. I don’t get mad. It is possible their momma probably had it or some – that’s why. Nothing wrong with it because their parents or somebody had died with it.

Ian described his knowledge of safe sex while HIV positive.

I learned that you should do what you have to do for it, as far as taking your medication and letting your sex partner know. I have protected sex because if not I can spread the disease. And you can go to prison if you don’t tell whoever in your relationship that you have this disease and you all are just doing it and they find out. There’s pretty much not nothing good about it. It’s not a good disease,

Karen recalled disclosing her HIV status to a previous boyfriend after a sexual relationship. She described the relationship going forward as ‘horrible’.

I told him after we had sex that I told him. I was nervous because I didn't want to let him know because I didn't want him to leave. I wanted him to still be my boyfriend and I was scared. So, it was just like after I told him, he was so like, "Oh, my god." I can't even describe. I think he hated me or at least didn't like me. Then, he got over it. He accepted my apology and then, it was just like I felt that he didn't -- he accepted it, but he didn't really fully accept it. I felt like everything that I did, he would just try to punish me for that. I can't really describe. It was horrible. I was really in love with him, so it was like for me. It's hard to explain that. It was a horrible feeling, though.

Karen recalled her conversation with her current boyfriend before sexual intercourse:

I remember saying, "Um, I need to talk to you." He was at a party and I honestly didn't want to tell him there, but I just felt like it was on my heart. I needed to talk to him, so I just said, "Can you go somewhere privately so I can talk to you?" He was just like -- at first I said, "You know what? I'll just wait." He was like, "No, no, no. Tell me now." That's when he went in the bathroom. Then, I was just like, "I just wanted to let you know that I was born with HIV. I hate to tell you like this, but I just rather you know now. I know I should have told you before, but I want to tell you now. I know it's a bad way to hear it, but I was born and I've been dealing with it all my life." After I told him, he didn't talk to me for a few days. Then, he called back and he said that he wanted to see me. I thought he was going to try to kill me or something, but he just really wanted to talk to me. He felt a sense of -- I think he felt bad and then, he also was still a little bit upset at the same time, so he didn't go off on me or anything like that, but it was just still a lot of anxiety on me. I was a little scared.

Nepal reported he is not sexually active and has never had sex. He described his plans for sexual activities in the future.
I’m basically just going off of the doctor’s orders and my mother’s orders to have safe sex, you know, use a condom, let the female know that I have HIV before we go into intercourse, or if I feel comfortable with telling people then go ahead.

**Hoping for better health**

In response to the question, how are health concerns expressed by young adults who have grown up with HIV, the participants provided vivid descriptions of the experiential lifeworld situations growing up with HIV. The essential theme, hoping for better health revealed the thematic themes of illness and life-long medication use. All of the reports of HIV related illness caused an interruption in the participant’s schedule, primarily education. The participants below described illness that had significant disruption in school activities. The events were so memorable that the participants had instant recall of the events.

**Trying to get better**

Vulnerable populations such as minorities with perinatal HIV suffer from a variety of health conditions. Cassi described a history of seizures and stroke as the two major illnesses with which she has been stricken with:

I had to be in the hospital for three months 'cause I had a seizure and I had a stroke at the same time. They didn't know I was going to survive after that, but I woke up and I was asking for food 'cause I was hungry. All I remember is they came 'cause I got real sick at school and I was at one hospital, but they was taking too long, so they transferred me to Children’s and then, when I got here, it was night-time, so the next day, that's when all the doctors came in. They asked me what school, like school, how it was and I was trying to get words out, but it wouldn't come out, like I kept stuttering and after that. I continue to have seizures in the 9th and 10th grade. I had another seizure in '09, January. And then, I had another one just recent, in July, 2013. I just know I black out. I know that the one in July, I fell on the hardwood floor 'cause I was at my grandfather house and at first; I was just talking to my uncle about the metro and stuff. And then after that, he just -- but they found out that it's probably because I had a sinus infection, I was using a seizure prescription that they gave me and it probably got connected as to that’s how come I had a seizure. But I went to the hospital, but I didn’t stay. They let me go later on that day. My grandparents think my illness is due to seizures and not HV.

Many of the participants suffer from a variety of life-threatening co-morbidities. Donita
vividly described a multitude of illnesses and suggested the illnesses occurred because she did not take her prescribed ARVs,

I was in the hospital. I’ll never forget the date, July 4th to December 23rd, this hospital. When they finally sent me home I was in a wheelchair. They said I was supposed to die when I first had meningitis. It said ninety-nine percent of the time I should have been dead. This only happened because my system still wasn’t strong enough to defend it from the meningitis because I didn’t take my medicine. That was when I was young and stupid. I had shingles. I had a lot of flu, cough, TIA, a lot of things going on, only because I didn’t take my medicine. Even sometimes now even when I do take my medicine I still get that stuff, not as much as I did when I was younger. The one thing I hate about the medicine – it’s a lot easier to take it now – it makes me very hungry, like I would eat, I would drink my medicine and I’d feel so hungry after, and I’m gaining so much weight, and I’m trying to lose it. It’s hard because I have weak legs. I’m suffering from weak legs. I had a stroke from that meningitis, and it made my legs weak. I can’t hear in one ear, but I’m living a normal life, and I’m blessed because of it. I should be dead but I’m blessed now. That actually teach me a lesson that I miss my medicine not one day. I can’t hear, and I have a lot of UTIs because my bladder is not strong enough. All due because of everything, the HIV medication, not taking it, and I wish I could go back and stop everything because I wouldn’t have a stroke when I was twelve years old.

Ella described a series of illnesses and hospitalizations over time.

One time I was in the hospital for thrush in the back of my throat. It was real bad. They hospitalized me for that. Then again I stopped my medications. I felt the same pain that I felt the first time they hospitalized me in my chest. They kept me again. Then I think they kept me for my neck, a big goiter. I was only hospitalized probably like three times, three or four.

Gretta described her high school years when she was hospitalized for Non-Hodgkin Lymphoma including relapsed episode:

I was in 11th grade or 12th grade, I don’t really remember, when I was diagnosed with Non-Hodgkin lymphoma. And that’s when I my grades just started slipping down. I went into remission in March of 2010, but then in September of 2012 it relapsed again with a cancer which is more higher than Non-Hodgkin lymphoma. And, of course, that ended in December of 2012. I also have asthma

Taking medication is difficult for Henrietta. She described how she feels after taking her medications.

I get hot flashes, sick on the stomach, like don’t want to eat anything after, drink, eat, nothing; I just want to sleep after. The worst thing about HIV would you put taking
medications. The score would 9 out of 10. I was admitted down from like skin problems to colds to being bit by something, or like I get sick from not taking my medicine and come here to regain, because I have like nurses help, because it’s annoying but it does help. You know, they come in in the morning, ask me do I want something for breakfast, give me what I want, eat, then they come with my medicine. Yeah. I mean, there’s a lot of help. I mean, I had the nurses at home, but it’s not the same like here. It’s more like you being annoyed and pressured at home, and then here is like you get to take your medicine on your own time, as long as you take it.

Oden stated a surgical procedure is being withheld for low numbers, that is, his viral load is high. He described his overall health as “terrible“

My health is terrible right about now. For the past month, I’ve been literally week from week in and out of the hospital Nobody wants that. My numbers are terrible. I have anal fissures. I have anal warts. I have ulcers. Why? Stress. I have to get surgery. I can't get the surgery until I can get my numbers up. This is why my numbers aren't good right now because I’m dealing with this. Everyday I wake up and go to take my medicine; all this is going through my head. Meanwhile, all of this is going through my head, I’m still dealing with the side effects of the medicine. I get nauseous, really, really nauseous. Sometimes I can't swallow the pills. They get stuck in my throat and start to burn my throat. I try to gulp it down with some water or whatever I have to drink”

Lifelong medication use

The participants were able to verbalize the understanding of ARVs and many of them said “this takes up all of my life” They did not recall the names of all of their ARV medications, nor did they recalled if the ARVs should be taken an empty stomach or with food, according to the instructions. Also the amount of fat eaten can make a difference to how well some drugs are absorbed.

Like most of the participant Donita described the taste of her medications as nasty.

I thought the medication was nasty, and I found out I had HIV when I was seven and they gave me liquid medicine. I hated it. I used to hate it honestly, and I know I’m not the only one. When you’re young when they give you your medicine you try to get rid of it. I did that. I would take the liquid and throw it down the toilet. If I swallowed it I would throw it back up. I did a lot of that, and I was young, I was stupid. I didn’t know how it would affect me. I thought it was like, if I take it one day I’m fine, the next day I don’t have to take it. That’s the way I thought. The only thing that I would say, if I ever miss one day or two days the next day I feel really weak and tired, and I see the
difference, and I hate that feeling. So I start taking it a hundred percent. The only thing that would stop me from taking it, I don’t have none left.

Ella recalled a similar experience regarding taking her HIV medications.

I wake up every morning and I know I’ve got to take medicine for the rest of my life. That’s a little stressful for me.

Henrietta is relying on the “Grace of God” and discussed how she is able to interpret possibly dying and the last time she took her HIV medications

Unh-uh, it’s like some -- probably about four, five months ago, the last time I took some medication. The last time I knew my viral load is or your CD4 count, I get confused. I mean, I’m not too bad about it, because life and death situation depends on the grace of God, really. And my motto is that I don’t really let any doctors or anybody determine whether I’m going to live or not, I’m just going by the life, really. At first, I was like, “Oh, this is a breeze, I’m okay. I can take the medicine, it doesn’t matter to me,” but after years and years and years, it’s like I started feeling like medicine is my life, I ain’t want it to be that way.

All of the participants described the taste of liquid ARV as unpleasant. Not surprisingly, Henrietta’s experience is similar.

It’s -- no. No. It’s more like sour, like lot sour, like you just had lemon juice all in your mouth without sugar. It’s just that, it’s just nasty. But, I mean, there is one medication called Bactrim, it’s supposed to be a bubble gum flavor, no, oh no, no. It’s like -- it tastes like melted gum, just like ugh, it’s like way different than bubble gum flavor. I’m supposed to take Bactrim twice a day, but when I have put it together and I take it once a day, but then it’d be too much on me, and I’d be running back and forth to the bathroom, not throwing up, no. But, I mean, Bactrim don’t give me like no for real symptoms, but the bubble guts, but then the Kaletra is like ugh, don’t even like -- anything that smells, tastes or even reacts like Kaletra is just disgusting. I don’t like it at all.

Ian refused to take his ARVs and described the taste:

There was plenty of times that I refused to take it because I didn’t like the taste. It was like, “Ugh.” I couldn’t get with the taste. I’ll take the pills any day over that medication.

Jake described taking medications throughout his life. He stopped for a period of time because the medication made him feel sick and he didn’t know why the medication was prescribed.
I’ve always had to take medication. I’ve always taken medication throughout my life. I think when I found out that I was taking medicine because I was HIV positive was when I was in middle school. There was a period of time I wasn’t taking it because when you’re young people just tell you take your medicine. They don’t tell you what it’s for, and I was going through a time when I didn’t want to take it because when I took it I felt sick taking it, and I felt better when I didn’t take it, but when I found out why it was important for me to take my medicine, I started taking it more.

The HIV medication was self-administered by Kate while she was a young child. She described taking medications at a younger age.

I did it myself. I did it myself. When I was younger, I don’t know who did it, but I remember doing it myself, like 13, 12 or 13. I remember taking it myself because you just measured it and it’d stop at a certain number and then, yeah. I’ve always been responsible since I was like, what, 14. I started learning the milligrams, the numbers in case of emergency of my medicine so I always knew what I was taking, how many and what milligrams and everything like that. So, certain things, if you ask me, I would be able to tell you like this many, even still with my medications.

Mark has other medications added to his ARVs and he described taking medications for the rest of his life. He said, “I take medication for Gout. It’s just taking more medicine added to the list every day. You’re just taking medicine every day and that’s it”.

As a child, Qual disliked taking his ARVs. He described the taste as “nasty”, He also Stated when he was twelve years old he did not know why he was taking ARVs.

It was liquid, and it was nasty. It was very nasty. And my grandmother would hold me down with a syringe and she would squirt it in my mouth. Because I didn’t want to take it. It was very nasty. And then they finally changed me over to pills, where I could swallow pills. Also I struggled because I didn’t want to take it. I didn’t want to take it because I felt like they were withholding something from me; like, at the age of twelve I felt like why -- I don’t know why I questioned it, but I was just like, “Why am I taking this? I don’t want to take this medicine.” And I rebelled a lot, I guess, on my grandmother. Because I didn’t have my mother in my life. I took it all out on her. And I’m remorseful for that now. But I didn’t want to take that medicine. You shouldn’t be giving me anything and I don’t know what it’s for. And my grandma got so mad at that. One day she told me, “If you don’t take your medicine you’re going to die.” But she said it in anger. And that will stick me through my life. Even though she said it in anger and she might didn’t mean it. That will stick with me. And that’s when really was like, wow.

Qual described being undetectable and taking his ARVs. When he was younger his
grandmother called the hospital for assistance to help with his ARVs adherence and now he takes his medication almost 100% of the time. Below he described the nurse visiting the home to help with his ARV’s adherence.

I’m undetectable. And that’s a big transition from when they used to come in. Keetra, she used to come in. And I did not like her then, because she was like the bad guy because she would always. She would always get on me. She doesn’t know this now, but how I appreciate her now. But she used to get -- She was the one. They used to always say, “You don’t like taking your medicine?” I used to be like, “I don’t like taking my medicine.” And they’d say, “We’re going to call Keetra in.” And she used to come in. She’d say, “You have to take your medicine.” She would tell me. And it was like -- my grandmother says all the time I don’t really listen to her. But when someone [laugh], she tried a little bit make me afraid of her. So I was just, “Okay; maybe I really do need to take my medicine.” But now it’s just like it’s all good reports about me taking it consistently, and being this person who changed for the better compared to people who still can’t; who still struggle with taking their medicine. And it’s not like every day I’m just like oh, yeah; I’m always on my medicine. I have to take my medicine. I do forget sometimes. But like I said, it’s just a part of my life that I have accepted that will always be a part of my life until maybe if there’s a cure or -- who knows? But I realized that I had to make the best out of it now.

Summary

Within the interviews, the young adults growing up with HIV spoke to their mothers and guardians with the intention of increasing their understanding of the young adults need: . One of the young adults asked, “How am I supposed to cope with it?” referring to HIV, “when no one ever reached out a hand and tried to teach me how to?” The statements are summarized as follows:

• Why didn’t you tell me what the medicine was for?
• Why did you keep secrets from me?
• Why won’t you answer my questions?
• I wish I knew I had HIV before having sexual intercourse
• Everyone’s focused on cancer right now which it’s sad that we can’t fight both, but it seems like well, AIDS, that was ‘80’s, ‘90’s. Now we’re focused on cancer.
Tell me the truth
I did not have a childhood. I have HIV
I wish I was not in so much pain
I want to have a family when I grow up
Why did you give me away?
Why did you die?
I wish you were here to fight this illness with me
Are you proud of me?
I am not safe
My future was as not planned
What will become of me?
I don’t know how to take care of myself
I am lonely
I am angry
I refused to take my medication because it had a bad taste and made me feel sick
I want a healthier life

From these themes, implications for nursing practice, healthcare clinicians' education, healthcare policy reforms, and recommendations for future research emerged. One of the main topics discussed in this chapter was the study design used in this research study. Van Manen’s (1990) phenomenological research method was used to explore the lived experience of young adults growing up with HIV. Along with study design, the selection of participants for the study, the research study setting, materials used, data collection and data analysis was discussed.
Chapter V

The Summary of the Findings

The purpose of this phenomenological study was to describe the essential themes of the participants’ perceived journeys, lived experiences, learning experiences, recent events and situations that affected growing up with HIV. The investigator grouped essential themes to determine the phenomenon (Van Manen 1990). The research questions that guided the initial focus of the study were: (a) What are the experiences of perinatally HIV-infected young adults growing up with HIV; and (b) What meanings do perinatally HIV-infected young adults ascribe to their experiences?

This chapter consists of five sections which discuss the major findings of the study. Study results help add to the perinatal literature and close the gap in the existing theoretical literature and research of perinatal infected young adults growing up with HIV.

The first section of this chapter addresses the methodology and key findings. The second section offers a discussion of the major thematic elements: a life of uncertainty, wishing for a purposeful life, longing for a future, managing emotions and hoping for better health in relation to the existential lifeworlds of lived space, lived body, lived time, and lived relation. The third section consists of a discussion of findings in relation to theoretical nursing models to provide knowledge for improving practice, guiding research and identifying the goals of nursing practice. The fourth section reviews existing phenomenological research on perinatally HIV infected young adults, and discusses thematic elements in relation to HIV young adults. The final section includes a discussion of the study limitations, and recommendations for nursing practice, education, research and policy.
The young adults’ experiences were reflective accounts of young adults growing up with perinatal HIV and are the basis for the findings. Patient education is time-consuming, therefore the SIS clinics utilized staff other than the primary care provider such as nurses who specialize in HIV clinical care. This interdisciplinary team approach is used to enhance the time the physician would spend with patients. The SIS clinics are positioned to create a new role for a Nurse Case Manager to provide patient education materials, social services assistance, nutritional guidance and financial advice during routine appointments to coordinate the patient’s needs.

**Methodology and Key Findings**

**Methodology**

The study employed the hermeneutic phenomenological inquiry approach put forth by Max van Manen (1990) to explore the young adults’ world of lived experience. In hermeneutic phenomenological science, the emphasis is to describe the lived experience. The purpose of phenomenological research was to borrow other people’s experiences and reflections to try to gain a better understanding of the phenomena and its meaning in the context of the human experience (Van Manen, 1990). This approach, which is both descriptive and interpretive, was appropriate for the exploration of the phenomena of young adults growing up with perinatal HIV because little was known about this phenomenon. “Phenomenology is a project driven by fascination, which is being swept up in a spell of wonder, a fascination with meaning” (Van Manen, 2007, p11).

The participants (n=17) were recruited from the pediatric and adolescent HIV clinics at CNMC. Experiential narrative data were collected in interviews conducted in a consultation room using a semi-structured interview guide and a demographic questionnaire designed by the
investigator. Data were analyzed using the phenomenological contextual processing and analysis proposed by (van Manen 1990). Several activities were incorporated into the study design to ensure methodological rigor, which undertakings included verbatim transcription of interview audiotapes, transcription verification, methods expert review of initial transcripts, member checking of analytic theme descriptions and interpretations and maintenance of an audit trail.

**Key Findings**

The findings demonstrate the range of social and emotional factors affecting growing up with perinatal HIV as experienced by the study population. Within the interviews, the experience of being exposed to HIV from a very young age was found to be a complex life experience that had a profound impact on the young adults’ life. The analyses of interview text revealed one overarching theme and five essential themes that emerged from the participants’ representations of the lived meaning of growing up with perinatal HIV. The young adults’ stories of growing up with HIV identified the overarching theme of “A Secretive, Uncertain and Harsh life”. Directly related to this theme were five essential themes that offered a fuller description of “A Secretive, Uncertain and Harsh life”. The essential themes were:

1. A life of uncertainty
2. Wishing for a purposeful life
3. Longing for a future
4. Managing emotions
5. Hoping for better health

The five essential themes are inter-related and co-exit to offer a new perspective of the experience of growing up with perinatal HIV. Within each essential theme were several sub-themes that further expressed the common thematic elements of this phenomenon.
The first group of essential themes described growing up with perinatal HIV and revealed the following thematic elements: growing up unprotected, relative foster-care, stranger foster care, my father is who he is, being different from others, an orphan’s life, an unstable household limited social support and unhappy tears.

When grandparents and family members placed the young adults in foster care, these young adults were “Living a life of Uncertainty”. During the interview, these actions were interpreted by the young adults as uncaring and selfish when they were children. When grandparents placed their orphaned grandchildren in foster care, it appeared to the young adults in the study that the grandparents should be denied the privilege of having access to them, but the circumstances surrounding their ill-health, age, financial ability and accommodations were acceptable reasons now that the young adults are older. One of the participants stated, “My granny was too old to take care of us and I did not want her to die too” and another stated “my mother was too sick to take care of us”. Conversely, one participant stated “my father signed my away” and she was satisfied not having a relationship of any kind with him. While it may be true that family members refused to care for the perinatally infected children, as reported in the study, many family members are often constrained by limited resources and face external pressures and battles serious illness of their own.

The second group of essential themes identified my relations, marriage and family and helping peers understand HIV. Most of the young adults were instructed by mothers and guardians that telling others they are HIV-positive may cause them to be rejected by that person, but they reported it was not one of the most difficult things to do. They realized that a more difficult emotion is the burden of carrying the secret alone. Although, some of the young adults kept the secret, most understood disclosing to everyone was not a wise decision. In the narrative
the young adults disclosed their HIV diagnosis to one close friend or relative. One participant experienced accidental disclosure resulting in the loss of her job. Several participants disclosed their HIV status to sexual partners expecting emotional or practical support, but were instead exposed to hostility in those relationships.

The third group of essential themes described the following: being out of work, an elusive or unplanned education, transitioned to adult responsibilities and acceptance of life’s circumstances. These thematic themes highlighted the following challenges for these young adults. In the narrative the participants described ill-prepared to find employment, inability to finish high school, having learning disabilities, missing school days due to illnesses, not being prepared for transition to adult responsibilities and having to face the reality of HIV.

During the early years of the perinatal HIV epidemic, the death rates from AIDS were extremely high. Today, ARV drugs allow perinatally infected HIV-positive young adults to live much longer, normal, and productive lives, but it is apparent that the young adults in the study are not prepared to transition to adult life since a majority of them are uneducated and unemployed. The seven (41.2%) young adults who did not complete their high school education listed barriers such as bullying, IEP’s that were removed too soon or limited guidance. The sample group comprised African American and were recruited from Maryland and the District of Columbia where in 2009, the less than high school completers were listed as 16.2% & 22.2% respectively (U. S. Department of Commerce, 2000). In addition, the U. S. Department of Commerce (2012) lists African American high school dropouts in the United States at 17 percent. The statistics for perinatal HIV high school drop-outs have not been published.

The fourth set of essential themes described emotions that included anger, loneliness, stigma, secrets, fear, surviving, and sex and HIV. The young adults reported the emotional
impact of learning they had HIV triggered various reactions to the persons disclosing the diagnosis. Most of the young adults were told not to disclose their HIV and were expected to internalize their emotions. From the narrative, several young adults reported, they had the disclosure meeting and never spoke of HIV again. “We never spoke about HIV again”. The participants who reported the deaths of their mothers, stated they wished they had additional time with their deceased mothers to ask questions about how they were infected with HIV. One participant said she was afraid to ask her mother questions because her mother was dying from AIDS related illnesses and she had already been living with her adopted mother. Others were angry and blamed their mothers for not protecting them from being born with HIV. While others accepted the reality of their diagnosis and said “I will do the best I can”.

The final group of essential themes described the thematic elements; trying to get better and lifelong medication use. The participants’ effort to get better and their resignation to a lifelong medication regimen included several ARVs that were not palatable when they were younger. Although, antiretroviral drugs are increasingly effective and extending the lives of many perinatally HIV infected young adults, they are expected to have access to the medicine. One young adult in the study access to prescriptions was temporarily challenged when he was asked to pay $3,000.00 for the prescription.

Many serious side effects to ARVs caused many adherences issues, which in addition to the drug-resistant strains of HIV make treatment an increasing challenge. In the study the young adults who refused to take their medications when they were younger, were prescribed a liquid formulation that had an unpleasant taste. Refusal to take the ARVs was primarily due to palatability and very little has changed over the years. According to the young adults, they did not recall being told that failure to take the medication as prescribed would result in a risk of
developing a drug resistant to the HIV and those medicines will no longer be useful in treating their HIV illness.

The young adults’ stories of disappointments, isolation, longing and challenges associated with the experience of growing up with perinatal HIV. Although, these young adults described elements that might be experienced by the horizontally HIV infected young adults, many elements essentially reflect the life of the perinatally infected HIV young adult. A major difference is the length of time the young adults were exposed to HAART and the prolonged stigmatic life exposures experienced by perinatally infected young adults living with HIV.

**Lifeworld Existentials**

The four lifeworld existentials, namely, lived space (spatiality), lived body (corporeality), lived time (temporality), and lived relation (relationality) provided the components for interpretation and discussion of growing up with perinatal HIV. Van Manen (1990) suggested these four fundamental structures are helpful guides for consideration, as these elements form the unity of the lifeworld to describe a life of uncertainty, wishing for a purposeful life, longing for a future, managing emotions and hoping for better health.

The four lifeworlds below were used to further explain the young adults in the world as experienced and lived. Therefore, these lifeworld existentials were selected as a guide to discuss the thematic elements uncovered in this study.

**Lived Space**

The first existential, lived space (spatiality has been defined as “felt space” (van Manen, 1990, p.102). Lived space is recognized as largely pre-verbal and something most individuals do not reflect upon. Van Manen (1990) proposed that in general, “we become the space we are in”, and that “lived space is the existential theme that refers us to the world and landscape in which
human beings move” (p. 102). Therefore, an examination of lived space offers the potential to uncover more fundamental meanings of the lived experience. For example, space has the meaning of time and the physical space spent in an experience. In the study, the young adults’ homes were central and the only place where most of their activities occurred. In a majority of the young adults’ narratives they described the bedroom in their homes as the only place they felt safe and relaxed. Most of the young adults lived in a residence with others and an adult, parent or guardian in that residence was responsible for maintaining the home. Even the participants who were living in a foster-care setting reported occupying a private bedroom. During the interview the participants living in foster care reported their bedrooms were the center for their activities. Although, the foster-care home placement was usually temporary, one participant stated he was placed in twelve different foster-care homes since his mother died. The young adults living in foster care learned to seek refuge in their bedrooms until the next placement or cycle of living accommodations. The bedroom for them was a safe haven from the stigma experiences unintentionally promulgated by the guardian and family.

Overall, the home had significant value and was the safe location for the participants. Very few, less than 10% of the participants lived in homes where the parent/guardians owned the property. One participant suggested he will probably own the family’s townhouse when he is 32 years old because according to his mother the mortgage will be paid off. In another narrative, the participant revealed that after her mother died, the life insurance benefits allocated for her college expense was used to repair the family home. Initially, she opposed that decision but has grown to accept the resolution because she feels safe in her home.

Conversely, one participant was homeless and pointed out the homes she lived in were
not safe after her mother died. Another participant suggested, that the dormitory room is his space away from home a refuge from sadness:

I think living in a dorm is better. I would rather be at school than back here, honestly. I feel like I found a pattern, in a way, to cope with my mother’s death at school. I would go to class and I would go to work, and it would just be like a routine. Here, I’m just sad looking at these pictures of my mother. Like rest in peace, and you know -- everywhere. And it’s just like I see my brother, I see my mother’s face. I see my sister’s face; I see my mother’s face. And it’s like -- wow. I see things they do and they say reminds me of my mother. Everything we do, I always say, “Remember when mom did this?” I will be always the one standing in the room when she did this. Because I remember -- everything someone does reminds me of something she did, basically, at home. So school it was just comfortable. But I was still alone. But I was making that loneliness my comfort for the time being.

The existential of lived space was also revealed in the physical proximity of the young adult’s room in the home. Two participants required assistive devices to ambulate. One participant became more wheel chair dependent and his bedroom was moved to the first floor while another described her bedroom as remaining on the upper floor and it has become more difficult for her to manage the stairs.

Family and friends were not usually invited to visit the home. A major concern was the participant’s privacy to take their ARVs, especially when the young adults were not prepared to disclose their HIV status to other family members and strangers. The young adults living with their birth mothers had the advantage of having the necessary privacy in the home to take their ARVs. Only one participant’s mother was more concerned about she would be affected by the HIV disclosure instead of how HIV disclosure would affect her HIV infected child.

Three participants shared the experiences of being given their own eating utensils that were disposable. At a formal family dinner, one participant was given a paper cup, paper dinner plate and plastic knife while the other members of the family had the usual china and silverware. The second participant revealed “I always had my own eating utensils” and the third participant
shared that her grandmother was afraid of being infected by her. Consequently, from a young age the participant remained in her room at all times and used disposable items.

The pediatric and adolescent clinics the participants visited frequently had significant value as lived space. The participants had scheduled medical appointments in the SIS clinic throughout their lives. The space the medical team created for them was a familiar environment for their routine and sick health care visits. Although, each participant has a primary care physician at another location, at this location they usually agreed and settled on the management plan of care which included ARVs adherence as well as plans for follow-up visits. Importantly, in the lived space, the participants received advice or treatment for any acute illness. In this space the healthcare provider educated the patient and caregiver about the causes, progression, outcomes and advice for maintaining health growing up with HIV.

In the SIS Clinic most of the young adults heard news of their HIV diagnosis where the disclosure process was conducted by several members of the perinatal HIV medical team. The medical team consisted of the physician, social worker, psychiatrist, nurse and the medication adherence specialists who are knowledge of the perinatal HIV infected populations they serve.

Only one participant was born in a foreign country and stated being transfused with HIV positive blood at birth made her vulnerable for the rest of her life and she is unable to understand why this happened to her. Another participant suggested riding the elevator has the same feeling as being locked-up in a closet as punishment the day her mother died.

A majority of the young adults enrolled in the study stated the school environment was a secretive “Lived space”. The young adults spend much of the time in school hoping never to disclose their HIV diagnosis. Very few school age peers knew of the participant’s HIV status and it was not a standard practice to disclose the HIV status to the school officials. Some participants
enjoyed being in the hospital and suggested the nursing staff did not create an atmosphere of stigma. Most of the participants were friendly and appear eager to tell their story of living with HIV. Since HIV was not discussed in the home the participation in the study provided an opportunity to reflect on the prospect of improving the quality of their lives.

**Lived Body**

The second existential theme lived body (Coporeality) refers to “the fact that we are always phenomenologically in the world” (van Manen, 1990, p. 103). Van Manen proposed that this theme emphasized when we meet another person in his or her environment or world and when we meet the person through his or her body. In describing the physical and body presence, the young adults reported living a somewhat secluded and secretive life and verbalized” I have newer described to anyone what it is like growing up with HIV”. This was apparent to the researcher that most of the participants identified themselves as part of an ethnic minority who could identify with the narrative of growing up with HIV from their individual perspective.

The analyses of the narrative data, explanation of the existential of lived body, offered insight into several aspects of growing up with perinatal HIV.

First, the young adults have very little expectations of their own lives and anticipation that others will help them improve their lives. A great majority of the young adults’ stories suggested they were describing for the first time emotional experiences of anger, fear, stigma and loneliness. The anger was described as experienced around the time their HIV status was disclosed to them. Fear of others finding out was not only to protect the participant, but also an emotional burden they carried to protect their mothers and other members of the family. In one instance, the young adult who was infected by blood transfusion was constantly reminded by her mother to keep the HIV secret and not to disclose her HIV status to family members including
her grandmother. Many participants offered the diagnosis of “Asthma” as the reason they were taking daily ARVs. Developing friendship were not encouraged that created a sense of loneness.

The study findings suggested the young adults, 18-24 years of age, for the most part, were compliant with medication adherence as they understood the purpose of the ARV. While growing up, they were admonished to “just take your medication and everything would be fine.” In addition, many of the participants stated they were deprived of youthful activities while growing up, as many of them did not participate in sports or physical activities. Some explained, “I go to bed early because I am tired” while others claimed not having the energy to play sports.

Most participants were not prepared for marriage and family, claiming adulthood is a distant experience and explained, “I did not have a childhood, I had HIV”. In addition to socializing with peers, the young adults “will have to reveal something about themselves” Van Manen, (1990, p.104). One young adult described not disclosing her HIV status to her new partner for fear of losing him, while others though afraid of possible rejections would prefer to take that chance and allow their partner to be informed. The young adults did not experience a normal childhood. The HIV illness limited their ability as young adults to have "normal" relationships, for example, although the young adults may desire having children, many reported it would be thoughtless and cruel to condemn a child to live with HIV for the rest of their lives.

Some of the participants are adopted or became an orphan at a young age and do not know their relatives. These young adults reported “everyone has a family” and not having a family is abnormal. One of the participants reported that at his friend’s birthday party, he met his friend’s relatives and wondered why he does not have an aunt, grandmother, cousins and siblings.
A young adult in the study experienced rejection in an intimate relationship from a partner when she had unprotected sex with him. She reported her partner punished her in several cruel ways and at some point “I taught he would kill me”. Her feelings of love and admiration quickly turned to fear and anxiety. Most of the participants stated they were not sexually active during the study and reported spending a great deal of time focusing on their personal health.

The absence of physical strength, tiredness was given a primary reason the study participants had no involvement in physical activities. It was also reported much of the time was spent concealing the HIV status from others.

The participants were not educationally prepared for employment. Most of these young adults did not graduate from high school and were unemployed. For many of the study participants their physical appearances did not reflect their chronological ages. One participant said, because she is short stature, employers may view her as a child and not suitable for employment.

Lived Time

The third existential theme lived time is “subjective time as opposed to clock time or objective time” and is “our temporal way of being in the world” (van Manen, 1990, p.104). Van Manen further suggested whatever happened in the past “now sticks to me as memories or as (near) forgotten experiences that somehow leave their traces on my being – the way I carry myself, hopeful, confident defeated, and gestures I adopted”. In other words I speak the language that ties me to the past (p. 104).

Most of the young adults have a vivid memory of the time around being told of their HIV status. They discussed feelings of anger and resentment in the past which negative feelings have improved under the pressures and influences of the present time. They now cope with the
emotional memories of the following time points: (1) the time of the HIV disclosure; (2) the time around the death of a mother; (3) the time around illnesses; (4) the time around taking medication; (5) the time of their awareness of poor educational and employment outcomes; and (6) the time around plans for transition to adulthood.

Most of the young adults who were able to articulate their needs identified interventions for support, particularly the handling of stigma and discrimination, for, they had no one to help them cope with their emotions of living with HIV. All of the participants were able to discuss the emotional experiences; they had no difficulty remembering part or most of their emotional experiences of anger, loneliness, fear and stigma growing up with HIV. For most the memorable experiences were taking ARVs when they were younger, being sick as a child, the day they were told they had HIV and when they had to disclose their HIV status to others. Almost half of the sample described events surrounding the mothers’ death and asked, “why me”. The individuals had many questions they never had the opportunity or courage to ask of their mothers.

The young adults’ accounts were examined to identify what they considered meaningful in terms of their memory of the lived experience growing up with HIV. This included the time and location of the HIV disclosure. “It was actually right across the room from over here at the hospital when I was told”. Another participant remembered “The location was three or four rooms away from this interview room”. Very few participants knew they were diagnosed with HIV for the first five years of their lives as they remembered how old they were when the HIV disclosure conversation occurred. A female participant found out she had HIV when she was 15 years old. For most of the young adults the HIV disclosure conversation occurred at an opportune time when they refused to take the ARVs. It was also at that time the participants found out they were the only sibling diagnosed with perinatal HIV and that their mother also had
HIV. One participant remembered blaming her birth mother for transmitting HIV to her and thinking that having HIV was her mother fault and the source of her illnesses. She remembered having angry feelings and frequent emotional outbursts. She described the difficulties her mother created by leaving her alone to cope with adoption, HIV related illnesses, taking medicine and having to conceal her HIV diagnosis from others.

The time around the death of a mother was described by several young adults as different and harsh. A participant remembered being a little girl and living with her mother. She recalled her mother had a cat. She also remembered the day of the funeral. “I remember her funeral. I remember the day”. Another said, “I can't really say that there was much good times with her because I had such little time with her.” Finally, one of the younger participants stated she misses her mother every day and sometimes thinks she is still living. She believes if her mother were alive, she would be happy and not lonely.

The time before learning about their HIV diagnosis, the participants were told their illness could get better by taking their medication. At least three of the participants thought they had Asthma. Many of them never questioned the caregiver or medical practitioner about their illness and if they did, the response was brief and they were not encouraged to inquire further. It was the caregivers who decided the time to begin the disclosure process. Usually, the disclosure process began when the participant health status was threatened by the ARVs non-compliance. None of the participants searched the internet to find out the indications of the medications.

Only one male participant had an opportunity to discuss his HIV status with his father. Prior to his disclosure process, they lived together as a family and soon after, the mother moved away from the home with an uninfected child and the father remained in the home with the participant. Except for living at different locations, the participant stated his relationship with his
parents remained unchanged. The participant’s HIV transmission was explained to him by his parents as “we were teenagers who made a mistake having unprotected sex”.

Most of the participants described illness when they were younger. The participants who reported significant illnesses had these conditions throughout their lives and are now living with HIV as a chronic illness. When the participants were feeling sick they have a vivid memory of events in the past. A happy day was described by a participant who received a car his 18th birthday. When the participants were feeling well, not much was reported. A seemingly happy event such as a trip to Disneyworld was described as an unhappy event

The Make-a-Wish Foundation took me to Disneyworld. It was supposed to be my time to have fun. That was my once-in-a-lifetime kind of thing and it was horrible.

Disclosure of the HIV diagnosis to the child negatively affected their relationship with the mother. Some participants described feelings of anger and hostility towards their mothers for months after the disclosure. Participants suggested their mothers were too embarrassed to discuss how they the HIV infection was transmitted to them. One participant stated her mother asked her not to keep bringing up the issue because she will “never tell” as it was her private business. Anger towards the living birth mother was revealed throughout the interview, although many participants reported their anger was fleeting.

Among the participants the appropriate time to disclose their HIV status varied significantly. The participants who found out their HIV status while they were six years of age and younger reported they were too young to understand the information given to them. The participants who were told they were HIV Positive when they were twelve years and older thought if the disclosure process began at a younger age, they may have been more medical and medication compliant. One participant stated if she knew she was HIV Positive she probably
would not engage in sexual intercourse. All of the participants in the study knew of their HIV status at the time of the interview and with one exception, there were no apparent differences in medical adherence. No relationship was noted between the timing of their disclosure and significant health concern.

The young adults reported not knowing how to cope with the secrecy of HIV which was part of the disclosure process. The caregiver also reminded the young adult that others will stigmatize them and family members if they found out they had HIV. Some of the young adults experienced the stigma from family members, when asked to use separate eating utensils. Other participants were fearful to speak-out in a group in fear of being stigmatized because they had too much experiential knowledge about the HIV illness.

Shingles, asthma, fatigue, cerebrovascular accident (CVA, flu symptoms, coughing episodes, fever, recurrent pneumonia, transient ischemic attack (TIA), seizures, kidney failure, thrush, hot flashes, stomach ache, gout, ulcers, enlarged thyroid glands, urinary tract infection, diarrhea and anal warts were among the illnesses reported by the young adults. The time around illnesses was described by several young adults as filled with angry emotions. The participants had the ability to recall significant dates of hospitalizations and illnesses. One participant reported being expected to die in 2008 during July 4th and December 23rd. During this time she recalled being in high school and was sent home in a wheelchair. Two young adults recalled the date and time when they realized a wheelchair may be a permanent assistive device because they had difficulty with ambulation. They are now using their wheelchairs more often, because it is difficult to walk for long periods of time. During the interview one of the participants acknowledged that over the past six months his health has worsened. He developed kidney failure and is on dialysis three times a week. This participant remembered when he was much
healthier and had a part-time job. Another participant described being hospitalized when his mother was alive. “I had pneumonia I think maybe twice. I remember one significant time. I remember my mom was at the hospital one time, and she would spend the night there. And yeah, I got really sick a couple of times. That’s when I wasn’t taking medicine”.

The time around taking medication was described by several young adults as “Ugh” They often refused to take liquid ARVs when they were younger because they couldn’t tolerate the taste. One young adult in the study has 0% medicine compliance and remembered taking ARV’s four or five months ago. Other young adults remember self-administering ARVs as they were taught to measure their liquid medications such as Kaletra.

The timing when the young adults become aware of their educational and employment outcomes was described as elusive or unplanned. Seven of the seventeen young adults enrolled in this study did not graduate from high school for various reasons and three participants attended college although they did not graduate. Of the remaining seven participants who graduated high school, two of them cited health reasons for not continuing their academic education. Most of the participants are unemployed. One of the seventeen participants is currently employed full-time and four of them work part-time. During the interview most of the participants revealed they were not prepared for college or employment after graduation from high school. One participant dropped out of high school while in the 10th grade and stated he knew he was in the wrong class to prepare for college or employment. He said, he was sick and missed school “In high school, I was placed in a mentally retarded class for most of the three years that I was there”. Another participant remembered attending Maryland schools when he was living with his grandmother. He said, “It was different. I liked it. I liked Maryland public schools better than the DC schools. It was fun. It was fun. I made a lot of friends, and I learned a
lot. Probably academically, too”.

The timing of the plans for transition to maturity was described by several young adults as unplanned. All of the young adults stated their awareness of being transitioned to an adult care facility at some point. One participant summarized the opinions of a majority of the young adults. “From the time I graduated from high school until now, I have done nothing”. One of the young adults in the study never learned to take her ARVs independently and on her 18th birthday she was surprised when she was expected to take care of herself. This included personal and financial responsibilities in the home she shared with her mother. The participant said, I remembered “she did everything for me. When you’re so used to help all the time and then it just stops, it’s not that easy to regain yourself”. Another participant described an important time when he visited the pharmacy a few months ago to re-fill prescriptions after being transitioned to adult care, and was told the cost of the prescriptions would be $3,000 because he no longer had insurance to pay for his medicine. What occurred to him at that point was that upon transition from the adolescent clinic to the adult health center, “unless it’s an emergency, you’ve got to get through it on your own”.

**Lived Relation**

The fourth existential, lived relation (relationality), is comprised of the relations “that we maintain with others in the interpersonal space that we share with them” (van Manen, 1990, p. 104). Van Manen proposed, “As we meet the other we are able to develop a conversational relation that transcends ourselves” (p. 105). He further suggested that the child experiences a fundamental sense of support and security that ultimately allows him or her to become a mature and independent person. And in this lived relation the child experiences the adult’s confidence and trust without which it is difficult to make something of oneself” (p. 106).
Within the narratives young adults explicitly and implicitly suggested the nature of their relationships with family members and peers involved wishing for a relationship others seem to have had. Several of the young adults wondered if it were better to live in the shadows of a relationship or not have a relationship at all.

The participants’ relationships with their mothers were described by most of the young adults. Mothers died and the young adults wondered if they too would die soon. The mother is central in the young adult’s life and from the narrative most revealed a life void of a parent after the mother died. Although several mothers were still alive during these interviews, the young adults still longed for the confidence of someone with whom to discuss their HIV. Very few stories told by the young adults revealed a time when they were enjoying life or a state of happiness. The elements revealed were typical of young adults who are living a secluded life. One participant said, “I did not have a childhood, I had perinatal HIV”. In describing her relationship with her mother, the participant said to avoid arguments “I usually try to stay away from any kind of conflict with her” referring to her mother.

The participants’ relationship with the father was described by 6 of the 17 young adults who participated in this study. Fathers were usually under-employed and if involved in the young adult’s life they have negligible roles in his family. Only one father was a primary care giver. That father was the head of the household and remained dedicated to the young adult throughout his life. This young adult reported living with his father for his entire life and is aware of his father’s HIV status. During the interview he stated his relationship with his father has “grown into a normal relationship over-time”. Another participant suggested he is getting to know his father now that he is an adult. Another stated he knew his father who died while he was too young to remember much about him. His father died very soon after his mother. Another
participant said his father is available and visits with him when he needs money or some form of assistance and suggested not having a father might be better. One participant wiped tears away as she talked about her father signing her away to the Social Services Agency and another participant reported his father has been in a foreign prison for an indefinite period of time.

Several participants described a limited relationship with family members as very few of them described relationships with siblings. Although the SIS clinic serves perinatally infected siblings there was none enrolled in the study which permitted the participants to ask “Why me?”.

According to another participant the mother gives more attention to the uninfected sibling which creates jealousy among them. Another, who is the oldest of three boys, stated he felt responsible and must be the role model for his siblings and plans to succeed in college.

Relationships with relatives were difficult to maintain for some of the young adults. A participant recalled living with her aunt after her mother died and stated, “she hit me with an orange thick extension cord and I had to defend myself. They used to bully me. At my mom's funeral, they locked me in the bathroom, so I have this phobia of being closed in places”.

Only one participant described knowing another perinatally infected young adult. Others described feelings of isolation and loneliness believing no other person is living as they are with perinatal HIV. The participants reported having few friends and described being “pushed away” from peers who do not understand what it means to live with perinatal HIV. The participants disclosed their HIV status to very few friends and relatives and summarized their relationships with peers as “It’s like a little secret you’re not supposed to tell people, but when it gets out you’re screwed”. While, some participants say, their uninfected peers have “moved on” which means they left for college or are now living in different life in a different community.
**Related Qualitative Inquiries**

Many of the thematic elements offer an opportunity to view this experience of growing up with HIV as a new phenomenon that needs further study. This section will discuss the thematic elements in other qualitative inquiries focusing on growing up with perinatal HIV. Many of the thematic elements uncovered in this phenomenological inquiry revealed only limited findings in the perinatal HIV research literature. For example, in the essential theme “A life of uncertainty” recent literature (Mellins & Malee, 2013) suggests perinatally HIV infected young adults experience emotional and behavioral problems at rates higher than the general population.

In the current study the thematic elements uncovered: growing up unprotected, relative and stranger foster-care abuse, an absent father, being different from others, an unstable household, limited social support and unhappy tears. These elements do not represent what is needed for the participants growing up with perinatal HIV (Mellins & Malee, 2013; Aday, 2001).

The essential theme, “Wishing for a purposeful life” uncovered the thematic elements: relationships, marriage and family and helping peers understand HIV. To support these finding, several authors Hawkins, Gilliland, Christiaens & Carroll (202) suggested integrating marriage education into perinatal education helps strengthen family relationships for those who want a family. The authors propose integrating couple-relationship education into the standard of perinatal care so that young adults planning a future will be prepared for adult responsibilities, such as caring for children. In another study, Walcott, Hatcher, Kwena, Turan (2013) conducted a qualitative research with HIV-infected pregnant women (n = 20) and male partners of HIV-infected women (n = 20) as well as two focus groups with service providers (n = 16) to obtain
information on approaches for safe HIV disclosure and found that the disclosure process preferred by the participants was by trained health workers during the home visits.

The essential theme “Longing for a future” uncovered the thematic elements: out of work, an elusive or unplanned education, transition to adult responsibilities and acceptance of life’s circumstance. A majority of the young adults in the study live in poverty. In a recent exploratory study, Foster & Volansky (2010) reported higher rates of HIV infection among blacks in the United States are related to a number of social factors, such as unemployment and poverty. In addition, the consequences of unemployment aggravated by poverty are factors that negatively impact health and emotional stability of the young adults growing up with perinatal HIV in this study.

The essential theme “Managing emotions” uncovered the thematic elements: anger, loneliness, stigma, secrets, fear, survival and sex and HIV.

Audet, McGowan, Wallston, Kipp (2013) conducted a qualitative interview of 32 adults over 18 years of age living with HIV and reported the following: HIV stigma and negative attitudes such as, fear of contracting the infection, and misunderstanding about transmission, acts of poor judgment by family members, peers, the medical care providers and others within the workplace, also the participants’ self-isolation. The fear of having HIV resulted in participants isolation from friends to avoid stigma. While the fear of stigma and isolation remained in the communities, authors reported the experience is lessening among the younger, non-religious and educated members of the community.

In qualitative analyses, Fair and Albright (2012) wrote “Don’t tell him you have HIV unless he is the one.” The authors discussed romantic relationships among adolescents and young adults with perinatal HIV infections and revealed participants who dated struggled with their
HIV status in their intimate relationships. Many never disclosed to a romantic partner, but managed intimacy by delaying dating or terminating the relationships early to avoid revealing their HIV status. The majority of those who disclosed their HIV status to past partners had experienced several forms of rejection. The author suggested HIV education must include transmission risk factors and developing and maintaining healthy relationships in a highly stigmatized environment.

The essential theme “Hoping for better health” uncovered the thematic elements: trying to get better and lifelong medication use. Kerr, Miller, Galos, Love & Poole (2013) reported in a systematic literature review (n=26) the challenges and coping strategies that qualitative researchers described in the HIV services field during the HAART era, (1998-2012) and their recommendations to organizations. The authors recommended that future research is needed to evaluate the need for increased support, capacity-building, and structural changes for people coping with HIV.

In a another study, Rydström, Ygge, Tingberg, Navèr & Eriksson (2013) described categories illustrating the experiences of growing up and living with HIV (1) to protect oneself from the risk of being stigmatized; (2) to be in control; (3) losses in life, but HIV is not a big deal; (4) health care and healthcare providers; and (5) belief in the future. The authors recommend evidence-based interventions to improve care and support, particularly in the handling of stigma and discrimination.

In the current study, the thematic elements are “trying to get better and lifelong medication use”. Some participants characterized their lives growing up with HIV quite satisfactorily or as "not that bad", while some described their experience as quite unhappy and sad. A range of types of unpleasant reactions fear, pain, loneliness, anger, physical symptoms
were reported by individual participants. Several sources of social support included both parents, single mothers, a father, a sister, a brother, an adopted mother, friends and nurses. Sports and other recreational activities were not reported by the participants as necessary.

Several of the young adults participating in this study did not experience the support and security needed to grow and develop as mature and independent persons. Two concerns for these young adults, medication adherence and transitioning to the future, remain constant themes throughout this study.

**Medication Adherence**

For several years health care providers informed the perinatally infected HIV young adults and their families that perinatal HIV is a chronic illness that can be controlled by medication, but there has hesitation or doubt about planning for the future and today the future remains uncertain. The 2010 CDC data indicate that 75% of HIV-infected African Americans diagnosed with HIV aged 13 or older are linked to health care, 48% are retained in health care, 46% are prescribed ARVs, and 35% have an undetectable viral load (CDC, 2014).

Although, poor medication adherence is consistently reported in the HIV literature, in this study medication adherence is high. Most of the young adults are now aware that ARV’s medication non-adherence can result in the development of drug resistance and an increase in viral load. During the interview, the young adults revealed that they did not understand the importance of medication intake when they were younger and they questioned the need medications when they were healthy complaining of the side effects.

Each year the amount of available ARVs has increased and today there are over 32 ARV’s approved for adults diagnosed with HIV and young adults need to be taught how to self-administer these medications. Most medications are to be taken with a high fat diet or with food;
the young adults had no memory of this information. Also, Drug resistance is an important area that must be taught. Skipping the prescribed doses or not taking the medications as prescribed may cause drug resistance. The young adults must be encouraged to not miss doses of the ARVs. Some of the participants experienced no symptoms of HIV infection, but felt sick while taking the medications. One participant had 0% ARV intake and it is possible participants may have some side effects from the ARV medicines. HAART requires the use of 3 or more ARVs and most of the young adults complained of one or more the usual side effects (nausea or vomiting, diarrhea, abdominal pain, severe fatigue or muscle aches). The most common long-term side effects of antiretroviral medicines (redistribution of body fat) was observed in at least two participants.

**Transition**

The study findings connected with the work of Lee King & Pate (2013) perinatal HIV transmission disproportionately affects African Americans in the United States. The study suggests that decades ago -perinatally infected children were not expected to survive and these young people have now reached young adulthood. There are many unknowns about how best to help these young adults make an effective transition into healthy adulthood. An important finding from this research is a need to improve the young adult’s emotional readiness and skills for adult medical care.

This final section includes a discussion of the study limitations, and recommendations for nursing practice, education, research, and policy. The stories told were reflective accounts of the experience of young adults growing up with perinatal HIV and are the bases for the findings. The overarching themes for the young adults telling their stories reported a Secretive Uncertain and Harsh life. From the overarching theme, the five essential themes emerged. The first
essential theme “A life of uncertainty” was revealed in the young adults’ stories of disappointment growing up unprotected with limited social support. The second essential theme, ‘Wishing for a purposeful life” was uncovered when the young adults’ described the reluctance to participate in adult relationships, fear and uncertainty of family life. This developmental milestone, Erikson (1998) will be delayed for this group of young adults. The third essential theme “Longing for a future” described the young adults’ educational preparedness and employment status. The forth essential theme “Managing emotions” described feelings and resentments living with HIV; and the fifth essential theme “Hoping for better health” described the young adult’s health status. The five themes are inter-related and co-exist to offer a new perspective on the experience of growing up with perinatal HIV. Within each essential theme there are several sub- themes that illuminate the common thematic elements in this phenomenon.

The four van Manen (1990) lifeworld guides are as follows: (1) lived space; (2) lived time; (3) lived body; and (4) lived human relation” (p. 101). In the lived relation, the young adult’s experiences did not include the adult or parental confidence and trust. It is essential to offer a safe, trustworthy, and professional healthcare environment during the period of time when young adults are growing up with HIV. One participant listened to play back of his taped responses and said, “This is the first time I was asked what it like to grow up with HIV”

The four lifeworld existentials Van Manen (1990) provided the components for interpretation and discussion of growing up with perinatal HIV. In the current study the young adults growing up with HIV experienced poverty in a lonely complicated existence that an individual cannot navigate independently. The absence of social capital or financial resources has a harmful affect not only on present generations, but also on future ones (Aday, 2001). Poverty is the familiar phenomenon that impacted the young adults in this study. A total of 41%
of young adults did not graduate from high school and the employed young adults (29%) were underemployed. The highest annual salary reported by one individual was $20,000.

Discussion

Since this is the first phenomenological, Van Manen’s method inquiry on perinatally infected young adult 18-24 years of age growing up with HIV the results will add to the gap in the qualitative literature describing the uncertain life of these individuals. To describe further the young adults growing up with perinatal HIV this section will discuss Michel’s Uncertainty of illness theory, and other qualitative inquires focused on the experience of living with HIV.

This study connected with Michel’s theoretical framework and offered an explanation of what it is like in the midst of many obstacles, growing up with perinatal HIV when the young adults’ survival was not expected. These young adults are growing into adulthood without the skills to live independently and are living a life of uncertainty. In the essential theme “A life of uncertainty”, the young adults described “growing up unprotected, living in foster care, not having a relationship with their father, being different from others, living in an unstable household, having limited social support and having several episodes of unhappy tears.

Uncertainty means dealing with all of the emotions that come with having a chronic illness including psychological emotions of anger and fears of ostracizing social responses (Brashers, Neidig, Reynolds & Haas, 1998).

Theory of uncertainty of Illness, the Theoretical Framework

Mishel’s Uncertainty in Illness Theory is a mid–range theory that has guided numerous descriptive studies of children with serious illnesses. The theory hypothesizes that uncertainty results when an acceptable plan of action was not formed with which to understand the illness-
related events, and this uncertainty leads to psychological distress if coping responses are insufficient to resolve the concerns or to manage negative feelings (Stewart & Mishel, 2000). For example, independence and future planning may not come easily for young adults growing up infected with HIV because they were not taught the necessary skills. In this study, many parents and guardians may not have planned for their perinatally HIV infected child's future, as the future was uncertain.

The Mishel’s Uncertainty of Illness scale Mishel (1981) has been used in previous research with individuals living with HIV. Using the uncertainty of illness scale, McCain & Cella (1995) conducted a correlational study on the relationships among psychological distress, quality of life, uncertainty, coping patterns, and found both higher levels of negative stress and more frequent use of emotion-focused coping was associated with uncertainty and lower quality of life was associated with more uncertainty.

Tuck, McCain & Elswick, (2001) descriptive correlational study explored psychosocial measures using Mishel’s Uncertainty in Illness Scale (1981) and found the instrument to be effective to measure aspects of stress and coping. Michel’s Uncertainty Illness theory lists the Stimuli Frame (Time of Diagnosis & Stage of Illness) and the structure provider (Family Routine & Parental Provider) the young adult in the center of the diagram leading or resulting in emotional responses of coping patterns. (Mishel, 1981).

Mawn (2012) conducted a longitudinal qualitative study over 7 years to examine the phenomenon of raising an HIV-positive child in the United States from the parental perspective. In the study, one of the commonly reported themes (uncertainty) emerged from the narrative.

**Limitations**
There were several limitations within the current study. First, the study findings and interpretation must be considered within the context of the research design and research methodology. The refusal to participate may bias the data, although the effect of this bias is unclear. It is possible that some of those young adults may have had a different experience growing up with HIV. As in most qualitative inquiries, a small number, 17 participants were enrolled. The findings of this study cannot be generalized, and only reflect the study participants’ experiences. Secondly, the sample was homogeneous as most participants were recruited from the same general clinic because they are well known to that medical team and they have a high level of comfort and trust with the staff. Although the recruitment team was in place to ensure participants’ privacy, a total of 9 participants refused to participate in the study by the recruiting team citing a busy schedule and others were reluctant to share their HIV narrative, or suspicious of investigator’s intentions, or did not have transportation. Consequently, the study findings are potentially biased as the sample might have only included young adults who wanted to share their HIV stories or had sufficient time to spend with the researcher. In conclusion, it is suggested that future research should enroll participants who have different life experiences. In other words enrolling young adults who have successful life stories to share may be beneficial and offer a different perspective to growing up with perinatal HIV.

**Recommendations**

The current study serves as a guide for future nursing practice, education, and policy to support young adults growing up with perinatal HIV. Nurses are among the primary professionals who are in a position to support and provide information to young adults growing up with HIV. This section will offer strategies for improving support for young adults growing up with HIV by way of practice, education, research, and policy change.
Recommendations for nursing practice

The current study will help nurses design adequate nursing interventions to support the young adults. The verbatim text gave a voice to the reality of living with perinatal HIV and described the overarching theme of the study a “Secretive, Uncertain and Harsh” life. The study also serves as a guide for future research studies to explore and better understand the phenomenon of growing up with perinatal HIV. The findings demonstrated the necessity of providing continuous education and support for young adults growing up with perinatal HIV and for nursing case management for these young adults.

Throughout the interviews many young adults described several emotions they kept to themselves for several years. This interview provided an opportunity for the participants to speak freely about living with HIV for over 18 years. The narrative included thoughts participants never had the opportunity to verbalize to anyone. One participant stated, “No one ever asked me about living with HIV before”. Very early in the interview it was apparent to the researcher that the participants had developed a sense of thrust and familiarity which facilitated a conversational relationship Van Manen (1990) between them. Although the questions were answered to the best of their abilities, most responses were vague when responding to future plans. It was apparent that this convenient sample of young adults could describe their own life events; and nonetheless, they were severely limited in providing information on plans for future health care, academic education completion, vocational training and goals.

It was of no surprise there was a sense of anxiety for the young adults preparing for transition to adult medical care. The young adults who are shielded by a living mother seldom had the opportunity to learn about self-care. These mothers still make appointments, attend the clinic visit and are very involved in the health care of their children. The other group orphaned
by the mother’s death was forced to self-medicate and currently make independent decisions regarding their health care needs to the best of their abilities.

All of the young adults in the study were aware that the transition date is in the future, but since no one expected either of the groups to live a long life, their health care education was usually omitted.

Many participants (41%) did not complete their high school education. One participant was not sure if a high school diploma or GED would insure a better paying job. Another stated going back to school was not a focus for him while he was younger and now it is too difficult.

Most of the participants were unemployed and only one participant attended a job training program. In that program, he was being taught how to conduct himself during the job interview. The instructions included how to introduce himself and have eye contact during the job interview.

The future goals for some of the participants included having a family, but very few verbalized the understanding of what that really means in terms of responsibilities. Since having a family and children could be considered to be two important areas discussed in the study, a plan of action or demonstrated knowledge on how to accomplish those important milestones was not clearly stated by the young adults.

**Nursing Case Management**

This report indicated the need for perinatally HIV nursing case management. The perinatally infected HIV diagnoses of all age groups and both sexes, all (100%) were linked to care and were retained in care up to this point. The entire sample (100%) was prescribed ARVs and most have achieved viral suppression. In this study, the young adults growing up with perinatal HIV have limited social and financial capital as described by Aday (2001). The
majority of the participants were African Americans, and as reported in an epidemiological report by Moore (2011), African Americans may also not seek, receive, or adhere to HIV care or achieve viral suppression for reasons including lack of health insurance, poverty, and stigma. Describing the conditions the young adults living with perinatal HIV are experiencing is the first step in the plan for improving health outcomes for these young adults.

In the current study, the young adults reported being absent several days from school due to illness and being absent affected their success in school. The IEP did not remain with them from throughout the grades of school or if they changed schools. Therefore, each perinatal HIV child should have an IEP in place from elementary school through high school.

The implementation of a nurse case-management perinatal HIV program would focus on care and treatment for the individual child and would strengthen the efforts to maintain viral load suppression from a very young age. At each session patient education would be conducted and goals reinforced for the participant. Included in this program would be an educational curriculum coordinated by the nurse case manager and school nurse that is tailored for the individual child to provide guidance to the child and guardian. This plan would be in place as the child transitions to adult life. The coordinated efforts of the nurse case-manager and the school nurse will be invaluable as this program will offer the resources to maintain the link to health care and education for the perinatally HIV-infected child. As the young adults grow up the link will promote access to the necessary referrals to achieve the optimal health outcomes.

Nursing case management already exists for adult HIV patients (Horberg et al., 2012; Johnson, et al., 2003) and this research suggests an opportunity for perinatally infected HIV nursing case management role for young adults since this position does not exist. Currently, perinatally infected HIV babies are still being born and nursing case management is needed to
coordinate the care of these children and the existing young adults to guide them through life.

This role will include careful supervision of children who may also have mild to severe developmental concerns or normal abilities in a central location. Glenn & Wilson (2008); Harberer & Mellins, (2009); Murphy, et al (2001) and Wilson et al (2005) described nursing case management, but the recommendation from this study is for the perinatally HIV infected young adults to have an individual plan of action for transition to a structured adult care setting instead of the one size fits all approach where the adult health care has multiple locations. Also, this plan can be evaluated using Donebedian's structure-process-outcome method (Donabedian 2003).

In summary, there still exists thousands of perinatally HIV infected young adults who are living a life of uncertainty because they were not expected to survive and nursing case management will help them transition safely to adult care.

**Recommendations for Education**

Many of the participants were unemployed and did they graduate from high school. Obtaining the General Education Development (GED may expand their job options. Several authors Marin & Brown (2008); Substance Abuse and Mental Health Services Administration SAMHSA (2007) suggest academic success and achievement are strong predictors of good health outcomes and the academic skills gained are associated with less risk of unhealthy behaviors. Other relevant education for the perinatal HIV young adult should be health care education communicated in a way that is culturally sensitive and based on an assessment of knowledge and understanding of the individual. The education should include family planning decisions, methods of preventing HIV transmission, negotiating intimate relationships and the ethics of disclosure with sexual partners.
**Recommendation for Nursing Education**

The U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA) issued guidance encouraging nursing schools to implement curricula that include HIV-specific training for the nursing staff (The White House Office of National AIDS Policy, 2010). Nursing schools in the U.S.A. have begun enrollment and graduating in a new HIV specialty to help people with HIV stay healthy. The White House’s initiative is to reduce HIV incidence, increase access to care and reduce HIV-related health disparities by replacing the HIV retiring sating with newly trained staff.

In a report on the services administered to HIV positive individuals, Craw, et al (2008) suggested that HIV infected adults do not receive adequate care when the care is decentralized and supports linkage to case management. In the study, Craw, et al (2008) found that approximately 79% of the participants surveyed visited their HIV health care provider at least once within 6 months prior to enrollment in the study. In another adult study, Rudy et al (2005) compiled data from 306 HIV infected individuals not receiving care who responded to a questionnaire. Twenty-two percent of the participants stated that not enough time was spent with them, 27% reported that they did not receive answers to all of the questions asked, and 7% stated that they were not treated with respect. The researchers identified deficiencies in HIV counseling services that were conducted in private physician offices, emergency departments and hospitals. These were considered to be important locations where the participants received medical care. The study recommended further staff training since this represented missed opportunities provide patients to appropriate HIV care. These authors highlighted the poor access to counselling and referrals for the HIV infected adults receiving care.
Since limited access to care is possible when young adults are transitioned to adult care, trained perinatal HIV nurse specialists are needed. The perinatal HIV infected young adults should be transitioned to a nurse-led perinatal HIV program which may increase the numbers of young adults retained in the HIV services.

**Recommendations for Research**

Future research is needed to gain a better understanding of the support needs of young adults growing up with perinatal HIV. This study suggests the need for improvements in the delivery of family-centered health care services and medication adherence at a young age for perinatal HIV infected children throughout their lives. This study also recommends several research questions

**Future research questions:**

1. Does improving the palatability of antiretroviral medications for the young perinatally HIV infected children improve adherence?
2. How effective are home nursing visits to administer anti-retroviral medications in prevention drug resistance in the perinatally infected HIV child?
3. What physical activities can improve the activity of level of young adults living with perinatal HIV infection?
4. Do perinatally infected HIV children and young adults complain of fatigue?
5. Would a program designed for the perinatally infected HIV child improve health?
6. What do perinatally infected HIV young adults expect from the health care team?
7. When should the disclosure process take place for the perinatally HIV infected child?
8. How successful is the transition process to adult health care for the perinatally infected HIV young adults?
(9) Do perinatally infected HIV young adults expect a relationship that includes marriage and children?

(10) What is the relationship between perinatally infected HIV children and their mother after disclosure?

**Recommendations for Policy**

Policies will have a positive effect on young adults growing up with HIV. Health organizations need to put in place policies that promote high quality health outcomes for all individuals, including those with perinatal HIV. Most of the young adults voiced uncertainty and having no plans for the future. The following policies are recommended for the young adults growing up with perinatal HIV: (1) Reducing the vulnerability and disparity in communities by improving transition access to health care; (2) Cultivating the social environment to eliminate stigmatic exposures; (3) Refining counselling techniques in order to expand access to care for patient and the family; and (3) Improving emotional support for the patient and caregivers to help improve communication among family members.

The young adults in the study shy away from support groups. The policies recommended above can be implemented in support groups. Support groups can provide a safe environment to discuss disclosure and stigmatic experiences. A perinatal HIV support group is needed for disclosed young adults and the parents of undisclosed children. The aims of support group will be (a) to provide emotional support and coping mechanisms to those people who are undergoing a difficult time in their lives; (b) to reduce isolation and discrimination while encouraging acceptance around HIV; (c) to discuss the de-stigmatization in the community for people living with HIV and their families; and (d) to provide information on medical supplies and skilled medical services. Disclosure may be difficult for some members because sometimes the parents
of undisclosed children have also not told their families, friends and this will be an opportunity to learn how to begin the disclosure process in a safe environment.

In the study, shared experiences of medication burden from ARVs were expressed by all of the participants. Nurses are in place to educate policy makers and the insurance companies on behalf of perinatal HIV individuals about the young adult’s medication adherence issues. For young adults the concern is that HIV infected young adults are denied by insurance companies the single dose HIV tablet regime prescribed by the health care provider. The denial from the insurance company often suggests that combinations of medications can be used. The education on barriers to teenager adherence should help guide insurance companies and policy makers to approve the one a day tablet for the young adult living with HIV. The one pill a day regimen may help several patients adhere to the medication regimen and minimize the development of the viral resistance.

Hanghøj & Boisen (2014) conducted a systematic review of 3,655 records and 28 articles with both quantitative and qualitative findings from January 2000 to May 2012 on barriers to medication adherence. Articles were included if they examined barriers to medication intake among chronically ill adolescents aged 13–19 years. They found that barriers to medication adherence included forgetfulness, organization skills and medicine complexity in the adolescent population.

Health organizations need to put in place policies that promote high quality health outcomes for all individuals, including those with perinatal HIV. The young adults in the study also voiced uncertainty of their future. They have limited knowledge about what will be possible for them in the future. Although, the future cannot be predicted, recommendation for policy is for frequent nursing visits to the home of the child when the child is very young. Since HIV is
now a chronic illness, regular home care visits can improve medication adherence at a young age and promote life-long adherence practices.

**Conclusion**

HIV treatment goals are primarily centered on reducing the HIV-associated morbidity and extending life. Effective antiretroviral treatment, HAART has increased the survival rate of infected individuals, such that HIV infection is currently considered a chronic disease. Many of these young adults have not focused on getting good grades in school and preparing for employment. As they enter adulthood, they are faced with learning how to live independently. The parents and guardians may not have believed attending school regularly was important for these children who are now expected to know how to make decisions, set their own limits, explore their sexuality and cope with peers which results in living a life of uncertainty. Data concerning the experience of living with HIV since early childhood is scarce and more empirical knowledge is needed to direct the development of adequate care and interventions for perinatally infected HIV young adults.

In the current study, relationships with peers and partners were uncertain in the young adults’ life. Sexual behavior carries adult responsibilities of knowing that the risk of infecting another is possible and disclosing the HIV status to a potential romantic partner could lead to rejection. It will be the decision of the perinatally infected young adult to act responsibly by disclosing to a potential partner and using protective measures. All of this is made even more “uncertain” if a young person is dealing with HIV.

This study was designed to describe the young adults’ experience growing up with perinatal HIV. It is essential to offer a safe, trustworthy, and professional healthcare environment during the growth and development of perinatally HIV-infected young adults.
Evidence-based interventions are needed to improve educational activates in planning for the future, care in the home and social support, particularly about providing safe surroundings, and monitoring stigmatic exposure.

This chapter presented a summary and discussion of findings of a qualitative investigation focused on the lived experience of 17 young adults growing up with perinatal HIV. A phenomenological approach, as put forth by Van Manen (1990), was used to explore the essences of the phenomenon of growing up with perinatal HIV and to interpret the meanings ascribed to the experience. The emotional aspects of living with HIV from birth were found to be a complex life experience that has a profound effect on many aspects of the young adults’ lives. The analyses of interview narratives suggested one overarching and five inter-related and co-existing essential themes. The overarching theme was A secretive, Uncertain and harsh life. The five essential themes: (a) A life of uncertainty; (b) Wishing for a purposeful life; (c) Longing for a future; (d) Managing emotions; and (e) Hoping for better health. These themes were discussed in light of limited theoretical and research literature. Additionally, this chapter described the limitations of this study, recommendations for future research, and implications for nursing practice, policy, and education. This study has given voice to the profound experiences of the young adults growing up with perinatal HIV. By gaining a better understanding of the phenomenon and the meanings ascribed to the experience, health care professionals have the potential to help support and sustain these young adults as they live a life that was not anticipated.
Appendix A Consent

CHILDREN’S NATIONAL MEDICAL CENTER
Department of Research/CRI
111 Michigan Avenue, NW
Washington, DC 20010
(202) 476-5000

CONSENT TO PARTICIPATE
IN A CLINICAL RESEARCH STUDY AND AUTHORIZATION TO USE PROTECTED HEALTH INFORMATION

TITLE OF STUDY: Growing up with HIV: The Lived Experience of Perinatally Infected Young Adults.

PRINCIPAL INVESTIGATOR: Elaine Fay Williams, MSN, RN, PhD student, The Catholic University of America

PhD Advisors: Janice Agazio, PhD, RN, The Catholic University of America; Janet Merritt, Ph.D., R.N., CNS-BC, The Catholic University of America; Natella Rakhmanina, MD, PhD, Children’s National Medical Center.

Children’s National Medical Center PhD Advisor: Pamela S. Hinds, PhD, RN

Sub-I’s Kathleen Ferrer, MD; Keetra Williams, BSN, RN, Marlene A. Lee, MSN, RN

INTRODUCTION: We would like to invite you to be part of a research study at Children’s National Medical Center. Before you decide if you would like to participate, we want you to know why we are doing the study. We also want you to know about any risks (anything unexpected that might happen) and what you will be expected to do in the study.

You are being asked to participate in a study describing your experiences growing up with Human Immunodeficiency Virus (HIV). Elaine Williams, a doctoral nursing student, is conducting this study to fulfill a requirement for a doctoral dissertation at the Catholic University of America School of Nursing.

This form gives you information about the study. The researcher Elaine Williams, RN, MSN, will talk to you about the study and answer any questions you have. We encourage you to discuss this study with your family and anyone else you trust before making your decision. We will ask you to sign this form to show that you understand the study. We will give you a copy of this form to keep. It is important that you know:
You do not have to join the study;

You may change your mind and stop being in the study any time you want.

A. PURPOSE OF STUDY
The purpose of this study is to learn more about what it has been like growing up with HIV. The knowledge gained from this research will assist nurses, healthcare providers, and community support personnel in gaining a better understanding of young adults living with HIV.

You qualify for this study because you are between the ages of 18-24 years old and have been diagnosed with perinatal HIV. Approximately 20 young adults will be asked to participate in this study.

B. PROCEDURE
During one visit you will be asked to complete a brief questionnaire after which you will participate in an audio-taped interview that will take approximately 60 minutes. The interview is a one-on-one session with the researcher. Two tape recorders will be used just in case one of the recorders fails to work. The interview will take place in a private room in the research center at Children’s National Medical Center

The researcher will request permission to contact you by phone to clarify the information obtained during the interview if needed. For example, during the phone call you may be asked to describe what you enjoy for recreation.

There are no medical exams, blood draws or treatments associated with your participation in this study.

C. POTENTIAL RISKS/DISCOMFORT
You may experience a feeling of uneasiness or distress during the interview. If so, you may ask for the interview to be stopped. The researcher is an experienced nurse who can provide support and guidance and, if necessary, refer you to a counselor if needed. Another suitable time may be scheduled to complete the interview.

The potential risk is a breach in confidentiality of information obtained during the interview.
In the event of a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceeding, the researcher has a Certificate of Confidentiality from the National Institutes of Health. With this certificate, the researcher cannot be forced to disclose any information that may identify the participant.
D. VOLUNTARY PARTICIPATION
Your participation in this study is voluntary. There will be no penalty or loss of benefits
to which you are otherwise entitled if you decide not to volunteer in this study.

E. POTENTIAL BENEFITS
You will not benefit from this study; however what we learn will be used to help young
adults growing up with HIV.

F. ALTERNATIVES TO PARTICIPATION
Participation in this study is voluntary and you may withdraw at any time without penalty.
You may request that the audiotape recorder be turned off at any time if you do not want
comments recorded.

G. QUESTIONS – WHO TO CALL
We want you to ask questions about any part of this study or consent form either now or at any
time in the future. If you have any questions about this study, call the principal investigator,
Elaine Williams, MSN, RN, at (202) 476-2245. If you have any questions or concerns about
your rights in this research study at any time, please call the Office for the Protection of Human
Subjects at (301) 565-8452, the chief academic officer, or the chair of the Institutional Review
Board of the Children’s National Medical Center. The last two parties may be reached at (202)
476-5000.

H. CONFIDENTIALITY
We will keep the records of this study confidential. Only the people working on the study will
know your name. No identifying information will be included on audio recordings or transcribed
notes, which will be destroyed thereafter.

The federal government can review the study records to make sure we are following the law
and protecting the young adults in the study.

HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY
In 1996, the government passed a law known as the Health Insurance Portability and
Accountability Act (HIPAA). This privacy law protects your individually identifiable health
information (protected health information, or PHI). The privacy law requires you to sign an
agreement so researchers can use or share your PHI for research purposes. This describes to you
how information about you may be used or shared if you are in a research study. It is important
that you read this carefully and ask the research nurse to explain anything you do not understand.

I authorize Elaine Williams, MSN, RN, and members of her dissertation team access, use,
and disclose my PHI for the purposes described below.

Protected Health Information that may be used and shared includes:
☆ Information that identifies you, such as name, telephone number, and date of birth.
☆ Information obtained from the study procedures outlined in this consent form; for example:
things done to see if you can join the study and medical information we learn from you about your health history.

**The Researchers may use and share my protected health information with:**
- The principal investigator and other investigators in charge of doing work for the study;
- Government agencies that have the right to see or review your PHI, including but not limited to the Office of Human Research Protections;
- Children’s National Medical Center Institutional Review Board (IRB); the Catholic University of America’s IRB.
- Audit committee of the Children's National Medical Center Institutional Review Board;
- Quality improvement program coordinator and other staff in the Office for the Protection of Human Subjects at Children's National Medical Center.

**In addition to the above people and organizations, the researchers may also use and share my Protected Health Information with:**
- Doctors and staff at other places that are participating in the study. The name(s) of the other place(s) that are participating in this study are (Children’s National Medical Center and the Catholic University of America);
- The patient advocate or research ombudsman (person who watches out for your best interest).

**Storage of PHI in a database:**
We would like to store personal health information collected from you in this study. Elaine Williams, MSN, RN, will maintain the data at Children’s National Medical Center, 111 Michigan Ave. NW, Washington, DC, 20010. The results will be used for research purposes only. Your name will be replaced with a study identification number. USB drives, digital recordings, written notes and transcribed papers will be kept in a locked cabinet in the office of the investigator.

Digital recordings will be destroyed after completion of the analysis. Only the researcher and her dissertation team will have access to the coded transcripts.

**Please indicate your approval of the following by initialing next to the statement:**
My personal health information may be stored by the investigator for analysis related to this study. ○ Yes  ○ No ____ initials
I grant permission for the audio tape in this study. ○ Yes  ○ No _______ initials

If you agree to participate in this research study, the research team may use personally unidentified study data. The personally unidentified study data does not include your name, address, telephone, or social security number. Instead, the researcher assigns a code to the personally unidentified study data, which may include your date of birth, initials, and dates you participated in the study.
**Personally Unidentified Study Data**
Data may also include the health information used, created, or collected in the research study. The research team may share the personally unidentified study data with other researchers in the United States or other countries, or use it to improve the design of future studies. You do not have to sign this consent/authorization. If you decide not to sign the authorization, you will not be allowed to participate in the research study. After signing the consent/authorization, you can change your mind and:

**Revoke this authorization.** If you revoke the authorization, you will send a written letter to Elaine Williams, MSN, RN, at 111 Michigan Ave. NW, Washington, DC, 20010 to inform her of your decision.

If you revoke this authorization your de-identified PHI may still be used and disclosed in the study.

You will not be allowed to review the information collected for this research study until after the study is completed.

**This authorization expires at the completion of the study.**
If you have not already received a Notice of Privacy Practices from Children's National Medical Center, you may request a copy and will be given one. If you have any questions or concerns about your privacy rights, you may contact the Children's National Medical Center privacy officer at 301-572-6348.

**I. Payment for Medical Care for Research-related Injury:**
Children's National Medical Center cannot promise that the risks we have told you about or other unknown problems will not happen. If you think that something unexpected happened because you were in the study, please call the principal investigator at (202) 476-2245 or the chief academic officer of the Children’s National Medical Center at (202) 476-5000.

**J. ADDITIONAL ELEMENTS**

**Payment for Participation**
You will be paid $25.00 for participation. A gift certificate will be given to you at the end of the interview.

**CONSENT/AUTHORIZATION:**
I am the participant; I have read this information and will receive a copy of this form after it is signed.

By signing this form, you agree that you have talked to your doctor about the study and understand it, and you want to be in the study. You agree that we have talked to you about the risks and benefits of the study and about other choices. You may decide to stop being in
this study at any time and no one will mind and nothing will change about your medical care other than not being in the study.

Copies of this form will be:  
(1) Kept in the study file by the principal investigator;  
(2) Given to you to keep. 

Please call the principal investigator, Elaine Williams, MSN, RN, at 202-476-2245 if you have any questions. 

Printed Name of Participant: ____________________________________________

Telephone Number of Participant: ____________________________________________

Signature of Participant: ____________________________ Date: ____________________

**AFFIDAVIT OF PERSON OBTAINING CONSENT:** I certify that I have explained to the above individual(s) the nature and purpose of the study, potential benefits, and possible risks associated with participation in this study. I have answered any questions that have been raised. 

Printed Name of Individual Obtaining Consent: 

Title: _______ Signature: ____________________________________________ Date: _______
Appendix B Demographic Questionnaire

Demographic Questionnaire

Date ____/____/___ Participant Code __________

(1) Your current age: ____________

(2) Gender (please circle your response) Male   Female

(3) Race (circle the response) 
    African American   White   Asian   Other ____________

(4) Ethnicity: Hispanic or Non-Hispanic

(5) Employment status [circle the response(s)]
    Full-time   Part-time   Unemployed   Permanent Employment
    Temporary Employment   Full time student

(6) Type of employment________________________/ Years of employment___________

(7) Salary range: [check the response]
    __ >(>$50,000
    __ ($30,000 - $40,000)
    __ ($20,000 - $30,000)
    __ ($10,000 - $20,000

(8) Marital status (circle the response)
    Single   Partner   Married   Divorced   Separated   Head of Household

(9) Education level (Below please circle your highest education level)
    Some High School   High School Graduate   GED
    Some College   2-year College Graduate   4-year College Graduate

(10) Household: Number of people residing in the participant’s family home:
    Relationships: __________: __________: __________:
    Who are the people who are close to the participant?
    Family member: __________: Relationship __________: Relationship __________: Relationship __________
    Friends: ______ m/f ______ m/f ______ m/f ______ m/f
    Significant other: ______ m/f

(11) Do you have children? ______ (circle one) Yes   No
    Age (s) of children: ______   ______

(12) Are you prescribed medications? (circle one) Yes   No

(13) What percentage of time do you take your medications as prescribed? (circle one)
    25%   50%   75%   100%
Appendix C: Interview Guide

Participant Code___________________ Interview #____________ Date ___/___/____

Van Manen lifeworld themes (lived space, lived time, lived body, and lived human relations) will be developed from this interview.

Lead question

Please tell me what it is like living with HIV

Probes

Family life and social support

- Please describe the people in your life who are close to you.
- Please tell me about a typical day in your life.
- What helps you get through the day?
  - What hinders you getting through the day?
  - What is most difficult for you during the day?
  - Are there any individuals that have had a positive or negative influence on you over the years? If so, who were they and in what ways were they influential?
- Who cared for you as a child?
- Where do you live now?
- How has the support or care changed over time?

(2) Health and/or Health Concerns

Please describe your health.

- What would you share about your health care in the adolescent and/or young adult years?
- Why are the health concerns important to you?
• Do you have a child?

(3) Peer relationships

• Please put in your own words how you feel about your relationship with your family and friends.
• What was it like growing up with HIV in early childhood, for example, grade school and middle school?
• What is living with HIV now that you are in adolescence or young adulthood?
• Do you have a partner?
• What it is like to be in a relationship with your partner?
• How has he/she reacted to you being positive?
• What caused you to disclose, and how did you feel at that time?
• Are there any important life events, turning points, or transitions that come to mind when you consider your life growing up with HIV?
• What do you think about marriage and family life in the future?

(4) Economic and educational status

• Are you employed or are you attending school or a job training program?
• What do you enjoy for recreation?
• Please explain what have been your expectations of yourself over time.
• Have these expectations changed over time?
• If so, how have you felt about these changes?

(5) HIV disclosure

• Please explain under what circumstance you were told you have HIV.
• Do you recall how you felt that day, and has that feeling changed?

• How long have you known you have HIV?

• What are you most concerned about?

• What would you tell somebody who was younger, like a teenager, about HIV?

• How do you think children should be told they have HIV?

• Are you able to tell me if you are contented, happy, sad, or fearful as you think about your life living with HIV?

• Are you able to tell me if you feel lonely or alone as you think about your life living with HIV?

• Is there anything we haven’t discussed that you believe is important for nurses and other health-care providers to know about your experience living with HIV?
Appendix D Invitation Letter

An Invitation

Young adults infected perinatally with Human Immunodeficiency Virus (HIV) are invited to share their experiences by participating in a nursing research study. This study is being conducted by Elaine Williams, MSN, RN, a doctoral nursing student at the Catholic University of America.

The aim of this study is to learn more about the experiences of growing up with HIV. The knowledge gained from this research will assist nurses, health-care providers, and community support personnel to better understand young adults living with HIV.

Young adults are invited to participate if they are:

1. Diagnosed with perinatal HIV
2. Between the ages of 18–24

Participation in this study will include one (1) 60-minute interview at Children’s Hospital and possibly one (1) follow-up phone call.

To learn more about this study, please contact by e-mail or phone:

Elaine Williams, MSN, RN
PhD student
Researcher
The Catholic University of America
School of Nursing
82willie@cardinalmail.cua.edu
(202) 476-2245
Appendix E Certificates

9/24/2013

Children's National Medical Center
Mrs. Elaine Williams
12408 Ronald Buei Road
Upper Marlboro, MD 20774

Dear Mrs. Williams,

Enclosed is the Confidentiality Certificate protecting the identity of research subjects in your project entitled, 'Growing up with HIV: The lived experience of young adults growing up with HIV'. Please note that the Certificate expires on 11/29/2013.

Please be sure that the consent form given to research participants accurately states the intended uses of personally identifiable information (including matters subject to reporting) and the confidentiality protections, including the protection provided by the Certificate of Confidentiality with its limits and exceptions.

If you determine that the research project will not be completed by the expiration date, 11/29/2013, you must submit a written request for an extension of the Certificate three months prior to the expiration date. If you make any changes to the protocol for this study, you should contact me regarding modification of this Certificate. Any requests for modifications of this Certificate must include the reason for the request, documentation of the most recent IRB approval, and the expected date for completion of the research project.

Please advise me of any situation in which the Certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the Certificate, they may contact the Office of the NIH Legal Advisor, National Institutes of Health, at (301) 496-6043.

Correspondence should be sent to:

Diane Adger-Johnson
NIAID Certificate of Confidentiality Program Coordinator
National Institute of Allergy and Infectious Diseases
NIAIDCertificates@mail.nih.gov
6700-B Rockledge Drive
Room 2150
Bethesda, MD 20892-7610
Telephone: (301) 402-8969

Sincerely,

Diane Adger-Johnson
CERTIFICATE OF CONFIDENTIALITY
CC-AI-13-19
issued to
Children's National Medical Center
conducting research known as
Growing up with HIV: The lived experience of young adults growing up with HIV

In accordance with the provisions of section 301(d) of the Public Health Service Act 42 U.S.C. 241(d), this Certificate is issued in response to the request of the Principal Investigator, Mrs. Elaine Williams, to protect the privacy of research subjects by withholding their identities from all persons not connected with this research. Mrs. Williams is primarily responsible for the conduct of this research.

Under the authority vested in the Secretary of Health and Human Services by section 301(d), all persons who:
1. are enrolled in, employed by, or associated with the Children's National Medical Center and their contractors or cooperating agencies and
2. have in the course of their employment or association access to information that would identify individuals who are the subjects of the research pertaining to the project known as Growing up with HIV: The lived experience of young adults growing up with HIV

are hereby authorized to protect the privacy of the individuals who are the subjects of that research by withholding their names and other identifying characteristics from all persons not connected with the conduct of that research.

The purpose of this study will be to interpret the study participants' perceived journeys, lived experiences, learning experiences, recent events, and situations that affected growing up with HIV. Study Design: Qualitative/Phenomenological. Inclusion Criteria: (a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview and follow-up data clarification phone calls if necessary; (c) be able to read and speak English; and (d) be between the ages of 18 and 24 years of age. Duration of patient participation: 60-90 minutes. Duration of study: 3 years.

A Certificate of Confidentiality is needed because sensitive information will be collected during the course of the study. The certificate will help researchers avoid involuntary disclosure that could expose subjects or their families to adverse economic, legal, psychological and social consequences.

All subjects will be assigned a code number and identifying information and records will be kept in locked files at the Institution.

This research is currently underway and is expected to end on 11/29/2013.

As provided in section 301 (d) of the Public Health Service Act 42 U.S.C. 241(d):

'Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil, criminal, administrative, legislative, or other proceedings to identify such individuals.'

This Certificate does not protect you from being compelled to make disclosures that: (1) have been consented to in writing by the research subject or the subject's legally authorized representative; (2) are required by the Federal Food, Drug, and Cosmetic Act (21 U.S.C. 301 et seq.) or regulations issued under that Act; or (3) have been requested from a research project funded by the National Institutes of Health (NIH) or the Department of Health and Human Services (DHHS) by authorized representatives of those agencies for the purpose of audit or program review.
CERTIFICATE OF CONFIDENTIALITY
CC-AI-13-19
issued to
Children's National Medical Center
conducting research known as
Growing up with HIV: The lived experience of young adults growing up with HIV

This Certificate does not represent an endorsement of the research project by the DHHS. This Certificate is now in effect and will expire on 11/29/2013. The protection afforded by this Confidentiality Certificate is permanent with respect to subjects who participate in the research during the time the Certificate is in effect.

Date: 9/24/2013

John J. McGowan, Ph.D.
Deputy Director for Science Management and Operations
National Institute of Allergy and Infectious Diseases
12/3/2013

Children's National Medical Center
Mrs. Elaine Williams
12408 Ronald Beall Road
Upper Marlboro, MD 20774

RE: CC-AI-13-19A1

Dear Mrs. Williams,

The enclosed Confidentiality Certificate protecting the identity of research subjects in your project entitled, 'Growing up with HIV: The lived experience of young adults growing up with HIV', has been amended to extend the Certificate expiration date until 06/30/2014.

This is to note the extension of your application for an additional 6 months.

If you determine that the research project will not be completed by the expiration date, 06/30/2014, you must submit a written request for an extension of the Certificate three months prior to the expiration date. Any such requests must include the reason for the request, documentation of the most recent IRB approval, and the expected date for completion of the research project.

Please advise me of any situation in which the Certificate is employed to resist disclosure of information in legal proceedings. Should attorneys for the project wish to discuss the use of the Certificate, they may contact the Office of the NIH Legal Advisor, National Institutes of Health, at (301) 496-6043.

Correspondence should be sent to:

Diane Adger-Johnson
NIAID Certificate of Confidentiality Program Coordinator
National Institute of Allergy and Infectious Diseases
NIAIDCertificates@mail.nih.gov
6700-B Rockledge Drive
Room 2150
Bethesda, MD 20892-7610
Telephone: (301) 402-8969

Sincerely,

Diane Adger-Johnson
CERTIFICATE OF CONFIDENTIALITY
CC-AI-13-19A1E1
issued to
Children's National Medical Center
conducting research known as
Growing up with HIV: The lived experience of young adults growing up with HIV
This certificate amends the certificate numbered CC-AI-13-19A1 issued on 12/03/2013.

In accordance with the provisions of section 301(d) of the Public Health Service Act 42 U.S.C. 241(d), this Certificate is
issued in response to the request of the Principal Investigator, Mrs. Elaine Williams, to protect the privacy of research
subjects by withholding their identities from all persons not connected with this research. Mrs. Williams is primarily
responsible for the conduct of this research.

Under the authority vested in the Secretary of Health and Human Services by section 301(d), all persons who:

1. are enrolled in, employed by, or associated with the Children's National Medical Center and their contractors or
cooperating agencies and

2. have in the course of their employment or association access to information that would identify individuals who are the
subjects of the research pertaining to the project known as Growing up with HIV: The lived experience of young adults
growing up with HIV

are hereby authorized to protect the privacy of the individuals who are the subjects of that research by withholding their
names and other identifying characteristics from all persons not connected with the conduct of that research.

The purpose of this study will be to interpret the study participants' perceived journeys, lived experiences, learning
experiences, recent events, and situations that affected growing up with HIV. Study Design: Qualitative/ Phenomenological.
Inclusion Criteria: (a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview and follow-up data clarification phone calls if necessary; (c) be able to read and speak English;
and (d) be between the ages of 18 and 24 years of age. Duration of patient participation: 60-90 minutes. Duration of study: 3 years.

A Certificate of Confidentiality is needed because sensitive information will be collected during the course of the study.
The certificate will help researchers avoid involuntary disclosure that could expose subjects or their families to adverse
economic, legal, psychological, and social consequences.

All subjects will be assigned a code number and identifying information and records will be kept in locked files at the
Institution.

This research is currently underway and is expected to end on 06/30/2014.

As provided in section 301 (d) of the Public Health Service Act 42 U.S.C. 241(d):

'Persons so authorized to protect the privacy of such individuals may not be compelled in any Federal, State, or local civil,
criminal, administrative, legislative, or other proceedings to identify such individuals.'

This Certificate does not protect you from being compelled to make disclosures that: (1) have been consented to in writing
by the research subject or the subject's legally authorized representative; (2) are required by the Federal Food, Drug, and
Cosmetic Act (21 U.S.C. 301 et seq.) or regulations issued under that Act; or (3) have been requested from a research
project funded by the National Institutes of Health (NIH) or the Department of Health and Human Services (DHHS) by
authorized representatives of those agencies for the purpose of audit or program review.
CERTIFICATE OF CONFIDENTIALITY
CC-AI-13-19A1E1
issued to
Children’s National Medical Center
conducting research known as
Growing up with HIV: The lived experience of young adults growing up with HIV
This certificate amends the certificate numbered CC-AI-13-19A1 issued on 12/03/2013.

This Certificate does not represent an endorsement of the research project by the DHHS. This Certificate is now in effect and will expire on 06/30/2014. The protection afforded by this Confidentiality Certificate is permanent with respect to subjects who participate in the research during the time the Certificate is in effect.

Date: 12/3/2013

[Signature]
John J. McGowan, Ph.D.
Deputy Director for Science Management and Operations
National Institute of Allergy and Infectious Diseases
Appendix F Approval letters

INSTITUTIONAL REVIEW BOARD (FWA00004487)  
REPORT OF PROTOCOL ACTION  
NOTIFICATION OF EXPEDITED NEW STUDY APPROVAL  

August 1, 2013  

From: Children’s National Medical Center Institutional Review Board (CNMC IRB)  
To: Elaine Williams  
Re: Study#: Pro00063823  
Growing up with HIV  
Growing up with HIV: The Lived Experience of Perinatally Infected Young Adults  

Risk:  

The IRB has reviewed and approved the protocol referenced above on 7/31/2013 for a period of 12 months. The IRB determined that the study meets the criteria for expedited review under category:  

This research involves the only the collection of data from voice, video, digital, or image recordings made for research purposes.  

As appropriate, approval of the study and the consent form(s) is for the period of 7/31/2013 to 7/30/2014.  

Please note that it is the Investigator’s responsibility to ensure that the Continuing Review Report is submitted to the IRB in a timely fashion.  

The Principal Investigator is responsible for the following:  
1. Submission in writing of any and all changes to this study (e.g., protocol, recruitment materials, consent forms, assent forms, etc.) to the IRB for review and approval prior to initiation of the changes, as applicable.  
2. Submission in writing of any and all adverse event(s) that occur during the course of the study.  
3. Submission in writing of any and all unanticipated problems involving risks to subjects or others.  
4. Use of IRB approved copies of the consent forms, assent forms, surveys, questionnaires, letters, advertisements, etc., in the research, as applicable. Do not use expired consent documents.  

For additional information, forms, and templates go to IRB Home > General Information.  

https://www.irbear.org/eResearch/Doc/0/7D5KD0NH05KC7FKK2PLA0E/fromString.htm[01/2013 2:11:17 PM]
September 3, 2013

Ms. Elaine F. Williams
12408 Ronald Beall Road
Upper Marlboro MD 20774

Subject: Project title “Growing up with HIV: The Lived Experience of Perinatally Infected Young Adults”
Protocol No. 13-040

Dear Ms. Williams:

Your research for the subject project was certified by the Committee for the Protection of Human Subjects (CPHS) as meeting the requirements of the Federal regulations governing protection of human subjects.

The reviewer finds that the protocol does not involve undue risk for the subjects. The protocol is currently approved by the IRB at the research site (Children’s National Medical Center Pro00003823). This protocol is approved by the CUA IRB, contingent upon continued approval by CNMC. Should CNMC approval lapse or expire, CUA approval is revoked. CUA approval expires 8/29/14. If the project continues beyond this period, please resubmit your materials for renewal in a timely fashion so that your research may continue uninterrupted.

CPHS will maintain a copy of your submission on file. You are obligated to follow the research protocol and procedures for obtaining informed consent as you have specified. If you wish to initiate any changes in the research protocol or the informed consent procedure, you should submit this request to CPHS in writing.

Sincerely,

[Signature]

Ralph Albano
Secretary
Committee for the Protection of Human Subjects

cc: [ ] File

13-040 ARP-08-29-13
Mrs. Flaire F. Williams, MSN, RN
Pediatrics for Experimental Therapeutics
Children’s National Medical Center
111 Michigan Ave., N.W.
Washington, D.C. 20010

July 1, 2013

RE: Protocol “Growing Up with HIV: The Lived Experience of Perinatally Infected Young Adults”

Dear Mrs. Williams,

The Nursing Research Advisory Committee (NRAC) has carefully reviewed your above protocol. I thank you for your very thoughtfully completed revisions. Your selected methodology is most fitting for your research questions. Your protocol is now fully approved for submission to the IRB at Children’s National. Please know that we shall contact you officially in approximately three months to make certain that you are not experiencing any difficulties or delays in initiating your study. We shall also invite you to attend the standing Research Huddle, a monthly meeting for principal investigators of research reviewed by NRAC. The purpose of this meeting is to assist with resource needs related to the research and resolution of any difficulties that you may be encountering. I wish you much pleasure and success with this study and I congratulate you on your good work.

Sincerely,

[Signature]

Pamela S. Hindu, PhD, RN, FAAAN
Director, Department of Nursing Research and Quality Outcomes
Associate Director, Center for Translational Research

[Address]
RESEARCH PROTOCOL

PROTOCOL TITLE: Growing up with HIV: The Lived Experience of Perinatally Infected Young Adults.

PI: Elaine Fay Williams, MSN, RN

PhD advisors: Janice Agazio, RN, PhD; Janet Merritt, Ph.D., R.N., CNS-BC; Natella Y. Rakhmanina, MD, PhD; Pamela S. Hinds, PhD, RN

Co-I’s: Kathleen Ferrer, MD; Keetra Williams, BSN, RN; Marlene A. Lee, MSN, RN; Lawrence D’Angelo, M.D., M.P.H.

Version 1.0

Date: April, 13 2013
Principal Investigator:

Elaine Fay Williams, MSN, RN
Pediatrics for Experimental Therapeutics
Children's National Medical Center
Research Nurse Coordinator
111 Michigan Avenue, N.W.
Washington, D.C. 20010
(202) 476-2245
efwillia@childrensnational.org
INVESTIGATOR'S STATEMENT

I agree to conduct the trial as outlined in the protocol and in accordance with all applicable regulations and GCP guidelines.

__________________________________________________________
Investigator's Signature                                        Date

________________________________________________________________________
Typed Name of Investigator

________________________________________________________________________
Institution Name and Address

________________________________________________________________________
Telephone Number
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Study Synopsis

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<td><strong>Background and Rationale</strong></td>
<td>The Centers for Disease Control (CDC) (2010) reported that 69% of all new perinatal Human Immunodeficiency Virus-1 (HIV) infections in the United States of America (USA) were among African Americans. In the District of Columbia in Washington, D.C. (DC), pediatric acquired immune deficiency syndrome (AIDS), the final stage of HIV disease that causes severe damage to the immune system ranks 11th in the (USA) (CDC, 2012). This is relevant because the percentage (69%) of new perinatal HIV infections in the USA has been among African Americans and that has been consistently higher than that of any other race or ethnicity (Whitmore et al., 2012). Since the beginning of the epidemic in 1980’s, the District of Columbia’s HIV and AIDS surveillance system reported 349 pediatric HIV and AIDS cases. In the early 1980s the majority of perinatally acquired HIV children did not survive beyond childhood and today with antiretroviral therapy (ART) the perinatally HIV acquired children have prolonged survival and many have reached adulthood. In a recent report approximately 190 reported cases of perinatal HIV/AIDS currently live in Washington, D.C. 68.0% (n=129) of the pediatric HIV/AIDS cases were over the age of 13 at the end of 2008 (Census, 2010). Today, most perinatally infected children in Washington,</td>
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D.C. area who are greater than 11 years of age are aware of their HIV status (American Academy of Pediatrics, 1999). A quantitative study suggests that globally greater than one million children infected with perinatally acquired HIV who have access to ARVs live into mature adulthood but cope with HIV-related stigma, discrimination, isolation, racism, unemployment, inadequate education, limited social support, and the need for taking medications for the rest of their lives (Brown, Lourie & Pao, 2000).

**Purpose**

The purpose of this phenomenological study will be to interpret the study participants’ perceived journeys, lived experiences, learning experiences, recent events, and situations that affected growing up with HIV after the disclosure process.

**Study Design**

Phenomenologic inquiry (Van Manen, 1990) as a means of exploring and gathering information for the narrative, and it can be used as a process to develop a conversational relationship with the participant about the meaning of the experience.

**Inclusion Criteria**

(a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview in the clinic setting and follow-up data clarification phone calls if necessary; (c) be able to read and speak English; and (d) be between the ages of 18 and 24 years of age.

**Number of participants**

20

**Duration of patient participation**

60-90 minutes

**Duration of study**

3 years

**Statistical Analysis**

Descriptive statistics will be used to summarize the demographic data in: 18--24 year old young adults living with perinatal HIV. Since this is a small sample, the data will be clustered and reported as themes. The analysis of the interview will lead to the identification of themes (content analysis) that describe living with HIV from the young adults’ perspectives.
RESEARCH PLAN

A. Purpose

1) To describe the study participants’ perceived journeys, lived experiences, learning experiences, recent events, and situations that affected growing up with perinatal HIV since the disclosure process.

(2) To find out the meanings the perinatally infected young adults living with HIV ascribe to their experiences.

Research Questions. What are the experiences of perinatally HIV-infected young adults growing up with HIV? and 2) What meanings do perinatally HIV-infected young adults ascribe to their experiences?

B. Background and Significance

In developed countries such as the USA, children infected with perinatal human immunodeficiency virus (HIV) (the transfer of HIV from mother to child) have normal life expectancy despite their complex health care needs (Chiappini et al., 2009; Fernet et al., 2011; Fielden et al., 2006). The Centers for Disease Control (CDC, 2010a) reported that 69% of all new perinatal HIV infections in the USA were among African Americans and it is estimated that this percent (69%) level is not found in any other race or ethnicity (Whitmore et al., 2012). In the District of Columbia in Washington, D.C., pediatric acquired immune deficiency syndrome (AIDS), the final stage of HIV disease, ranks 11th in the USA (CDC, 2012 a & b). In the early 1980s the majority of perinatally acquired HIV children did not survive beyond childhood and today with antiretroviral therapy (ART) the perinatally HIV acquired children have prolonged survival and many have reached adulthood. In a recent report 190 reported cases of perinatal HIV/AIDS currently live in Washington, D.C. and 68.0% (n=129) of the pediatric HIV/AIDS cases were over the age of 13 at the end of 2008 (Census, 2010).

Thirty years ago, perinatally HIV-infected young adults were children who most likely spent less time in school, and as a result today are frequently unemployed or underemployed as adults (Souza, Santos, Valentini, Silva, & Falbo, 2010). Unemployment or job instability is prevalent among individuals living with HIV, a majority of the HIV-infected population in the USA is unemployed (CDC, 2010b). Today many individuals living with HIV continue to face challenging financial, and health decisions that impact their lives and the lives of their partners and children (Cho & Chan, 2013). A recent publication suggested the health care infrastructure is inadequate to provide care and treatment of older adults living with HIV (Cahill & Valdez, 2013).

In 1998, the US public health services proposed the use of highly active antiretroviral treatment (HAART) to mitigate perinatal HIV infection (the transfer of HIV from mother to child), resulting in less HIV positive births; however, children continue to be born with HIV. Each year
the Centers for Disease Control and Prevention (CDC), reported approximately 100 perinatal HIV positive babies born in the USA.

**Perinatal HIV in the USA**

Since the outbreak of HIV in the 1980s in the USA, there has been 17,000 cases of perinatal HIV, which represents 91% of all pediatric cases. In the early stages of the HIV epidemic, the illness rapidly progressed to death of the individuals. In 2005, the estimated number of perinatally infected persons living with HIV was 6,051 for the 33 jurisdictions with HIV reporting in the USA (CDC, 2006) Since then and subsequent to the introduction of HAART it is estimated that there are currently 9,129 individuals with perinatally acquired HIV living among the population of the USA in the jurisdictions reporting the HIV infection (CDC, 2011a). Perinatal HIV is usually associated with babies and the exposure to the HAART regime starts much younger than in the horizontally or high risk HIV infected young adult (Bush-Parker 2000).

**Significance**

The significance of this study for nurses is that perinatally HIV-infected young adults are now living with the infection as a chronic illness. Young adults who were infected at birth through no fault of their own may become detached from the seriousness of HIV health consequences (Ferrer et al., 2012), and nurses must be able to provide the needed medical and psychological guidance to encourage medication adherence and faithfulness to the medical regimes which are inherent in the challenge of living with HIV.

Creating an overview of the young adult growing up with HIV requires combining different views of the disease, such as memories and experiences, just as from the perspective of a child or adolescent with cancer (Peterson & Bredow, 2004; Spinetta & Maloney, 1975, 1978). Therefore, this research will show what it is like growing up with HIV, learning about the diagnosis, and becoming an adult with perinatally acquired HIV. In addition, this study will be important in providing insight into the health concerns of perinatally infected young adults growing up with HIV.

The primary focus is on the young adult’s experience growing up with HIV as part of a family or social group. Van Manen’s framework helps describe how the young adult endures the intense accumulation of demands often associated with chronic illness. In the future, nurses caring for young adults with perinatal HIV will have additional practical information from the self-reported qualitative information obtained from narratives (Burns & Grove, 1997). Moreover, this research will support the ongoing proposals to assist children born with HIV. The reflection and knowledge gained from this study may generate new hypotheses and implications for future studies related to perinatally infected HIV young adults living in the United States and the world.

**Growing up with HIV**

During the early 1980s when the first perinatally acquired AIDS cases were documented, the infection usually progressed rapidly to death. In the USA and through public health strategies that emphasized prenatal HIV screening and use of ART, the number of perinatal HIV cases have decreased dramatically from 1,650 in 1991 to fewer than 100 in 2009. The perinatally acquired
HIV Young adults who have access to ARVs live into mature adulthood, but they continue to cope with HIV-related stigma, discrimination, isolation, racism, unemployment, inadequate education, limited social support, and the need for taking medications for the rest of their lives (Brown, Lourie & Pao, 2000).

There is an extensive review in the literature of quantitative studies on growing up with HIV and much less on young adults growing up with perinatal HIV. In addition, there is a dearth of qualitative literature on young adults growing up with perinatal HIV. The findings across all studies suggest health care providers of perinatally infected young adults encounter health issues and there is little or no evidence to guide them. For example, one study found that adolescents perinatally infected with HIV are often cared for in pediatric infectious disease clinics where reproductive health issues may not be routinely addressed. Another study found that 70% of the perinatal HIV infected young adults expressed the desire to have children (Ezeanolue, Wodi, Patel, Diedonne & Oleske, 2006) and most of the perinatally young adults demonstrated limited knowledge of safe sex practices (Wiener, Battles & Wood, 2007).

The literature on parental absence in the care of young children with HIV is relatively new. The guided interview in this study will include questions related to the following topics: (1) family life and HIV social support; (2) health concern; (3) peer relationships; (4) economic and education status; and (5) HIV disclosure in young adult. Some of the social interaction and family life issues evolve from trying to cope with HIV infection, low income, poverty, or urban environments.

C. Preliminary Studies
Janice Agazio PhD, CRNP, RN, LTC (Retired, U.S. Army) is an Associate Professor/Director of PhD and DNP Programs at The Catholic University of America. She teaches qualitative research methods in the masters in nursing programs and is the chairperson of this dissertation. She has numerous publications and most recently published a qualitative article (grounded theory) titled “Mothers going to war: The role of nurse practitioners in the care of military mothers and families during deployment”

Janet Merritt, PhD, APRN-BC, RN is an Associate Professor and Director of Psych/Mental Health Masters in Nursing Program at the Catholic University of America. Graduate teaching responsibilities include Advanced Psychiatric nursing courses including Bio-behavioral Psychiatry, Mental Health of the Individual, and Psychopharmacology. She is a member of the dissertation committee.

Natella Y. Rakhmanina, MD, FAAP, AAHIVS, focuses her overall research interests on clinical application of therapeutic drug monitoring in the field of pediatric and maternal HIV. She is an associate professor of Pediatrics, clinic director, and attending physician for Special Immunology Services. She provides care to the HIV-infected children and adolescents in the Children’s National Medical Center-based clinic serving metropolitan Washington, DC. Her HIV research centers on pharmacogenetics and pharmacokinetics of HIV treatment in children and adolescents, with the goal to optimize and individualize treatment of HIV-infected pediatric patients. Her funded research for
industry and National Institute of Health centers on the care of children and young adults growing up with HIV. She is the Children's National Medical Center HIV content expert and a committee member on this dissertation. She most recently published an article titled “Pharmacotherapy of pediatric HIV infection”.

Pamela S. Hinds, PhD, RN, FAAN is the Director, Department of Nursing Research Children's National Medical Center and the Editor-in-Chief of cancer Nursing, An International Journal for Cancer care. She is an accomplished author of several books and numerous articles and has been a funded researcher for many years. She is known locally, nationally and internationally for her work. She is the Children's National Medical Center mentor on this dissertation and her most recently published qualitative article is titled “From qualitative work to intervention development in pediatric oncology palliative care research”

Experience and competence of the principal investigator Elaine Fay Williams
The Principal Investigator, Elaine Fay Williams, MSN, RN is an experienced nurse with over 30 years of pediatric nursing experience with 13 years of that experience in research specializing in the care of children and young adults living with HIV, including questionnaire administration to participants enrolled in HIV research studies. She has completed the required courses for her doctoral studies at the Catholic University of America including phenomenology, the qualitative method used in this study.

Relevant qualitative poster presentation
2009- Elaine Williams, RN, MSN, Juanda Pryor RN, MSN; Karen Coish, RN, BSN, CPON; Katherine Patterson Kelly, RN, PhD, CPN; Marlene Lee, RN, MSN; Renee Roberts Turner, RN, MSN; Andrea Ewing-Thomas, RN, BSN; Catherine Williams, RN MSN; Pamela S. Hinds, RN, PhD, FAAN Nursing Research Priorities for 2009 – 2011. Identified by Nurses and Non-Nurses at Children’s National Medical Center.

Relevant Publication on HIV

As a research nurse coordinator and PI, Elaine Fay Williams, MSN, RN is responsible for obtaining consents and conducting interviews on numerous studies

Participants and sample formation.

Following approvals by the Institutional Review Boards (IRBs) of Catholic University of America and Children’s National in Washington, DC, a purposive sample of adolescents and young adults with perinatal HIV will be recruited from the Special Immunology Services (SIS). Once a week, the SIS team members will identify and contact potential participants who meet the study criteria and introduce them to the study. The nurse researcher will contact the participants who are agreeable and schedule a convenient time to enroll them in the study.
The SIS clinic provides specialty medical services to children and adolescents perinatally infected with HIV up to 24 years of age. The SIS Clinic is staffed with attending physicians, residents and nurses. The clinic hours are Monday through Wednesday and patients are scheduled quarterly or as needed for physical examinations and laboratory assessments. In the main clinic, there are approximately 175 perinatally infected children and adolescents, of whom 90% are African American/non-Hispanic; 5% White/Hispanic; and 5% other or mixed ethnicity. Approximately, 20 young adults will meet the criteria for the study. As of May 2013, there are no qualitative studies being conducted in the SIS clinic.

A purposive sample is commonly used in phenomenological inquiry. The power of purposive sampling provides theoretical saturation when the participants no longer generate new information (Higginbottom, 2004). Purposive sampling seeks detailed information from the well-informed participants (Patton, 1990). This method will enroll a sample of individuals with the experiential knowledge of a phenomenon for the purposes of telling their lived experience (Speziale & Carpenter, 2007).

Participants will meet the following inclusion criteria: (a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview in the clinic setting at Children’s National and follow-up data clarification phone calls if necessary; (c) be able to read and speak English; and (d) be between the ages of 18 and 24. An invitation (see Appendix A) to participate in the study will be disseminated at the Special Immunology clinics throughout the Children’s National main campus by the director of the Special Immunology Services.

**Literature Review**

Perinatally infected children are now living longer into adulthood, but poor adherence to the medical regime creates major health complications which impacts significantly the virologic status.

Adherence to AVRs is poorer during adolescence in HIV-infected individuals compared to younger children and adults (Ding, et al, 2009). Adolescence is known to be a time of increased risk taking behaviors. When growing up with HIV the individual had additional burden of stigma, secrecy and the risk of infecting partners and offspring. This literature review of research of persons with perinatal exposure to HIV is to summarize, describe and explain the findings on adherence to treatment, social support, health, peer relationships, education and employment in the young adults living with HIV.

Most children enjoy healthy childhoods with little need for specialized health care services. However perinatally HIV infected children experience difficulties from early in life that require lifelong health care resources. Gaps in the science identified are described below and addressed by the proposed research. A quantitative literature review on 140 studies summarized as young adults living with perinatally acquired HIV live into mature adulthood, they continue to cope with HIV-related stigma, discrimination, isolation, racism, unemployment, inadequate education, limited social support, and the need for taking medications for the rest of their lives (Brown, Lourie & Pao, 2000).
Adherence

In a quantitative study on adherence to HAART Steele & Grauer (2003) reported that administering HAART from very early in the infant’s life is a health and medical challenge for the child, family and medical team. Young children n=13 were reported to have particular difficulty taking medication because of taste, or the ability to swallow tablets (Best et al., 2011). Adolescents were reported to refuse to take medication as a manifestation of otherwise normal rebellious behavior (Martinez et al., 2000; Reddington et al., 2000). Currently, there are approximately 31 antiretroviral (ARVs) approved by the Food and Drug Administration to treat HIV infection and prolong life expectancy (NIH, 2013). Recent case management research reports an improvement in medication adherence by combining the efforts of a pharmacist, nurse coordinator, and primary care provider (Horberg et al., 2012). Longer life expectancy is already evident as HIV has shifted to a chronic condition where long term effects of HIV and highly active antiretroviral treatment (HAART) are emerging resulting in comorbidities (Hazra, Siberry & Mofenson, 2010)

Several authors reported HAART adherence and its effects in individuals related to antiretroviral therapy (Besch, 1995; Chesney 2000; Chesney, Ickovics, Hecht, Sikipa, Rabkin, 1999; Chiappini, Galli, Gabiano et al., 2006; Holzemer, et, al., 1999; Lerner 1977; Williams and Friedland, 1997). Brown, Lourie & Pao (2000) conducted a literature review on 140 quantitative studies describing horizontal and perinatal HIV infection and its psychological, social implications and mental health significance on children and adolescents living with HIV. They reported that as children continue to live longer with HIV, 100% of them experience non-HIV factors such as poverty, insufficient medical services, and limited social support, which add to the HIV burden. In summary, the state of the science suggests a longer life expectancy for the perinatally infected young adult is already evident as HIV has shifted to a chronic condition where long term effects of HIV and HAART.

Social support

The literature review on the young adult’s inner circle characterizes the individuals’ usual support in three categories; (1) emotional; (2) instrumental, and (3) informational (Norbeck, Lindsey & Carrieri, 1983). The first category, emotional support provides self esteem and stronger relationships (Norbeck, Lindsey & Carrieri). Frank, Blount & Brown (1997) suggested that coping, attribution style and social ability predict the capacity to adjust to emotional problems. The second, instrumental support includes economic or housing assistance (Gielen, McDonnell, Wu, O'Campo & Faden, 2001). The third, informational support provide advice and information on social, health, or employment issues (Turner, Hays and Coates, 1993)

In a qualitative report, Woodring, Cancelli, Ponterotto & Keitel (2005) described adolescents’ experiences with perinatal HIV in terms of themes such as parental loss, transition in care, HIV disclosure, coping in school, and support networks. The HIV adversity described above when linked to poverty may intensify the HIV condition. Health care professionals, especially nurses must consider the challenges and special needs faced by perinatally infected young adults when
providing care (Lee, Detels, Rotheram-Borus, Duan & Lord, 2007; Rotheram-Borus, Murphy, Kennedy, Stanton & Kuklinski, 2001; Steele, 2001). Social support is an important HIV issue because of how the stigma associated with the illness affects the individual.

Bal, Crombez, Van Oost & Debourdeaudhuij (2003) described the importance of social support in a group of adolescents experiencing stressful issues associated with perinatal and horizontal HIV that affected the needs for social intervention. Eight hundred and twenty adolescents between 12 and 18 years of age filled out questionnaires assessing social support including a Social Support Questionnaire (Sarason, Shearin, Pierce & Sarason, 1987). A total of 42% of the adolescents reported stressful experiences. This finding suggests that almost half of the participants needed social support, especially the subjects who experienced abusive or stressful events. The state of the science suggests that many perinatally HIV-infected young adults have suffered from stressful events, bereavement from losing their mothers, leaving them to care for other family members.

A major focus today concerns using HAART over a period of time from birth (Hazra, Siberry & Mofenson, 2010). Concerns exist about the effect on several major body systems such as: the central nervous system (e.g. Shanbhag et al., 2005); endocrine and cardiovascular systems (e.g. Fisher, Miller, & Lipshultz, 2006; Vigano, Pattarino, Cerini & Zuccotti, 2009); the skeletal system (e.g. Basu, Kumar and Bhatia, 2011; McComsey et al., 2011; Mora et al., 2001); the urinary system (e.g. McCulloch & Ray 2008). In summary, about 25% of patients stop HAART therapy within the first year on HAART because of side effects (d'Arminio Monforte, Lepri & Rezza, 2000). The side effects of HAART can create physical and psychological burden that patient skip doses or stop taking their medications which increases the resistance to the medications.

Education
The perinatally infected youth when absent from school frequently rely only on home schooling. The social opportunities and the effects of their developmental stage and peer norms remain unknown (Henry, Schoeny, Deptula, & Slavick, 2007; O'Donnell, Myint-U, O'Donnell, Stueve, 2003). With Perinatal HIV as a chronic illness, absence from school affects education and career development. Also, there is no evidence of coordination of health care services or health care information sharing in the schools. Schools and preschool centers are not made aware of the child's HIV infection status (Melvin & Sherr 1993).

Glenn, Ford, Moore, & Hollar (2003) suggested exposure, education and employment are fundamental ways to fit in and form strong work relationship. The authors stated success in education and employment lead to meaningful associations instead of loneliness and isolation in contrast to the uneducated or unemployed person (Glenn, Ford, Moore, & Hollar 2003).

Glenn & Wilson (2008) reported that the barriers to effective HIV prevention may be overcome by educational programs appropriate to the needs of vulnerable adolescents. A group of eight adolescents (n=8) at an African American church participated in a focus group to discuss vulnerability and resilience to HIV. The adolescents developed collages from pictures in African American magazines to help express their thoughts about HIV. Themes using content analysis revealed confidence, safe social activities, innocence, image, music, drug culture, and peer
pressure. This qualitative study explored African American adolescent perceptions of vulnerability as well as resilience to HIV/AIDS within competency paradigm where culture influence disclosure patterns. Therefore- state of science suggests that barriers to effective HIV prevention may be overcome by educational programs and this study will add to the literature of young adults growing up with HIV.

**Disclosure**

Caregivers who disclose early to children tend to be HIV negative, have higher socioeconomic status and reported greater satisfaction with their social support system (Wiener, Battles, Heilman, et al., 1996). In addition, disclosure of HIV to a child is a significant anxiety producing event for the family and requires a tremendous amount of social support from others involved (Wiener, Mellins, Marhefka and Battles (2007).

Therefore the state of science suggests that HIV disclosure can help the child who is not cognitively impaired understand the illness and adhere to medical care. The American Academy of Pediatrics (1999) encourages the disclosure of HIV infection status to school-aged children. This study will add to the literature emphasizing early disclosure to children who are not cognitively impaired.

**Summary**

Little is reported about what it is like to grow up being perinatally HIV infected. This study will add to the body of literature that can inform health care infrastructure of the needs of young adults with HIV. Thirty three years ago, it was inconceivable that perinatally HIV infected newborns would grow up to become young adults and HIV would be seen as a chronic illness (Foster & Fidler, 2009). Despite the increased availability of HAART that are effective against HIV, the HIV epidemic continues to grow as approximately 100 HIV mothers continue to deliver HIV positive babies in the USA. Perinatal HIV remains a concern particularly with the African American young adults. The goal of this perinatal literature review is to summarize, describe and explain the findings on social support, health, peer relationships, education and employment in the young adults living with HIV as the empirical research on social support among HIV infected young adults is scant (Lee et al., 2007).

**D. Research Design and Methods**

This is a single site (free-standing pediatric medical center in the mid-Atlantic region) phenomenological study (Van Manen, 1990). The findings will be thematically reported. The participant will be asked to complete a brief demographic form after which they will participate in an audio taped interview that will take approximately 60-90 minutes.

**Demographic Questionnaire completed by the researcher**

Date ____/____/___ Participant Code ____________

(1) Your current age: ____________
Two tape recorders will be used in the event one of the recorders fails to work. The researcher’s aim is to answer the following core questions: 1) what are the experiences of perinatally HIV infected young adults? and 2) what meanings do the perinatally infected HIV young adults ascribe to their experiences?
There may be follow-up questions to help the researcher inquire about the phenomenon. The purpose of the study is to describe the study participants’ perceived journeys, lived experiences, learning experiences, recent events, and situations that affected growing up with perinatal HIV since the disclosure process; and to find out the meanings the perinatally infected young adults living with HIV ascribe to their experiences.

Inclusion criteria: (a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview in the clinic setting at Children’s National, and follow-up data clarification phone calls if necessary; (c) able to read and speak English; and (d) between the ages of 18-24 years. Exclusion criteria: Ages range less than 18 and older than 24 years of age and not diagnosed with perinatally acquired HIV.

Methodology

Qualitative analysis

- This research method will be thematically described using four fundamental themes as guides (Van Manen, 1990). (1)”lived space” (spatiality): Lived space is felt space; (2)”lived time” (temporality); (3)”lived body” (corporeality), and (4)”lived human relations” (relationality or communality). Lived time is when we are happy and enjoying life, lived body is knowledge of our body and our relationships. While these four themes can be identified, they cannot be separated in the lived world of experiences as; they are all related to the human experience (Van Manen, 1990).

Phenomenology:

- Phenomenology is a deeper understanding of the meaning of the everyday life, and the purpose of this phenomenological study is to interpret the study participants’ journeys, lived experiences, learning experiences, recent events, people, and situations that impacted the young adult growing up with perinatally transmitted HIV positive status. Therefore, investigating the phenomenon of living with HIV in each of these areas will be explored in this research. In the human participants, this translates into gathering information and perceptions through qualitative methods such as interviews, discussions, observation and representing the data from the perspective of the research participants.

- Investigating the lived experience, involves “searching everywhere in the lifeworld for lived experience material that, upon reflective examination, might yield something of its fundamental nature” (Van Manen, 1990, p. 53).

For the current study, the primary form of data collection will use the hermeneutic interview in which the researcher serves as both participant and instrument. The researcher’s role in the hermeneutic interview is to keep relevant the question of the meaning of the phenomenon and guide the interview. In phenomenology, the interview serves as a means for exploring and gathering the narrative and it can be used as a process to develop a ”conversational relation with the participant about the meaning of the experience” (Van Manen, 1990, p.66. This style of hermeneutic interviewing will be for the purpose of
information gathering. The interview will have a collaborative conversational structure that leads to phenomenological meanings.

The semi-structured lifeworld interview attempts to understand the themes of every day lived experiences from the participants’ own perspectives. Kvale and Brinkmann (2009), proposed that the aim of the interview is to seek a description of the lived experience, including specific situations and events, with the interviewer exhibiting openness to new and unexpected phenomena.

For the current study, a hermeneutic semi-structured interview guide (will provide the open-ended questions that will facilitate the interview process.

**Interview Guide Reviewed by Clinical Experts in HIV**

Participant Code___________________ Interview #___________Date____/____/____

Van Manen lifeworld themes (lived space, lived time, lived body, and lived human relations) will be developed from this interview.

**Lead question**

**Please tell me what it is like growing up and living with HIV**

**Probes**

- Please put in your own words how others in your family have been a part of your experiences of growing up and living with HIV.

- How have the circumstances of learning you have HIV been a part of your experiences of growing up with HIV?

- Please describe how you discuss HIV with others.

Several physicians and nurses who work closely with this patient group reviewed the interview questions for relevance and face validity (Anastasi, 1988). The clinicians were asked to review the questions and attempted to answer the questions as they related to a young adult 18-24 years of age growing up with HIV. Questions than were not relevant to this population or the research questions were removed. The study has one lead question and 4 probes that remain. In phenomenology, as a research method the participants’ responses will guide the research project (Van Manen, 1990). The young adult’s description on the phenomena of growing up with HIV will describe the personal knowledge, perception and interpretation. Phenomenological research seeks to describe rather than explain, starting from a perception free of hypotheses and presumption (Husserl 1970). To produce lived-experience descriptions Van Manen, (1990, p. 64-65) suggests the following: “(1) describe the experience the subjects lived in; (2) engage in the phenomenological reflection which involves conducting thematic analysis (3) describe personal experiences and emotions; (4) exploring the phenomenon and generating data; (5) focus on a precise and truthful account of the phenomena; and (6) avoid fancy phrases to explain the phenomenon”
Timetable:

The anticipated time table for the completion of this study will be approximately three

Study & duties

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<th>Elaine Williams, MSN, RN PI</th>
<th>Janice Agazio, PhD, RN</th>
<th>Natella Rakhmanina, MD, PhD</th>
<th>Janet Merritt RN, PhD</th>
<th>Kathleen Ferrer MD, PhD</th>
<th>Pamela Hinds, PhD, RN</th>
<th>Keetra Williams, BSN, RN</th>
<th>Marlene Lee, MSN, RN</th>
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Instrumentation

In phenomenological research, the interview and the researcher serves as the primary instruments; and the second instrument will be the Demographic Questionnaire which will be completed by the researcher to collect demographic data about the study participants. The interview guide will provide structure for the interview.

The demographic Questionnaire collects information on the participant’s gender, age, race, employment status, (type of job), marital status, siblings, education level, number of children and activities in the home, description of health, adherence, risk exposure, and access to health care.

Interviewing in qualitative research, the principal investigator Elaine Williams, RN, MSN will conduct the semi-structured interview in order to ensure a similar interview style throughout the research. The researcher has a list of questions, for example, how long have you known you have HIV? The specific topics will be listed on the interview guide, and the researched will allow the interviewee a personal flexibility in the response. Every attempt will be made to ask the questions and prompts exactly as outlined on the schedule. Questions that are not included in the guide may be asked based on how the interviewees’ responded. The introducing questions, follow up questions, probing questions will be asked throughout the interview. Specific questions and direct questions, such as are you happy, will be asked towards the end of the interview, in order to not influence the direction of the interview. Kvale (1996) suggested being clear, knowledgeable, sensitive, and allowing for silence are essential criteria of a successful interviewer.

Data Analysis Procedures

The phenomenological analysis will include a review of semi-structured interviews, questionnaires data, and several types of field notes. All interviews will be transcribed verbatim, and these transcriptions of the audio recordings, observations, and all written documents collected from the participants will be the text used for the data analysis. Rigor and credibility will be the criteria used to ensure quality in this research. The phenomenological approach suggested by Van Manen (1990) will be used as the study design to reveal the experiences of young adults growing up with HIV. The data derived from the demographic questionnaire will be analyzed using SPSS21 software to obtain descriptive information about the participants. The descriptive statistics will be used to summarize the study sample, using measures of central tendency and a table giving the overall sample size, demographic such as the average age, marital status, education household, relationships, medication use, employment, income, education, and the proportion of participants of each sex.

A qualitative software program will be used to organize the narrative transcript data and to record thematic associated notes. The two sources of data collection strengthen the study and give a different perspective.

The interview will be transcribed by a company to be identified by the researcher. The field notes will be collected in the form of field experience logs or diaries, and notes on theme of the study. The analysis will consist of looking for patterns that might emerge creating relationships (Lincoln & Guba, 1985). The study team will evaluate the first two audio-taped interviews to provide guidance for the research questions. Approximately 20 participants will be invited to participate in this research and the
participant’s responses will be listened to carefully for data redundancy. At approximately 20 participants or data redundancy, the study will stop enrolling participants.

The researcher will condense raw data into codes and establish a link between the research questions and the findings. A thematic analysis of the data will be created to describe the lived experiences of growing up with HIV. The data will be summarized from the participant’s responses from the interview questions.

The lead question will be please tell me what it is like growing up with and living with HIV.

Probes

- Please put in your own words how others in your family have been a part of your experiences of growing up and living with HIV.
- How have the circumstances of learning you have HIV been a part of your experiences of growing up with HIV?
- Please describe how you discuss HIV with others.

The following steps will be followed in establishing credibility

The techniques for establishing credibility are as follows: (1) prolonged engagement or spending sufficient time in the field to learn or understand the culture, social setting, or phenomenon of interest; (2) persistent observation which provides scope, persistent observation provides depth" (p. 304); (3) peer debriefing, exploring aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind (p,308); (4) negative case analysis, which involves searching for and discussing elements of the data that do not support or appear to contradict patterns or explanations that are emerging from data analysis; (5) referential adequacy, which involves identifying a portion of data to be archived, but not analyzed; and (6) member-checking which is technique for establishing the validity of an account. An unstructured interview is the mode of choice when the interviewer does not know the answers to the questions and must therefore rely on the respondent to determine the trustworthiness of qualitative inquiry (Lincoln & Guba, 1985).

In establishing credibility, the development of rapport and trust facilitates understanding. The investigator will establish credibility through peer debriefing of the categories, interpretations, and conclusions and member checking with participants from whom the data were originally collected. Through this process of debriefing, the researcher could become aware of the participants’ attitudes toward the data and the analysis. In qualitative research, rigor is needed to show the credibility of the research (Lincoln & Guba, 1985). Credibility allows for the vividness and faithfulness of the interpretation of the phenomena (Koch & Harrington, 1998).

The use of member checking is useful in establishing the validity of qualitative research. Member checking relies on the assumption that there is a fixed truth of reality that can be accounted for by a researcher and confirmed by a respondent. The members and researchers in a scholarly project may recall the interview differently. These perceptions could result in different findings reported in the data. It is also possible that the information obtained in the interview could make the members feel
embarrassed. Also, the members may have poor memory. They may forget the important details of the interview, or have different views of the same data (Sandelowski, 1993).

Transferability allows for describing a phenomenon in vivid detail and is the responsibility of the investigators, who must engage in continuous data analysis so that all pertinent information is reported from the research. Transferability is the degree to which the results of qualitative data can be generalized or transferred to other settings. The investigator has the responsibility to provide a database that makes transferability judgments possible for new researchers and to describe the research assumptions and findings that were central to the research (Lincoln & Guba, 1985). Thus, transferability of the research findings to other settings is also very important in qualitative research (Hammersley, 1992).

Audit inquiry is a technique used to establish dependability. External audits promote the accuracy or validity of a research study. They also provide an opportunity for an independent person to challenge the process and findings and to adequately assess preliminary results and final data leading to more strongly articulated findings. The drawbacks to external audits share many of the same problems as member checking. An external auditor may disagree with researchers’ interpretations, and then the question of whose interpretation should stand becomes an issue (Lincoln and Guba, 1985).

Quantitative research gives several examples of reliability: (1) the degree to which a measurement, given repeatedly, remains the same; (2) the stability of a measurement over time; and (3) the similarity of measurements within a given time period. Qualitative research describes dependability and examines both the process and the product of the research for consistency, which enhances dependability. Since there can be no credibility without dependability, a demonstration of the former is sufficient to establish the latter (Lincoln and Guba, 1985).

Confirmability is” the degree to which the researcher can demonstrate an unbiased interpretation of the results through a confirmability audit (Lincoln and Guba, 1985, p321)” An audit trail may consist of any of the following: 1) raw data, (2) analysis notes, (3) reconstruction and synthesis products, (4) process notes, (5) personal notes, and (6) preliminary developmental information (Lincoln and Guba, 1985). In the current study, notes will be listed as field notes and all of the above will be carefully examined with the dissertation committee to allow for a vigorous report on the findings of the study.

Limitations

The investigator will adhere to strategies for protection of research participants while preserving the integrity of qualitative investigation. The research team will be somewhat dependent on the permission from clinicians to approach potentially eligible individuals about the study. This dependence could risk influencing study findings (Holloway & Wheeler, 1995).

**E. Study Population (Gender and Minority Inclusions):**

The population for this study will include 20 participants both male and female young adult patients from all ethnic backgrounds.
Inclusion criteria: (a) have a documented diagnosis of perinatal HIV; (b) express a willingness to participate in an interview in the clinic setting at Children’s National, and follow-up data clarification phone calls if necessary; (c) able to read and speak English; and (d) between the ages of 18-24 years.

Exclusion criteria:

The age range less than 18 and older than 24 years of age and not diagnosed with perinatally acquired HIV.

Setting and Participants

The current study will be conducted in a private clinic setting in the Research Center at Children’s National Medical Center. (CRC). The setting will provide a comfortable atmosphere for the participant and privacy for carrying out the 60-90 minute interview. Twenty subjects 18-24 years of age will be invited to participate in the study.

Participants and Sample Formation

Following Institutional Review Board (IRB), approvals at Children’s National in Washington, D.C, followed by Catholic University of America (CUA), a purposive sample of young adults with perinatal HIV will be recruited from the Special Immunology clinic to participate in this study. In the main clinic in the hospital, there are approximately 175 young adults who meet the criteria for the study: 90% are African American /non-Hispanic; 5% White /Hispanic; and 5% other or mixed ethnicity.

A purposive sample is commonly used in phenomenological inquiry. The power of a purposeful sampling provides theoretical saturation when the participants no longer generate new information (Higginbottom, 2004). Purposeful sampling also seeks detailed information from the participants who are well informed (Patton, 1990). This method enrolls a sample of individuals with the experiential knowledge of a phenomenon for the purposes of telling their lived experience (Speziale & Carpenter, 2007).

Participants will be required to meet the following inclusion criteria: (a) have a documented diagnosis of Perinatal HIV; (b) express a willingness to participate in an interview in the clinic setting at Children’s National, and follow-up data clarification phone calls if necessary; (c) able to read and speak English; and (d) between the ages of 18-24 years. An invitation (Appendix A) to participate in the study will be disseminated to the Special Immunology clinics throughout the Children’s National main campus by the Director of the Special Immunology Services.

Sample size with justification

Van Manen, 1990 does not indicate a specific sample size for his phenomenological method, while others suggest the sample size should be 6-12 participants (e.g. Haase, 1987). In determining an appropriate sample size of the research under investigation, the plan will be to collect a great deal of information form a small number of participants (n=20). The data will collected from the interview and questionnaire
F. Human Subjects

In the process of the protection of human subjects, the following are essential: ethical principles of autonomy, beneficence, and justice (Orb, Eisenhauer, & Wynaden, 2001; 1996). The following concerns will be addressed in this section: informed consent; benefits and risks; and confidentiality. The written informed consent is an essential document in the conduct of ethical research (United States Department of Health and Human Services (USDHHS) 2012). The investigation’s consent form will include the requirements for informed consent in research as outlined by the Code of Federal Regulations 45, Section 46.116 (USDHHS, 2012). A statement that the study involves research; an explanation of the purpose of the research; a description of the procedures in the study; the expected duration of the study; a description of any foreseeable risks or discomforts; a description of the benefits to the subjects; a statement describing confidentiality of records and identifying the subject; information that the data collected will be secured by using passwords and encryption; audio and/or video recordings of subjects will be transcribed and then destroyed to eliminate audible and visible identification of subjects; and information about the Health Insurance Portability and Accountability Act (HIPAA), the privacy law that protects individually identifiable health information (protected health information, or PHI).

This privacy law requires the participant to sign an agreement permitting researchers to use or share the PHI for research purposes. This section will describe how information may be used or shared in the research study. Included in the consent form will be information about the individual the participant should call in an emergency and the participant’s right to terminate the interview or request that the audio recorder be turned off. Finally, the collection of sensitive information about subjects will be limited to the amount necessary to achieve the aims of the research, so that no irrelevant sensitive information is collected.

Prior to the start of this investigation, the IRBs of Catholic University of America and Children’s National reviewed the research procedures. IRB approval will be necessary to facilitate research subject recruitment and enrollment. The participant will be contacted in person by the attending physicians or medical staff of the Special Immunology Services at Children’s National and will be informed about the study. A convenient time to enroll in the study will be discussed. If the participant agrees, the consent form will be made available for review followed by a verbal explanation of the study by the nurse researcher. In addition, the participants will be given enough time to have their questions answered prior to the actual participation in the study. A private area will be used for this study to assure confidentiality. The consent states that the participant could withdraw at any time without reprisal.

The completed demographic questionnaires and transcribed interviews will be assigned codes, kept in a locked cabinet in the investigator’s office and separated from the consent documents to assure anonymity. The computer containing the study data will be password protected and the electronic databases with patient identifier data will be user-access protected. All information regarding the subjects will remain confidential and access to the database will be restricted to the research staff.

There are no immediate risks anticipated for participation in this study. However, if a participant exhibits signs suggesting emotional distress during the interview, the investigator would provide emotional support and refer the individual to an appropriate source after consultation with the director of Special
Immunology Services. Potential benefits of participation in this investigation includes offering the participant an opportunity to talk about their experiences and concerns in a confidential environment and potentially gain personal insights into the participant’s life growing up with HIV.

**Procedure for Data Collection**

Once a week, the Special Immunology multidisciplinary team will identify and contact the participants who meet the study criteria and introduce them to the study. The nurse researcher will contact the participants who are agreeable and schedule a convenient time to enroll them in the study. The consent form will be made available for review followed by the consenting process per Children’s National Medical Center’s protocol. One questionnaire will be collected from each participant and the procedures for data collection used throughout this study are described below. Children’s Research Center (CRC) and special immunology staff will be trained about the study at the study activation meeting after IRB approval. The special immunology staff will be given weekly updates about the study at the weekly meetings.

1. At the time of initial contact between the investigator and the prospective participant, the information about the study will be provided, and the participant will be interviewed to confirm the eligibility criteria have been met.

2. If the participant meets the criteria and agrees to participate, an interview will be scheduled in the CRC.

3. In preparing for and prior to each interview, the investigator will reflect on personal beliefs, preconceptions, intuitions, motive and biases to achieve a state of “openness”. These thoughts will be recorded in a personal journal.

4. At the beginning of the interview, informed consent will be obtained, and the demographic questionnaire completed.

5. A code or number will be assigned to the demographic questionnaire; placed on the questionnaire by the investigator and then placed in a sealed envelope. The coded questionnaires will be stored by the investigator in a locked place separate from the interview tapes and transcripts.

6. Two digital audio recorders will be placed on a convenient surface so that the investigator can control the devices at all times. Two recorders will be used to ensure recording in the event of mechanical failure of one of the recorders. Participants will be reminded that at any time during the interview they can request that the recording devices be turned off for any reason.

7. Consent for audio-taping will be verbally acknowledged at the beginning of the taped recorded interview. The lead question will be presented, and the probes interjected during the interview. The interview will last about 60-90 minutes. When the interview is completed, or upon the request of the participant, the tape recorder will be turned off. The code number will be verbally noted at the beginning and end of each taped interview.

8. The investigator will request permission from all of the participants to contact them by phone if clarification of the
narrative material is needed. An opportunity for all participants to review their transcriptions will be provided at the end of the study.

(9) The audio recordings, consents, and demographic questionnaires will be secured in separate locked drawers. The recordings will be deleted after the completion of the dissertation defense and in compliance with IRB rules.

(10) Field notes describing emotional experiences of the participants, logs or diaries will be collected throughout the study.

(11) A professional service will be used to transcribe the interview tapes. Upon receiving the transcribed records, the investigator will listen to each recording to detect and correct transcription errors. The de-identified information will be shared with the research advisors.

(12) Written transcripts, consents and other materials will be preserved for three years upon completion of data analyses and then shredded in compliance with IRB rules.

(13) In responding to the study questions, the participant may share sensitive HIV information with the researcher. To help further protect the participants’ privacy, the researcher will apply for a Certificate of Confidentiality from the National Institutes of Health. With this Certificate, the researcher cannot be forced to disclose any information that may identify the participant, even by a court subpoena, in any federal, state, or local civil, criminal, administrative, legislative, or other proceeding.

The researchers will use the Certificate to resist any demands for information that would identify the subject, except as explained below.

The Certificate of Confidentiality does not prevent the participant or a family member from voluntarily releasing information about involvement in this research. If an insurer, employer, or other person obtains the participant’s written consent to receive research information, then the researchers may not use the Certificate to withhold that information.

The researchers will make voluntary disclosure about things such as child abuse, intent to hurt self or others, or other voluntary disclosures. The Certificate of Confidentiality will not be used to prevent disclosure to state or local authorities of child abuse and neglect, or harm to self or others.

- Voluntary participation: Patient can agree to participate after speaking in person with PI or Co-investigator and reading consent, or decline participation as it is voluntary, with no penalty for not participating.
- Complete the interview by thanking them for their time and willingness to review information, again reminding the participant that they could be contacted for additional questions.

The Investigator will assign a code number to each participant in this study. This code number will consist of a letter for the study group (normal weight or obese) and a number for the individual participant. The investigative team will keep a master sheet with the identification number and full name of each patient that is kept in a locked cabinet. The study data, personal medical records and a list that
links each patient's name to his or her code number may be kept until completion of the study. When the study is completed the data will be shredded. Privacy will be ensured throughout the duration of the study.

G. **Risks and Side Effects:**

The potential risks associated with this study are minimal. The participant may experience a feeling of uneasiness or distress during the interview. If so, they may ask for the interview to be stopped. The researcher, Elaine Williams, RN, MSN, is an experienced nurse who can provide support and guidance and upon the recommendation of Dr. Natella Rakhmanina, a psychologist or social worker will be available to provide emotional support. If necessary, another suitable time will be arranged for the participant to complete the interview.

H. **Benefits:**

This study will add the gap in knowledge in the scientific literature about young adults growing up with HIV. The new descriptions of living and maturing with HIV will be valuable to health-care providers as they work with perinatally HIV-infected young adults.

This research also has the potential to identify strategies that support case management with the goal of improving health outcomes for the perinatally infected patient and families.

I. **Outside Consultants/Collaborators**

The Catholic University of America  
School of Nursing  
620 Michigan Avenue, NE  
Washington, DC 20064

J. **Contractual Agreements**

There are no contractual agreements.

K. **Costs To Subjects:**

There are no anticipated costs to the patients participating in our study.

L. **Conflicts Of Interest:**

There are no conflicts of interest.

M. **Confidentiality:**

Subject confidentiality will be upheld at all times. Provisions that will be in place to protect the privacy of patients and maintain confidentiality of medical record data include: each subject will be assigned a code number and only the subjects’ code number will be recorded on study worksheets report forms.
Information will be recorded in such a manner so that patients cannot be identified directly or through identifiers linked to the subject. The study necessitates that a master subject enrolment log contains the patients name and medical record number be kept in the study files, but limited access to this log (consisting of site study personnel and Federal Regulatory personnel in the event of an audit) will be implemented. All study worksheets will be stored in a locked cabinet in the Researcher’s office/office suite at Children’s National Medical Center, 111 Michigan Ave Washington, DC 20012, floor 3.5, Room 102. The computers containing the database will be protected with a password. The results of this study may be published in scientific journals or presented at professional meetings, but the subject’s identity will not be disclosed. HIPAA compliance will be adhered to at all times per IRB and Institutional standards.

N. **Subject Compensation:**

Each subject will be paid $25.00 for participation. A gift certificate will be given to each participant at the end of the interview.

O. **Facilities and Equipment**

The study will be performed within the Children’s National Medical Center’s research area and all materials used will be specifically for the study.

P. **References & Literature Cited**

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## Q. Appendix

Appendix a: The consent document

Appendix b: The information sheet

## R. Acknowledgement

Sigma Theta Tau International- Kappa Chapter $2,500.00

This project will be supported by Award Number UL1TR000075 from the NIH National Center for Advancing Translational Sciences. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the National Center for Advancing Translational Sciences or the National Institutes of Health.
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