The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) While Residing in a Rural Region of Northern Appalachia

Renee Elizabeth Gilhousen

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A Dissertation
Submitted to the School of Nursing

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Renée E. Gilhousen

May 2017
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2017
THE LIVED EXPERIENCE OF INDIVIDUALS LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) WHILE RESIDING IN A RURAL REGION OF NORTHERN APPALACHIA

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ABSTRACT

THE LIVED EXPERIENCE OF INDIVIDUALS LIVING WITH HUMAN IMMUNODEFICIENCY VIRUS (HIV) AND ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) WHILE RESIDING IN A RURAL REGION OF NORTHERN APPALACHIA

By
Renée E. Gilhousen

May 2017

Dissertation supervised by Lenore K. Resick, PhD, CRNP, FNP-BC, FAANP, FAAN

The purpose of this research study was to describe and understand the lived experience of individuals living with HIV/AIDS while residing in a rural region of northern Appalachia. A hermeneutic phenomenological method following the Utrecht School was used for this study. The setting for this study was a rural region of northern Appalachia. The sample consisted of 15 individuals, 18 years of age and older, self-identified as being HIV infected. Two semi-structured interviews were conducted. Transcripts of the interviews were analyzed for identification of themes across the data. Six themes were identified: surviving the predators, walking the road to death, the brink, rebirth/second chance, creating a nest of safety, and living in the shadows. The participants found meaning in sharing the history of their life that led to infection with HIV/AIDS. As participants accepted their illness and found support they embraced a rebirth/second chance and accepted support in order to continue living a life with
purpose and creating a legacy in life. Participants created a nest of safety where they and their loved ones dwell to hide from the “shadows” in rural Northern Appalachia. Findings from this study suggest implications for nursing practice, nursing education, and nursing research.

Implications for nursing practice include assessing for past and current physical and emotional abuse among people living with HIV/AIDS (PLWHA), assessing for concerns associated with personal safety in the home environment and in the community, and providing early and appropriate referral for ongoing support over time. Implications for nursing education include ongoing development of an ethical comportment in nursing education programs, assisting students in recognizing patients’ histories, unique attributes, and experiences, and developing continuing education programs on HIV/AIDS focusing on accurate knowledge regarding HIV/AIDS, beliefs and attitudes, and the psychosocial issues. Future research recommendations include exploring attitudes and beliefs of individuals living in rural Appalachia toward PLWHA, issues specific to women living with HIV/AIDS, attitudes of health care providers in rural Northern Appalachia, and replicating this study in other areas of rural Appalachia.
DEDICATION

Dedicated to God who planned an interesting and unfolding life journey for me, with mountains, valleys, twists and turns. And to my participants, who with courage and grace shared their sacred stories with me.
ACKNOWLEDGEMENT

With gratitude, I would like to thank my dissertation chair, Dr. Lenore K. Resick. I could not have traveled this journey without you walking beside me. You are my role model and I hope you will continue to be a mentor to me as we continue to use this important research method. Your encouragement throughout this process has sustained me.

I would like to express my thanks and gratitude to my dissertation committee, Dr. Joan Such Lockhart and Dr. Linda Rose Frank. I appreciated and am grateful for your wisdom, knowledge and suggestions while I attempt to create a quality dissertation, as well as give voice to the voiceless. I appreciate the time you gave to me throughout this process.

I would like to thank my editor, Betsy McKinley PhD. I appreciate your expertise as I grow as writer. I believe that findings from research studies need to be disseminated in order to give voice for the voiceless. I believe this is part of my purpose in life. Your input was valuable to me.

I would like to offer my thanks and gratitude to the staff members at the regional AIDS service organization. I could not have conducted this study without your help. I am forever grateful for your efforts in distributing the information regarding this study to the individuals who are affected by HIV/AIDS. I hope that the findings from this study provide useful knowledge to you.

I would like to acknowledge my children, Ann and Grant, son in law, Brian, and grandchildren, Corbin and Hudson. You have given me your patience and understanding as I journeyed through process of obtaining this degree. I would like to express my thanks to other family members. To my mother Marjorie, you are always there to keep me encouraged. To my
brother, Harold and sister in law, Linda, you have always celebrated this journey with me, never questioned why I was doing it, and you continually kept me encouraged. Your unconditional love is always with me.

I would like to thank my special friend, Richard (Dick) Whitcomb, Jr. You walked into my life in the midst of this journey. Your understanding, patience, love, and support were amazing and beautiful. As Dr. Resick said, “You are working on a dissertation too.” My thanks to Mary Whitcomb, my first charge nurse and mentor. Thank you for all the cooked dinners you sent over and all of your help while I was writing. I would like to also thank my friends, Jerry Heckathorn, Deborah Alexander, DNP, and Mark Daniels, PhD. You inspired me to pursue my PhD, believed I could do this, supported me throughout the journey as you both have walked this journey, and believed I would finish.

I would also like to acknowledge my father, Harold O. Mong, Sr. You were a man ahead of your time. You encouraged me to dream my dreams and stressed the importance of work hard in order to accomplish them. You believed women should pursue higher education in order to have a profession. I would also like to recognize my aunt, Margaret Mong. You began the legacy of nurses in our family during World War II. I hope you both are watching over me and are proud of this accomplishment.

All my love to all of you
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CHAPTER 1

BACKGROUND OF STUDY

1.1 Introduction

At the start of the 21st century, human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) remains a major public health issue. By the end of 2012, an estimated 1,201,100 persons, 13 years of age and older were living with HIV/AIDS in the United States (US) including 168,300 individuals whose infections were undiagnosed (Centers for Disease Control, 2011, p. 104). Overall the HIV/AIDS epidemic continues to be known as one of the most devastating public health disease epidemics in both the U.S. and globally. During the early years of the epidemic, AIDS was a terrifying and lethal disease (Broder, 2010). Two years after the onset of the epidemic, the causative agent was identified as HIV (Alizon et al., 1984; Luciw, Potter, Steimer, Dina, & Levy, 1984). With the identification of HIV/AIDS came the development of surveillance programs, prevention strategies, education programs, screening programs to identify infection in individuals at risk for HIV/AIDS, and antiretroviral treatment for individuals infected with HIV/AIDS (Wolitski et al., 2006). Disease surveillance programs identified that many of the individuals at risk for HIV/AIDS were socially and economically marginalized leading to poorer health outcomes. Additional challenges burdened individuals infected with HIV/AIDS and individuals affected by HIV/AIDS such as violations of civil liberties, confidentiality, and discrimination (Bryan, 2002). Many of the research studies describing the disease burden of HIV/AIDS, the disparities, and challenges experienced by individuals infected and affected by HIV/AIDS have been extensively conducted in urban and suburban areas. Studies have suggested that this was due to researchers having access to people living with HIV/AIDS (PLWHA), established HIV specialty care clinics, and higher prevalence
of PLWHA in urban and suburban areas (Cousar, 2006; Gillespie, 1995; Goggin, Catley, Brisco, Engelson, & et al., 2001; Habegger, 1997; Munro & Edward, 2008). However, HIV/AIDS affects all socioeconomic levels, genders, races, and crosses all geographic regions. Research studies conducted in rural areas are limited. Many studies have suggested the need for more research studies conducted in rural areas, including the specific region of Appalachia, known for multiple economic and health disparities. Little is known about PLWHA residing in the Appalachian region.

1.2 Discovery of HIV

The first cases of AIDS were reported in June 1981. The Morbidity and Mortality Weekly Report (MMWR) described five previously healthy males living in Los Angeles, California presenting with Pneumocystis carinii pneumonia (PCP), an unusual illness in healthy individuals (Gottlieb, Schanker, Fan, Saxon, & Weisman, 1981). The next month the MMWR reported that physicians in New York City were diagnosing PCP and Kaposi’s sarcoma (KS) in previously healthy males residing in metropolitan areas (Centers for Disease Control and Prevention, 1981). By the end of 1982, the immunodeficiency illness was being diagnosed in injecting drug users, infants, and hemophiliacs (Centers for Disease Control and Prevention, 1982a, 1982b, 1982c; Masur et al., 1981). Reports surfaced in 1983 that female sex partners of men with HIV/AIDS were acquiring opportunistic infections (Centers for Disease Control and Prevention, 1983). Later in 1983, a pivotal moment occurred with the identification of HIV, the new retrovirus that caused AIDS (Alizon et al., 1984; Luciw et al., 1984). With this discovery came the development of an antibody test to detect the virus (Weiss et al., 1985). However it was not until March 2, 1985 that the Food and Drug Administration (FDA) licensed the first antibody test for the detection of HIV. With the availability of the HIV antibody test, on April 26, 1985, cooperative
agreements between CDC and 55 state and local health departments were initiated for a 90-day period to establish HIV testing sites for individuals with high-risk behaviors associated with acquisition of HIV/AIDS. The testing sites provided pretest and posttest counseling and referral to medical evaluations, if needed. Sex partners and needle sharing partners of individuals who were seropositive for HIV were referred for testing and medical evaluation (Centers for Disease Control and Prevention, 1986; Wolitski et al., 2006) Blood banks, blood donation centers, and plasma centers began testing the blood supply for HIV per Public Health Service recommendations (Wolitski et al., 2006).

1.3 Era of HIV/AIDS Prior to Treatment

Initially, the U.S. federal and state governments were reticent to address the epidemic. According to Novick (1989), the Reagan administration was reluctant to publicly acknowledge the epidemic and members of Congress avoided a commitment to develop a comprehensive national agenda to address the AIDS epidemic. Within the U.S. the response to the AIDS epidemic was delayed, fragmented, and inconsistent (Merson, O'Mallery, Swewadda, & Apisuk, 2008). Wolitski et al. (2006) reported that the first AIDS prevention programs were initiated in 1982 at the grassroots level. According to Merson et al. (2008), the early prevention programs evolved from individuals living with and affected by HIV/AIDS who were confronted with stigma and discrimination. Wright (2013) reported that fears stemming from the lack of knowledge about the disease, as well as political and social tensions associated with the new epidemic, were the catalysts for AIDS activism.

According to Wright (2013), self-disclosing gay men infected and affected by AIDS began to organize political activity within the gay community. The formal foundation of AIDS activism began in Denver, Colorado in 1983. A small group of gay men spearheaded the
formation of the People with AIDS advisory committee. The leaders within the group included Bobbi Campbell from San Francisco, California and Michael Callan from New York, New York. Campbell and Callan crafted a document known as the Denver Principles. The Denver Principles were fundamental to HIV/AIDS activism, calling for a new relationship between people with AIDS, their medical provider, and society. By the end of 1987, advocacy communities formed around gay organizations, such as AIDS Coalition to Unleash Power (ACT UP). As members of ACT UP gained power they were influential in the development of research, accelerated approval of HIV/AIDS medications, and the development of HIV/AIDS policies (Killen, Harrington, & Fauci, 2012; Wright, 2013). According to Wolintski et al. (2006), gay men, lesbians, and their allies initiated early prevention programs designed to increase HIV/AIDS awareness, reduce fears, provide basic information regarding the disease and disease transmission, and reduce risk of infection.

The Centers for Disease Control (CDC) was the first federal agency involved in the AIDS epidemic. The involvement of the CDC began at the onset of the AIDS epidemic in 1981 while conducting the first disease surveillance and the epidemiologic investigations of the initial cases of AIDS. In 1983, the CDC, along with the Food and Drug Administration (FDA) and the National Health Institutes (NIH), issued the first recommendations for the prevention of HIV/AIDS based on epidemiological data (Curren & Jaffe, 2011). The CDC established the National AIDS Information Line to provide basic knowledge and awareness regarding the disease and reduce fear regarding transmission (Curren & Jaffe, 2011; Wolitski et al., 2006). In 1987, the National AIDS Clearinghouse was established. In the same year, U.S. Surgeon General, C. Everett Koop and the CDC initiated a public information campaign, “America
Responds to AIDS. A brochure Understanding AIDS, was mailed to every residential address in the U.S. (Wolitski et al., 2006).

Although many gains were achieved due to the efforts of grassroots organizations and the CDC, the challenge of motivating behavior change among individuals at high risk for HIV/AIDS remained. The CDC AIDS Community Demonstration Project, consisting of five cities, was developed to establish more intensive targeted interventions for difficult to reach populations (Wolitski et al., 2006). The CDC HIV Prevention Research Synthesis Project conducted a meta-analysis of data and determined that behavioral interventions significantly reduced sexual risk among men and women and drug users (Centers for Disease Control and Prevention, 1999).

Along with the disease burden of HIV/AIDS came the additional burdens associated with social and bioethical issues. According to Bryan (2002), social issues associated with sexuality and addictions were brought to the forefront and difficult discussions related to these issues ensued. People living with HIV/AIDS and their families experienced violations of civil liberties, breaches in confidentiality, and discrimination. Challenges surrounding bioethical issues included moral responsibility, blame, and prejudice. The social and bioethical issues deterred the development and utilization of resources for individuals infected and affected by HIV/AIDS. The consequences of these barriers were poorer health outcomes (Bryan, 2002). Many of these issues will be discussed in the review of literature.

The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act ("Ryan White Comprehensive AIDS Resources Emergency (CARE) Act," 1990) was an act of the U.S. Congress in honor of Ryan White, an Indiana teenager and AIDS advocate who died April 8, 1990 of AIDS. Ryan was infected with HIV after receiving a hemophilia treatment in 1984. After school administration learned of his illness, White was expelled from school because of his
illness. White advocated for AIDS awareness and research. The act is the United States largest federally funded program for people living with HIV/AIDS. The act sought funding to improve availability of care for low-income, uninsured, and under-insured individuals living with HIV/AIDS and their families (Hayes, Gambrell, Young, & Conviser, 2005; Rundall, Kwait, Macrconi, Bender-Kitz, & Celentano, 1999). The CARE Act provided emergency assistance to geographical areas most severely affected by HIV/AIDS, provided grants to states and territories of the U.S., provided primary health care and family centered services in outpatient settings for PLWHA, and provided funding for various HIV/AIDS related programs. Those programs included special projects of national significance: the AIDS Education and Training Centers Program, Dental Programs, and Minority AIDS Initiative (HIV/AIDS Bureau, 2015a). Since 1990 the Ryan White CARE Act has been amended and reauthorized four times and remains an integral component in the delivery of services for PLWHA in the U.S (HIV/AIDS Bureau, 2015b).

1.4 Era of Monotherapy

According to Broder (2010), certain beliefs held by individuals within the scientific community complicated or delayed the development of HIV/AIDS treatment. Those beliefs included active retroviruses did not exist in humans, or, if retroviruses did exist in humans they did not cause disease. Others in the scientific community believed that the role of retroviruses in human illness was minor, and if the retroviruses did exist in humans they were untreatable (Broder, 2010). However, contrary to these beliefs, on March 19, 1987, the Federal Drug Administration (FDA) approved zidovudine (AZT, ZDV) (Brand name Retrovir), the first antiretroviral medication and first nucleoside reverse transcriptase inhibitor (NRTI) for the treatment of HIV/AIDS (Broder, 2010; Este & Cihlar, 2010; Vella, Schwartlander, Sow, Eholie,
& Murphy, 2012). The new antiretroviral treatment suppressed the replication of HIV. AZT increased the number of circulating CD 4 helper cells and decreased the number of mononuclear cells infected with HIV (Broder, 2010). Treatment with AZT was found to be associated with greater survival at 24 weeks of treatment. However, by 48 weeks the survival benefits diminished (Vella et al., 2012). Serious side effects associated with AZT monotherapy included bone marrow suppression, toxic myopathy, non-Hodgkin lymphomas, and rare seizures (Broder, Mitsuya, Yarchoan, & Pavlakis, 1990). The most discouraging challenge was emerging drug resistance while using AZT as monotherapy (Broder et al., 1990; Walker & Hirsch, 2013).

Following the development of AZT, newer antiretroviral medications were developed to alter viral replication at various viral targets. Nonnucleoside reverse transcriptase inhibitors (NNRTIs) attack an enzyme that synthesizes viral DNA within the infected cells from the RNA template carried by the virus. Protease inhibitors (PI) medications stop the enzyme that cleaves and processes the viral proteins that assist in the maturation of a virion (National Institute of Allergy and Infectious Diseases, 2006).

Another major milestone occurred in 1994 with the use of AZT in reducing the maternal-infant transmission of HIV (Connor, Spirling, & Gelber, 1994). Administering AZT during pregnancy and during labor and delivery, as well as administering the drug to the infants during the first six weeks of life, reduced the transmission of HIV by approximately two thirds. The drug was found to reduce circulating virus. The treatment was found to have minimal short term toxicity to the mother and infants (Connor et al., 1994).

1.5 Era of Combination Treatment

Combination therapy using three or more medications, known today as Highly Active Antiretroviral Therapy (HAART), brought about a revolutionary change in the treatment of
HIV/AIDS, creating a more synergistic approach in the treatment of HIV/AIDS. The combination therapy reduced plasma viremia as well as reduced the emergence of drug resistance (Este & Cihlar, 2010). With the advent of the use of combination therapy, HIV/AIDS became a chronic illness for PLWHA who had access to HAART. However, with this life changing treatment came new challenges. The challenges included issues related to adherence to medications, adverse effects, drug toxicity, emergence of resistant strains of HIV strains, and lack of access to treatment (Este & Cihlar, 2010).

According to the Centers for Disease Control, the National Institute of Health, and the HIV Medicine Association of the Infectious Disease Society of America (2015), prior to the advent of HAART, opportunistic infections (OI) were the principle cause of death in individuals with immunosuppression due to HIV/AIDS. HIV is the cause of immunosuppression allowing for OIs in PLWHA. Conversely, OIs and other infections affect the natural history of HIV/AIDS causing increases in circulating HIV viral loads leading to progression and transmission of HIV/AIDS. The use of chemoprophylaxis and immunizations continue to contribute to the quality of life and the improved survival for PLWHA (Centers for Disease Control and Prevention et al., 2015).

Initiating HAART early in HIV infection had public health implications. Combination therapy was found to decrease transmission of HIV/AIDS by decreasing the plasma levels of HIV (Walker & Hirsch, 2013). The risk of HIV infection to uninfected partners appeared higher from untreated acutely infected partners than from chronically ill partners on HAART (Walker & Hirsch, 2013). With the advent of HAART, one study followed steady heterosexual discordant couples from 1991-2003 (Castilla et al., 2005). In couples where the infected partner did not receive antiretroviral therapy there was an 8.6% HIV prevalence. With the use of HAART, a
reduction of approximately 80% in heterosexual transmission was observed (Castilla et al., 2005).

With the absence of a preventive vaccine, HAART therapy has been used as post exposure prophylaxis (PEP) for individuals exposed to potentially HIV contaminated blood and body fluids (Este & Cihlar, 2010). According to Kuhar et al. (2013), preventing exposure to potentially infectious blood and body fluids is an effective method in preventing HIV/AIDS infection. Consistent use of the principles of Standard Precautions has been an effective primary prevention strategy for preventing acquisition of HIV/AIDS in an occupational setting. Standard Precautions are the consistent and appropriate use of work practices, work controls, and personal protective equipment for preventing acquisition of HIV/AIDS. In the event of an occupational exposure to potentially infected blood or body fluid, post exposure prophylaxis can be utilized (Kuhar et al., 2013).

CDC issued the first PEP guidelines in 1990. The utilization of the earlier guidelines identified challenges associated with the interpretation and implementation of the guidelines. Challenges identified included difficulties in interpreting the level of risk to HIV based on the exposure, determining if two or three HIV medications were appropriate for PEP, and issues related to side effects and toxicities associated with HAART. With the development of newer antiretroviral medications and additional information regarding treatment of HIV, the guidelines have been updated with the most recent update occurring in 2013 (Kuhar et al., 2013).

According to Kuhar et al. (2013), the current 2013 PEP guidelines recommend the use of three or more drugs for all occupational exposures. The severity of the exposure is no longer criteria used to determine the need for PEP treatment. Testing of the source patient is recommended when possible. The regimen of treatment should have minimal side effects and
have a convenient dosing schedule. Currently the recommended treatment should include Truvada (emtricitabine and tenofovir) plus raltegravir (RAL). This regimen has been found to be tolerable, convenient, have minimal drug interactions, effective, and can be administered during pregnancy. PEP administered for 4 weeks is considered protective. Medical experts in HIV treatment should be consulted during PEP administration (Kuhar et al., 2013).

Individuals at risk for acquiring HIV/AIDS have been associated with being socially and economically marginalized. Many of these individuals do not have access to prevention information, condoms, clean syringes, or mutual monogamy (Philpott, 2013). In 2014 the U.S. Public Health Service (PHS) issued guidelines for preexposure prophylaxis (PrEP) for the prevention of HIV/AIDS acquisition in individuals at risk for HIV (United States Public Health Service, 2014). Individuals at risk include sexually active men who have sex with men (MSM), heterosexually active men and women, adult injecting drug users, and discordant couples (one partner is HIV positive and the other partner is HIV negative). Current data on the use of PrEP in adolescents are insufficient to recommend PrEP to adolescents at this time. Tenofovir disoproxil fumarate (TDF) 300 mg and emtricitabine (FTC) 200 mg once daily is the only medication regimen approved by the FDA and recommended for PrEP. Guidelines recommend that HIV/AIDS should be assessed every 3 months and renal function should be monitored prior to the initiation of treatment and every 6 months. Individuals treated with PrEP should be provided access to effective risk reduction services and referrals (United States Public Health Service, 2014).

In spite of all the painstaking and monumental advances made in the HIV/AIDS epidemic, Wolitski et al. (2006) noted that the magnitude of the HIV/AIDS epidemic and the number of deaths are still unimaginable. By the start of the 21st century, the U.S witnessed more
than 400,000 premature deaths from HIV/AIDS. Currently over 800,000 Americans are living with HIV/AIDS (Wolitski et al.). According to the United States Public Health Service approximately 50,000 people in the U.S are infective with HIV annually with the greatest number of new cases among young African American and Latino MSM (Philpott, 2013; United States Public Health Service, 2014).

1.6 Challenges and Disparities for PLWHA

    Research studies have provided evidence of a multitude of challenges and disparities associated with living with HIV/AIDS. Many of the challenges described in research studies have been extensively identified in individuals living in urban and suburban areas. Research findings have suggested that many HIV/AIDS related studies have been conducted in urban and suburban areas due to the accessibility to PLWHA. Many PLWHA seek health care in urban HIV/AIDS specialty care clinics. Additionally, a higher prevalence of PLWHA reside in densely populated areas (Cousar, 2006; Gillespie, 1995; Goggin et al., 2001; Habegger, 1997; Munro & Edward, 2008; Opacich, 2003).

    One hermeneutical phenomenological study explored the lived experience of African American women recruited through a safety net clinic and an infectious disease clinic located in a Midwestern metropolitan city (Peltzer, Domian, & Teel, 2015). The study did not discuss if the sample of women lived in the metropolitan area or a rural setting. The findings suggested that the women described chronic depression that impacted their ability to care for themselves or their children. The women experienced socio-emotional suffering while attempting to hide their illness and depression from others, fostering a sense of aloneness. Spiritual practices were the strongest form of self-care because it alleviated emotional and spiritual distress. The limitations of the study included the women were of a lower socioeconomic status and receiving monetary
compensation might have motivated participation in the study. The description of the sample did not include if any of the women were of higher socioeconomic status or lived in a rural setting (Peltzer et al., 2015). Despite the findings from numerous quantitative and qualitative studies conducted in urban areas, one must consider that HIV/AIDS crosses all geographic regions, socioeconomic levels, and affects all genders and races.

Research studies related to PLWHA while residing in rural areas are limited. The limited rural studies suggested that the challenges related to living with HIV/AIDS in rural areas are similar to challenges reported in urban studies. The challenges identified in the rural studies included stigmatization, barriers in accessing social support, and the lack of mental health services (Habegger, 1997; Munro & Edward, 2008). Other studies suggested the existence of unique challenges and disparities encountered by individuals living with HIV/AIDS in low prevalence areas, such as rural areas. The challenges identified included lack of access to HIV/AIDS specialty care, fear of disclosing HIV/AIDS, and decreased quality of life (Bletzer, 2007; Foster & Gaskins, 2009; Heckman, Somlai, Kalichman, Franzoi, & Kelly, 1998; Heckman, Somlaj, et al., 1998; Kempf et al., 2010; Sowell et al., 1997; J. Walker, 2002; Yannessa, Reece, & Basta, 2008). The findings in rural studies suggested the need for more research studies related to living with HIV/AIDS in rural areas in order to develop culture specific interventions for individuals living with HIV/AIDS in rural areas. Yannessa, Reece, and Basta speculated that possibly the challenges and disparities identified in rural areas are correlated with conservative cultural norms found within rural areas (Yannessa et al., 2008).

1.7 Purpose of the Study

The purpose of this research study was to describe and understand the lived experience of individuals living with HIV/AIDS while residing in a rural region of Northern Appalachia. The
most recent studies identified regarding HIV/AIDS in Appalachia were conducted in 2006. None of the studies explored the lived experience and have not obtained the perspective of those affected and living with HIV/AIDS while residing in rural Northern Appalachia. Due to the lack of current studies conducted in states located in the Northern Appalachian region, more research was needed regarding issues related to understanding the experiences of PLWHA in rural Northern Appalachia. Using a hermeneutic phenomenological approach, the focus of this study was to describe and understand the lived experiences of PLWHA residing in a focused area of rural Northern Appalachia. Previous research findings regarding health in the Appalachian region could not be generalized to PLWHA in rural Northern Appalachia. By identifying themes based on the experiences of PLWHA in the rural Northern Appalachian region, strategies can be developed and implemented for culturally appropriate nursing interventions to mediate the impact of HIV/AIDS on PLWHA living in rural Northern Appalachia. Newly identified knowledge can be used to improve access to specialized HIV/AIDS care and improve outcomes associated with HIV/AIDS disease in rural areas, particularly rural Northern Appalachia. Research findings from this study can lead to future research studies in the Northern Appalachian region.

1.8 Research Question

The research question is: What is the lived experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia?

1.9 Definition of Terms

In the context of this study, the term HIV/AIDS referred to any individual who has a positive result from an HIV-1 antibody-screening test; reactive enzyme immunoassay (ELISA) with a confirmatory test such as a Western blot or indirect immunofluorescence assay test.
HIV-1 infection can also be laboratory confirmed by a positive result or report of a detectable quantity of the following HIV-1 virologic tests: qualitative HIV-1 nucleic acid (DNA or RNA) detection test, HIV-1 p24 antigen test, quantitative HIV-1 nucleic acid detection test (viral load assay), or HIV 1 insolation (viral culture) or HIV-1 nucleotide sequence (genotype) (Schneider et al., 2008; Selik et al., 2014). In April 2014, the Centers for Disease Control and Prevention (2014) revised the surveillance case definition for HIV infection. A confirmed case for HIV-1 infection was classified in one of five stages (0, 1, 2, 3, or unknown). For individuals 18 years of age and older, Stage 0 is considered early infection in an individual who had a negative or indeterminate HIV antibody test within 6 months of having a positive HIV antibody test. Stages 1, 2, and 3 are based on specific CD4+T-lymphocyte count or CD4+T-lymphocyte percentage of total lymphocytes. The criteria for the three stages are outlined in the table found in the surveillance case definitions for HIV infection located in Appendix A. As HIV transiently depresses particular white blood cells known as CD 4 and T-lymphocytes, the immune system loses the ability to fight infection (National Center for HIV/AIDS, 2014). In this study individuals 18 years of age and older, self-identifying as being HIV-1 positive were eligible to participate in the study.

Many definitions exist pertaining to rural. According to the U.S Census Bureau (2010) urban areas consist of 50,000 people or more. Rural clusters consist of 2,500 to less than 50,000 people. Rural areas are defined as populations not living in urban areas. For this study individuals living in a rural area of less than 50,000 people as defined by the U.S. Census Bureau were eligible to participate in this study.

The region of Appalachia is defined as lands extending from southern New York State to northeastern Mississippi, 205,000 square miles following the Appalachian mountain range.
The Appalachian region consists of 399 counties with 299 counties designated as rural. Forty-two percent of the region’s population is designated as rural, compared to 20% of the national population that is designated as rural (Appalachian Regional Commission, 2014).

Findings from research studies (Chesson, Kent, Owusu-Edusei, Leichliter, & Aral, 2012; Coyne, Demian-Popescu, & Friend, 2006; Fletcher, Slusher, & Hauser-Whitaker, 2006; Halverson & Bischak, 2008; Hutson, Dorgan, Phillips, & Behringer, 2007; Lane et al., 2012; Lengerich et al., 2005; McGarvey, Leon-Verdin, Killos, & Cohn, 2011) (Wewers, Fickle, & Paskett, 2006) have suggested that the Appalachian region is associated with numerous disparities related to health access, education opportunities, and lower socioeconomic levels. The disparities in Appalachia are discussed in depth later in this document. For this study, the map in Appendix B illustrated the region designated as Northern Appalachia. People living with HIV/AIDS infection and residing in the states designated as Northern Appalachia were eligible to participate in this study.

1.10 Assumptions

This study used an ontological approach to understand the experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia. The following assumptions reflected the emic perspective of this study.

Participants were willing to talk about their experiences of living with HIV/AIDS while residing in rural Northern Appalachia. Participants were comfortable sharing honest experiences and feelings regarding their view of their world while living with HIV/AIDS residing in rural Northern Appalachia. The meaning of the participants’ experiences would lead to heightened
knowledge and understanding regarding what it is like to live with HIV/AIDS in rural Northern Appalachia.

1.11 Limitations

This study was limited in that the participants might be reluctance of individuals living with HIV/AIDS meeting the inclusion criteria to participate in this research. The meaning of the lived experience of individuals who did not to participate in this study remain unknown and might be different from the individuals who participated in the study. Due to the sensitive nature of the topic of HIV/AIDS, this study was limited to the participants who were willing to share intimate thoughts and feelings related to living with HIV/AIDS. This study was limited to a specific situation, place, and time.

The researcher must also be cognizant of her personal preconceptions and biases. Specific measures, described in Chapter 3, were taken to limit researcher bias. This researcher’s personal profile, educational preparation, and work are listed later in Chapter 1 to outline how the researcher arrived at the question, purpose, participants, and approach to this research study.

The possibility exists that contextual and temporal aspects might be lost from the original report of the individuals’ experience (van Manen, 1997a). According to van Manen (2007) phenomenology is less concerned with the factual accuracy than the plausibility of an account; in other words it is true to the individual’s living sense of it.

1.12 Significance to Nursing

An important component of the nursing discipline is to seek understanding of the human experience “in order to contribute to better practical nursing” (Benner, 1994, p. 4). It was the intention of this study that understanding the experiences of people living with HIV/AIDS while residing in a rural region in Northern Appalachia contributed to the body of knowledge of
nursing. Healthcare providers need to understand the lived experience of their patients in order to provide quality of care and culturally appropriate interventions. Interpretation of the narrative of the PLWHA would ascertain important and practical issues for nurses to consider when improving the quality of life for PLWHA while residing in rural Northern Appalachia. New knowledge would lead to improved access to specialized HIV/AIDS care and improved outcomes associated with HIV/AIDS in rural areas. Conversely, the lack of knowledge regarding the experiences of living with HIV/AIDS while residing in rural areas could lead to additional negative health outcomes; particularly the overlooked rural Appalachian region already known for a disproportional number of health disparities as discussed in the review of literature.

Research findings have suggested the importance of integrating the experience of living with HIV/AIDS as a holistic life view for those infected with HIV/AIDS (Russell & Smith, 1999). According to Roth and Nelson (1997), the impact of HIV/AIDS can be integrated into the identity of the patient and future life experiences. Roth and Nelson suggested the use of narrative analysis as a method to integrate of the experience of living with HIV/AIDS. Studies have reported that patients are more likely to develop a positive role in the HIV community if the identity integration occurs (Roth & Nelson, 1997).

1.13 Aspects of the Personal Biography of the Researcher Related to the Study

The researcher is a midlife American born woman living in a region in rural Northern Appalachia. The initial interest in this study grew from the researcher’s work as a family nurse practitioner and former public health nurse living and working in a region of rural Northern Appalachia. The researcher has been involved in HIV/AIDS advocacy since 1981. Within this region in rural Northern Appalachia, the researcher was instrumental in establishing a county and regional HIV/AIDS service organization and case management services for PLWHA during the
1980s and assisted in establishing a rural HIV/AIDS clinic in the 1990s. Additionally, the researcher has interacted with PLWHA while conducting HIV counseling and testing and being engaged in clinical practice. Throughout the years, the researcher has maintained contact with the staff at regional HIV/AIDS organizations, public health professionals, and PLWHA.

The researcher’s interest in this research arose from encountering many experiences and challenges while working with PLWHA. The researcher was interested in learning more about the actual experiences of PLWHA from an emic perspective. From an emic perspective, the researcher sought to understand how PLWHA residing in rural Northern Appalachia see their world. The individuals living with HIV/AIDS were provided with the opportunity to voice the reality of their life. What was not known are the experiences of individuals living with HIV/AIDS in this particular rural region in Northern Appalachia. The literature supports that more research is needed in the Appalachian region to identify specific factors associated with the health experiences of the individuals that reside in the Appalachian region (Halverson & Bischak, 2008; Halverson, Ma, & Harner, 2004).
CHAPTER 2

REVIEW OF LITERATURE

2.1 Introduction

This review presents an overview of the literature written in English and related to health disparities and HIV/AIDS in rural Appalachia. The review includes quantitative studies, qualitative studies, and mixed methods studies. The aim of this review of literature was to describe what is known regarding rural Appalachia, especially as it relates to health disparities throughout the region and what is known about HIV/AIDS in the region. The review identifies and appraises the evidence regarding the dynamics, challenges, and experiences of individuals residing in rural Appalachia as related to health disparities and HIV/AIDS infection.

The desktop search was conducted using the health, philosophy, and psychology databases CINAHL, EBSCOhost, PubMed, Psychinfo, ProQuest and Scopus. The search retrieved papers between September 2012 and March 2017. The range of dates of the studies was between 1981 and 2017. Searching reference lists of the articles also led to more studies and information. All identified papers were entered into an electronic reference management system, EndNote©. All papers were examined to determine if they were relevant to the review.

2.2 Aims and Objectives

The review objectives were to determine:

What is currently known about socioeconomic disparities, health disparities, and HIV/AIDS in rural Appalachia?

What are the settings and populations in which research studies related to health disparities have been conducted with individuals residing in rural Appalachia, specifically PLWHA?
What gaps are identified in the literature related to PLWHA while residing in rural Appalachia?

2.3 Search Terms

Subject headings and word truncations were entered into the databases. The following search terms were used: “lived experience”, meaning, phenomenolog*, narrative, HIV, “human immunodeficiency virus”, AIDS, “human immunodeficiency”, “HIV”, human immunodeficiency virus”, “AIDS AND Appalachia” “Appalachia”, “HIV, human immunodeficiency virus, AIDS AND rural”, “rural HIV”.

2.4 Results

A total of 715 papers were retrieved from the databases. After reviewing abstract, actual articles, and further exploring select papers, 39 papers met the inclusion criteria and were used for the review (See Appendix C, Table 1 and Table 2). The following is the inclusion criteria used for this review; any research studies published in peer review journals, dissertations, textbooks, or government websites were included. Studies describing health disparities and HIV/AIDS related issues in individuals residing in any rural region of Appalachia were included in the review of literature. Due to the sensitive nature of HIV/AIDS related confidentiality, some studies specified the location of the study as the state. If the study was conducted in a state designated as part of the Appalachia region, the study was included in the review. Studies related to children were not included as children were not included in this study. Studies conducted more than five years ago were also included in the review, as it appears the majority of studies related to health in Appalachia and HIV/AIDS related studies were conducted prior to 2010. To have a thorough understanding of health in Appalachia and HIV/AIDS these later studies were included.
2.5 Socioeconomic Disparities in the Appalachian Region

Out-migration of the population in the Appalachian region is a contributing factor to the lower socioeconomic levels in Appalachia. Gebremarian, Gebremedhin, and Schaeffer (2011) conducted a study to examine the determinants of growth in Appalachia between 1990 and 2000. The study included 418 Appalachian counties and utilized several databases for the data analysis. The researchers obtained data from county business patterns, Bureau of Economic Analysis, Bureau of Labor Statistics, Population Survey Reports, County and City Data, United States Census of Population and Housing, United States Small Business Administration, and the Department of Employment Security. The main focus of the study was to learn about the in-migration and out-migration of people within Appalachian counties. The findings suggested that people move or travel to counties with high employment and higher wages. Appalachian counties characterized by small, dispersed communities have been losing more educated and skilled individuals. The out-migration resulted in the erosion of community income and the property tax bases that provide major sources of revenue to finance local public services. As individuals migrate out of counties, individuals in surrounding counties also migrate out to counties with employment. Home ownership was higher in distressed counties and lower in more prosperous counties with the highest home ownership found in central Appalachia. It was suggested that owning a house is expected to decrease the propensity to migrate due to the transaction costs and the illiquidity of real estate in locations of economic distress. The average income of the in-migration is lower than the median income of the non-movers. Lower income counties are clustered in Central Appalachia, while higher incomes are clustered around larger cities in the northern and southern areas of Appalachia. Female head of households have greater opportunities for employment in higher income counties whereas poorer counties have few
opportunities for employment with lower wages. Long periods of lack of economic opportunity in Appalachia has led to out-migration of individuals with more education and skills (Gebremariam et al., 2011).

Other factors contributing to out-migration in the Appalachian region are the economic restructuring on the global scale, the outsourcing of manufacturing jobs, and the growth of service industry jobs and labor markets what are smaller, less diverse, and lack human capital (Gurley, 2016). During the 1990s, counties with greater manufacturing employment experienced the greatest impact of loss of jobs in rural areas of Appalachia. According to Lobao, Zhou, Partridge, and Betz (2016) the shift to energy sectors; such as coal, as well as oil and gas, need to be scrutinized as employment as these industries can create new rounds of poverty and prosperity in a limited number of rural communities within rural Appalachia. Although some communities have employment gains due to the oil and natural gas industry, long term prosperity to communities is questionable (Lobao et al., 2016).

Other research studies have suggested that the aging Appalachia population contributed to lower socioeconomic levels in the region. Haaga (2004) used data from the decennial censuses from 1990 and 2000 to examine the demographic, socioeconomic levels, and trends in the Appalachian region to show how and why the age structure of individuals residing in Appalachia differed from the national average and varies within the Appalachian regions. The findings suggested that in 2000, 14.3% of Appalachian residents were age 65+ compared with 12.4% of all U.S. residents. Northern Appalachia had the oldest population. Pennsylvania and West Virginia were ranked 2nd and 3rd respectively with Florida being 1st for the states with the oldest population. The findings suggested that the major reason for the difference in the age structure between the Appalachian populations compared to all of the U.S. was a result of the net
out-migration of young adults from Appalachia to other parts of the country. The high poverty rates among the elders residing in Appalachia, as well as living alone, are problematic for the region (Haaga, 2004).

Another study suggested the Appalachian region is made up of an elderly population (Skinner, Gottlieb, & Carmichael, 2011). Skinner, Gottlieb, and Carmichael used data from the Medicare expenditures at the hospital referral regions for 2003-2008. The findings suggested that the per capita expenditures increased more than $1000 per beneficiary in Johnstown, Pennsylvania located in Northern Appalachia. The highest Medicare spending region in the United States was Miami, Florida (Skinner et al., 2011).

2.6 Health in the Appalachia Region.

Several research studies were conducted to ascertain if health disparities existed in the Appalachian region. The studies explored health disparities and diseases related to premature mortality; for example, cancer, perceptions of health, issues regarding access to health care, aging peoples of Appalachia, and risky behaviors exhibited by the people of the Appalachian region.

One of the first studies exploring health disparities in Appalachia was conducted by Halverson, Ma, and Harner (2004). This study was the first analysis found in the literature that conducted a regional review of mortality, morbidity, and behavioral risks and health disparities in the Appalachian region. The researchers compiled standardized baseline information to explore health disparities in Appalachia. The findings identified specific causes of death in the Appalachian region; for example, heart disease, cancer, cerebrovascular disease, motor vehicle accidents (MVA), chronic obstructive pulmonary disease (COPD), diabetes, accidental deaths, suicide, and infant mortality. The Appalachian region had a higher prevalence of negative
behavioral risk: higher rates of obesity, smoking, physical inactivity, lower rates of mammography screenings, and the lowest rates of health care coverage. The findings of the study also suggested that there are significant barriers to adequate medical care. Specialty health services for the people of Appalachia were centralized in the region’s metropolitan areas. One limitation of this study was lack of clarity on the role of socioeconomic conditions in health disparities (Halverson et al., 2004).

Later, Halverson and Bischak (2008) conducted a retrospective descriptive study to investigate the association between measures of socioeconomic conditions and the rates of premature mortality as the leading causes of death in the United States (U.S.) particularly the Appalachian region. Analyzing death certificates, population counts, and socioeconomic data from 1995-2001, Halverson and Bischak found a statistically significant association between socioeconomic indicators and premature heart disease mortality in Southern and Central Appalachia. Southeastern and Central Appalachia dominated premature mortality from all causes of death. The contributing factors included lower levels of income, high poverty rates, high unemployment, and high numbers of uninsured. Premature cancer deaths were found to be highest in central and southern Appalachia (Halverson & Bischak, 2008).

Fletcher, Slusher, and Hauser-Whitaker (2006) conducted a community assessment in nine counties in an Appalachian region of Kentucky. The area consisted of 2,180 square miles. The findings suggested that 16.8-39.7% of the individuals living in this area were living in poverty. The area consisted of primarily Euro-Americans with 30,393 residents living without health insurance. The physician to patient ratio was 1:2500. High incidence of heart disease, cancer, diabetes, hypertension, and COPD were found in this population. Dental health was a significant issue with a dentist to patient ratio of 1:1800. The limitation of the study was that the
Community assessment was limited to nine Appalachian counties in Kentucky. The assessment was conducted to support the establishment of a nurse managed rural clinic in that designated area (Fletcher et al., 2006).

Wewers, Katz, Fickle, and Paskett (2006) conducted a descriptive study to describe the prevalence of risky behaviors in Appalachian adults residing in Ohio. Twenty-nine Appalachian counties located in Ohio were included in the study. Twenty of the 29 counties of the counties had the lowest median household incomes in the region. Using cancer surveillance data from the Ohio Department of Health, it was suggested that between 1999 and 2003 the proportion of current smokers in Ohio Appalachian counties was 31.5% compared to 26.2% of non-Appalachian Ohio counties. Wewers et al. (2006) analyzed data from the 2003 Ohio Behavioral Risk Factor Surveillance System and found that 73.6% of Ohio residents participated in any type of physical activity, compared to the national rate of 76.9%. Adults in the Ohio Appalachian region had higher rates of obesity 23.4% compared to 22.3% in non-Appalachian counties. Ohio prevalence data on risky sexual behaviors was not available. In the study, Wewers et al. (2006) analyzed data from the 2003 West Virginia Youth Risk Behavioral Surveillance system. The findings suggested that more female high school students in West Virginia reported having sexual intercourse before age 13; 54.9% vs. 43.5% nationally. The limitation of this study was that only prevalence estimates were used for this study. Wewers et al. suggested that research was needed to understand the role of social and contextual variables to understand the risky behaviors of individuals living in the Appalachian region of Ohio (Wewers et al., 2006).

Three studies explored perceptions of health among individuals living in Appalachia. Griffith, Lovett, Pyle, and Miller (2011) conducted a cross sectional descriptive study with 1,576 adults from rural Appalachia who visited a West Virginia state fair blood pressure screening
booth. The aim of the study was to evaluate self-rated health of Appalachian adults in relation to their objective health status and current health behaviors. The findings suggested a disassociation existed between perceived health and actual health. The findings also suggested that some health issues may not be perceived as poor health among individuals living in Appalachia until the health conditions limit functional abilities. The limitation of the study related to recruitment of sample individuals attending a state fair and visiting the blood pressure screening booth (Griffith et al., 2011).

Hanson and Resick (1990) conducted an ethnographic study to discover prevailing health beliefs among Appalachian mothers. The representative sample included five mothers less than 30 years of age living in an Appalachian mountain community. The findings suggested that mothers did not perceive themselves as highly susceptible to common illnesses; except colds, flu, cancer, and complications of pregnancy. The seriousness of an illness was described in terms of varying degrees of dependency and how it affected the individual’s functioning. The mothers experienced barriers inhibiting access to health care; such as lack of access to transportation, limited communications, negative experiences with health care providers, inaccurate health perceptions, and the cost of health care. The participants believed that self-care was appropriate for perceived minor illnesses and external care was appropriate for serious illnesses (Hansen & Resick, 1990).

McGarvey et al. (2011) conducted a telephone survey with participants who resided in the state of Virginia to investigate the health perceptions of community residents in Appalachian communities related to their health status and health care utilization compared to those who did not live in Appalachian counties. Approximately 60% of both samples were women with 80% white, while 90% of the non-Appalachian participants were white. Approximately 89% of the
Appalachian participants had health insurance while 87% of non/Appalachian participants had health insurance. The average income of the Appalachian residents was $15,000-$34,000 while the average income for the non/Appalachian residents was $50,000-$74,000. The findings suggested that individuals living in Appalachia had higher cancer rates. The findings suggested no difference between the two samples in rates of diabetes or hypertension. The probability of having a chronic disease was not significantly higher for participants from Appalachia, but having a chronic disease was higher for black participants overall. Individuals living in Appalachia reported their health as significantly worse, poor, or fair. Individuals with chronic diseases had lower perceptions regarding their health. White participants reported higher rates of good or excellent perceptions of health. Healthcare utilization depended on education level, race, and having a chronic disease, but was not associated with living in Appalachian and non/Appalachian counties. Black participants reported greater use of the emergency room for health care (McGarvey et al., 2011). The limitations of the study included the participants were over age 18 years and had access to a telephone. The average age of the participants was 54 years of age, with a median age of 36 years. McGarvey et al. suggested that there was a need for a more diverse race/ethnic population. Participants with fewer health related barriers were more comfortable talking with strangers and participated in the study (McGarvey et al., 2011).

Several studies explored issues related to access to health care in Appalachia. Bardach, Tarasenko, and Schoenberg (2011) conducted a mixed methods, cross-sectional descriptive study using semi-structured interviews to explore social support and self-management of chronic conditions of vulnerable residents. Forty-one participants residing in Appalachian Kentucky diagnosed with 2-6 chronic health conditions requiring self-management were included in the
study. The average age of the participants was 63 years. Findings from the study suggested that participants perceived great affection and positive interaction with health care providers.

With the Appalachian culture known as a culture of self-reliance, the findings suggested that increasing medicalization led to less reliance on family members. Participants attempted to meet their own self-management needs, as the participants emphasized their self-reliance. Although support services were available participants did not utilize the services until absolutely necessary (Bardach et al., 2011). The limitations of the study included a small sample size. The researchers suggested an evaluation of overall disease burden, health trajectory, or specific disease type could have provided additional information (Bardach et al., 2011).

Huttlinger, Schaller-Ayers, and Lawson (2004) conducted a descriptive survey with 922 Appalachian households to explore the availability, need, and access to health care services in southwestern Virginia. The random sample consisted from 16 rural and urban municipalities in coal-producing counties in Virginia. The average age of participants was 54 years with 90% with health care insurance. Participants voiced the need for free or low cost primary health care, dental care, vision care, and specialty health care. Participants were generally satisfied with their health care provider. Many participants reported dealing with depression at home and sharing prescription medications. Transportation was a needed service. Limitations cited by Huttlinger et al. included difficulty generalizing the findings in this study with other areas of Appalachia. The researchers were unable to associate the findings to the Appalachian culture (Huttlinger et al., 2004).

Coyne, Demian-Popescu, and Friend (2006) conducted a qualitative study using focus groups to examine social and cultural factors associated with health and illness in the Appalachian region. Using purposeful sampling, 10 focus groups from southern West Virginia
participated in the study. Five focus groups consisted of men, while the participants in the other five focus groups were women. The participants was 35 years of age and older. Many of the participants lived most of their life in West Virginia; their parents and grandparents were born and reared in the state. Both men and women in the focus groups expressed a sense of place, strong family ties, and strong spiritual belief for faith in God. Patriarchy was not considered a strong cultural value. Health beliefs were strongly related to religious beliefs and practices. Participants believed that individuals living in the region had low levels of medical knowledge. Many individuals in the region kept discussions regarding physical and mental health issues within the family. Many health problems affecting the people in the region were related to health behaviors. Participants expressed distrust toward physicians and questioned the quality of the healthcare they received. Other participants expressed concern regarding the lack of American-born physicians in the geographic area and the high turnover of physicians. The participants acknowledged barriers that deterred them when attempting to access and receive affordable health care. Many of the participants did not have health insurance making it necessary to travel long distances to access health care. Limitations in the study included the participants were from one small area of Appalachia. The findings could not be generalized to all of Appalachia (Coyne et al., 2006).

Lane et al. (2012) conducted a study using several measurement indexes to develop an overall index that would consistently measure health care access and cost disparities of the Appalachian region compared to the rest of the United States. The indexes used in the study included; CMS Medicare Hospital Wage Index from 2005, percentage of persons under 65 who report having health insurance reported in 2007, acute short term hospital bed, and the supply of primary and specialty physician and dentists reported in 2007. The findings suggested
Appalachian counties have more disparities related to healthcare cost, coverage, and access than the rest of the United States. Regarding health care payments and health care resources, the average values for the counties in the Appalachian region were worse than all counties in the United States. The insurance coverage for the residents of Appalachia were slightly better due to high Medicare disability enrollment and high Medicaid participation. The findings suggested the residents of Appalachian counties die younger than the general population of the United States from preventable causes. Economic distress led to poor health and factors associated with less access to health care. Most of the Appalachian region had high Medicare expenditures per capita in 2009. Lane et al. noted that 15% of the population in central and southern Appalachia received Medicare disability payments. Military veterans living in the central Appalachian region and western Pennsylvania were among the highest users of the Veterans Health Administration (VA) medical services (Lane et al., 2012).

The final study exploring access to health care was conducted by Denham, Meyer, Toborg, and Mande (2004). The researchers conducted a qualitative study using 52 focus groups. The study explored questions regarding culturally sensitive health education in Appalachia and used the findings of the study to create health education materials. The 52 focus groups consisted of 469 individuals from 24 Appalachian counties in 10 states. The findings suggested the family unit played a central role in the health of family members, with women having the major role in maintaining health among family members. Men preferred succinct factual statements and preferred pictures rather than words when receiving health information. Children and youth preferred concrete to abstract messages. Youth viewed talking about health problems as valuable. Overall, participants preferred one-on-one health information and
preferred politeness. The limitation of the study was the findings could not be generalized to other populations (Lane et al., 2012).

Three studies explored cancer issues in Appalachia. Lengerich et al. (2005) conducted a descriptive study to characterize cancer incidence in Appalachia, particularly in the rural areas of the region. Lengerich et al. aimed to ascertain differences in the cancer incidence between Appalachia and other regions of the United States. Using 1994-1998 data from the central cancer registries of Kentucky, Pennsylvania, and West Virginia (3 contiguous states); age adjusted cancer incidence rates were calculated for rural and non-rural regions in Appalachia. The state rates were compared to rates from the national Surveillance Epidemiology and End Results (SEER) program for the same years. The incidence for all cancers in the Appalachian region from 1994-1998 was 471.7 per 100,000. The rural and non-rural regions of Appalachia had similar rates of cancer. The findings suggested rural regions had a lower rate of staged cancer but conversely had a higher rate of unstaged cancer. Rural regions had a higher rate of lung cancer than non-rural areas. Rural regions had a lower rate of colon cancer, breast cancer, and cervical cancer than non-rural regions but had a higher rate of unstaged cancers. Compared to national SEER data, the incidence of lung, colon, rectal, and cervical cancer were higher in the Appalachian region. The rate for each local stage and unstaged disease were higher in Appalachia than the entire United States. The findings suggested that rural residents diagnosed with cancer had not received comprehensive diagnostic or treatment services (Lengerich et al., 2005).

Hutson, Dorgan, Phillips, and Behringer (2007) conducted focus groups in eastern Tennessee and southwestern Virginia to explore regional findings regarding cancer disparities in Appalachia. Four major themes emerged regarding cancer disparities. The participants discussed
how cancer stories were communicated throughout the rural mountainous communities between and within families. According to the participants, the cancer stories influenced perceptions of health, healthcare, and cancer of individuals residing in Appalachians. Cancer experiences affected everyone in the community especially families and communities. Rural communities and families relied on one another for providing support while caring for cancer patients. Participants expressed doubts about their abilities to access, navigate, or trust the healthcare system. The findings suggested that Appalachian communities had a lower expectation of the cancer care provided in the healthcare system. The participants expressed there was a sense of despondency within the communities regarding standard of cancer care. According to the participants, a subculture of individuals residing in Appalachia believed that cancer and cancer treatments were always fatal (Hutson et al., 2007).

Kluhsman, Bencivenga, Ward, Lehman, and Lengerich (2006) conducted a quantitative retrospective study to analyze 2002-2004 data collected by eleven rural cancer coalitions located in Pennsylvania and the state of New York. The findings suggested partnerships between coalitions and academic researchers greatly enhanced the potential to reduce the cancer burden in rural Appalachian populations. Combining resources and intervention strategies led to improved health outcomes and led to community sustainability and community change in the rural regions supported by the eleven coalitions. The cancer coalitions and their partners were able to achieve more goals through participatory partnerships than any one coalition. The limitations of the study included the coalition data system was not formally tested for validity and reliability. The data collection system was developed from an established community based intervention model: Community Coalition Action Theory. Community change was infrequently reported. In the study, the data resulted in an underestimation of the true number of community changes that
resulted from the eleven community cancer coalitions. Another limitation was the population data used in the study consisted of mostly rural white individuals (Khuhsman et al., 2006).

Three studies were found addressing injecting drug use (IDU), sexually transmitted infections (STIs), Hepatitis B, and Hepatitis C in the Appalachian region. Chesson, Kent, Owusu-Edusei, Leichliter, and Aral (2012) conducted a study to examine the rates of three sexually transmitted infections in areas of disparities. This cross-sectional descriptive study used surveillance data to calculate the incidence of syphilis, gonorrhea, and chlamydia rates in eight race/ethnic groups or geographical regions in the United States, including Appalachia. The findings suggested low-income whites in Appalachia and the Mississippi Valley had lower STI rates than the other seven groups. The groups with the highest rates for STIs were mid-America blacks, southern low-income rural blacks, and high-risk urban blacks. The limitations of the study included the surveillance data could have been incomplete. The reported infections were only for those seeking treatment. Groups for the study were only race-county aggregates; other groups could have been considered to be included in the study. Rates were quantified across the eight groups but did not exam the reasons for the disparities (Chesson et al., 2012).

Christian, Hopenhayn, Christian, McIntosh, and Koch (2010) surveyed 92 health department clients in the Kentucky River Area Development district; an Appalachian region of Kentucky. The aim of the study was to identify correlates of exposure to Hepatitis B and Hepatitis C viruses, investigate risk factors for transmission, and determine the frequency of use of preventive measures. The study was the first study conducted in the Appalachian region that explored Hepatitis B and Hepatitis C infection and risk factors. The 92 participants in the study were screened serologically for the Hepatitis C antibody and the Hepatitis B surface antigen. Twelve out of 80 participants (15%) tested positive for previous exposure to Hepatitis C. Two
out of 50 participants were positive for the Hepatitis B surface antigen. No participants were positive for HIV. The positive tests results were significantly associated with injecting drugs, having sex with injecting drug users, having sex with someone known or suspected to have hepatitis, and having tattoos or body piercings from somewhere other than a tattoo parlor. Eight of the 14 injecting drug users were found to be positive for Hepatitis C (Christian et al., 2010). Limitations of the study included; the participants in the study possibly differed from those who did not participant in the study, the participants were possibly less educated than the community at large, and the test used to screen for Hepatitis B indicated current infection rather than previous exposure to Hepatitis B. The test used for Hepatitis C indicated exposure to Hepatitis C (Christian et al., 2010).

A cross sectional correlation study was conducted by Havens, Lofwall, Foster, Oser, Leukefeld, and Crosby (2013) to determine factors associated with Hepatitis C infection among rural drug users who resided in an Appalachian region in Kentucky. Compared to the general population, the prevalence of Hepatitis C infection was greater than 50% in this rural cohort of Appalachian injecting drug users. The findings suggested that specialized Hepatitis C medical treatment is limited in Appalachian Kentucky. Rural injecting drug users are at higher risk for HIV/AIDS. The findings suggested that sharing of needles was significantly associated with being infected with Hepatitis C. Individuals injecting drugs for more than 5 years had three times the odds of being infected with Hepatitis C. Two forms of lifetime substance injection were independently associated with infection with Hepatitis C: injecting prescription opioids and injecting cocaine. The findings suggested that individuals injecting cocaine were significantly more likely than non- injecting cocaine users to have a longer duration of injecting behavior. Many of the injecting drug users in this rural Appalachian region were socially isolated.
suggesting the reason for no HIV/AIDS among the participants. Injecting drug users that admitted to having post-traumatic stress disorder (PTSD) were more withdrawn from other drug users and drug using networks, decreasing the odds of acquiring Hepatitis C infection by 65%.

The limitations included only individuals exposed to Hepatitis C were measured. The data were cross-sectional and no conclusions could be made regarding the directionality of the reported associations (Havens et al., 2013).

2.7 HIV in Appalachia

Several studies were found addressing people living with HIV/AIDS (PLWHA) in states located within the Appalachian region. A majority of the studies were conducted in the southern and south central regions in Appalachia. The studies focused on issues related to stigma, disclosing HIV/AIDS to others, patient-provider relationships, reorganizing life while living with HIV/AIDS, risks associated with HIV/AIDS, and the delivery of specialized HIV health care. Due to the limited number of current studies conducted in states located in the Appalachian region, studies conducted in the earlier years of the HIV epidemic were included in the review.

Lansky and Steinberg (2003) conducted a cross-sectional study to compare the surveillance data of cumulative AIDS cases for Appalachia and the United States overall. Lansky and Steinberg used surveillance data from states within the Appalachian region collected between 1981 through December 2000. The data included 19,222 persons greater than 13 years of age. The findings suggested the incidence rate of AIDS for the Appalachian region was 6.0 per 100,000. The following are incidence rate for each sub region of Appalachia: southern Appalachia 8.4 per 100,000; central Appalachia, 2.0 per 100,000; and northern Appalachia, 4.5 per 100,000. The largest proportion of cases was among men who had sex with men. Cases in women in the south and central region of Appalachia were attributed to heterosexual
transmission, 65% and 61% respectively. A large proportion of cases among women in the northern region were attributed to injecting drugs use (43%). In each Appalachian sub region, the largest proportion of AIDS cases were among white men. The southern region had a larger proportion of cases among black men (39%). For women in the central and northern regions, the largest proportion of AIDS cases were in white women; 79% and 57% respectively while in the southern region the largest proportion of cases were black women (59%). Over half of the AIDS cases among men and women were aged 30-39 at the time of AIDS diagnosis. A notable limitation of the study was that the data encompassed rural areas as well as urban area; (e.g., Pittsburgh). The various regions of Appalachia may have different demographic characteristics and different challenges providing care and treatment to individuals with HIV/AIDS. The findings suggested in addition for the need for more complete and standardized AIDS surveillance data, more information is needed regarding HIV related risk behaviors, and cultural beliefs regarding HIV/AIDS of individuals residing in the Appalachian regions (Lansky & Steinberg, 2003).

Hall, Li, and McKenna (2005) conducted a study analyzing HIV/AIDS data collected from the Centers for Disease Control and Prevention HIV/AIDS Reporting System. The aim of the study was to determine the burden of HIV in four rural or distressed geographic areas of the United States. Hall, Li, and McKenna (2005) used data collected on men and women reported to be living with HIV/AIDS while residing in areas of Appalachia, Mississippi Delta, Southeastern United States, and the United States-Mexican border. Analysis of the data suggested the crude rate for new HIV/AIDSs were the highest in the Mississippi Delta and lower for the United States-Mexican border and Appalachia. The majority of individuals diagnosed with HIV/AIDS were men. Heterosexual transmission in the Southeast United States consisted of a larger
proportion of men. Most women living with HIV/AIDS were infected through heterosexual transmission, however one third of the women at the United States-Mexican border became infected with HIV while injecting drugs. Rates for new AIDS diagnosis were lower in rural areas. Hall, Li, and McKenna noted that rural residents were less likely to seek HIV testing. Thirty-three to 50% of sexually active individuals with HIV/AIDS residing in rural areas reported they did not use condoms (Hall et al., 2005). Hall, Li, and McKenna (2005) cited a major limitation of the study was the possibility of incomplete data by region used in the study. The data collected were limited to 29 states that mandated confidential reporting since 1999. The completeness of AIDS reporting for the 29 states was 85% or greater. Lastly the researchers noted the possibility of misclassification of race/ethnicity of individuals participating in the study (Hall et al., 2005).

The effects of HIV/AIDS on issues related to quality of life while living with HIV/AIDS were explored in several studies. One of the earliest study addressing quality of life issues was conducted by Sowell, Lowenstein, Moneyham, Demi, Mizuno, and Seals (1997). Focus groups and face-to-face interviews were used to examine the characteristics of 82 women living with HIV/AIDS in rural communities located in rural areas of Georgia. The women were recruited through HIV/AIDS service organizations. More than half the women were African American and 72% were single. Over half the women were infected with HIV through heterosexual transmission, while 7% were infected through injecting drug use, and 17 % did not know the source of their infection. The findings suggested that many of the women feared having HIV/AIDS and feared others would find out. Women who were HIV infected had more difficulty obtaining services than women diagnosed with AIDS. Over 50% of the women felt stigmatized. The women reported using public sector entitlement programs but reported having inadequate
resources in daily living. Younger women feared blame by others and feared losing friends. Many of the women feared rejection by their families and feared their family would be hurt if others in the community learned of their HIV/AIDS According to Sowell et al., (1997) the one limitation of the study was the findings were limited to rural women with access to HIV services.

A more recent study was conducted by Vyavaharkar, Moneyham, Murdaugh, and Tavakoli (2012) examined the physical, psychological, and social factors associated with quality of life for PLWHA. The cross sectional correlation study used the variables of age, race, and time since HIV/AIDS, perceived stigma, internalized stigma and depression to examine the quality of life of 199 rural women living in southeastern United States. The participants were recruited from community based AIDS service organizations from rural areas of South Carolina, North Carolina, and Alabama. The findings suggested that African American women reported higher quality of life than white women. Older women had higher quality of life scores as they had less stress balancing family responsibilities and raising children. Women diagnosed with HIV/AIDS after the development of highly active antiretroviral therapy (HAART) treatment reported a lower quality of life due to experiencing side effects of medications and the pill burden of their treatment. Disease symptoms, stigma, internalized stigma and depression were negatively associated with quality of life scores. However, these variables were not predictors of quality of life. Conducting a cross sectional study limited the ability to establish causality was one limitation of the study. Another limitation of the study was the findings of the study could not be generalized to other populations. The last limitation of the study was that the measures depended on self-reporting and a desirability response could affected the data (Vyavaharkar et al., 2012).
The only study described as a phenomenological study was conducted in Appalachian states in southeastern United States (Phillips, Moneyham, Thomas, Gunther, & Vyavaharkar, 2011). The aim of the study was to explore the meaning of living with HIV/AIDS in isolated, impoverished circumstances while residing in southeastern United States. The data were collected from notes of peer counselors written during home visits. A notable limitation of this study was the process of data collection, as the data were not obtained directly from the women living with HIV/AIDS. The data were obtained from peer counselor notes documenting visits to 280 women living with HIV/AIDS residing in rural areas of South Carolina, Georgia, and Alabama. Eighty-four percent of the women were African American. The findings suggested that women struggled with loss and depression related to living with HIV/AIDS. Living with the disease did not dominate the women’s existence but placed more demands on their energy and efforts. Instability was part of their life. Stigma and hiding their illness existed in their interpersonal relationships and their social systems. The findings suggested that the women experienced loss of physical integrity and loved ones. The women strived for more independence but conversely became more comfortable with dependence on others (Phillips et al., 2011).

The last study identified in the literature addressed the impact of living with HIV/AIDS in the Appalachian region (Bletzer, 2007). Bletzer conducted a case study analyzing the life histories of two African Americans living with HIV/AIDS in the rural south. The aim of the study was to explore life reorganization and change in self-identity after receiving a positive test results for HIV. Bletzer also explored how HIV/AIDS differs from other chronic medical conditions that can disrupt life. The participants felt that their individual self was not weakened by HIV/AIDS. Their adulthood was constructed in relation to family background. Their world of
illicit drugs fell outside the bounds of their family background. Both participants described their self-sufficiency. Each participant constructed a new life after becoming infected with HIV. The participants reconstructed a sense of personhood living with HIV/AIDS through immersion in the immediacy of family relations (Bletzer, 2007). Limitations of the study by Bletzer (2007) included the sample size for the study consisted of two individuals living with HIV/AIDS. The findings of the study could only be associated to the two participants and could not be generalized to other populations.

Two studies explored the existence of HIV related high-risk behaviors among in injecting drug users living in the Appalachian region. McMasters, Tripp, and Argo (2008) conducted an exploratory study using interviews to document the existence of known HIV related high-risk behaviors among rural methamphetamine users, to discern the perceptions regarding of the impact of methamphetamines use and the need for services among the methamphetamine users. The study sample consisted of 97 current and former methamphetamine users from the Cumberland Plateau area in a rural mountainous Appalachian region in Tennessee. Eighty-nine percent of the participants were Caucasian, with 85% heterosexual, and approximately 91% had a household income below $30,000. Approximately 79% of the participants were native to Tennessee and were recruited while in drug treatment services. The researchers found that the participants using methamphetamines engaged in HIV related high-risk behaviors. The participants stated that methamphetamines were easier to obtain than marijuana. According to the researchers, the impact of methamphetamine use in rural areas included ruining lives, creating a negative impact on children and families, and creating increased strain on law enforcement. Seventy-three percent of the participants reported they had access to substance abuse treatment and expressed the need for targeted drug treatment and long-term drug treatment
programs for methamphetamine users. The high-risk behaviors associated with HIV/AIDS included; engaging in sexual activity with multiple sexual partners without using condoms, trading their bodies for methamphetamine, and being forced into unwanted sexual activity. Approximately 87% of the participants reported engaging in high-risk drug injecting practices such as needle sharing. Limitations of the study included the study was conducted among individuals in drug treatment in a rural area of Tennessee (MacMaster, Tripp, & Argo, 2008).

A second study described the risk network structure among high-risk rural drug users residing in a rural county in Appalachian Kentucky in order to determine the potential for HIV transmission, as well as the amenability of the drug using network to receive substance abuse treatment (Young, Jonas, Mullins, Halgin, & Havens, 2013). The researchers conducted a cross-sectional study using random network generation. The findings suggested that risk relationships within the drug-using network were bidirectional ties representing syringe-equipment sharing and unprotected sex. Eighty-nine percent of the participants were connected within one large main network of drug users. On average, the drug-using network members were approximately six steps from any other drug-using network member. The findings suggested that there was more cohesiveness and centralization than would be expected at random, possibly being a protective factor for acquiring HIV/AIDS. Conversely, HIV/AIDS entering into the drug-using network could be facilitative for transmission of HIV (Young et al., 2013). Limitations in the study included cross-sectional data limits the ability to make causal inferences. Social networks are dynamic and therefore accounting for relationship timing in disease transmission was variable. The key members in the drug-using network might not have been included in the study. The participants could have had recall and response bias (Young et al., 2013).
Other studies found in the literature explored issues related to disclosure of HIV/AIDS and HIV/AIDS related stigma. One study, conducted in Alabama by Foster and Gaskins (2009), used focus groups to explore HIV related stigma experiences of African Americans over the age of 50 years living with HIV/AIDS in the deep south in the United States. Participants completed the following measurement tools: The Self Perception of HIV Stigma measurement tool (Sowell et al., 1997), Stigma Impact of HIV measurement tool (Fife & Wright, 2000), and a socio-demographic questionnaire. The participants reported rarely or never experiencing stigma. However, the participants did experience stigma on the internalized shame scale. Participants were most likely to disclose their HIV status to family members. Participants used non-disclosure or selective disclosure to manage or decrease experiencing stigma. The participants expressed they always worried about experiencing stigma, especially in rural areas. Many of the participants sought medical treatment in larger cities to decrease the risk for stigmatization. Spirituality was used by the participants to embrace their disease and gave them hope. Many of the participants felt education decreased the likelihood of experiencing stigma (Foster & Gaskins, 2009).

Preston, D’Augelli, Kassab, and Starks (2007) explored the relationship between stigma and high risk sexual behaviors of men who have sex with men (MSM). A convenience sample of 414 rural men residing in 48 rural counties in Pennsylvania participated in the study. Using mailing lists of non-profit political action groups, social recreation groups, and two AIDS service organizations; each participant received and completed a questionnaire. The findings suggested the existence of an inconsistent relationship between stigma and mental health variables related to sexual risks. Men who experienced intolerance from others reported less self-esteem, high sexual sensation seeking, and higher levels of sexual risk taking. Men who felt comfortable with
being gay but who also experienced intolerance from others also reported high sexual sensation seeking and higher levels of risk taking. The findings suggested that risk taking might be a coping mechanism for rural MSM as a way of dealing with stress caused by intolerance from others. The limitation of the study was that the researchers were only able to access men who were most social and who self-identified as being gay (Preston et al., 2007).

Gaskins, Foster, Sowell, Lewis, Gardner, and Parton (2011) conducted a descriptive exploratory study using interviews to explore why 40 African American men living in a rural area of Alabama chose to disclose their HIV/AIDS status to others. Several reasons to disclose were shared by the men. Disclosure helped to relieve stress, remedied the need to tell, and helped to receive support from others. Many participants indicated that disclosure helped to strengthen family relationships. Many shared that they disclosed to sexual partners but not to anonymous casual partners. Reasons not to disclose included fear of being stigmatized, fear of others being told, the belief that no one needed to be told, the participant was not ready to tell, and didn’t want to burden others (Gaskins et al., 2011).

Vyavaharkar (2009) conducted a cross sectional correlation study with 340 African American women living with HIV/AIDS while residing in southeastern United States. The aim of the study was to examine the relationships between HIV related stigma, social support, and depression. The findings suggested that social support decreased HIV related stigma. Stigma was significantly positively correlated with depression. The findings suggested the need for more individualized support networks for rural women and the need to understand HIV related stigma to develop strategies to address the issues related to HIV associated stigma (Vyavaharkar, 2009).

Akers, Heckman, Holtgrave, and Yarber (2003) held a work group meeting with 70 participants from 13 states located within the geographic region known as Appalachia. The aim
of the study was to identify specific issues related to living with HIV/AIDS while residing in Appalachia. Issues identified by members of the work groups included the need to understand cultural issues and identify geographical barriers related to living with HIV/AIDS within Appalachia. The work groups’ members expressed the need to generate quality data to assist in identifying the needs related to living with HIV/AIDS while residing in Appalachia. Work group members identified the need for more research exploring efforts in HIV prevention programs and the need for the delivery of specialized HIV health care to individuals living in Appalachia. More research studies are needed to focus on the effects of HIV/AIDS on individuals living in rural Appalachia. Lastly, research is needed to identify the types of risks groups associated with HIV/AIDS in Appalachia (Akers, Heckman, Holtgrave, & Yarber, 2003).

The remaining four studies identified in the literature addressed health care and service delivery issues experienced by PLWHA while residing in states located in the Appalachian region. Boehme et al. (2012) conducted a study using focus groups to explore the patient/provider relationship from the perspective of women living with HIV/AIDS. Four focus groups consisting of women living with HIV/AIDS were recruited from four HIV service organizations located in 23 rural counties in southern Alabama. The participants discussed the attributes they sought in health care providers: caring, non-judgmental, active listener, communicative, closeness, and knowledge regarding HIV treatment. Conversely the negative attributes deterring positive relationships with health care providers included: non-caring, disrespectful attitude towards PLWHA, lack of courtesy, lack of interest in the patient, and exhibiting a judgmental or stigmatizing condescending attitude. Limitations included that participants were limited to women living with HIV/AIDS in the rural south. The participants
were recruited through AIDS service organizations and did not include women not participating in HIV specialty care (Boehme et al., 2012)

Kempf, et al. (2010) conducted a descriptive qualitative study using focus groups to generate detailed descriptions of HIV care experiences and to describe barriers and facilitators of adherence to clinic appointments. Forty women living in Alabama were recruited for the study. Thirty-seven of the women were African American and 3 women were Caucasian. The women discussed important facilitators enhancing adherence to care: patient-provider relationship, friendly faces in the health care setting, health care providers exhibiting respect for concerns of the women, appointment reminders, access to transportation, organization and management of the clinic, and showing empathy for peers and family relationships. Limitations included that participants were currently in HIV specialty care and did not include women not in care. Women lost to follow up were not included in the study. Almost all the women participating in the study were African American and 77% of the women were over the age of 40 years. One focus group consisted of 16 women: the largest of the four focus groups (Kempf et al., 2010).

Moon, Vermund, Tong, and Holmberg (2001) conducted a study using interviews to identify opportunities and the effectiveness of HIV prevention interventions for rural women before acquiring HIV/AIDS and medical and social services offered to women living with HIV/AIDS. The participants included 211 women living with HIV/AIDS residing in rural Mississippi and Alabama with the majority being African American (67%). Prior to acquiring HIV/AIDS, 37% of the women reported being seen at a HIV testing site with 30% of the women receiving risk reduction counseling. When diagnosed with HIV/AIDS, 21% of the women were not directed to HIV treatment services. Of the women who became infected with HIV due to drug use, 30% of the women were enrolled in some type of drug treatment program. The drug of
choice for the women living with HIV/AIDS included crack/cocaine (35%). A small percentage of women (10.5%) reported injection drug use with 82% sharing needles. Approximately one quarter of the women (24%) reported trading sex for drugs. Limitations included the possibility of recall bias with some of the women. The data was unable to determine “missed opportunities” in primary prevention (Moon et al., 2001).

Kilwein, Curtis, and Woodman (2008) conducted a study using focus groups to describe various aspects of HIV/AIDS service delivery system in Pennsylvania, and describe and categorize the perceptions of HIV/AIDS service providers, regional planners, and administrators. The participants forming the focus groups included administrators of seven regional HIV planning coalitions in Pennsylvania, state officials from the HIV/AIDS Bureau and the Pennsylvania Department of Health, self-selected administrators from 20 states with similar characteristics to Pennsylvania, and individuals referred by national experts of exemplary HIV programs. The findings suggested the need for improved communications between the Pennsylvania Department of Health and the seven regional planning coalitions. Needs existed for specialized medical care and transportation for PLWHA residing in rural Pennsylvania. Improved access to mental health services was identified as a need in rural Pennsylvania. A continuum of care model sensitive to needs of rural Pennsylvanians living with HIV/AIDS was identified as a need. Improved access to timely HIV surveillance data collected by the Pennsylvania Department of Health was needed for justifying services for PLHWA. The seven regional planning coalitions throughout Pennsylvania had dissimilarities. The findings suggested the need to adopt comparable structures to achieve greater efficiency between the seven regional coalitions. Interventions to reduce chronic disease should be community based and participatory because of distinct heterogeneous communities in Appalachia. Few evidence-based approaches
have been developed or evaluated with the characteristics of the Appalachian populations in mind (Kilwein et al., 2008).

2.8 Discussion

The Appalachian region is comprised of significant health disparities compared to other regions in the United States. Health disparities within the Appalachian region include premature death (Halverson et al., 2004), higher rates of morbidity (Fletcher et al., 2006; Halverson et al., 2004; McGarvey et al., 2011), issues related to high cancer incidence, limited access to cancer screening and treatment (Halverson et al., 2004; Hutson et al., 2007; Lengerich et al., 2005), and risky health behaviors (Chesson et al., 2012; Christian et al., 2010; Halverson et al., 2004; Havens et al., 2013; Wewers et al., 2006). Challenges exist related to accessing health care and existing health care provider shortages (Bardach et al., 2011; Coyne et al., 2006; Fletcher et al., 2006; Halverson et al., 2004; Huttlinger et al., 2004; Lane et al., 2012). Halverson and Bischak (2008) conducted the first study suggesting an association between socioeconomic factors and premature heart disease in Central and Southern Appalachia. Socioeconomic factors contributing to health disparities in Appalachia include out-migration of the population of young adults (Gebremariam et al., 2011) leading to an aging population (Gebremariam et al., 2011; Haaga, 2004; Skinner et al., 2011). The health perceptions of the Appalachian population have a negative impact on health leading to the creation of more health disparities (Denham et al., 2004; Griffith et al., 2011; Hansen & Resick, 1990; McGarvey et al., 2011).

Risky health behaviors associated with illicit drug use identified in the Appalachian region are associated in acquiring infectious diseases such as Hepatitis B, Hepatitis C, and HIV/AIDS (Christian et al., 2010; Havens et al., 2013). The studies conducted by Christian et al. (2010) and Havens et al. (2013) confirmed Hepatitis B and Hepatitis C infection among
individuals living in Appalachian Kentucky; however no HIV/AIDS was found among the participants.

Studies have been conducted substantiating the existence of HIV/AIDS among individuals living with HIV/AIDS in the Appalachian region. Lansky and Steinberg (2003) suggested that various regions in Appalachia have different demographic characteristics and different challenges when providing and delivering care to PLWHA. Although the study conducted by Hall et al. (2005) showed the crude rate of new HIV/AIDS in Appalachia was lower compared to other rural areas in the United States, other studies suggested surveillance data are incomplete and there was lag time in obtaining timely and accurate data (Hall et al., 2005; Kilwein et al., 2008).

Several studies explored the effect of HIV/AIDS on issues related to quality of life while living with HIV/AIDS while residing in Appalachia. The studies identified issues related to disclosure, stigma, fear, loss, balancing families, raising children, depression, isolation related to stigma, and a new self-identity (Bletzer, 2007; Gaskins et al., 2011; Phillips et al., 2011; Preston et al., 2007; Sowell et al., 1997; Vyavaharkar, 2009; Vyavaharkar et al., 2012).

HIV/AIDS in Appalachia is associated with HIV-related high-risk behaviors. Studies conducted in Appalachia associated HIV-related high risk behaviors with injecting drug use, unprotected sexual activity, being forced into unwanted sexual activity to obtain drugs, networks of individuals using drugs (McMaster et al., 2008; Young et al., 2013), and multiple sex partners (McMaster et al., 2008; Preston et al., 2007).

Studies also explored issues related to access to culturally sensitive HIV specialty care by caring health care providers (Akers et al., 2003; Boehme et al., 2012; Kempf et al., 2010), prevention programs (Moon et al., 2001), and a continuum of care model sensitive to PLWHA in
Appalachia (Kilwein et al., 2008). These studies stressed the need for research studies focusing on the effects of HIV/AIDS on individuals living in rural Appalachia, creating interventions to decrease barriers to specialized HIV health care, educating health care providers regarding the needs for compassionate quality care and prevention counseling, and the need for intervention programs for individuals living with HIV/AIDS.

Research findings have suggested the need for more studies to identify specific factors associated with health experiences in Appalachia (Coyne et al., 2006; Griffith et al., 2011; Havens et al., 2013; Huttlinger et al., 2004; Lane et al., 2012). Measures of health service availability in the Appalachian region are crude and limited in terms of utilization rates, barriers to accessing health care, and quality of health issues (Coyne et al., 2006; Fletcher et al., 2006; Halverson & Bischak, 2008; Hutson et al., 2007; McGarvey et al., 2011; Tessaro, Mangone, Parkar, & Pawar, 2006). The review of literature revealed that a majority of studies exploring the Appalachian region were conducted in 1999 and early to mid-2000s. The majority of Appalachian studies were conducted in Central and Southern Appalachia with a very limited number of studies conducted in Northern Appalachia. Three studies were conducted in Northern Appalachia: Ohio, New York, and Pennsylvania. County level health status reports suggested that many health disparities were highly localized in Appalachia (Haaga, 2004; Halverson & Bischak, 2008; Halverson et al., 2004). The literature supports the need for research studies at the local level throughout the regions of Appalachia to understand the causes of health disparities and the experiences associated with health disparities in Appalachia (Coyne et al., 2006; Fletcher et al., 2006; Halverson & Bischak, 2008; Halverson et al., 2004). A lack of studies exists for identifying and exploring health disparities related to Northern Appalachia.
The review found a lack of recent studies regarding PLWHA in Appalachia, particularly Northern Appalachia. The majority of studies were conducted before 2010. Seven studies related to individuals living with HIV/AIDS were conducted after 2010. Of the 18 studies related to HIV/AIDS, most HIV related studies were conducted in the Deep South (11 studies) and two studies were conducted in Central Appalachia. Three studies that included the entire Appalachian region were conducted prior to 2006. Only two studies related to HIV/AIDS were conducted in Northern Appalachia. Many of the HIV studies were guided by focus groups. No studies were found using a phenomenological method to understand the meaning of living with HIV/AIDS while living in a rural region in Northern Appalachia. No studies were found using phenomenology to understand meaning attributed to the experiences of PLWHA while residing in a rural region in Northern Appalachia.
CHAPTER 3

METHODS

3.1 Introduction

Hermeneutic phenomenology is used for research questions that ask for the meaning of a phenomenon with the purpose of understanding the lived experience of that phenomenon (Crist & Tanner, 2003). The purpose of this research study was to explore and understand the lived experience of people living with HIV/AIDS (PLWHA) while residing in a region in rural Northern Appalachia. Using a hermeneutical approach, the focus was on understanding the experiences of individuals living with HIV/AIDS while residing in a focused area in rural Northern Appalachia. This chapter will discuss hermeneutic phenomenology as the method of research that was used to guide this study. The discussion begins with an overview of hermeneutic phenomenology. Following this overview, a description of the research design, the setting, the sample, the recruitment process, and protection of human subjects will be discussed. Explanations of the process of data collection and the procedure for data analysis will also be addressed.

3.2 Hermeneutic Phenomenology

Humans conduct research in order to explain, describe, or predict the world in which they live. According to van Manen (1997b), phenomenology, a human science, attempts to understand human behavior and find meaning in the lived experience of an individual or a group of people. Phenomenology explores a particular phenomenon in the world of human existence. This is unlike natural science, where the emphasis is on conducting research from the aspect of positivism in an attempt to explain nature, taxonomize natural phenomenon, and explain behaviors (van Manen, 1997b). The positivism research method is conducted in a procedural
manner, using observations and controlled experimental conditions to conduct the research, then utilizing statistical analysis to measure and predict the results. The knowledge gained using natural science is generalizable, repeatable, and the subjects are replaceable. The rigor of the natural science methodology is strict, using quantitative results or “hard data”. However, this methodology does not explain the nature of human being or the nature of human life, as it can be understood. In contrast, human science requires sensitivity to the lived experience. Human science research studies individuals who have consciousness and act with purpose, creating meaning, and expressions of how humans exist in life. According to van Manen (1997b), phenomenology attempts to understand human life and find meaning of the human experience; attempting to see humans in their being, realizing that to know the world is to be in the world.

According to van Manen (1997b), phenomenology, a human science methodology, describes the orientation of the lived experience. Hermeneutic phenomenology describes how individuals experience and interpret their own lives. Semiotics is utilized to study the meaning of the experiences of individuals. Reflective phenomenological descriptions aim to construct a description of human actions, behaviors, intentions, and experiences humans encounter in the world; aiming for full and complete description of the phenomenon being addressed (van Manen, 1997b).

Phenomenology has been described as a movement broadening the range of inquiry (Stewart & Mickunas, 1974). The following will review the major tenets of the evolution of the phenomenology movement. The word phenomenon originates from the Greek word *phaemesthai*, to flare up, to show itself, to appear (Dowling, 2007). Edmund Husserl played a pivotal role in the origin of phenomenology (Stewart & Mickunas, 1974). Husserl believed that the previous assumptions of Kant were limiting, as they were empirically based assumptions of
experience. Kant believed that “only all phenomena are knowable and that there is nothing behind a phenomenon-or if there is, it is unknowable” (Stewart & Mickunas, 1974, p. 49). Husserl believed that phenomena were the appearances of something. Husserl, a mathematician, was initially interested in accounting the foundations of logic and mathematics in terms of psychologicist assumptions, but eventually he was led to reject his own initial work. This led to the development of the method of phenomenological reduction, when individuals narrow their attention to what is essential and ignores any previous prejudice about the world. This involved the suspension of certain commonly held beliefs; placing attitudes toward the world into brackets or epoché, when one can approach an inquiry focusing on a specific understanding of the phenomenon by distancing oneself from previously held theories or assumptions and allowing only the phenomena to remain (Stewart & Mickunas, 1974). Later Husserl argued that individuals were unable to bracket all beliefs, attitudes, and assumptions, for phenomenological epoché cannot bracket out pure consciousness. Husserl coined this “phenomenological residue” as he believed even if we suspend the entire world we still apprehend things on “pure consciousness in its own absolute being” (Husserl, 2014, p. 91). According to Stewart and Mickunas (1974), Husserl posited that in order to deal with empirical phenomena one had to know the essence of the phenomenon. For Husserl, the essence or *eidos* was an ability to have an insight prior to the empirical experience that is then removed from the experience (Husserl, 2014). According to Stewart and Mickunas (1974), this was an attempt by Husserl to develop phenomenology as an eidetic science, separating phenomenology from empiricism. Husserl wanted to show that essences are part of an individual’s experienced world; however his close associates saw this as a type of idealism. Other contemporary philosophers contributed to the expansion of phenomenology in order to avoid this movement of idealism. The accusations
made by his associates led Husserl back to re-analyzing his previous beliefs and leading him to the notion of the lived world. Husserl moved from the eidetic phenomenology, a form of transcendental philosophy, to emphasizing the lived world. The lived world was the notion that an individual has an unshakeable belief regarding the world in which one lives (Husserl, 1931). Life experiences, such as changing things, expectations, emotions, ideas, are always found in the context of what Husserl referred to as the “horizon” that “included time, space, the world and surrounding entities” (Husserl, 2014; Stewart & Mickunas, 1974, p. 45).

According to Stewart and Mickunas (1974), contrary to Husserl’s notion of transcendental phenomenology in which the observer was detached when describing the lived world, existential phenomenologists shifted the notion of the lived world, or *lebenswelt*, emphasizing *being-in-the-world*. The notion of *being-in-the-world* expanded phenomenology by considering the totality of human relationships in terms of an individual’s existence. In other words, “man is only man as a result of his actions which are worked out in the world” (Stewart & Mickunas, 1974, p. 64). This defines man in the context of his situation. According to Plager (1994), a major contributor to existential phenomenology was Martin Heidegger, a student of Husserl, who did not agree with Husserl’s notion of the importance of description. Rather, Heidegger emphasized the importance of understanding and uncovering the meaning of *being* (Plager, 1994). While Husserl’s focus was epistemological, Heidegger’s focus was ontological (Mackey, 2005). Heidegger rejected Husserl’s notion of describing how the world is experienced through conscious acts (van Manen, 1997b). Instead, Heidegger posited the notion of seeking understanding of the meaning of *being*, rather than what can be known. Phenomenologists using Heidegger’s philosophy seek answers related to the nature of existence of being rather than
utilizing Husserl’s philosophy of seeking answers to questions about the world and the objects
within it (Mackey, 2005).

Heidegger described ontology as the process of understanding and interpreting those
things that appear (Palmer, 1969). The rules and principles for interpreting texts pertaining to
those things that appear, is known as hermeneutics. Overall, hermeneutics is known as a science
of interpretation. The word hermeneutics is derived from the Greek god Hermes, a messenger
who interpreted the messages of the gods into human understanding. Hermeneutics brings a
situation or thing that is not understood into understanding (Palmer, 1969; Stewart & Mickunas,
1974). The Greeks believed that language and writing were the tools used by humans to convey
to others understanding or meaning of life situations (Palmer, 1969).

The field of hermeneutics has been interpreted in several different ways throughout
history. The field of hermeneutics began with interpretation of Biblical texts. Later hermeneutics
evolved into a philosophical methodology. The science of linguistic understanding was derived
from hermeneutics (Palmer, 1969). Dilthey developed Geisteswissenschaften or the study of the
stretched the conception of hermeneutics to the phenomenology of existence and existential
understanding. Ricoeur applied hermeneutics to the philosophy of interpretation of the meaning
behind myths and symbols (Palmer, 1969).

Heidegger influenced the notion of using hermeneutics, suggesting that all human activity
can be an interpretive process. What should be interpreted was not human activity but the
experiences of being. Heidegger believed that humans cannot abstract themselves from the world
(Lopez & Willis, 2004). Heidegger believed that the lived experience or being-in-the-world
should be viewed as an interpretive process rather than Husserl’s notion of a descriptive process.
Referring to being as Dasein or the nature of being in the world, Heidegger suggested that interpretation was the foundation of being. The meaning of being was to ask for the meaning of the phenomenon. For Heidegger, being-in-the-world referred to the way in which humans exist, act, or are involved with the world (Dowling, 2007). Heidegger believed that being-in-the-world was constantly evolving, moving along a continuum of past, present, and future and could not be pieced together. The most significant way of being-in-the-world was to be aware of one’s own Being and to live being authentic (Mackey, 2005). Humans find themselves engaged with others, attempting to understand Heidegger’s concept of matters of concerns. Matters of concerns are matters, topics, things, beings, or entities that emerge as concerns are addressed. The matters of concerns are phenomena that manifest themselves in an open clearing of the experience of being (Diekelmann & Diekelmann, 2009).

Heidegger believed that humans are embedded in their world such that experiences are linked to social, cultural, and political contexts, coined by Heidegger as situated-freedom. The idea of situated freedom is contrary to Husserl’s belief in radical autonomy: that is humans are free agents who are responsible for influencing their environment and culture (Lopez & Willis, 2004).

Heidegger introduced the concept of co-constitutionality. Co-constitutionality occurs when the researcher conducting interpretative research arrives at meanings that are derived from blending information articulated from both the researcher and the participant. Gadamer called the act of intersubjectivity, understanding, and interpretation the fusion of the horizon. The horizon is the background of assumptions, ideas, meanings that one experiences in living. When one interacts with others, understanding and meaning are based on the personal horizon consisting of experiences and meanings (Lopez & Willis, 2004).
Disagreeing with Husserl’s belief regarding the use of bracketing, Heidegger believed that it was not possible to bracket *being-in-the-world*: Heidegger believed that presuppositions and expert knowledge guided the researcher to inquiry and assisted in making meaningful understanding of the lived experience. The researcher’s prior understanding and experience in the world were part of the interpretation of the data and that no research can be free of judgment or influence of the researcher (Lopez & Willis, 2004). Heidegger believed it was not possible to bracket *being-in-the-world* as Heidegger believed that understanding the world is a reciprocal activity or the *hermeneutic circle* (Dowling, 2007).

The hermeneutic circle is based on Heidegger’s notion of the circle of understanding. Humans understand phenomena because they have a shared background of existence and practices. There is an understanding of the world, how humans are situated in the world, and how things fit into the world (Benner, 1994; Chang & Horrocks, 2008).

Gadamer contributed to the development of phenomenology by further advancing the concept of the *hermeneutic circle*. Gadamer, following the work of Heidegger, argued that individuals couldn’t become detached from self-prejudices, for it is self-prejudices that facilitate understanding. Understanding comes from the personal involvement of the researcher in a reciprocal process, while interpretation is related to one’s *being-in-the-world*. Dialogue is an important component in interpretation while also considering gender, cultural, and social implications. Gadamer also believed that the process of interpretation should include feedback and discussion with study participants regarding the acquired data (Dowling, 2007).

Recent school of thought proposed that bracketing is an essential aspect of data analysis (De Chesnay, 2015). Throughout the study the researcher reflects on his/hers personal preconceptions, assumptions, and prejudices in order to stay open to the inquiry (Cohen, Kahn,
With the use of bracketing the researcher reports the experiences of the participants from an unbiased approach (De Chesnay, 2015). Van Manen suggested that it is through bracketing that one can see the world through a different lens enabling the researcher to refocus on the world while researching the lived experience (Van Manen, 2014). According to De Chesnay (2015), the researcher utilizes a self-reflective diary and field notes in the process of bracketing to avoid premature closure of the data analysis. The use of bracketing within this study is described in Section 3.10 during the discussion regarding trustworthiness and accuracy of data.

The inspirations of Husserl, Heidegger, and Gadamer coalesced at the Utrecht School in the Netherlands in the 1950s. Phenomenology was introduced into the Netherlands through a series of lectures delivered by Husserl himself in 1928. The Utrecht School was initiated by a prominent psychologist, F.J.J. Buysendijk as well as M.J. Langeveld (Spiegelberg, 1994; van Manen, 1978). The emphasis of the Utrecht school was phenomenological pedagogy, as it referred to educational topics and questions regarding teaching-learning concerns. The intention of Langeveld was to develop phenomenology from the aspect of a philosophy and a method. Following Husserl’s philosophy, Langeveld wanted to develop a science to study the life-world and human becoming. Langeveld believed that phenomenological descriptions were useful in enlarging and deepening the everyday experience in the life-world by using interpretation. Langeveld believed that human maturation involved self-interpretation. In this regard, the Utrecht School employed an interpretive methodology, embracing aspects of existential phenomenology (van Manen, 1978).

were reflections of Langeveld regarding phenomena encountered in his private practice as a child-rearing consultant and educator. All English translations of the writings of Langeveld and the Utrecht school were found in books and articles written by Van Manen (van Manen, 1978, 2007).

The Utrecht School is concerned with Wesenchau, the search or essences or ground structures of selected life-world phenomena. Some of the essential features of the Utrecht School included the development of phenomenological pedagogy as a science, the idea of situation analysis to describe life-world descriptions, and using the gained knowledge for practical action (van Manen, 1978).

According to van Manen (1978), Langeveld initiated the concept of pedagogy as a practical science. Pedagogy is a science that seeks to understand it objects, to understand how things are, and how they act. For Langeveld, the word science was grounded in hermeneutics. Consequently, the Utrecht School focused on pedagogic situations, interpreting the situations from an inner experience and the structures of the lived world. From the perspective of the Utrecht School, phenomenological pedagogy is an objective and interpretive science, using both participant observation and life-experience data. The Utrecht school embraces Husserl’s idea of the search for the essence or nature of a phenomenon of the life world (van Manen, 1978).

Situation analysis played a major role in phenomenological pedagogy. The situation is the viewpoint of the human being in the world. Being is being-in-the-situation (van Manen, 1978). According to van Manen (1978), Langeveld believed the function of the situation analysis led to practical action. Proponents of the Utrecht School believed it was possible to obtain insights into the essential structures and relationships of a phenomenon by the study of concrete examples of an experience. This was adopted from Husserl’s desire to develop a science of
subjectivity of the life-world. The three distinct features of situation analysis developed by the proponents of the Utrecht School included gathering life situation materials, using the material for descriptive analysis, and making recommendations for practical action (van Manen, 1978).

Langeveld suggested that there is a secret place in the lives of all humans (Langeveld, 1983c). According to van Manen (1978), the use of analytic descriptions of human experiences uncovers these secret places. The intent of all pedagogic knowledge is developing meaningful knowledge from concrete situations. The challenge is to link knowledge into practical action. Hermeneutic phenomenological insights from life of humanity contribute to communicating the deep structure of a certain phenomenon. The idea of deep structure refers to human sense making and is a device for analyzing phenomenological inquiry. According to the proponents of the Utrecht school, phenomenological knowledge is not practical in the sense of technical skills but the knowledge can contribute to an orientation to the life-world and give wisdom to act in human situations (van Manen, 1978).

Van Manen (1984), a proponent of the Utrecht School, offered approaches to further develop hermeneutic phenomenology as a research methodology. Using the Utrecht School approach, van Manen suggested six guiding factors in conducting phenomenological research. The procedural activities include; turning to a phenomenon that interests the researcher and commits the researcher to the world as humans know it, the researcher investigates an experience as individuals live it rather than as the researcher conceptualizes it, the researcher reflects upon the essential themes of the phenomenon under investigation, the phenomenon is described through the art of writing and re-writing, importance of the researcher to maintain a strong and oriented pedagogical relation to the phenomenon, and the need for the researcher to balance the context of the research from the aspects of the parts and the whole (van Manen, 1984).
Hermeneutic phenomenology is used for research questions that ask for meaning of a phenomenon with the purpose of understanding the human experience of that phenomenon (Crist & Tanner, 2003). According to Dowling (2007), van Manen’s approaches to phenomenology offer solutions to nurse researchers and is well suited for nursing research. Using the Utrecht School approach, descriptive and interpretative phenomenology guided this inquiry seeking to understand the lived experience of individuals living with HIV/AIDS while residing in a rural region in northern Appalachia. The research focused on the lived experience of the participants within the context of their experience and the meaning of their experiences.

3.3 Setting

This study was conducted in a rural region in northern Appalachia. After approval from the Duquesne University Institutional Review Board (IRB) (Appendix D) and the IRB of the university (Appendix E) that provides administrative support for a regional AIDS service organization (ASO), interviews were conducted in a private setting, such as a private office at the ASO or at a private meeting place that was agreeable and convenient to the participant but also maintained the confidentiality of the participant. Interviews were not conducted in a public setting. A regional AIDS service organization was identified as a setting because it is where PLWHA receive services.

3.4 Sample

Byrne (2001) stated that the qualitative researcher must describe the demographics of the sample of participants in order for others to understand why the sample was chosen. According to Sandelowski (1995), adequate sample size in qualitative research is one that “permits new and richly textured understanding of the experience” (p.183). Sandelowski (1995) suggested a sample size of 10 may be adequate for particular homogeneous case sampling. Morse suggested
approximately 6-10 participants are needed to reach richness in the data in a phenomenology study (Morse, 2000). Byrne suggested that once the experiences of the participants have been captured in the categories or themes, then the data regarding the phenomenon has been saturated (Byrne, 2001). In data saturation, the researcher has collected enough data that no new information is obtained, or new information is redundant (Morse & Richards, 2002; Polit & Beck, 2012). Based on these recommendations, the researcher planned for recruitment of approximately 10 to 15 participants out of an estimated 500 individuals known to be living with HIV/AIDS while residing in a rural region in northern Appalachia, with the knowledge that data would be collected until saturation of data was reached. No new themes were evident after the analysis of data from twelve of the participants. To assure data saturation, the researcher recruited and interviewed three additional participants. Since no new information was obtained in the last three interviews, data saturation was confirmed.

Inclusion criteria for this study were: individuals willing to participate (men, women, or transgender from all racial/ethnic groups) with an age range of 18 years of age and older, who self-identified as being HIV infected, who spoke and understood English, and who self-identified as living in a rural area of Northern Appalachia. If unable to read the information regarding the study and the consent, the information and consent were read to the participant. The study did not include individuals under the age of 18 years, since the research topic is not relevant to children. To stay true to the research question any individual living with HIV/AIDS meeting the inclusion criteria and who are representative of the population and knowledgeable about living with HIV/AIDS was included in the study (Endacott, 2007).
3.5 Recruitment

Purposeful sampling and snowballing were used to select volunteer participants for this study (Patten, 2009; Polit & Beck, 2012). In purposeful sampling, participants are selected because it is believed they will be good sources of information or have the specific characteristics or features (Miles & Huberman, 1994; Morse & Richards, 2002). Snowballing is beneficial when attempting to locate isolated participants. The researcher invited study participants to share information about the research study and the researcher’s contact information with others who might be interested in participating in the study and who met the inclusion criteria (Endacott, 2007; Patten, 2009). Currently, the regional ASO provides services to approximately 500 individuals in northern Appalachia.

Recruitment was conducted according to the following plan. Prior to the distribution of recruitment flyers, the researcher met with the staff of the ASO on December 15, 2015 and other key individuals and discussed the aim of the study and the recruitment process. The researcher stressed to the staff of the ASO that the research study was voluntary, reviewed the inclusion criteria, and stressed that participants may withdraw from the study at any time. The researcher emphasized the need for confidentiality of the participants. Recruitment flyers (Appendix F) were distributed by the researcher, the current staff of a regional AIDS service organization, and key individuals within the HIV/AIDS community, such as consumers. Consumers, who access services at the regional ASO, had access to recruitment flyers if they were interested in sharing information about the study.

Written recruitment flyers regarding the study were distributed or posted by the researcher, staff members of the ASO, and other key individuals on bulletin boards, private offices, private rest rooms within the offices of the ASO, private meeting places of HIV/AIDS
support groups, private offices and clinic rooms of a rural HIV clinic. A recruitment article in a newsletter published and distributed by the ASO was also used. Further, case managers within the ASO shared information regarding the study to individuals living with HIV/AIDS. The case managers employed by the ASO distributed the recruitment flyer to individuals living with HIV/AIDS, and if interested in volunteering for the study, the individuals contacted the researcher. Some participants preferred that the researcher contact them by telephone. The interested participants were given the option to sign a release of information consent form to allow the staff at the ASO to share their preferred contact information with the researcher and permit the researcher to contact the participant. A protocol amendment was submitted to the Duquesne University Institutional Review Board allowing the participants to sign a release of information consent form to allow the researcher to receive the participants’ contact information and contact the participant (Appendix G). Early participants in the study were invited to share information regarding the study to other individuals who might have an interest in participating in the study.

Potential eligible participants referred for the study were given a telephone number to contact the researcher. A second option was to allow the potential eligible participant to sign a release of information consent to allow the staff at the ASO to share their preferred contact information with the researcher and permit the researcher to contact the participant. If the participant did not have a telephone, the regional AIDS service organization assured the researcher that the participants had access to private telephones in private offices of the regional ASO to communicate with the researcher. During the initial telephone call from the participant, the researcher explained the study and determined if the inclusion criteria were met. The researcher then scheduled a time and a private meeting location convenient for the participant to
conduct the interview. The interviews were conducted in a private setting, such as a private office at a regional ASO or ancillary offices, private office at the university, or the participants’ home, all of which provided a private, convenient and confidential setting for the interview. No one but the researcher and the participant were permitted in the private room during the interview and the door was closed until the interview ended. No information was audible outside the confines of the private office/room where the interview was conducted. All of the interviews were conducted in the private homes of the participants except for 2 interviews that were conducted in a private office at a regional ASO, and one interview that was conducted in a private meeting room of a public library per the participant’s request.

3.6 Compensation

Payment of research participants has been a contentious practice with a variety of ethical issues (Grady, 2005; Sears, 2001). According to Sears (2001), the gift model may decrease concerns regarding coercion; while keeping in mind that compensation for research participants should be an ethical approach of respect for human subjects and offering of self. Compensation should be proportional to the risk and “annoyance of participation in the study as compared with the standard of care, to minimize coercive effects” (Sears, 2001, p. 659). McGee (1997) wrote that the proportional reward should be based on the amount of time, effort, or inconvenience. Additionally the Institutional Review Boards reviewed the proposal to determine that the amount of payment, proposed method of payment, and timing of the payment were not coercive or created undue influence (Sears, 2001). According to Grady (2005), the appreciation gift model may have the least impact on study recruitment. The appreciation gift model is determined by the local economic norms for the area and the time frame necessary in order to participate in the study. As a token of appreciation for participating in the study, each participant received a token
gift in the form of a $10 gift card to a convenience store at the completion of the first face-to-face interview and completion of the second face-to-face interview. According to Dickert, Emanuel, and Grady (2002), payment should be received at the time the participant contributes to the research as this lessens the pressure to complete the study.

3.7 Procedure for Protection of Human Participants

Permission was obtained from the Duquesne University Institutional Review Board (IRB) on September 17, 2015 and the IRB of the university that provides administrative support for a regional AIDS service organization on October 29, 2015 as part of the procedure for the protection of human subjects. All data were collected by the end of July 2016. The researcher submitted an annual review report to Duquesne University IRB and received approval to continue the study on August 26, 2016 (Appendix H). The Duquesne University IRB annual review report approval was sent to the IRB that provided administrative support for a regional AIDS service organization on October 19, 2016.

Participation in the study was voluntary. The research participants were not obligated to participate in the study. The participant could withdraw from the study at any time without reason.

Each participant received a consent form from the researcher to read and sign if they agreed to participate in the research study (Appendix I). If unable to read, the consent form was read to the participant by the researcher. Included in the consent form were the names of the researcher and her advisor. The researcher reviewed with the participant the source of the study and the purpose of the study. The consent form provided the participant with the risks and benefits of participating in the study. The consent provided information about compensation, maintaining confidentiality, and the right to withdraw from the study at any time. The
participants were offered the opportunity to obtain the findings of the study. The consent explained how the participant gave consent. Contact information for the researcher was included in the consent form. Each participant was given a copy of the consent form.

Once it had been determined that the participant had met the inclusion criteria and after agreeing to participate in the study and signing the consent form to participate in the study, the participant was interviewed in a private setting as described previously. Following the interview, confidentiality of all participants was maintained by securely maintaining the data in a locked file cabinet in the researcher’s office until the data is destroyed. Upon completion of the dissertation, the original transcripts will be destroyed using a personal cross cut shredder. The data will include written materials, audiotapes, and consent forms. The identity of the participant was not revealed in the data analysis. Participants’ names and identifiers were encoded using pseudonyms. Pseudonyms were changed to labels (e.g. “participant number 1” etc.). All references to geographic locations and personal information were removed.

The data manager, NVivo 10© (QRSInternational, 2012), was loaded onto a password protected computer to organize the data. Transcripts were loaded into NVivo10© by the researcher. Upon defense of this dissertation, the researcher will retain all de-identified data for any further research studies associated with the current study. The researcher will delete audio sound files and transcripts. Hard copies of the transcripts will be shredded by the researcher using a personal shredder in the researcher’s office upon successful defense of this dissertation. Demographic data were presented in aggregate form only.

The interviews were audiotaped. In addition to signing the consent to participate in the study, the participant gave verbal consent at the beginning of the taping of the interview. The researcher asked for permission to audiotape the interview at the start of the tape and this
permission was recorded. If the participant did not give permission for audiotaping, the researcher planned to stop the audiotaping and use paper and pencil to document the interview information. All participants gave permission to audiotape the interview. To maintain the confidentiality of the participants, the audiotapes were transcribed using a professional transcription company, Verbalink™. The professional transcriptionist was required to sign a confidentiality statement (Appendix J and Appendix K).

There was no physical risk from participating in the study outside the risks of normal everyday living. During the interview, if questions caused the participant discomfort, they had the option to not answer the question or to end the interview. If needed, the researcher had the ability to provide participants with the names of mental health care professionals in the community to access psychological services. To the knowledge of the researcher, this was not requested nor indicated as a need by the participants.

3.8 Data Collection

Once the Duquesne University Institutional Review Board (IRB) and the IRB of university which provided administrative support to a regional AIDS service organization granted approval, and after meeting with the staff of the ASO and the researcher reviewed the requirements for the study, recruitment for the study began. The researcher worked collaboratively with staff at a regional ASO to recruit participants. Potential eligible participants referred for the study were given a telephone number to contact the researcher. Once a participant was found to meet the inclusion criteria, he/she was invited to participate in the study. During the initial telephone call the researcher explained the study to the potential participant and scheduled a time and private meeting place, as previously defined, convenient to the participant.
Data were collected using a semi-structured interview conducted by the researcher. The confidential, face-to-face interview, with the time allotted for the interview being approximately 1-1.5 hours in length, was conducted at a regional AIDS service organization, using private offices within the organization, or in a private setting agreeable to the participant. In order to ensure the safety of the researcher, the dissertation chair was provided with the address of the location of the interview and a telephone number to contact the researcher. The researcher notified the chair when she was leaving for the interview, when she arrived at the site of the interview, and when she left the interview. Upon learning that the researcher was safe, the chair destroyed the contact information provided by the researcher by shredding the information.

After obtaining consent from the participant, the interview was conducted. During the face-to-face interview, the researcher explained the study and the participant signed the consent to participate in the study. Once the consent was signed, the participant was asked to complete a demographic questionnaire (Appendix L). The researcher conducted the face-to-face interview. The interview questions were open-ended to ensure the participant guided the interview. The research focused on the research question, “What is the experience of PLWHA residing in a rural region of Northern Appalachia?” Probe questions were used to clarify meaning and encourage shared conversation (Appendix M). Probe questions included, “Can you tell me about that?” “Can you give me an example of that?” “What comes to your mind?” “What do you remember most?” “Is there anything else you would like me to know or feel it is important for me to know?” The interview ended with the question, “Is there anything you would like me to know regarding your experience participating in this interview?” and “if you had to give a title to your experience of living with HIV/AIDS what would the title be?”
With the completion of the first interview, the audiotape was transcribed. All of the interviews were transcribed verbatim by the transcriptionists who signed the confidentiality statement based on available time or availability to do the transcribing soon after the interview was completed. The typed transcriptions were received within 3-5 days after submission. Upon receiving a typed transcription, the researcher listened to the taped interview and compared it to the typed transcription for accuracy. Once the researcher verified the accuracy of the typed transcription, the researcher began the analysis of the data. The data were managed using the software NVivo10 (QRSInternational, 2012) and manually by the researcher. The researcher reviewed the first 2-3 interviews with her dissertation chair to ensure accuracy of coding and identification themes, clustering, and analysis. Independent of each other, the chair and the researcher reviewed data, assigned themes, and clustered themes. Findings were compared. Any disagreements were discussed in person, via telephone, or via email. A final meeting to conclude data analysis was held between the researcher and the dissertation chair on September 30, 2016. The dissertation chair also critiqued the interview technique of the researcher to assure the interview was conducted appropriately and without leading the participants’ responses.

A second interview with the participants was conducted to validate accuracy of the interpretation of data with participants. Of the 15 participants, 13 participants participated in the second interview. Two participants did not respond to the invitation to participate. The coding of the data and the conclusions about the meaning based on the codes were verbally reviewed with the participants (Prion, 2014). In all the second interviews, participants agreed with the interpretation without exceptions. The participants elaborated on the experiences and the meaning became more valid. The second interview was conducted in a private setting as previously described. The second interview lasted approximately 1-1.5 hours.
3.9 Procedure for Data Analysis

For this research study, the researcher used analysis methods congruent with the Utrecht School tradition (Barritt, Beekman, Bleeker, & Mulderij, 1984; Cohen et al., 2000; van Manen, 1978, 1984, 1997b, 2007). The aim of phenomenological data analysis was to “transform lived experience into a textual expression of its essence in such a way that the effect of the text was at once a reflexive re-living and a reflective appropriation of something meaningful” (van Manen, 1997b, p. 36) Phenomenological descriptions aimed at elucidating lived experiences. “A good phenomenological description elucidates some aspect of the “life-world” that resonates with a sense of lived life, also known as the phenomenological nod” (van Manen, 1997b, p. 27). Using the line-by-line approach, each transcription was read and re-read several times to identify statements that revealed the experience being described (van Manen, 1984). Van Manen (1997b) referred to this as immersion. Themes and variation in the themes were identified. The next phase of the analysis was data transformation or data reduction. The researcher made decisions regarding what data were relevant and what were not relevant (Cohen et al., 2000). Based on the Utrecht School of phenomenology, thematic analysis was the next phase. After obtaining an understanding of the overall text, phrases were underlined or highlighted and tentative theme names were noted in the margin of the text (Cohen et al., 2000). Once identified, themes were compared to ascertain unique emerging themes (Barritt et al., 1984; Tesch, 1987). In addition to themes, textual data in the language of the participant, also known as exemplars, were also used to convey the meaning of living with HIV/AIDS in a region of rural northern Appalachia (Cohen et al., 2000).
3.10 Trustworthiness and Accuracy

Questions regarding trustworthiness and accuracy surround the use of interpretive phenomenology as a research method. According to de Witt and Ploeg (2006), the need for qualitative rigor emerged during the debate regarding the legitimacy of qualitative research. Reliability and validity are terminology used in quantitative research. Phenomenologists rejected this terminology, and preferred the use of trustworthiness and accuracy (Cohen et al., 2000).

Byrne (2001) succinctly outlined and discussed the terms related to trustworthiness and accuracy in qualitative research. Credibility is attained when the researcher documents things such as personal experiences, qualifications, perspectives, assumptions, and presents strategies for the research study that are congruent with the methodology. Trustworthiness and accuracy can be achieved by developing strategies for data collection and analysis of the data. The researcher kept a journal of the progression of her research study.

Member checking can also add to the trustworthiness and accuracy of a study. With member checking, the researcher confirms or clarifies the interpretation of the data with the participant. Member checking, to determine the accuracy of the data, was used to ensure trustworthiness and accuracy to the study (Creswell, 2009; Prion, 2014). This researcher conducted member checking during the second interviews with 13 of the 15 participants.

Transferability is used in qualitative research to “judge the extent to which the findings can be applied to other contexts. This is achieved by writing “thick descriptions using themes or labels and using purposive sampling” (Byrne, 2001, p. 104). Confirmability is achieved using an audit trail. The audit trail is a record of how decisions were made and what steps were taken in conducting the study. The audit trail could include a researcher’s journal, the original data such as audiotapes, transcribed data, written interpretations of the data, analysis of the data, and
communications with colleagues and research participants (Byrne, 2001). This researcher’s audit trail was achieved using the researcher’s journal, the original audiotapes, transcribed data, NVivo 10, written interpretations of data, analysis of data, and communications with colleagues and research participants.

Bracketing, derived from the term reduction, requires one to be aware of feelings, preferences, inclinations, or expectations that would interfere with exploring the phenomenon being studied (Sokolowski, 2000; van Manen, 1984, 1997b). The researcher needs to let go of any previously held preconceptions of the phenomenon being explored (van Manen, 1997b). During bracketing, the researcher suspends personal beliefs about the world in order to study the essentials of the world (Beck, 2009). Long and Johnson (2000) suggested that researchers examine their own beliefs in the same manner as they examine the beliefs of the participants. This researcher accomplished bracketing by keeping a researcher’s journal that included field notes and personal reflections before interviewing began and while conducting the study.

Inter-coder reliability enhances the trustworthiness and accuracy of a qualitative study. For this study, trustworthiness and accuracy were maintained using various approaches. This researcher achieved inter-coder reliability as established between the researcher and faculty advisor. Meetings with the faculty advisor were held at least in monthly intervals to discuss the researcher’s emerging findings and to explore perspectives at various stages of the data collection and analysis. Agreement between the researcher and faculty advisor was obtained 90% of the time. If the researcher and faculty advisor disagreed, discussion followed until a mutual agreement was reached. Inter-coder reliability prevents premature closure in the search for meaning and patterns in the data, as well as gain constructive criticism (Creswell, 2009; Long &
Johnson, 2000). To ensure fidelity of the data collected, the faculty advisor monitored the audiotapes for consistency in the researcher’s interviewing techniques.

Confirmability was achieved by using an audit trail. An audit trail was kept to add dependability and replication of the study. Details of all sources of data, collection of techniques, field notes, and analysis were kept. To prevent researcher bias, the researcher used bracketing of personal responses to the research questions prior to starting the interviews and throughout the study (LeVasseur, 2003). The audit trail assisted in following the researcher’s decision making process throughout the study (Prion, 2014).

3.11 Summary

The purpose of this research study was to describe and understand the lived experience of PLWHA while residing in a rural region in Northern Appalachia. This study used a hermeneutic phenomenology design. The study participants were recruited with the assistance of staff from a regional AIDS service organization, key informants, and word of mouth. To be eligible for the study the individuals needed to self-identify as being positive for HIV/AIDS, speak English, be male, female, or transgender, across all racial/ethnic groups, be 18 years of age or older, and reside in a rural region in Northern Appalachia. The participants were asked to participate in the first face-to-face interview lasting approximately 1-1.5 hours to describe the lived experienced of living with HIV/AIDS in a rural region of Northern Appalachia. Data were collected, transcribed, and coded using hermeneutic phenomenology methods based on the Utrecht School. Thirteen participants were interviewed a second time. The purpose of the second interview was to validate the researcher’s interpretation of the participant’s experience. Data collection and analysis occurred concurrently until data saturation was attained.
The findings were used to bring to light the experiences of individuals living with HIV/AIDS while residing in a rural region in rural Northern Appalachia. Illuminating the experiences of these individuals will assist nurses in providing support to all PLWHA living in this rural region of Northern Appalachia.
CHAPTER 4

FINDINGS

4.1 Introduction

Using a hermeneutic phenomenological approach, the focus of this study was to describe and understand the lived experience of people living with HIV/AIDS (PLWHA) residing in a rural region of Northern Appalachia. This chapter is divided into the following sections: description of study participants and main themes identified across the data: surviving the predators, walking the road to death, rebirth/second chance, building the nest of safety, and living in the shadows.

4.2 Description of the Study Participants

The study consisted of 15 participants self-identified as living with HIV/AIDS and residing in a rural region of Northern Appalachia. Participants included 4 women and 11 men. Fifteen initial interviews and 13 second interviews were conducted. The second interview satisfied member checking. Two participants were not available for the second interview. At the end of each face-to-face interview each participant received a $10 gift card for a local convenience store.

Sociodemographic characteristics and HIV/AIDS related data of the participants were collected from the demographic tool completed by the participants at the beginning of the first interview (Table 1). Eleven of the participants fell within the age ranges between 46 years and 65 years. Two of the participants were younger than 45 years. Two of the participants were older than 66 years. Participants self-identified as single, married, divorced, widowed, or living with a domestic partner. Seven of the participants lived in a relationship with a significant other. Nine participants lived alone. The range of years living with HIV/AIDS was noted by participants.
Participants documented having lived with HIV/AIDS from 1 year to 30 years. All of the participants received various support services. For many of the participants the number of years receiving services was not the same as the length of time living with HIV/AIDS. Many participants did not receive services at the time of their diagnosis. All of the participants documented they received case management services.

4.3 Study Findings

Thematic analysis was used for data analysis. After obtaining an understanding of the overall text, common phrases frequently occurring throughout the text were identified and compared to identify unique emerging themes (Barritt et al., 1984; Cohen et al., 2000). The major themes emerged from frequently occurring phrases and experiences described by the participants in the data (Barritt et al., 1984). Six major themes captured the essential meaning of living with HIV/AIDS while residing in a rural region of Northern Appalachia. The six major themes are shown in Table 2.
Table 1.

*Demographic Characteristics and HIV/AIDS Data of the Sample (n=15).*

<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age range</th>
<th>Marital status</th>
<th>Years living with HIV/AIDS</th>
<th>Years receiving services</th>
<th>Types of services</th>
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<tbody>
<tr>
<td>01</td>
<td>M</td>
<td>36-45 years</td>
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<td>M</td>
<td>46-55 years</td>
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<td>1-5 years</td>
<td>10 months</td>
<td>CM, SP, HC</td>
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<td>56-65 years</td>
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<td>30+ years</td>
<td>18 years</td>
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<td>56-65 years</td>
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<td>06</td>
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<td>66-75 years</td>
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<td>13</td>
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<td>CM, HC, SP, SG</td>
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<td>15</td>
<td>M</td>
<td>46-55 years</td>
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<td>10-20 years</td>
<td>10+ years</td>
<td>CM, SP</td>
</tr>
</tbody>
</table>

Notes: Gender (M: male; F: female); Marital status (S: single; M: married; W: widowed; D: divorced; DP: domestic partner); Types of services (CM: case management; HC: rural HIV clinic; SP: special pharmaceutical program; SG: support group)
Table 2.

Major Themes.

1. Surviving the predators
2. Walking the road to death
3. Encountering the brink
4. Rebirth/Second chance
5. Building the nest of safety
6. Living in the shadows

To assure confidentiality of the participants, each participant is referred to as “Participant [number]”. All other identifying information was removed.

**Theme 1-Surviving the Predators**

Fifteen participants revealed early experiences of surviving what several participants referred to as “predators”. The participants shared experiences of poor relationships or sexual/physical abuse with relatives, such as fathers and cousins. Several participants experienced betrayal, infidelities, and abandonment by loved ones. All participants elaborated on experiences with predators that occurred prior to becoming infected with HIV. Several participants suggested that their experiences with the predators contributed to the high-risk behaviors that led to acquiring HIV infection.

Participant 12 shared an experience with her abusive father.

My dad was an abusive person, a child molester and everything else, so I didn't get along really well with my dad so they had to put me in a foster home so I was
raised pretty much in foster homes. Not that I stayed in a foster home. I ran away from foster homes and ended up living in the street.

Participant 2 shared his experiences of surviving sexual abuse perpetrated by his cousin.

The family I grew up was an incestral family. My cousin, (name), raped me at the age of six – brutally. It wasn't sex. It was brutal rape, and that continued till I went to the military. One time, I was having sex with my one cousin, and he said to me, “It's so different when I have sex with you vs. when I have sex with our cousin, (name), because he's always so mean to me.” And it's like – He was a predator.

Surviving situations associated with being molested by men, experiencing emotional abandonment by her parents, and abusing alcohol, Participant 4 believed that the experiences led to the high risk behaviors associated with acquiring HIV.

So, I had really – I was prone to get HIV, actually. When I read about some of the situations – being molested, the abandonment, the alcohol – it all put me right there to get infected with HIV. And to have all these predators throughout my life is just – [Laughs].

Participant 5 shared experiences associated with physical abuse by his father who suffered from post-traumatic stress disorder (PTSD) as a result of serving in the Army during World War II. He stated:

Dad came out of World War II. He was in the war and then the beaches got blown up. Shot three times…shell hit him. He was not stable in his mind. Not at all. That wasn’t right. He whipped me with a cat o’nine tails when I was a little kid while I was in bed. Whatever I did. If he was alive today he couldn’t do this.

During his youth Participant 13 described a turbulent relationship with his parents.
My mom and dad had a hell of a marriage. I had bleeding ulcers in 7th grade from the stress of their marriage. It was horrendous. I mean terrible. Then you’d sit in church and never know and they’d take it out on me. I was the oldest son. I was a pretty big kid. So I got some undeserved roughing up.

Some of the participants shared experiences of betrayal by significant others who failed to disclose their HIV infection. Participant 10 shared his experience of being betrayed and abandoned by a partner who infected him with HIV.

He was royally pissed at me 'caus I confronted him about being infected with HIV and everything else. Well, about three weeks later I didn't see him, nothing. I just didn't go – I was so depressed I didn't go out with anybody.

Participant 9 shared his experience of betrayal by his partner.

One night we went all the way and I played the passive role, and we didn't use anything, and I thought he would have said something if there was any – if it would have been a bad idea anyway. But if he knew there was some reason not to he would have said something. So the next morning I said (person), about last night, and he cut me off and said, “That was a decision you made”, and I was taken back by that. I didn't know what to say. What I should have said was no, it was a decision we made, and is there anything you didn't tell me. But I was dumb struck and I didn't say that. Then we cooled off immediately and I asked one of his friends – no that didn't come until later. What came eight weeks later was a fever and a sickness that lasted about a week, and I was sick as a dog.
Theme 2-Walking the Road to Death

In this study, living with HIV/AIDS initially meant walking the road to death. Participants described experiences along the road to death. Participants provided profound descriptions of the difficulties they encountered after the diagnosis of HIV infection. Fourteen participants described “walking a road to death” either prior to learning of their infection or at the time of their diagnosis. Participants struggling with addictions stated that they knew eventually the addiction would lead to their death. Other participants contemplated suicide that would lead to their death. Fourteen participant believed the diagnosis of HIV infection was a death sentence.

Five of the participants shared that their high risk behaviors such as substance abuse and sexual activities put them on their road to death. Purposely behaving recklessly, Participant 11 shared he believed he was traveling on a road of slow suicide. “Interesting to use roads to death, because I think when I was exposed, I was behaving recklessly fairly much on purpose. I think I had somewhat of a death wish at that time. Slow suicide, not necessarily by my own hand, so to speak. Because of all the issues I hadn’t been dealing with.”

Involved in high risk behaviors that led to his HIV infection, Participant 15 shared his experiences of abusing alcohol and being sexually promiscuous that placed him on a road to death.

But, I’m not sure how I contracted HIV, but I lived for about 15 years in California and north of San Francisco and back then I did a lot of drinking and partying and had a pretty promiscuous lifestyle, so I’m sure putting two and two together, it would probably be a safe guess that I did it when I was out there. Then everything just sort of snowballed into, you know, a bad situation when I found
out. I was surprised but in a way I wasn’t because I was just praying that I wouldn’t be diagnosed with a positive result, but I was. I watched a friend of mine contract it, he found out in the spring of one year, and by fall he was gone. I mean he just overnight he lost tons of weight and it was an ugly thing to see. I mean it’s scary. I thought this is going to be me. When I found out about it I thought that’s going to be me. I remember I was like telling the doctor, I said, “I can’t believe I’m going to die.” He said, “You’re not going to die.” I just steadied myself and thought I got to do what I can to survive.

Dominated by a drug addiction, Participant 3 feared becoming HIV positive as he believed it would be a death sentence. At the time he learned of his HIV infection, he not only thought he was going to die of HIV but he described the losses one experiences due to addictions. Participant 3 stated:

I knew what he was going to say before I got there so when he told me it really didn't knock me over like you think it would, you know. So it took -- then once I became positive then I started -- and I kept replaying that statement because it stuck with me. And what it was is that, you know, when you're negative, you're so fearful that you're going to become positive because at that time you were going to die. If you get a positive result you're going to die. You know this from the 80s and 90s. I was in a very intense, devastating drug addiction while I was there and I became positive during that time. My addiction was getting worse and worse and worse. So my family had to come down and extract me from there. In a way you're right because the addiction will take everything you have from you. You know, I knew that I was -- I was smart enough to not ever let myself die from my
addiction but people do that, you know. You lose everything. You lose all – you
know, you lose your dignity. You lose your finances. You lose your home.

Two of the women, who were in a monogamous relationship with their male partners
who were HIV infected, shared how they continued to put themselves at risk for HIV infection
even though they were aware that they could become infected. The women were aware that they
could die from the infection. Reconnecting with a former boyfriend, Participant 14 shared how
she knowingly put herself at risk for HIV infection during their relationship.

I got back with him, still went unprotected, still all that stuff. And then, he wanted
to go to California. So we went to California. And I started using IV drugs with
him, knowing he had HIV, knowing what IV drug use does. I knew all this. And I
was purposely out to kill myself, obviously. When I realized I actually was killing
myself, I wanted to come home. I wanted to come home. Because I was on
death’s door when I got here.

Participant 6 shared:

I kind of – I almost hate to admit this, but if I'm being honest, I have to. I just kept
– I was waiting for the ball to drop, so to speak. I was waiting for it to happen
because my husband had been tested and was positive. I was negative at the time
and I had not been as careful as I should have been, and so I almost knew that it
was gonna happen. It was in the very early, early, early days of HIV. I found out,
like, I was having blood tests done regularly at the health department. They said,
“You're positive,” and I just kind of accepted it and thought, okay, well, you
know, this is what it is. I'm probably gonna die. He's probably gonna die.
Two participants shared their experiences of contemplating suicide upon learning they were HIV infected. The diagnosis was shocking and led to a sense of hopelessness.

Participant 7 shared his experience of hopelessness after receiving the devastating diagnosis.

Getting hit with the HIV was, again, one of the most hardest things in my life. I mean it's harder than being shot it really is. Being shot, you know, if you make it through it you live to tell the story, but HIV is something that I have to deal with every single day of my life, for the rest of my life and I know this. But at that time the only thing I thought about is just dying. But again, it's something that I had to wake up from. I had to either accept what I have and deal with it and move on or commit suicide. Before when I found out, I just wanted to die. I just, I just, I didn't want to die the way I saw my friends and family die. I mean I just wish you could've saw me when I first found out how I went from, like I said, 155 to like 90. I mean it happens, it was like that. [Snaps fingers] I couldn't fit in any of my clothes. I didn't want to go anywhere. I was nothing. You could see the ribs, my ribs that's how bad I was. The shelter either was at a point where they wanted to put me in the hospital, in a mental hospital because I wouldn't eat anything. I couldn't eat anything. I was deeply, deeply, deeply depressed. And I have never ever been depressed.

Upon learning of her HIV infection, Participant 12 described her experience with shame, hopelessness, and contemplating suicide.

The doctor and nurse wanted me to come back 'cause they needed to talk to me about the test. When they first told me I was like, Oh my God, I’m going to die.
I’m going to die. Oh my God, it was like somebody pretty much had put a knife through my heart and stabbed me. I wanted to kill myself. I ran into the road and tried to kill myself when I first found out because they told me, the hospital told me and they didn't explain to me and I had heard about it before and I was told that if you get it that means it was a death sentence to you. You know, you died that was it. You got it and a couple months later, you died. For a long time there, I felt dirty, I felt worthless. It was a really bad struggle with me. I mean I tried to kill myself a couple of times and commit suicide because of my HIV.

Two of the participants who were diagnosed with HIV infection immediately saw it as a death sentence. Participant 13 was diagnosed with his infection during the early months of the epidemic. At that time health care professionals did not know what was causing the fatal illness. Participant 13 shared his experience of receiving a letter in the fall of 1981 after he received blood transfusions during the summer due to a vehicle accident.

The letter was very ambiguous. It stated that I had been possibly, through the blood transfusions, been exposed to a recently identified virus, acquired human immunity. Shock of… because there’s no counseling or anything. Even when I went to… I had the blood test. And did you know back then it took three weeks for the Western blot blood test? I’d wait three weeks wondering what the heck got in my body.

Participant 2 described his experience when he learned of his infection, “So I don't know, but I just couldn't believe I had HIV. Just could not believe it. Oh, I thought I was gonna die from one thing. And all I dwelled upon that I was gonna die.”
Unlike other participants, during the first interview Participant 1 stated that he did not see his HIV infection as a death sentence. During the second interview he had received news regarding new complications associated with side effects from the medications that were causing a decline in his health. He stated he had received bad news since our first interview 3 months ago.

I never thought of it as a death sentence. Two months ago I got all bad news. I take my meds like I’m supposed to. Yet they’re killing me. You know, you can keep the bad news, but when you get all that bad news at one time, and they say, don’t get depressed because that’s going to drop your T cells. OK. Don’t give me all bad news. I don't know. Sometimes I think I’m going crazy. I know I’m not going crazy because I’m not crazy. Maybe I am. Do you think I am? It’s a death sentence. I don’t care what they say. I don’t care what kind of pills they give you.

It’s a death sentence.

**Theme 3-Encountering the Brink**

All of the participants in this study described the experience of being diagnosed with HIV as a pivotal life event. The brink seemed to be the place where the road to death came to an intersection. The participants described being “at the brink of death”. It was as if the participants were standing on the edge of a mountain cliff where death was impending. While at the brink, many of the participants struggled with issues of past traumas or issues related to their identity and HIV infection. Participants accepted the things they could not change. In this study the brink symbolized a turning point where participants began the acceptance of self or becoming their authentic self.
Participant 7 described his experience at the brink as being in shock, losing everything in his life, and contemplating suicide until he realized he had to deal with all of the issues in his life.

And that's when pretty much depression started kicking in because I realized that I not only lost, at least I thought, not only have I lost my life but I lost my family at the same time. So it took a while. It took at least six months, eight months for me to finally start getting over it. But for the first six months it had to be one of the most, I mean besides being shocked it had to be one of the worst experience of my life. And at a point, I realized I needed to stop feeling sorry for myself. I needed to either deal with this and realize that there's more to life or end it and I thought about suicide quite a few times. Thought about it quite a few times. You need to accept it, realize there's nothing you can do to change it, and deal with it.

And until whoever or whatever faces that, it's only going to get worse.

While hospitalized with a life threatening infection, Participant 11 described his experience of standing at the brink and staring death in the face. At this turning point he realized he needed to let go of his past and had to make changes in his life if he lived.

I had an experience where we went to visit my sister in Texas. And I had been sick before we left and ended up in the hospital with pneumonia that didn’t respond to the first medications they used on it. I was very weak and just understanding. The new med doesn’t work. This is potentially – Yeah. And, at that point, I was okay. I had regrets, yeah. But, you know. It’s like, it’s all right. It wasn’t stressful. It helped me identify some things I needed to do when I got
better, but I wasn’t thinking of it like that. It was just, oh, yeah. I wish I had. And that was all right.

Participant 10 shared that his experience at the brink consisted of hopelessness. He had thought of suicide while at the brink. He never told his daughter that he had thought of suicide. “I will admit, I even contemplated suicide. She (his daughter) never knew that, but I did contemplate suicide.”

Sharing her experience at the brink, Participant 12 described a life of feeling worthless, shameful, hopeless, while contemplating suicide multiple times using violent ways.

Oh, it took me a very long time to even accept it. It did not come very easy at all. For a very long time period there, I would do like risky stuff, use drugs and stuff and then try to kill myself. I tried to run into cars before. I tried to put myself into guns. If I did have a gun I would have put it in my face to blow my head off ’cause I didn't want to live. I've been stabbed before. I've been shot in my legs before. Because when I lived on the streets I think I was barely keeping it up as it is and then find out I was HIV didn’t help the matter it just made things a lot worse for me. For the life that I was living, I should've been dead. The drugs didn't kill me, I got myself free from drugs, and it was a long battle between my drug addiction and HIV disease. It became really hard to be able to survive everything. My drug addiction, living in the streets for so many years, even eating out of a garbage can and not knowing where your next meal was coming from or when you were going to get your next bath that was really hard. For a long time there, I felt dirty, I felt worthless. It was a really bad struggle with me. I mean I tried to kill myself a couple of times and commit suicide because of my HIV.
Participant 13 shared his experience at the brink as a time of hopelessness, anger, and apathy. He was infected with HIV in the fall of 1981. He had been injured in a motorcycle accident. During his hospitalization after the accident he received a blood transfusion.

Yeah, I was pissed off. Forgive me. Not very gentlemanly. I did the why me thing. Also, it was painful. I damn near lost my leg. It was pretty bad, mangled. So, I had that and then the kick in the keister from the letter. So I wasn’t even healed I was still hurting pretty good. I had some broken ribs and things and almost lost this finger. Yeah, I was trying to get over that and then boom. Yeah, I was pretty angry. I was thinking like Gone with the Wind, outside like, God, how could you do this? Like Gone with the Wind, I should have never been born. I was like I’ll never talk to you again dude. But, yeah, so that’s a biggie. I didn’t care about a lot of things. I figured what the hell, I’ll keep smoking. I drank fairly heavy for a while to deal with it. Yeah, I went from sipping a beer with my friends to sipping hard shots of whiskey just to paralyze myself. I did that for a few years. I kept working, but it didn’t interfere with my work, but boy I’ll tell you I loved that escape for a while. Didn’t really care once I got half bogeyed up on. But those phases… I tried, you know what? Anger really destroyed me.

During his encounter at the brink Participant 3 shared his experiences associated with his struggles with addiction, HIV, loss, and disappointment in himself. He stated,

I was in a very intense, devastating drug addiction while I was there and I became positive during that. And I was about three years, three more years or so. And towards the end of those three years I was just really unhappy with my life. I knew that there was more in the world for me because you can tell I'm very
intelligent, and I knew there was more but my addiction was getting worse and worse and worse. So my family had to come down and extract me from there. In a way you're right because the addiction will take everything you have from you. You know, I knew that I was – I was smart enough to not ever let myself die from my addiction but people do do that, you know. You lose everything. I became violent and I'm not a violent person. It was the drugs. I even surprised myself. I mean when I look back at the things I did I just like – that's not – I would never do that. It's not me. The addiction just – I'm a very strong person, very strong inside, very willful. And so I can control my environment. Methamphetamine and marijuana. But I would wake up and say I don't want to do this, but I couldn't stop. I just literally didn't have control. I couldn't stop. And that was the first time in my life where I was out of control, where I didn't have control of something in my life, you know. So it's kind of like driving and your car's steering wheel breaks off the car.

Participant 5 shared that his four year experience at the brink was one of drinking heavily.

I drank a friggin’ gallon of vodka every day. How I dealt with it. I was really drinking heavy. It was vodka every day: a gallon of vodka. Drunk a gallon of vodka every day for how many years? About four years.

While living at the brink over a time period of approximately eight months, Participant 7 experienced the worse depression of his life. At the brink he eventually realized that he was either going to die or he had to turn his life around. He felt it was God’s will that he should live.
And that's when pretty much depression started kicking in because I realized that I not only lost, at least I thought, not only have I lost my life, but I lost my family at the same time. So it took a while. It took at least six months, eight months for me to finally start getting over it. But for the first six months it had to be one of the most, I mean besides being shocked, it had to be one of the worst experiences of my life. And at a point, I realized I needed to stop feeling sorry for myself. I needed to either deal with this and realize that there's more to life or end it and I thought about suicide quite a few times. Thought about it quite a few times. No, I stayed at a $50 a week hotel. I mean I worked. I got lucky and as soon as I got there… it was a car dealership and it was winter and I was one of the people that shovel snow and clean cars off. So I was going over there every day and doing that, just buying a week and buying some food and going, and I was in deep, deep depression. But then when I went to the homeless shelter, when they let me go from that job and I started staying at the shelter, and again, I believe it was God. I think he was like, you need to get up off your ass and you need to stop feeling sorry for yourself and move on. So since you’re not going to do it, I’m going to take this job from you and I’m going to force you to go into this, live on the street, or go into this center, and then go from there. I really don’t think that… if that car dealership would have kept me, I probably would have died in that hotel. I’m pretty sure I would have, because I was just for the work just enough, feed myself and that’s it. I wasn’t on any meds or anything and I was really, really getting thin every day. If you don’t seek help or look for support elsewhere, your family doesn’t give you support, if you just go into as you say in that cocoon, the only
person you really hurting is yourself. Again, I probably would have continued to be in that way if I didn’t lose that job, if I didn’t go to the shelter. If things would have kept going, again, I don’t mean to keep repeating myself, but I probably would have died in a motel because I did not want to go out. I did not want to do anything.

Overall the brink was the specific time and place where all of the participants in this study made a conscious attitudinal shift regarding living with HIV/AIDS.

**Theme 4-Rebirth/Second Chance**

The “rebirth” or “second chance” seemed to be the point when the participants made the choice to somehow survive and travel onward. The participants described the moments in their lives when they decided to accept who they were, embrace the freedom to be who they were, and face and accept their illness and mortality. Participants described the experiences associated with receiving family support, seeking support from AIDS service organizations, and embracing a personal spirituality. At the point when they were experiencing a rebirth or realizing they had a second chance at life, some participants felt as if they were rising out of the ashes.

**Rebirth/Acceptance of Self/Be Me.**

The process of the rebirth began with acceptance of self, the freedom to be who they were meant to be; experiencing what some participants called “a rebirth”. Participant 11 described the experience of having an epiphany as he began to come to terms with who he was.

I could have easily died having never fully accepted who I was. And people don’t always like the unconscious so much, but it saves your life so many times. That’s what worked on it for me. I woke up understanding one morning that I just did not believe anymore some things about myself and that I just was fine with who I
was. I had worked it all out in my head, I just hadn’t admitted it. I had the epiphany. I understood who I was and my relationship with things. And, after that, a huge weight lifted from my shoulders. I can totally understand not wanting to give up. You fight to keep it even though it’s so bad for you. Because everything you have trusted and learned to accept in a way of thinking about things from, well, every moral decision you’re ever going to make. What’s that based on? That had to be reevaluated. Everything. Because the thing I had based everything on wasn’t true for me. And so, everything had to be gone over again.

But, yeah, it makes you very self-aware for a long time until you can get things sorted out and you’ve got your equilibrium again. But, on the good side, you understand exactly why you believe what you believe.

When Participant 11 accepted he was gay he noted he felt a sense of peace.

Peace for the first time, often. Oh, absolutely. Yeah. One I’d been carrying since I was a child. Very young child. Yeah, I knew I was – I didn’t have the word gay, but I understood who I was from very, very young. And understood that nobody around me liked that. And that opened me up to it because I made it to 37. I was quite capable of going on longer in denial. You can live there for a long time. Some people live their whole lives there. And I was strong enough to do that. It would hurt, but I would have done it. But once you start looking, opening yourself up to what has happened in the past and who you are because of it, you do start to look at who you are and why you’re that way. And when you’re questioning what made you the way you are, you have to look at everything – or at least I did. And, like I said, I didn’t do it consciously. You can’t speak for somebody else. You
can’t ever know exactly what’s going on, but I think some people are just –
They’re not necessarily certain they’re going to like what they see when they get there. Not realizing that, yeah, everyone that goes there doesn’t like a lot of what they see. But you do find what you do like. And you do find a way to deal with, accept, or, at least, find a way around the darkness. Everyone’s got darkness in them.

Participant 12 described the experience of rebirth as an acceptance who she was and being happy with who she was.

But I learned to live with it. I learned to let it go because I got myself really sick thinking about how people thought about me. I'm happy. Today I'm happy with who I am and that took a long way and a long road to be happy with who I am now because it's not an easy task to do especially when you're HIV positive. It's not easy to be accepting of yourself for who you are. It wasn't easy. It wasn't easy for me either. I don't know, I really don't know. I think I became at peace with it. I think once you become at peace with it, you do come to peace with it then things start to look a little different. I'm happy with who I am today. I wasn't before though, it took me a long time but I became humble enough to know I'm happy where I'm at.

Participant 15 shared that he felt like he didn’t fit in his hometown in rural Northern Appalachia. Like other participants, attending a local support group gave him a chance to be who he was.

It’s like here I’m the odd man out for the most part. That’s why group’s kind of nice, because there’s other people in there, like the same way I am. Positive and
I'm happy. Today I'm happy with who I am and that took a long way and a long road to be happy with who I am now because it's not an easy task to do especially when you're HIV positive. It's not easy to accept yourself for who you are. Yeah. I couldn't control what happened to me as a child but I can control what happens to me now. And nobody makes choices for me now but as child, my parent made the choices for me and I couldn't do nothing about it. Today I don't have to worry about that no more. Nobody tells me what to do and how to live my life because I went through so much there's nothing you could tell me that it's gonna be like, oh my God, you shocked me because I've been through all of it. I have seen my dad do some crazy stuff.

Prior to his rebirth, Participant 2 shared about an experience in his life when he used two different names to hide from others that he was gay. One evening he encountered two different group of friends on the street. Each group knew him by one of his two names. He walked away during the simultaneous meeting with the two groups of friends.

And I spent all night drinking, and the next morning, as soon as the bars opened up, I went to the bar and started drinking, and I thought, Wow, who am I? You know? Well, I think I'm gonna be (name of Participant 2).
Hiding his identity of being gay, Participants 8 was married to his high school sweetheart and they had a daughter. His wife was approached by someone in the community informing her that her husband was gay. His wife confronted him about being gay. He shared his experience of “the breaking” into a rebirth where he no longer had to hide his identity.

Well, actually it is really a good – I don’t know. It’s like the breaking – I don’t know. I was ready for her. She said, somebody told me at work that you were gay. I don't know to this day who it was. I would have probably killed him. It was probably the best thing. I said, I sure am. You can have this frickin’ house and everything else. I'm out of here.

For Participant 9, the experience of his rebirth and the freedom to embrace his identity seemed like arriving in the Land of Oz.

Well, I peeked out of that door like Dorothy seeing the colorful Oz and everything for the first time. I didn't leave the door cracked. I put some dynamite on the hinges and pulled it off [Laughs]. Oh, my God. I was so frickin' gay for a while it was really kind of funny. [Laughs].

He went on to described attending a support group where one of the members, because of attending the support group, was given the opportunity to be who he was.

I know this one guy who says, “Where I can go and be gay for the day”. [Laughs]. And I'm like, that's cute, but remember we have some straight people here and some of them are women and they don't come here to be gay for the day [Laughs]. But it's cute that he says that. Be himself for one day.
Two of the participants described their experience of realizing they had a second chance at life. After waiting years to die, Participant 6 described her second chance as bringing her to a new place in her life.

But it just – it brought me to a whole new place in my life, and so I stopped waiting to die and I stopped counting the years, and so if you asked me today, how many years are you positive? I can give you a generalization and actually have to sit and figure it to be sure because I don't pay attention to these things anymore and I am pleased to say that.

According to Participant 13, a second chance at life felt like he was experiencing a reprieve.

It’s the two biggest events, the death sentence and then the reprieve. All in all it hasn’t been that… it may have in a way, believe it or not, there’s part of play on words, some positive aspects of being positive because yeah, I think all in all it probably made me a better person. I said, well, if I survive I want to be a better man now than I was before I was positive. That’s my goal is to be a better person than I might have been otherwise. I’m always tweaking how I think. You always have to … some people are so set in their mindsets, but mine will go in like how can I be a better guy today when I get up. I need to adjust something, do more for others, something.

All of the participants described that acceptance meant incorporating HIV infection into their life. With the recognition of their own mortality and realizing an opportunity existed for a second chance to live an authentic life, the participants had to accept that their HIV infection would be traveling with them.
Participant 13 discussed the difficult process he experienced in accepting his illness and his mortality.

The demise, I was afraid of that, how I’d go. I pretty much accepted, I felt I lived a pretty good life. I thought I worked hard and just been happy, very happy person. Yeah, I got over that pretty quick and accepted it and I pretty much just accepted that death would be horrible at any time. You learn to live with it. It’s hard to accept. You see it so many times. You know. You see all kinds of things.

Responsibilities in the life of Participant 5 helped him to accept and come to terms with his illness. “That’s how I live. I know I got AIDS, but I don’t dwell on it. I don’t think about it. I think of takin’ care of her and dogs like a normal person would do every day in life.”

Participant 7 described in detail the process of how he came to terms with his diagnosis and the importance of acceptance in continuing to live his life.

It was something else. It was accepting it and then dealing with it is the main thing and I think that's what took me the longest to deal with was accepting it and then dealing with it. And at a point, I realized I needed to stop feeling sorry for myself. I need to either deal with this and realize that there's more to life or end it and I thought about suicide quite a few times. Thought about it quite a few times. You need to accept it, realize there's nothing you can do to change it, and deal with it. And until whoever or whatever faces that, it's only going to get worse. That person's going to go out and infect this person and this person will go out and will infect this person because in their mind they don’t want to face the fact that they have HIV or AIDS. Well, dealing with it what I mean by is accepting it, number one. Okay, I have this disease, and again, it's like same thing I just said,
you know, do I want to deal with it or do I want to put myself in a closet and just kick the door close. You just have to open that door. But again, it's something that I had to wake up from. I had to either accept what I have and deal with it and move on, or commit suicide. A lot going on, but again, it has come full circle, Renee. It really has. It was lots of bumps and climbing and challenges but the main thing of having HIV is being able to deal with it and understand it. And knowing you're not going to die. Okay, you take your medicine, you do what you need to do, and you'll be just fine. But when I realized that I was being a drama queen, if you want to be and overreacting, and not dealing with it. Instead of running away from it, I wind up running towards it, and it has made me stronger, it really has. And I think hearing that started my way to recovery about acceptance and dealing with it. It's just, I think just dealing with it every day and knowing that this is something that's gonna be with me for the rest of my life. And knowing that now, and knowing that, I think it has helped me. It definitely has made me stronger. Again, appreciating life a little bit better than I did before. Of course, like most people, I took things for granted and it can't happen to me. Now I’m this, that, and the other, and I'm traveling here, I'm gonna go there. But it definitely makes me appreciate things more, it does. It really does. I mean, basically, I mean I look at it again. I’m blessed. I’m very, very lucky. I’m blessed. Yeah, I do look at life completely different before. I mean, to have not… I no longer have a carefree life. I no longer think now I’m going to live forever like most people do. I do realize now that my time will come eventually. But again, it won’t be because of the HIV or the AIDS or anything else. It will be a normal
life. So, it took me a while to turn the corner. It did. Once I turned that corner, once I achieved that objective as far as accepting and moving on, my life has gotten better. Again, as long as I got my girls, my family, and they all know, I could really give a damn about what anyone else thinks or says.

As the second chance/rebirth continued, all of the participants accepted support from family and friends, began practicing a personal spirituality, and sought support from AIDS service organizations. Participants shared experiences associated with acceptance by family and friends. Personal spirituality provided them with courage to encounter the difficulties associated with living with HIV/AIDS, while directing them toward a purpose in life. Being connected to HIV services gave them the ability to care for themselves and provided them with social capital. Without acceptance and support, they would not have been able to incorporate their new identity or embrace their second chance.

**Family support.**

Because of the unconditional love and support by their family and friends, all of the participants found the courage and strength to embrace a second chance. Participants shared that they feared rejection when they disclosed to their family and friends that they were infected with HIV. Some participants described relief when they received support from their families.

Participant 2 described the experience of surprise when he received acceptance from his conservative family. “But surprisingly enough, the family was very accepting of us. My family accepted me more.”

Participant 9 was pleased when he received family support, especially his elderly mother. My family was very supportive when they found out which is great. When I think of the way she (mother) acted when she was – I don't know how old she was back
in – when I said I'm gay and she said, “Then we’ll go to your gay church”. This time I think she's got to get a lot of princess points for that and for going to the Gay Pride Parade.

Later during the interview Participant 9 shared a time when he was a speaker at a conference. The topic of his presentation was regarding family support. He shared with the conference attendees:

What I said when I got up there was my mom's 90 and she knows why I'm here, and she thinks it's awesome. [Laughter] I just – everybody – I just wanted to take a minute and say it's not all like this. Some people are cool.

Although he kept his diagnosis secret for a few months, Participant 11 was pleasantly surprised when he found his family to be supportive. Acceptance by his family gave him the courage to share his diagnosis with others.

I’m gonna say it was a good two or three months before I actually told anybody about it. And when I did share my diagnosis with my family they were more accepting than I thought. My mother, I really didn’t have a problem with. But after the family’s reaction and – I was able to share more widely after that and, again, I was very fortunate I didn’t receive any rejections from any of my friends.

Participant 5 and his wife described the support he received from his wife during the first moments after he found out he was HIV positive. “She (wife) was there from the beginning through everything. The wife of participant 5 stated, “We were in (Doctor’s name) office and he had his head down and he had a hold of my hand and he said, I have AIDS. What did I say? Somethin’ like, we’ll get through it.” Participant 5 described his commitment to his wife in the
following way. “I'll stick by her until she dies or I die. It's as simple as that. It's down in the
soul.”

Participant 7 described the lifesaving power of family support, especially support from
his mother.

You just have to be able to realize, you know supportive family is tremendous, it
really is. Again, hearing my mom asking me to come home and saying she didn't
give a damn about what's going on she just wanted me home and we can deal with
it together. She (mother) was my rock during that time and I think I needed to
hear that. I needed to hear her support and I think what threw me off that she
(mother) wouldn’t support me is how my ex-wife acted when I told her. I didn't
want to hear that, I mean who wants to hear that from your mom of all people. So
I thought for sure that she would act that way and after a year, I knew that I
needed to get in contact with her because I knew being her only child I knew she
was going to worry. So I finally reached out to her, and again, just hearing her say
come home, I don't know care, come home. I actually reached out to my mom and
she passed away last year but before I actually reached out to her and one of the
things that she told me that sticks with me today is that no matter what you're my
only son, we will get through this. She was the first one I called and she was like
“Where are you?” and my nickname was (Nickname) because she said when I was
a baby my eyes light up. She was like well, (Nickname), “Where are you? Where
have you been for a year? Where are you?” And I was like “Mom, I'm all right.”
She's “come home. I don't care what's going on you come home, come home
now.” And I told her and I said, “I just need to deal with this. I just wanted to let
you know not to worry.” And she said, “Well, it's too late for that. Do you need anything?” And I told her I was living in a shelter and oh my gosh, she went off. “Why in the hell are you living in a shelter? Do you need money?” “No, I do not I just need you to know.” But just hearing her say that, I actually thought that she would be angry with me, which is why I didn't want to have anything to do with her because I thought she would be angry but she actually surprised me. She's like “no, you're my only child, come home. Why are you living in the shelter? Where are you at? I don't care, come home.” You just have to open that door. You just have to be able to realize, you know supportive family is tremendous, it really is. Again, hearing my mom asking me to come home and saying she didn't give a damn about what's going on she just wanted me home and we can deal with it together. Even though I didn't go home just hearing her helped me get through a lot, it really did. It woke me up. I realized I needed to move on. And having the support of my girls, they don't care, I mean I'm dad. And I love that. I love that because they have accepted it, they don't care, you know. But just getting those e-mails from the girls and having them remind me to take the medicine and everything else.

Participant 12 described the unconditional love she received from her husband, who recently died. He helped her to realize she was lovable, changing the lens in which she sees life. “He showed me that I could be loved I think that's probably why I see things more positive now.”

Living with an intense and devastating addiction, Participant 3 described how his family, in order to save his life, rescued him by extracting him from a life of addiction.
My family pulled me out before that happened, but it was almost ready to happen. I was ready to lose everything, but I was – you know, like I said, they knew that was coming so they extracted me. And so I knew that something significant had to happen because it was not going to heal itself. And that's what happened. My family came and pulled me out, rescued me.

Participant 14 shared experiences of the unfailing love and support from her husband even throughout their off and on courtship.

Well, he wasn’t my husband then. I said, you’re going to have to get tested. And he said, Okay. He’s never – he’s never wavered from me ever, no matter what I did to him. You know? He’s never… And even… Yeah, he still wanted me back. And even after I came back from – I moved out to (city) for a little while and I came back up here. And he found me again. And we got back together again and that’s when we got married. He’s never faltered from me. He’s never questioned it. It’s never been an issue for him. Ever. He's not – he won't go anywhere, and, like I said, nobody loves me as unconditionally as he does ’cause even my mother has conditions.

She shared the experience of telling her son about her HIV infection and his calm acceptance.

And with my son, I didn’t tell him right away because he was 11 at the time, 12 maybe. I would wait until he was older to kind of understand what was going on. And when I did finally tell him, he just said, “okay”. He didn’t have – he didn’t freak out. He didn’t have any real questions about it. I explained as much as I could. Didn’t affect him.
Her family was unaffected by her HIV infection and have been supportive. “My family, it never affected them. They just – my grandma just said that’s such a shame. As my grandma will. But nobody’s ever thought it was an issue that I’ve told. So I’ve never had a problem that way.”

Participant 14 told how her grandmother picked her up at the bus station when she arrived home from the west coast.

I was just death warmed over when I got back. My grandma said, when she picked me up – because I begged her for a bus ticket home. And she – my mom and my uncle said, “Don’t do it. Don’t do it. It’s another one of her tricks.” And my grandma sent me a bus ticket home. And she said, “Well, I thought we’d take you to Perkins.” Because I had to turn myself in, because I was in trouble. I said, “I don’t want breakfast. I want to go to the ER.”

Participant 14 shared that her mother was with her when she learned she was infected with HIV. “My mother she wanted to make sure she had all the information, and she wanted to – ’cause we all pretty much knew but needed confirmation.”

**Support from AIDS service organizations (ASO).**

All of the participants in this study felt that if it was not for the case managers and staff at the ASO, they would have died. Many of the participants felt as if the ASO saved their life. Three participants had received HIV specialty care in urban areas prior to relocating to rural Northern Appalachia. The participants described experiences of receiving significantly more personal attention and individualized care from the rural HIV specialty care organizations. All of the participants described how the compassionate and ethical care they received made a difference in their life.

Participant 12 described how the support she receives from the ASO saved her life.
This town can be good and this town can be bad. They got good people here. I love this town here because of (ASO). I've been with the (ASO) for a very long time and these ladies here had never seen me any different, they don't see me any different now than they seen me when they first met me. They're pretty good people. They help you as much as they can. And just find a place and a good organization like this around, wherever you at, 'cause you'll be surprised the kind of help you get through those people. And all you had to do is reach one person and that makes a lot of difference. I met with (case manager), she's the boss here now, and I think if it wasn't because they, the shelter introduced me to these people here, I wouldn't be here now. If I would've kept my mouth shut and not say nothing to the people at the shelter because my being afraid what people thought about me, I probably would've been dead now. I remember anytime I was trying to give up and stuff like that and this caseworker told me, “Don't do that. Don't give them the satisfaction 'cause that's what they want you to do, for you to give up.” I learned that the hard way. Like I said, this could be a bad – I think anywhere you go, you got good people and it got bad people. Just try to stay away from the negative and try to get connected with positive people who not going to judge you for who you are and really give them a helping hand and it just might give you a helping hand too, you know. If it wasn’t for these people here, I would have given up a long time ago. I told her yesterday, I say, I hope you know that I appreciate you for never giving up on me even though when I was… in my addiction, drinking and stuff that she was there for me, she never gave up on me.
Participant 7 was living in a homeless shelter at the time he reached out to the ASO. He shared that he felt the support of his case manager and the ASO saved his life.

So I think having that support, you know, sort of helped me get through this. I mean, I really was giving up on life. I really was. Well, that’s the thing about me. Once I went in that depression, I was in it. But when I came out of it, once I made that contact with (case manager) and started taking care of myself, I was done with it. And I finally called her. I can understand in a bigger state, (city), you’ll probably be just a number. You have to go in and sit down, wait for your meds to go through and all this. I can understand that, because there’s so many. But then in small rural towns like this, I’m sure there’s a lot more people that has it that, you know, but you do get that personal attention. (HIV specialist), (case manager) and the team, the whole team over there, they’re always calling to check up on you. They always helping you with something that you need. The (ASO) and (case manager) really, really, really helped me get through a lot. I mean, again, it was, I mean even she says that from the day we first met up until I just met her a couple days ago she said, “you look really, really good.” At first I refused. I didn't want to do anything. And (ASO) they stayed on me, you know, she constantly was like its light years from what it was back then try this, try that. So they've given it to me every month so every month (pharmacist) from the pharmacy called me and say, “hey (Participant 7) do you need your meds” and I'm like “yeah.” So they just delivered the meds to me every day. Coping with it and dealing with it to me is one of the main things. Once you get over that hump you’re OK. You’re OK, but everyone that gets it… I strongly, strongly recommend support. You
really, really need that support. So I reached out to (Case manager) and we been
talking ever since. I mean, again, that (ASO) pretty much saved my life. As I went
on with it and talked to people like (ASO) and everything else, they, you know,
gave me the courage to face it and to also get on medicine that I can afford.
Again, if it wasn’t for the health department of (ASO) I don't know what I would
do, because I could not afford the meds. I don’t even think my insurance at work
would even cover it. And even so, it’s really expensive meds. It really was.

Participant 8 met his case manager after his discharge from the hospital. At the time of
his diagnosis he was ill and his viral load was high.

Shortly after I came home, I connected with (ASO). (Case manager) came out to
see me. We talked. She's a good person…counselor. She's a really good
counselor. She walked me through it and got me on the drug program. I've been
undetectable for probably about eight-years. She said that she thinks we caught it
at a good time because my counts were pretty good. They were high at first, but it
didn't take long to get down. I've been undetectable for seven-years. I get checked
every six-months.

Three participants described the differences in services received in rural areas compared
to services in urban areas. The participants felt that the services provided in a rural area were
more personalized. Participant 3 stated:

My family extracted me and brought me back here, and that's been about ten
months I've been here. And I've been – my life is like – I call it a cleansing. I don't
say that I moved home. I'm just here temporarily, you know, springboard. But
AIDS – (Caseworker’s name) work here has been above and beyond what I
would have expected. There is a level of service here, is better than where I was in the big city of (city). Yeah, because in (city) you're a number, and you know, to get your prescription refilled you walk in a room the size of this with, there's a big board on the top with a number. And you have like one of those pull out numbers. You could wait for as long as 45 minutes just waiting to get your number to get your drugs, you know. And that's just…the city life is like that. Ten weeks to get an appointment and if you miss your appointment you'll wait ten more weeks. It's not like that here. It's like a luxury hotel here compared to Motel 6.

Participant 2 described his experience in this way. “Well, I have to say that the young lady I have met through the (ASO) – her name is (case manager) – is better than anyone I have ever dealt with in (city). She has more time for me.”

Participant 13 stated:

Yeah, here. (Case manager), hard to believe in a rural community I have someone that, you would mention something and she takes it and runs with it. Down there I had like supplements, the nutritional supplements, when they went through paying for them, (health insurance plan) or whoever I had then. I asked caseworkers and well, we’ll check into it. And I’ll call them a week later, Oh we forgot or we…I’m going like, I’m losing weight here. And I didn’t know how to pursue things like that. Then I’d get one that I’d call and they found the place, the food co-opt, they continued for a while. So I got it from there, paid for. But I mean I got a caseworker that found it. But other ones, so again, it’s like any person doing a job, how much effort they put into it. She’s (case manager) very nice and I thought these folks are for me. I thought, well these folks are for me. To be honest if it
weren’t for the (ASO) I don't know when I’d get the creating done I thought I’d sell it and move back to (city) or something, but I think I can tough it out here with them.

Participant 15 felt that if he hadn’t received the support from the ASO he would have died.

If it wasn't for the (ASO), I think I'd have been dead. It was definitely a godsend at that time in my life anyhow. Yeah. She definitely went the extra mile. I had more information, I knew what I was dealing with, and knew there was options and medication and everything else. At first, I was pretty upset and didn’t know what to do. (Case manager) came along. I don’t even know how because I was still sort of, you know, loopy, for lack of a better term. She just came out of nowhere and pointed me in a good direction to get treatment at the (HIV Clinic) in (city). Then shortly after, she organized our support group, so that helped a lot, because I met other people that were in the same position as I was. I mean, my family was very supportive when they found out, which is great. I know a lot of families of people aren’t so much, and that’s even tougher for the person, I’m sure. But, I mean I just was lucky that (case manager) came along and that I got in the right direction to get it under control and start taking meds. If I’d have stayed out there I probably wouldn’t have survived. She was, she was the catalyst for getting my life back on track.

Participant 1 described the difficulty he had being networked into support. He described how at the time of his diagnosis he was not given information on support and community resources. Because of a health department contact he was linked into services.
So I got a dentist, I got a doctor, I got a clinic, I got a group. Everything’s good now. The hardest thing for me was trying to get in the network, or whatever you call it. That was the hardest thing about that.

Participant 10 shared how receiving support lessened his anxiety when he first received his diagnosis. Initially he felt isolated. He was receiving treatment is an urban treatment center and was not yet linked to the ASO. He discussed the anxiety he experienced when he was forced to tell his employer because his health insurance denied payment of medications.

And I told him (administrator at work) what was going on. And he asked me a lot questions about it. He says, “I'm gonna make some phone calls.” He says, “I'll get to you with an answer.” I said, “Well, I don't even know whether I'm gonna come to work tonight or not.” I says, “State of mind” – he's “don't let it knock you down.” He says, “one way or another, it's gonna be taken care of.” And he says, “I do have that authority.” Well, I went to bed and the phone started ringing. And I answered it, and it was (work administrator) from the shop. And he says, “That is taken care of with the insurance company. It will be paid for.” He says, “You turn your prescription in, and you will get it.” And he says, “If they say that it's not gonna be paid for, tell them to call me here at the (workplace).”

Later his workplace hired a new administrator.

She says, “(Participant’s name), I'm gonna take care of this for you the same as (previous administrator) did.” She says, “I can do it.” And she did. I had a hospital bill or something one time the insurance jerked on and what not. I took it up to her and showed her 'cause I had got a bill stating it was on you to pay it and whatnot. Insurance had rejected it and all this and that like some of ’em do. She
says, “This will be taken care of before the day is over.” That night when I went – the next day when I went into work there was an envelope for me in the boss's office. And I took it and looked at it. And it was a note from her saying this is taken care of. It'll be – they'll be paid immediately by the insurance.

He also described the support he received once he was linked to the services from the ASO.

And (ASO) bailed me out there. I called (case manager). Christ, before the evening was over, she was here. I started feeling more relieved and some anxiety went away from it. Well, then (case manager) started talking to me about support groups. Sixty-five miles one way once a month. And in the wintertime, if I miss a meeting, it's because of the weather.

Participant 14 described how her HIV specialist referred her to the ASO. The participant stated she connected to her case manager but was hesitant to attend the support group. She joined the support group and is happy with her decision to join.

(HIV specialist) is the one who put me in touch with (case manager) in the first place. He said, “I think you need to call these people and they’ll get you set up with help.” And I called her and she kept wanting me to come to group. And I wouldn’t go, I wouldn’t go, wouldn’t go. And then I came home and I decided to start going to group. And that was a good decision, I’m glad I started doing that. Well, it gets me out once a month. It gets me out with like people. And they’re not all alike, but you know, we all have something in common that we can talk about. And that – we have other common interests besides that (HIV). It’s the camaraderie of it. But I didn’t want to go at first. And I just told (case manager), “I’m not going. No, no, no, no, no.” And then I finally gave in after I came back
from (city). So I do that now, too. They have got a lot of services, and they've been really – they're pretty awesome.

One participant described the support and encouragement he received from this health care providers. Initially Participant 10 received medical care in a large urban treatment center. He described he believed he was going to die. The encouragement he received at his first appointment gave him hope.

(HIV specialist) back at that time told me, no, don't think of it that way. You're gonna live 20 years or more. I mean, I was still just on AZT when he told me that, but he says, we got new drugs coming. One night, he says we're gonna have people survive 20 years. He says, “We got people right now.” He says, “Surviving on the AZT.” He says, “Actually, with no drugs, they've been gone.” He was very positive about it. That was one thing that I really liked about that man.

**Personal Spirituality.**

Five participants described spiritual revelations they experienced that led to the development of a new personal spirituality. Participants struggled to find words to describe their spiritual experiences. The participants described experiences where they felt God had allowed them to become infected with HIV because God had a purpose for their life or had a lesson for them to learn. One participant believed God allowed him to become homeless in order to save his life. Another participant said that HIV was a blessing not a curse. Spirituality allowed participants to see life through a new lens. The participants described spiritual activities, such as prayer and forgiveness.
Participant 12 reconnected with her belief in God as a result of her HIV. She believes that God spared her life because He has a purpose for her.

I don't know, maybe for my kids not to be afraid of people like me. I really don’t know what was God purpose for me to have it, but I know that he knew it before I got it that I was gonna get it. You know, everything has a purpose in life and I think I have a purpose in life 'cause I should've been dead a long time ago. I should've been dead a long time ago with the life I was living. So that's how I learned to be positive and a lot of prayers. I turn to myself to the Lord a lot more and realize that there's a purpose for everything in this world. There's a purpose why we have a cat, there's a purpose why we have a little dog, little chipmunk. We all have a purpose in life and there's a reason why I'm here. I don't know why I’m here. I don't know what the reason I'm here, what I'm supposed to do to be here. I really believe there's a power higher than me out there who really wants me here for some reason. Whatever the reason that might be they have me here I accepted it. I learned to accept it. I learned to live with it. I didn't believe in everything spiritual here. Just being able to wake up and open my eyes and see another light, another day, you know. Yeah, in the spiritual way too, you know. I was so against God when I first found out I was HIV positive. I hated him because of my HIV 'cause I thought that I had those thoughts so bad that God didn't like me and had to punish me more. And it wasn't God's fault, it really wasn't. It is just Mother Nature, I guess, you know. It could be a lot worse. I don't know, I guess, I don't know, it's just I don't know how to explain it. I don't know how to explain it. It's just so weird to be able to sit here and realize that I'm so
much better than I thought that I could be. I always put myself down and I'm not
good enough. I ain't worth this, I ain't worth that, but I truly am. I think that's just
for the grace of God it put me through everything I've been through it taught me
to realize I have a purpose 'cause it’s God, the one who pushed me through all
those trials. How did he create this world in seven days and we not perfect 'cause
people say well, you're supposed to be perfect. No, because if you were meant to
be perfect we would all be on the same level. God didn't want us to be perfect.
God made us to make mistakes and learn from those mistakes. God didn't make
criminals, okay, killers and stuff, those I think they were just born psycho like and
mental problems. I just believe that God made this world for a reason and before
we did it whatever we did wrong God already knew we were going to do it. I'm
sorry, Lord, I'm sorry. Well, He already knew you were going to fuck up anyway.
 Seriously. And so this is not a death sentence that God gave me. This has given
me a life because I don't see things the way I used to see. I'm not stupid and naïve
as I used to be. Maybe he gave it to me for me to learn something. Maybe I was
going to be naïve or maybe my kids were going to be stupid and naïve about it
and be mean to other people. Maybe he gave us to be humble, humble me. It
humbled me in life. I appreciate every little thing I have in life, where before I
was trying to destroy my life. So I think I've learned how to humble myself to a
lot of things. Medication, what I used to hate, I still hate taking them but if I don't
take them I die and I don't want to die. And I'm still here. I just look at life
different and I don't know. I'm not a very good Christian, don’t get me wrong
'cause I don't go to church or anything, but I read the Bible and I believe in nature
and stuff like that. And sometimes I say to my Mom how God created those birds to fly in the air with just wings and how do they stay up there in the sky flying for hours. How do they do that? I've been through, like I almost died, literally died, almost died from having this disease and if was meant for God wanted me to die then I would've been dead already since I got pretty close. And just make the best of what God gave you 'cause you never know what you gonna get tomorrow. Be blessed for the time you go there or whatever with the family you have and if you don't have no relationship with your family and you're sick, try to make one because you don’t want to die with regrets in your heart or regrets in your life. And you don't want your family to have regrets in their heart either. So you do the best you can with the life that God had gave you and that's how I see it now. That felt so, I don't know, weird saying it coming out of my mouth. Yeah, we came here to be some kind of a light and when he's ready to come, when he's ready for it, he has a place set up for us in heaven. When he's ready for us and he thinks he really needs us by his side then you will get to meet him face to face. And until then, we going by beliefs and strong faith that there's somebody out there bigger than us. There has to be because somebody created us.

Later she shared more about her purpose and her relationship with God.

To me it is a blessing, because if I have… I got into that accident, you know, so when I found out I was HIV positive I did took me to move…I did move into addiction because I didn’t care, but then…. You know, and then I was like, if I’m going to die, I’m going to try to take as much people as I can with me. Then I realized that’s not the way to think. You don’t want that to happen to you, I mean
it happened to me, but mine was through blood transfusion. But when you find that out, the rage is so bad. Like well, if I’m going to die then I’m going to take as many people with me as I can. But that was not the right way to think. That was like being selfish and not caring for other people. And I used to be that kind of person. I’m not going to lie; I used to be that kind of person. I feel blessed today because God gave me this disease that I have now. I think he gave it to me for a purpose. And the purpose was that before I found out that I was HIV positive, I was destroying my life, in the first place. I wasn't taking care and when I first found out I was HIV positive I seemed to care less and went more into drugging and more into doing stupid stuff. (Crying) To me, it's a wonderful experience to me, in a way, because not just because I can help other people, but it changed me. It changed me in a way I don't know how to express it. I don't see things the way I used to see things, destructive, no hope, no dreams. Me being HIV positive actually helped me realize that I’m worth something. That I got family who cares about me and even though I’m dying they're still there for me and love me for who I am. Not too many people have been kind to me to love me for who I am.

Participant 7 shared that he was raised as a Christian. He blamed God for allowing him to become infected. However, he felt God put him out in the streets to save his life. He came to terms with his relationship with God.

Well, I’ve always been a Christian. I was born and raised in a church. But, I think I was just the opposite. Just like anything else and like everyone else, I was blaming God. I was like, what did I do to deserve this? Why did you… And again, it’s just something I have to face it to myself. It wasn’t God’s fault. It was
my fault. It was something I did to myself. I knew about this disease. I saw a
friend pass away with this disease. And here I am still having unprotected sex,
especially in different countries. That, I mean I realized then and I do now that it
wasn’t smart. I’m a pretty smart guy. But it was really, really stupid. It was
something obviously where… I don't know. I think again, I think it was destined
to happen to me. If it’s going to happen, it’s going to happen. I think it was
destined to happen to me and I think that having it has made me more confident in
myself because I look at it really like if I can get through this, I can get through
anything. I really can. I could care less about what people think. Of course I’m not
going to go out and advertise it- I’m HIV positive. But I could care less. If
somebody found out I could care less about what you think of me, or you don’t
want to sit next to me. That’s fine. I don’t care. What’s important is that you take
care of yourself, you deal with it and you move on. I think again, I know for a fact
that it was God that got me fired from that job. It was God that put me in the
street, because I really do believe, I know he was telling me, “Since you’re not
going to help yourself and I’m not ready for you to come to heaven, then I’ll help
you. We’ll put you in the street.” My excuse was it was winter. I gain weight
during the summer and lose weight. I said I will get all the way down to like 110
pounds and say that’s just me. But that wasn’t the truth. I was just making
excuses. I was losing weight really, really fast. Rapid. Five pounds probably a
week or something like that. And I saw it in myself. My clothes wouldn’t fit and
everything. I saw it. You were able to see my ribs and everything else. I was like
I’m going to die in this hotel. I know I am. But then when they let me go from
that place and I went to the shelter. So I really do think that it was God telling me, “OK, since you’re not going to help you, I’m going to help you. This is what I’m going to do for you. Yeah, something else. It’s not your time and I’m not ready for you yet. And you’ll know when I’m ready for you. So until then I’m going to put you in the street.” Now remember, I’m an only child. I’ve never been on the street before. So that was rough to move to be on the street and that shelter. But again, I think he led me that way and just the guy that just gave me the card, it was completely off. There was no conversation about it. There was nothing about it. I obviously had to mention something to him because I remember him giving me the card and saying to contact her. Then he kept pushing me every day, “Did you call her? Did you call her?” “No, I’m not calling her.” I need to do it alone. Finally, you know, I called. I went in and you know, she introduced herself. First it was someone else and then (case manager) came in. I was sort of new. Again, everything changed for the better.

Participant 14 shared that HIV was her “blessing”.

You know, I know that this is my blessing, not my curse. Because if I hadn’t gotten sick, I would have died in California with my ex from a drug overdose or a stabbing or gun shot or – you know, from drugs or something. And if I hadn’t gotten sick, I wouldn’t have been able to come home and have a life.

Two of the participants shared nontraditional spiritual beliefs. Participant 11 believed his was guided by his unconscious.

I wasn’t thinking about religion, about things like that. But the unconscious is making all the connections because that’s what it does. Because it will work on
something even if you don’t want to see it. Because that’s part of survival. That’s what it’s there for. I’m very happy with my unconscious. [Laughs] It has done some really wonderful things for me.

Later he commented, “Much growth only comes through pain.”

Participant 9 found his new spiritual beliefs during a hospitalization for a mental breakdown. He shared that he would have never met the priest if he hadn’t had his mental breakdown.

The priest he put his hand on everybody and prayed with each person. I was first, and then he – then when he was done he said, “You have a gift. I don't know – I don't know what it is, but boy is it strong.” I was – I never thought anything about it at the time. Later on I found out what it was and I thought I can't believe he knew and he felt that. I can't believe he knew. I know. I feel really lucky. To know who you are, where you came from, where you're going, and why you're here, what else is there.

Participant 15 shared that he struggled with guilt over his choices in live. He struggles with believing he is forgiven.

Well, that I lived and made such bad choices that it almost took my life. It’s like do I not cherish my life that much that I would just be like that. And I’m a Catholic and in my mind that’s always there too. The moral choices that I’ve poorly made you know, it’s like I’m always asking for forgiveness.

Theme 5-Building the Nest of Safety

Once the participants experienced a rebirth/second chance they found a place to build a nest of safety. All of the participants shared the primal need for a home or a nest. Several of the
participants had experienced some degree of homelessness throughout their life due to the predators. Twelve interviews were conducted in the homes of the participants. Two interviews were conducted in an office of an ASO. One interview was conducted in a private meeting room chosen by the participant. From the outside, the participants’ homes were non-descriptive and blended into the neighborhoods of small towns or were located in remote rural areas. Upon entering the homes of 12 participants the researcher found beautifully decorated “nests of safety”.

Participant 4 summarized what all the participants desired to have for their refuge. “You need to feel safe. Everybody has to have a safe place. I had predators there, too. This is the first time I’ve really been in control of my own domain. Control of your own domain without the predators.” Later, she described the struggles she had in creating a home due to conflict over possession of family property after the death of her father and a toxic relationship with her mother.

I’ve never had a place to call home until now. Yes. Never had a home. Never once. And my mother would say things like, “Well, what if I need it? What if – Why should you get it? You’d just sell it. You’re father’s not here to help you.” And in ’04 I left – was leaving – and I asked my mother again, “Can you please, at least give me some sense of security here?” It wasn’t until 2009 the deed to this property was finally put in my name. My property’s paid for, I have a home.

Participant 13 shared his belief about the need to have a home and to love your home. “You can make new homes. This is my home and I love this.”

Participant 15 had experienced homelessness due to the loss of his job due to his addictions. Upon finding himself homeless, he made the decision to come back home.
I had several jobs. And then once my lifestyle caught up with me I didn’t work for the last, maybe, year and a half that I lived there. Then I started doing some heavier drugs and I thought, I was out of money and I lost my apartment. I was just staying on couches at friends’ houses and stuff. It was a bad situation, so I just decided just to come back home. I brought all that with me, including the HIV. I’m still staying with her (mother). I’m trying to look for a place of my own, because (ASO) has the program where they can help out with rent and bills and stuff. So I’ve been at the top of the list like twice now. Didn’t follow through with it for whatever reason. Sometime soon I hope to get my own little place. I’m pretty solitary and it’s hard to be when you live with somebody. I loved living in (non-Appalachian state) but in my heart I knew I would come back somehow or some way. I hope to get some little piece of Planet Earth for myself. Just the landscape, what I'm used to, the seasons. The wildlife, of course, 'cause that's just something I've always really enjoyed, being closest to nature as I can.

When this researcher entered the home of Participant 1 the researcher found a beautiful home. It was decorated in colors of yellow and green. There was a large fish tank full of beautiful fish. The home was full of life and beauty. Participant 1 stated “Well, you’re always at home in this house. I like my house. You’re safe here. Nobody would ever do anything to you here.”

Three of the participants moved back to their hometowns to original homesteads of their family. Two of the participants lived with a parent in order to prevent homelessness. Participant 13 currently lives in the town where he was raised. He left the area and moved to the city when
he learned of his HIV infection. Moving to the city shielded him from people of the small town learning of his infection. But he returned to his hometown.

So I decided to come here. It’s a little easier. As I age I think it’s easier and safer in a community like this, getting around and the bustle of the city. It’s just more laid back life, so I thought I’d give it a try. I miss a lot about the city.

Participant 3 shared he was so happy to leave his hometown upon graduating from high school. He said he would never come back to his hometown. However, he did return when his family extracted him from the city where he was living in the throes of his addiction. I met him at the home of his mother. He had created his own personal space in the basement.

Well I always said in all my life – I've been gone for 30 years. My whole life, you know, people worry about the worst things that could happen to them and I knew and I would tell my friends the worst possible thing that could happen to me is I have to go back and live in my hometown. And it happened. So while I was in my addiction I knew that the only way out was to leave. I knew that. If I could get out of the environment, then I'd probably be all right. You know, and so I wanted to come home. I didn't want to come home per se, but I wanted to get out of where I was and I really didn't have anywhere else to go, except home. I have had a friend who was in a similar situation that he lived with his grandmother and he had a basement. He redid the whole basement and I remember that. And it was really cool, really nice. And I remember that, but I didn't redo the basement because my mother would never let me do that, but I did do this little corner, similar idea.
After learning of his HIV infection and retiring from his job due to his health, Participant 5 and his wife moved to her family homestead that was in disrepair. They moved to the area because of a lower cost of living. The couple described the condition of the home when they moved back to the area and how they renovated the house. The wife shared:

He had everything in there, a couch. He was *(inaudible)* everything till we get some kind of heat in this room. Windows were flappin’. All the windows were fallin’ out of this place. It was two years of a rough road, but he slapped it together. It was cold, but we pulled it together. It's a safe place.

This researcher met Participant 12 in an office of an ASO. Participant 12 was staying with a family she considered to be her foster family/parents. Otherwise, she would have been homeless. She shared the dream of having a home of her own.

Yeah, my journey has been so long and so destructed in my life so this can't get any worse. I don't have a place to live. Right now, I'm staying with my foster parents, but I'm not living in the street either. I'm not sleeping on the floor. I got a bed that my mom gave me, a room that I sleep in. I could be so much worse. I could be in the woods with no blanket in the rain, no food, not knowing where the food next was going to come from like before. Every little thing is a blessing to me now than it used to be. Every little thing.

**Protecting others.**

All of the participants expressed their passion for protecting others while living with HIV/AIDS. Participants described their experiences of being obsessed with protecting their spouses, significant others, children, and health care workers.
Participant 12 was lived with her “husband” for 18 years. Her husband, who recently died, never became infected with HIV.

So I could've been through a whole year, a year and a half, before I found out that I had it and that state of mind that I could cause other people harm because not knowing it – they sometimes say its better off not knowing what you have. I think sometimes it might be harder, painful, but I think sometimes its better off that you do know that you have health problems than not knowing at all. He knew I was HIV positive. He never judged me for who I was. He wasn't HIV positive and we lived together for 18 years and he never was HIV positive. He used to get tests done here every two months or three months to make sure he was safe.

Protecting her children was also important to Participant 12. She shared her concern about the youth today engaging in high risk behaviors. As a result of her experiences with betrayal, danger, and HIV infection, she is aware of the consequences. She wants to shield her children and others from similar difficult experiences.

I always tell my daughter, be careful with people you hang out with because you don't know. Not everybody is going to be honest about this disease. I don't care what anybody says. Not everybody gonna be honest about their health and especially with something like this. I know my kids love me and especially my youngest daughter, you know, she got into a couple of fights over me because people talked bad about me and stuff. I never thought that my daughter would be protective of me, because you're supposed to be protective over your children, not your children be protective over you. But somehow, it works both ways for us, you know I protect her with all my life and she protects me as much as I protect
her. And that's with all my kids, you know. You know, being there for other people and be there to the teenagers who nowadays are, excuse me, not trying to be rude or anything, but screw around without thinking the consequences and always doing stupid things and stuff without protection. I tell my daughter that all the time. I said, “Don't make the same mistake I did as a child. Don't go that path, you see ______ time. Don't go that path, it's not a good path.” I've been blessed, I have seven kids, and none of my kids has it. I seen my dad shoot people in front of me and stuff like that. That’s why when I had my kids that was…The most scary thing was for me was that because I have a bad temper, as it is already. And seeing that, my dad… I was raised by bad dad and stuff like that, my biggest fear was if those kids get me upset or something, what if I hurt them or something. Maybe I should just get a place that I know they’ll be safe and I know they’re not going to do something stupid.

Participant 4 shared her experience of having to contact her ex-partners to inform them of her HIV infection.

I made the phone calls, too, to ex-partners. Fortunately, no one was infected and they were glad that I made the call. It was hard. There was over a handful. [Laughs] You know. I was single, I was always sexual. And I am so grateful that I didn’t infect anyone.

Participant 4 has been outspoken when it came to sharing information in regards to risk reduction for HIV infection.

Yeah. I kind of went a little overboard different times, I think. I think that was my way of coping with the reality that I was facing. You really have to know that this
is out there. I fear for these next generations, that they’re just so out of touch with reality. Again, I’m glad I’m as old as I am. I liked it up there because it was through the gym coaches and I would have sessions with all girls. And that was really important. There were all these open questions and how to keep safe, and why should they, and trying to build self-esteem in them. And it worked that way with some.

Participant 5 shared the difficulty he had when he had to disclose his HIV infection with his wife and his obsession with protecting her.

I found out I got AIDS, I felt dirty. I don't want her to get AIDS. She don’t have AIDS. She don’t have AIDS. They test her every year. We had sex when I was shaking and chilling and all this crazy. I was amazed that she didn’t get it, but now if she does get it, her cycle of life, it’ll finish out. Even if she goes into the 80s and 90s. I hope she never gets it.

His wife interjected into the interview, “He protects me.” Participant 5 shared how he protects others when he is at risk for bleeding.

But I bleed, I get away from people and take care of the problem. Well, I had someone else gut it out because I had AIDS. I never touch deer. I shoot a deer. They gut it out (deer) and cut the meat up for me. Yeah, I got Hepatitis. I got Hepatitis C. I told him “I had Hepatitis and don’t touch me.” I came up with something else besides AIDS ‘cause they wanted to take care of me blood wise. That’s what I think I told him. I got Hepatitis. They can face Hepatitis better than AIDS.
Participant 6 became involved with extensive education initiatives once she realized she had a second chance. For several years she spoke with youth at schools and with peers regarding prevention and compliance with treatment regimens. Because she is older and a grandmother she feels that her message is more powerful.

Because when I can stand up in front of a group of 18 – 20 – 23-year-olds and say, Listen, I'm gonna tell you one thing that's really important and I say this all the time, and “Young ladies, please, pay attention. I don't care if you leave the house in the morning and you forget to put your shoes on. Don't forget to put a condom in your purse 'cause you never know where your day is gonna go and what's gonna happen,” and they do this – you know. I said, “Because it's important. Don't wait for somebody else to protect you. Don't assume that somebody's gonna protect you. If you don't protect yourself, then you have nobody to blame but yourself, you know?” And by – again, same things that don't come out of a grandmother's mouth, usually. It makes a difference, you know? But I – again, I was out, I was meeting people. I was interacting with people. And I was interacting with people that knew some of them because some of them looked at me just like, Oh, this is the educator. Not that I was positive, but those – when I went to speak – and speaking made it such a big difference because partly – partly because of my age. Especially if I spoke at the colleges or high schools and you have these kids sitting there, and I always – I'm always amazed because you go in and it's – you can see, especially in high school, the kids are sitting there like, all right, we gotta listen to this now, and they're fidgeting and they're playing with this and they're – and they're not – they don't wanna hear this.
And I start to talk and they're still – and then all of a sudden, when I say that I'm HIV-positive and have been for 10 years or 15 or 20 years – they quickly snapped to attention. I mean, you can see the – and they look at me. And I say – and, you know, “Yes, I'm so many years – I'm a grandmother. I'm a great-grandmother.”

And that just blows their minds. They just – from then on, they are so attentive because this is not what they expected, and I'm very honest, and I'm very open, and I will answer anything that I can, and then I allow them that – I say, “Ask me what – if I can answer it, you'll hear an answer, an honest answer.”

Participant 7 shared that he was full of fear when he had to disclose his infection to his ex-wife. He feared he infected his wife and his daughters.

Well, I was married and my first thought was how in the hell am I going to tell my wife that I'm HIV positive. And now, don't misinterpret, I never cheated even in any relationship I've ever had. I never strayed outside the relationship, but they said that it is something, obviously, you might have had and didn't realize it and for years on. And my main concern was my girls. I did not want them to have it, so when I found out, I immediately had them go to their PPC and had them tested. And, again, I was blessed because they didn't have it. And then my ex-wife, she didn't have it. But you realize at a point that if it could happen to you it can happen to anyone. Well, we actually sent the girls away and we actually sent them to the grandparents. We sat at home and I told her ’cause I didn’t want her to have a scene out at dinner or something like that. And of course, the very next day she made an appointment and went and got herself checked and everything else and I was really blessed, but then the marriage went downhill from there. And once I
realized that they was okay with that, which is probably like a month, six months, probably like six months after everything, that's when I did the disappearing act. I just packed up a duffle bag and got to my car.

He shared that he is always discussing protection with his daughters.

And that's why I tell my girls today and I'm very, very blessed with two smart girls, “please, cover yourself. And I'm going to tell you right now, guys will say anything to get with you. Okay, trust me, I'm a guy, we do that, so please cover yourselves.” And I couldn't believe it, (daughter # 1) is still a virgin and she's a senior in college and (daughter #2), well, (daughter # 2) says she's having sex and I'm like please, tell me. “Daddy, yes, dad, I don't want to talk about this with you.” I said “I don't care.” I said “you know what's going on with me.” She says “I know.” I worry about them especially with the HIV now. I worry about them every day and I know I get on (daughter #2) nerves. (Daughter #1) she's just like her mom, she's strong. (Daughter #2) is just like me. I mean she's strong, but she's a people person and I worry about them every day and I talk to them, I do talk to them. I give them a call every other week or something like that and I'm like “you, please, take care of yourself.” And they're like “yeah, daddy, I don't talk to you about this.” With me of course, having two daughters I’ve always been very protective, very nurturing over them. But, it did sort of intense, make it more intense as far as me making sure that they knew. I mean, I purposely, I’m not sure a lot of people, a lot of adults or a lot of parents will tell their kids this so they don’t have to worry. I told my daughters where they could know for sure, OK, this could happen. They can do this. This could happen to you if you do this.
Participant 7 shared how he and his current girlfriend have successfully maintained a trusting relationship.

And then I met my girlfriend up in (city) and I told her right up front. I said, just to let you know, I am HIV positive, so if you don't want to pursue a relationship right now, I need to know now. And it really didn't, surprisingly, it didn't really bother her. I mean, I told her I was taking the Atripla and she actually went with me a couple times when we did the bloodwork and they said there was nothing in the bloodstream, you seem to be fine, but you gotta keep taking the meds. I’m one of these people, now, that I am really, really a mentor of go be tested. Go have yourself tested – it's better to know than not know.

Participant 8 shared the experience he had when he became infected. Although he was using condoms, he still became infected because it was after a condom broke did his sexual partner share that he was infected with HIV. He shared the difficulty in having to disclose his HIV infection.

I was petrified. I kind of knew I had it because I had these night sweats. I knew that was a good sign that it probably was. I went and got checked. The first time that I went to get checked, I was with a guy in (city). He was telling me he didn't have anything. After the condom broke, he told me he did and that he was HIV-positive. I was scared and I walked the floor for two weeks. I was so mad at him. You've got to take responsibility for yourself. You take that chance. We call them tricks, which I don’t do it too often anymore, but anyways it’s hard to tell them, but they ask. I haven’t always told them. I told ______. Nobody does. They think I’m crazy that ______ _______. I’m telling you they don’t. You get tired of hiding
and that’s with me being positive like me putting it in chat rooms. Someone said, “You wouldn’t have to put that in there.” Some people are and they just don’t wanna talk about it. Most of them are. I said, “Well, it’s me.”

Participant 13, who has been infected since 1981, never told any family member, including his parents who are now deceased. Living in a conservative rural area with an ultraconservative family, he spoke of the fear he had if his family learned he was infected with HIV. The fear was based on the violence experienced by other cousins. He shared how a cousin was treated by the family because the cousin was gay. Participant 13 protected the wife of another cousin from domestic violence.

One thing I was taught bigotry and I was, my cousin (cousin) took a beating in the family because he left for San Francisco as soon as he could. Family was so tough on him. He was very feminine and I always felt always badly with kids, I used to have to defend him and stuff in school. Bigotry is so ugly. That exposed me firsthand. We volunteered in the task force in the gay community. I become very understanding. Some wonderful people died that I know. My mom said my cousin was disgusting. “He’s going to hell.” I had another cousin that beat the hell out of his lovely wife. Well, that’s OK, his brother, (cousin 2), that’s OK. I’m going, “What about (cousin 1)? (Cousin1) doesn’t hurt anybody. He’s a nice kid.” But see, they worked him over and the one that we knew, matter of fact, I stuck up for (cousin 2 wife). I said “(cousin 2), I see you lay a hand on her I’ll kill you.” You know, and here’s (cousin 2), this horrible monster, this lovely lady. Finally she got away from him, which we kicked in some money and got her moved to (city),
and I don't know where she is. Yeah, and to think of how I wanted a wife. Here he has a lovely wife and I couldn’t have that.

Participant 14 shared her concerns regarding protecting her husband and son from repercussions related to her HIV infection. She shared how she protects her husband and son. She discussed how she and her husband grapple with issues related to protecting him during sexual activity and how she diligently makes sure her husband is tested.

Cause that’s all it is. I don’t – you know, I have precaution things here, in case something were to happen to me. So the guys have gloves. And the guys know, don’t touch me, use a towel, use a shirt, use anything. Don’t – you know. I have all the precautionary things. But I’m very careful not to hurt myself or cut myself. Or, if I am bleeding, you know, I take care of it myself. My husband and I don’t take precautionary measures in the bedroom, but I know that the chances of me giving it to him are slim. He understands the risks involved and he’s willing to take those risks. So…It’s like I said, I’ve talked to him about it a hundred times. And I still make him get tested regularly. I'm very careful. I'm very careful, but if something happens, and I have an open cut or something or a nick or whatever, I'm very careful to make sure (husband) – I mean, (husband) doesn't care. (Husband) doesn't – he doesn't care, and I'm like – [silence while some action occurs, then laughter]. It don't bother him. But if he has, from working on the car, and so he'll have nicks and cuts on his fingers or whatever, and it's like, okay. “You gotta be real careful where you're sticking your finger.” And (son), he’s – I mean, there’s not a whole lot of precautions with him unless I were to hurt myself and he were to try to help me. You know? But he’s pretty good about it. And he –
but he needed to know, because that was my worst fear, was that I would have an accident and be passed out and not be able to warn him not to touch me 'cause he bites his nails down to the nub. And that's – I was just wigging out about it. But he was old enough to absorb the information. I know that when the time comes and there's a reason for me to have to tell somebody, if I am bleeding profusely or something like that, then I have to tell somebody. And absolutely, I will.

Participant 14 also shared her concerns about certain family members learning about her HIV infection. Her concern is that if certain family members knew of her HIV infection her son would be stigmatized.

And my aunt is one of the ones who knows everybody and talks to everybody. And so, it's just best that we don't, you know, don't tell her because she will tell everybody. And that was really my decision in not telling them is just because they have big mouths. And we didn't want everybody to know because, at the time, we were protecting (son), and he didn't need that stigma.

After learning he was infected with HIV, Participant 2 shared his experience of disclosing his infection to past partners.

And then, I decided I was gonna call the people that I – 'cause we're not monogamous. And so other people that I had played with and both of us played with, I had called them and told 'em, I tested positive for HIV. That was a real difficult thing to do.

He shared what a burden it was to protect yourself and protect others.

All of it – that you have to deal with protecting yourself. Plus, you also are given the burden of protecting other people, which not everybody has that burden, too.
‘Cause you do feel like you have to protect other people, so – I do play safe. And then, you deal with people who don't care. That puts a burden on you, and I've seen the switch from the HIV in the early days, telling everybody, protect yourself to then, it was up to the HIV community to educate and protect the rest of the world. And I went from being someone who was scared to death I was gonna give someone HIV to over a period of time, being scared to death I was gonna catch something else. And I've probably given out a million condoms, seriously. They feel – I talk to them. I've had ’em to say, “Well, if I do get infected, I'm not really that afraid of it because I know I can just take medication. It’ll take care of it,” at which point in time, I go into my speech to them – do they know about the diarrhea and the depression – I have been in many situations in the last few years where people were not playing safe, and I've actually handed them condoms and they said, “No, thank you.”

The experience of protecting others for Participant 1 was protecting his nieces and nephews from risky decisions made by their parents. “Give me your kids – If you’re going out drinking in your car, I’ll keep the kids, ‘cause you’re gonna be drinking and driving with your baby in the car.”

Participant 10 shared his experience of fear of infecting a health care provider who was attempting to start an IV. The health care provider had taken off the gloves he was wearing during the procedure.

Anyway, he was having trouble getting the needle in. He had gloves on. He took ’em off and to find it put it in. And I was pissed. I didn't say anything right to him because there was a lady in the ambulance with him, I worked with her husband.
But when I – they took me into the emergency room and I ended up being admitted. And as soon as (physician) came in, I told him about it. I said that bothered me bad. I told him why I didn't say anything. He said, “I will take care of that.” He said that is totally out of protocol for them on the ambulance and for staff. He said “That one,” he said, “will be addressed.” And I heard later it was. That guy was a little upset because somebody said something about something he did. Well, tough.

Participant 10 went on to share his encounter with another gay man who is continually involved in risky behaviors. “And I have said to him more than one time, ‘people are absolutely nuts.’ And he said, ‘it's my life.’ I said, ‘yeah, but when you get a diagnosis of something your life is sure as hell gonna change’.”

**Nurturing others.**

Several of the participants shared how they believed another purpose in their life was to nurture others. Although participants alluded that they believed they were always nurturing, living with HIV/AIDS intensified the need to nurture others. Six of the participants believed that nurturing/caring for others was one component of giving purpose to their life. One participant felt that nurturing children energized him. Two of the participants nurtured children/youth by sharing their wisdom gained from past mistakes in hopes that the youth would not make the same mistakes. Two of the participants described how they nurture and care for family members as a way to reconcile and rebuild relationships that experienced a stormy past.

For Participant 1 nurturing others meant babysitting for his nieces.

Well, I babysit. I babysit for my niece. I watch a five-year-old, a three-year-old, and a one-year-old. And they love (partner), Uncle (partner), Uncle. They’ll say,
“Uncle (partner) and (Participant 1),” I’m like, “No, it’s Uncle (Participant 1) and (partner).” You know, to me, kids just bring this energy with them. I had six babies under the age of a year.

Participant 10 felt that he was always nurturing. He shared how he cared for his elderly father during the end days of his father’s life. He shared how impressed the health care providers were with the care his father received from him.

Now, the doctor even said that. And one of the nurses – he was in the intensive care the last few days. And one of the nurses in there said something when the doctor was there about what nursing home he had come from because he was so clean and no bed sores or nothing else. And he says, “I'll tell you what,” he says, “He didn't come from a nursing home. His family has had him at home.” One of the nurses in there told us and the doctor told us. “God bless you that you were taking care of him like that at his age and the condition he's in. You got all the praise in the world for his condition compared to some them that we get at that age.” And it was hard, but we did it. And then I'd bathe him from top to bottom and change his clothes. He never had a bed sore. And put his diaper on and then dress him. And then he had a power recliner in there. He'd go. Well, then he'd say “I gotta pee. I gotta pee.” And before he could get the recliner up, he had a wet diaper. At times even through the diaper and on the chair. Thank God the chair was vinyl. Scrubbed the chair, Lysol it and whatnot. But we kept him there. I've told this one (daughter 1) and told my other one (daughter 2) if I ever get that bad don't feel bad if I have to go in some facility on that. Don't put yourself through that.
Participant 12 felt her HIV infection gave her a purpose to nurture others, especially her children. She was estranged from her oldest children due to her lifestyle and addictions. She has been reconciling her relationship with her children and forming relationships with her grandchildren.

I appreciate, I'm not happy that I have the disease 'cause I don't think I'll ever be completely settled with it. To be able well, you know, but I learned to say, Well, I have it, here is me, and what do I need to learn from it and what can I get out of it to be able to help other people like people with me? So it's a blessing for me. It's been a struggle and it hurts me sometimes because I don't want this disease, I really don't but I have to live with it so I have to make the best of what it is, what God gave me. But I believe that God gave it to me for a reason maybe to me to understand about the disease a little bit more maybe to help other people. Yeah. Well, one of my grandbabies, I seen her being born. My other ones, I've seen them through Facebook and stuff like that 'cause I'm trying to get my life together with my children. I mean that's what my dream is before I die, you know. If I were to die tomorrow having my family and my kid – not just my mom and that, just my family and my kids, the ones I gave birth to that God blessed me with, I'd die happy. All I want is my kids to be together, real nice to each other, and my grandbabies to get to know their grandmamma. And if God gave me that, then I think I've lived my purpose. And then I'm blessed. I'm blessed being able to see my grandbabies and hear my little granddaughter call me ‘granna’, ‘grandma’, you know. I never thought I would ever see that. My positive change came when I had my daughter, my youngest daughter and even though I was a single mom
'cause I did raise my kids by myself, I pretty much been a single mom for all my kids. So seeing (daughter) you know -- I've got so much to give. I got so much to give and I want, I just want to see my grandkids grow up now and I probably won't see it but just to know that just a little tiny string that I might be able to, I wouldn't change for nothing in the world. One is for me to be here for my grandkids and one, for my daughters because my youngest daughter goes through a rough time and if He were to take me down I don't think my daughter could handle it. That's just one of them, to be honest. Because my daughter's in a fragile situation because a lot of people have picked on her all her life 'cause of me and sometimes she don't think she's worth being loved. And that's what I said about myself, you know, well, I ain't worth being loved look at me, I'm dying why would anybody care about me? But that's not true 'cause a lot of people care about me. I told her, (Daughter), no matter where I’m at, no matter where I go, no matter whether I’m here alive or dead, I’m still going to be your mom and I’m always going to still protect you.

Participant 14 shared how she nurtures her son and attempts to protect him from the mistakes she made.

But, you know, at least he (son) has plans and goals and dreams. And that’s half the battle. I came back from...And I was, and I know I was. But I learned a lot from it, and I can pass that knowledge along and watch for the signs in my own kid. You know? And I can't have him be punished for something I did kind of thing.
Even though Participant 2 had a tumultuous and unsettling relationship with his mother, he attempted to reconcile the relationship by remodeling his mother’s house over a time period of months. “I completely redid my mother’s home for her.”

Participant 3 shared how he attempts to nurture younger men through sharing his own life experiences and educating the men regarding safer sexual practices and being compliant with their medications. He reminds the younger men that he was in the same place they are once in his life. He wants them to not make the same mistakes he did.

This was me giving back to all, to society what they, the gifts it's given to me. Well I would tell people that are younger than me. Like I met someone that's 25 the other day and we're having a hard time relating. I said look, I need you to understand something. I said “look, I was 25 for a whole year once so I know where you're going. I know what you're experiencing. Unfortunately you've never been 48 so you don't know where I'm coming from but just take my word for it. I know what to do. Just listen to me, you know. Just listen to what I tell you and it will work.” Well I tell the young kids I said “look, HIV medicine, you have to take it every day even if you feel okay. You know, you just have to. I'm not used to taking pills. Like you're going to have to get in the habit because you – trust me because I went through it.” Like I had affected legs, lymph nodes and I, all I needed to do was take my pill.

Although Participant 4 never had children of her own, she recognizes the difficulties she experienced in her life and she attempts to educate youth so that they do not make the same mistakes she did. She recognized that today’s youth have the same challenges she did as well as new challenges.
To see it, have to think about children having to deal with what I was dealing with, well, there’s empathy again. You do what you got to do. I fear for these next generations that they’re just so out of touch with reality. Again, I’m glad I’m as old as I am.

Participant 5 felt his purpose is to nurture and care for his wife and dogs. His wife is older than him and has multiple chronic illnesses. “I got a wife to take care of and dogs and lots of responsibility.”

When first diagnosed with her HIV, Participant 6 was living while waiting to die. With new treatments, Participant 6 realized she needed to focus on continuing to live out her life. Participant 6 felt her purpose is to nurture others through education and peer support. She shared that her HIV infection changed her life in a positive way.

Only that I'll, again, be more involved, but it isn't going to make a difference in my feeling about myself or have me every day thinking, Oh, okay, I'm positive, I'm positive. You know, for a long time, that was it. That was my every day. That was my life, and now, it's far from my – from any part of my life, other than it's there, somewhere. No, I don't think – I can be part of the (ASO) and – just to know that I'm doing something that benefits others and gives me a sense that I'm making a difference, and that's a good thing. So –well, now, it's changed. [laughs] I guess my purpose at the time, when I was drawn into the (ASO) and was doing education and working with people, my purpose was to help make people's lives better, and so I spent a number of years, in different ways, doing that.
Married for years, Participant 7 shared the experience of when he disclosed to his wife that he was infected with HIV. His first concern was to make sure his wife and daughters had what they needed to continue on in their life.

You know, she wanted to split the house and I didn't want to take away from my girls. I didn't want to take them away from their house. I didn't want to take money out of their pocket or food out of their mouths. So, pretty much for the first year, they had no idea where I was. I didn't tell anyone. I didn't tell my family. I didn't tell my mom. I didn't tell anyone.

He shared how he will always be a father to his daughters. He described ways in which he nurtures his relationship with them and keeps them informed about his life today.

And I do, and they know, I'm going to tell them exactly what's going on with that and they also know that I love them more than life. They know that there's nothing that I wouldn't do for them. But you just, like you said, you being a parent yourself, you worry every day. You think it’s gonna stop, it never stops. And like I say, I'm planning on – I'm blessed.

Participant 7 shared how he nurtures others by being kind and compassionate toward others. He shared a story about a young woman who committed suicide when she learned she was infected with HIV. He shared his frustrations that he was not there to support her and prevent her death.

And I appreciate every day now, I really, really do. I take nothing for granted. I try to be as thoughtful, as helpful, as I can with others. I reach out and I try to reach out to people that I do know, that does have HIV, and let them know you're not dying. The nurturing part has always been there. It’s just enhanced. I wish that
we could have met that young lady at the time and told her, hey look, if I would have told her, number one, I don’t think that she would have believed me because she probably thought I was just trying to cheer her up. So I would probably have to show her some of my records and say “you can get through this. It’s not a death sentence. It’s not the end of the world. You can get through this. You don’t have AIDS. You have HIV. You don’t die from HIV. It’s like having high blood sugar and stuff like that. You have to treat it.” I wish I could have been there to talk to her, to talk her out of it, and give her my experience of what I went through. And I really do think she probably would have listened. I think she might have needed that type of support. And my thought was what kind of support did she have when she found out? Did she go to a clinic and they just… because if you go to the clinic and you got it, they just tell you. That’s it. They don’t show any type of compassion or any type of concern.

Participant 9 felt having HIV has given him purpose in life and that there are no coincidences in his life. Even though he has daily challenges associated with living with HIV, he stated he plans to continue to be open to his life’s journey. He believes one of his purposes is to nurture relationships by bringing people together. He was instrumental in introducing two friends, who are now together in an intimate relationship.

I was just a facilitator and I don't know how many times people have said, “You bring people together that are supposed to meet.” If I didn't have HIV that would had a terrible butterfly effect on everybody else's life, so you're damn right, I wouldn't trade it for anything. I'll take one pill a day and be tired, and a little tired, but…
He reflected on his experience of how difficult times in the past helped others and led him to where he is now. He shared how he has reconciled his relationship with his mother and how he nurtures and cares for her.

After I had that nervous breakdown, I was never really 100 percent after that. I was starting to feel overwhelmed, and I thought – I planned ahead. My brother was in debt terribly with credit cards, and we both owned mom's house together, and he literally owned enough he needed to sell his half of the house to pay it off. So I said what if I – he was suicidal, and I finally got – he said – he actually said, “I'm thinking about ending it all. I can look at these credit card bills and I don't know how we're ever going to get out of this.” I just thought okay we've got to do something. I was at a company that was growing and I had stock options that I was able to buy him out of that house. I wouldn't be home with mom who's 95 years old, I'd be in Texas and she'd say I can't live alone anymore, and she'd have to go to a nursing home. She's legally blind and she can't operate a can opener because of arthritis and she can't see to find out why the TV isn't working right. It doesn't sound like it's very important, but she couldn't be alone if I wasn't there. She gets on my nerves like [laughter] – while I'm getting better, and it's hard to come home. When your mother is used to controlling everything and running her kid's lives beyond the point of normal period, and into the not healthy area. But you can't teach a 90-year-old dog any other way; so you have to do all the work. I hate to say it. I have learned to have a new relationship with my mom and it's been like getting all your teeth pulled without anesthesia. But it's really been good for me to try to put up with some things and let it go, and just look at her and
think she's so sweet, and even I don't think that very often, as you can kind of imagine.

Participant 13 broke off his engagement with his fiancée when he learned he was infected with HIV. He never told her the reason for breaking the engagement. He dreamed of having a wife and children. He shared how he nurtures children through volunteering.

I volunteer at (agency) too. We build bird houses. My workshop (his house), and this has a real nice basement. We build bird houses, a couple friends of mine and I, because we want to give to kids, and they just love them. And give them bird feed. In the winter they feed the birds. But girls are pink and the boys are blue. I just love children so much. I just gave everything away. I still do a good share, but that’s my nature. I don’t know that HIV didn’t change that. I thought well, I need to shift into another mode and help others. I started volunteering for the (ASO), working the food pantry for years. That helped me. Yeah, I did that a lot. My art skills are terrible. My friend (female friend) paints them. She’s very good. That’s my therapy. That’s how I dealt with, I found that I really needed people. And I understood illness and felt you get a certain vulnerability, weakness comes with it. So I related to the kids at (agency) and Special Olympic folks. A lot of them have deformities. They have horrible health issues too. So I found that I understood others that way. So I found a niche. Again, I believe in empathy in a big way because my mom didn’t had eye for another. She could not put herself in their moccasins. I do that regularly. I don’t have it so bad. That’s what I determined early in the game. You almost have survivor’s guilt and health guilt because I go in there (HIV specialty clinic) and I see these skeletal people. I’m
going, that poor girl. That poor dude. That’s maybe his last appointment. Very awful. I’m always tweaking how I think. You always have to … some people are so set in their mindsets, but mine will go in like how can I be a better guy today when I get up. I need to adjust something, do more for others, something.

**Enhanced life/legacy.**

When participants recognized the opportunity for a rebirth or second chance and discovered their resilience, they realized they had a desire to leave a legacy for their families and the world. Many voiced wanting to make a difference in the world, especially being a support to others living with HIV. Several participants believed that having HIV gave them purpose. One participant believed that living with HIV/AIDS was not a death sentence. It was a death sentence if you chose it to be.

As part of her legacy, Participant 12 shared she wants to write a book in order to educate people about living with HIV. She would like people to see her through different eyes.

I really want to write a book. I’ve been thinking about it. I got people, a lot of people misjudge me from my HIV, but they don’t know nothing about my past or what I’ve been through to get to where I’m at now. And that sometimes upsets me. Sometimes I just want to put on Facebook just fill the whole page of Facebook and say, “Look at my story before you judge me because you just judge me for my looks. But you don’t know me at all.”

During another time in the interview Participant 12 shared how she wanted to be remembered by her children and grandchildren.

I'll just sit here and be the good mother I can be and definitely spoil my grandkids as much as I can 'cause God knows – I don't know how, you know I want them to
remember me for what is inside me not for my health and stuff like that, when grandma was sick and stuff. No, I don't want them to remember me that way. I want them to remember me for the good times we had together. And that's what I can give my kids is the time. I know what my purpose is. My purpose is to be here for my children, to make sure my children, when it’s time for me to go, they will be able to accept it and deal with it and not hurt themselves in the process.

Later she shared details of her purpose of having HIV and why she was allowed to live.

It comes time in your life that you have already have done so much damage in your life and nothing has happened. I'm still here; no matter what I did wrong, I'm still here. It's a purpose for me being here. Today I see this as a purpose I don't see this as a disease. I see this as my chance of staying alive because 20 years ago my daughter was born, my youngest daughter, she'll be 20 here, I remember having my youngest daughter an making plans for my daughter to be raised by other people. (Crying) I didn't think I would see her be 20-years old. I gave up my hope a long time ago. And to be blessed, I have seven grandchildren, wonderful grandchildren, to be blessed to be able to see my grandchildren that I never thought that I'd be here for. Well, one of my grandbabies, I seen her being born.

Participant 13 recalled the time he was diagnosed in 1981. “I made my funeral arrangements right away. That was a big relief back then.” Today he believes his purpose is to helps others and to be productive.

Now since I’m an enigma I’m donating this carcass to research, because I figure it can help others probably, especially that many years of living with it. There’s always something going on in me and affects me. When you remodel me. It does,
it’s motivation. I found yeah, I always need a focus, a project of sorts to keep me motivated.

Participant 15 shared he had time to think about his legacy and purpose while on several months of house arrest.

At the time I was still on house arrest, I mean right after that. So, I did quit drinking or couldn’t go anywhere and get into trouble. I was stuck in the house. So that sort of clarified things for me for a while. Which I think is what the purpose was of all of that in the end. I would be pretty happy that I have such a trunk full of memories and things that I did to look back on.

Participant 11 felt HIV infection had a purpose in his life.

I am a much better person for having HIV than I would have been without. And, quite possibly, I’m living longer because of it. There are a lot of negative things in my life that I had to prune away if I was going to live, and I made that decision.

Participant 7 felt his purpose was to help others to find support and overcome the challenges while living with HIV.

And that’s the thing about it again, if I did decide to write a book I would go on a lecture circuit. I would go, and I would just like Magic Johnson and other people who actually has this. I would actually stand up and be like, “you no longer have to be afraid of it.” And I would expose people who are ignorant, who are small minded, who think because you have this disease that you can’t be eating the same restaurant that I’m in, or you can’t sit next to me. I would expose the doctors and lawyers who don’t want people who have HIV or AIDS, to come to their facilities, because in that case you are in the wrong line of work. Your job is
supposed to be healing and helping, not being judgmental and God and making choices in people’s lives. That’s not what you’re a doctor or a nurse for. So I would definitely go on a circuit, and I would stand up, and I would definitely be heard about this disease and I would let people know it’s not a death sentence. It’s only a death sentence if you choose for it to be. And that reason is not doing anything about it. Stand up. Face it. Move on. It's just, I think just dealing with it every day and knowing that this is something that's gonna be with me for the rest of my life. And knowing that now and knowing that I think it has helped me. It definitely has made me stronger. Again, appreciating life a little bit, more better than I did before. Of course, like most people, I took things for granted and it can't happen to me. I’m this, that, and the other, and I'm traveling here, I'm gonna go there. But it definitely makes me appreciate things more, it does. It really does. I mean I'm looking so forward to at 55, I turn 55 in May, to retire and spend my days off on an island somewhere and just enjoy myself. Every payday I pay $50 for lottery, the mega millions, because it’s too expensive to play Powerball and I always said that if I ever do hit I will give them a million dollar donation right up front, because that’s how passionate I am with (ASO) and what they’ve done for me. I mean they’ve helped me out a lot, really. Just finding the support is… well it’s not as hard as it used to be, but it’s still hard. You got to find people that you can trust. You got to find people that you can talk in confidence. You got to find people that know you have it, but is willing to take you to your appointments and do this. Believe it or not, it’s hard. It’s really hard. And I’m surprised that I have
found the support that I have with (case manager) at (ASO), but they’ve been great. They really have. I couldn’t ask for a better support team than (ASO).

Participant 6, living with HIV for many years, felt her purpose for living with HIV was to make a difference in the world.

Well, I've had a very different life. [Laughs] Yeah, and it has. I mean, I look back, again, it just – it led me down a path that I never, ever would've expected, and gratefully, staying healthy the whole time. [Laughs] Because that was always – again, because of – because I experienced the scary years, I was waiting for scary. The fact that my kids know that I was running around, handing out colored condoms or flavored condoms all over the place – [laughs] – didn't always make them happy, but they knew this was what I did, you know? And you do whatever you do to make a difference in this world, and this is my difference, I guess, you know? I could fry chicken all day long, and it's great. People love it, but it doesn't – [laughs] – does not make a difference in the person's life, and so I guess that's why I kind – I missed it for a long time, and I knew – again, going back to the early days, there was nobody. There was nobody you could talk to; there was nobody that could say to you, listen, I understand. I probably am one of the only people that will say this to you, but it's made a difference in a positive way, being positive, because had I not been positive, I wouldn't have progressed to where I am today. I wouldn't have had the experiences. I wouldn't have been involved in a lot of the things I've been involved in. I wouldn't have met people that I've met. I wouldn't have gone to conferences and gatherings, and it's just – actually – [laughs] – the fact that I'm very healthy, of course, makes it a plus. So it kind of –
it threw me into what I became with the \((ASO)\), and then that just kept snowballing. I did different things. I learned more. I became more. It opened a whole new world to me and allowed me to make a little bit, and still, there was always in the back of my mind, how come I'm not getting sick? How come? You know, and I still – to this day, I don't even get a cold. I get – I don't remember what it's like to get a cold. I'm lucky, you know? I'm quite – I'm lucky now, again, learning all that I've known, You know, for me, personally, if I wasn't doing – people say to me, well, again, you're almost 70. You're gonna retire? Retire from what? I just spent almost 20 years retired. And that's the bad thing for me. I am now so gung-ho, and it's killing me that there's so many things I wanna do that, at this point in my life. You – if you feel like you – now, it's different, again, but years ago, if you feel like you're gonna die, you kinda lose purpose, and so – and I think this is what happened with being part of the \((ASO)\) and doing so much. It gave me a whole new purpose. But I think at that point, things changed. Now, again, they may change for the better or the worse, but it just depends on the kinda person that you are, the – you know, who you are either takes you to a whole new place with it or pulls you down and takes you to another whole new place, but not a good one, you know? So, for some of us that realized that, for a while, there was nothing else we could do and wanted to do, so we looked for a direction – an uplifting direction, a new direction that would give us a purpose. Because at that point, you have no purpose.
Theme 6-Living in the Shadows

The lived experience of living with HIV/AIDS while residing in rural Northern Appalachia meant living in the shadows. Prior to becoming infected with HIV, several of the participants in this study chose to leave their rural hometowns to pursue a life in urban centers where there were educational, cultural, and employment opportunities. Participants shared various reasons for relocating to rural Northern Appalachia during the journey on the road to death. Three of the 15 participants were residing in rural Northern Appalachia at the time of diagnosis. The remaining 12 participants relocated to the area after being diagnosed with HIV. With a rebirth/second chance in their life, the participants shared experiences associated with living in rural areas in Northern Appalachia. While creating their own legacy in life and nurturing and protecting others, the participants shared that they lived within “the shadows” of “isolation”/“living under the radar”, “emptiness”, “small minds”, fear of rejection, and physical danger. The participants spoke of several burdens that they carry. The burdens included financial burdens, staying compliant with their HIV/AIDS treatment, end of life issues, and past mistakes. Health care disparities experienced by the participants were an additional burden. The health care disparities experienced by the participants included gaps in health care services, health care providers lacking education related to HIV/AIDS issues, lack of compassionate in health care providers, and experiences associated with health care providers inappropriately disclosing the participants’ HIV related health information.

Shadow of “isolation”/“living under the radar”.

Several participants lived in isolation within rural towns. They live subdued lives purposely blending into the background so that they are hidden as a result of their diagnosis. The
participants isolate themselves from the people of the small towns in which they live. Participant 15 shared that keeping to himself is like living in the shadows.

And I keep things to myself of course, but yeah, I mean, it’s sort of still living in the shadows. When I lived out in California it was no big deal. I mean, it was like a lot more freeing, feeling free, and now I’m back here, it’s like, hmm, you know, I can’t be as much of myself as I normally would in public. I mean I’m not very flamboyant or anything, but just gestures, any signs of affection, you got to wait until you get behind closed doors. That’s kind of not really living. I mean it is, but not openly. I’m not much of a working with people person, so I’m more into like a janitorial job or office cleaning, some sort of out of the way job. It’s like here I’m the odd man out for the most part. That’s why group’s kind of nice, because there’s other people in there, like the same way I am. Positive and gay. I know. I mean, get on any website for hooking up with gay people and 80% of them are married or have a girlfriend or kid or something. It’s like well, you know, I might be the odd man out, but I’m not alone. They’re there, they’re just not admitting to it or admitting to themselves.

Participant 1 seldom leaves his home in the small rural town where he lives.

I hate it. I don’t leave this house. I don’t want to know anybody else in (town), ‘cause it’s all guns and drugs and – I have a Taser I carry when I take her (dog) for a walk at night. It’s very depressing – you don’t leave the house.

Other participants live in remote rural areas. As one drives through the countryside one would not notice the remote roads leading to their homes. Participant 2 stated:
I really wouldn't go out in public. I really didn't wanna be bothered by people. This is all, back here, state game land. We're surrounded by 5500 acres of state game land. The older I get, the more private we become, I guess.

Participate 5 and his wife live in a remote rural area for solitude and protection. “Just solitary up here. I’m used to it. But the (neighborhood family), they found out about you. They cut us off completely.”

Participant 11 lives in a remote area where his partner was born and raised. Participant 11 lived in a large metropolitan area in another state prior to moving to the area several years ago. He reflected upon the culture shock of living in a remote rural area.

It’s a little different living back here and a little isolating because, like I said, I’m used to larger groups of people and you’ll eventually find your group in that. And you don’t always find a group in a small town. I’ve met lots of nice people, but it wouldn’t have been the group of associates I would have had. Nothing wrong with them, nothing – It’s just common interests are usually what pull you together with people – or, at least, a section of your group of people. And just not as much of that. Like I said, I’m very happy with the friends we have. It’s not a question of them. That’s something within me. It never quite connected. And that’s a little lonely. I don’t regret being here at all, but it’s just being honest with myself. That’s something I have to deal with in being back here. But, if I left here, I’d miss it terribly. [Laughs] So, that’s not even an option ‘cause I’d never leave (partner) anyway. But if it weren’t for having somebody here, this is not where I would be. This has been completely different than every other time. Like I said, just simply the idea of mass transit was quite a nice thing. And again, you live in a
large enough population center and there are things happening. You know, if your interest is in this area, you can go there. Used to go to universities and have – hear talks on astronomy. Different lectures from different people. And you can do that here, but it’s hours driving and then you’re driving at night on the way home. And it’s – since I didn’t start driving ‘til I was in my forties, I’m not real comfortable with that. Yeah, well I never had to. Yeah, so isolation has always been a part of it for me. And perhaps that’s why it’s a little harder here, it’s just because that’s a recurring theme in my life. And I kind of worked past that a bit, and… Coming into my own and understanding myself, being able to build friendships and relationships based on that. Now I’m back in a place where it doesn’t – it doesn’t work that way. The options and you have to be careful. Who knows what? I’ve just made the decision if friends ever asked, I would tell them. But I have no intention of volunteering it to anybody, really.

Participant 6 also lives in a remote isolated area. She moved here from another rural area in another state. She and her husband moved to the area because it was isolated, lower cost of living, and it removed her husband from the environment of his drug addiction so that he stayed clean.

Right now, I have my – I have kids here, so I have my little bit of family. I do what I do. Very seldom does – I have very little company, which, that, I don't enjoy, 'cause I like having company. [Laughs] But I just – as far as the neighborhood goes, I mean, I've been here 20-something years and they're – I only know these couple of people, like, that's it. I don't – 'cause I don't need to know everybody, you know? So…Well, I told you, how – 20-something years, I
don't have any friends. [Laughs]. And I'm sometimes ashamed of myself for not allowing me to – or not allowing my status to be out there, and I say – I think, Well, if you're embarrassed by – and it's not that I'm embarrassed by it, and see, that's the thing. I'm not embarrassed by it, but I know the repercussions, and so – but it bothers me that I've had to hide it sometimes. But again, it's where I live.

Several of the participants were born and raised in the area where they reside. Participant 10 was born and raised in the remote area where he lives. He lives quietly under the radar of the area. “I worked, stayed here and whatnot. I was myself only. Keep your mouth shut, you gotta keep your mouth shut, so to speak, stay quiet.”

Participant 13 also lives in his hometown. At one point in his life he moved to a large metropolitan area to receive medical care. He moved back to his hometown three years ago. He shared:

I’ve lived with it alone. I kept working and hiding it. It weighed heavy…no one to talk to because people just didn’t, they still don’t in rural areas especially I think more under educated people. I’ll be honest, I chickened out… I thought about switching to this clinic (local clinic), but then I got to thinking, well, I think it would be obvious and walking in there and saw people I knew from here. So that’s why, anonymity. So that’s why I have the pain, kept going to (city) and the expense just for that because people are terrible. I mean… and I know in the day around here if someone say didn’t like another person they would start that rumor about them and they travel fast. I know that cruel things happened before. People would say, “Oh, yeah she’s passed around AIDS or something.” The poor girl wouldn’t even have it, but you know, pull that one up. How else can you hurt
someone worse than that, start a rumor like that? I had a tackle box with all these (medication) bottles I had my tackle box. Then to hide it I always kept them hidden in lock and key. Scared to death someone, my mom if I would stay with them visiting or something she would have no problem going through things. She’s very nosey. She would have found that in a minute. So I had to keep them in my car, my van.

Participant 8 always felt isolated throughout his life due to being gay and now that he is living with HIV.

I always knew I was gay because I was kind of a loner. I knew I was different. It took me a long time to figure it out. I wish I had somebody though. Sometimes I don’t want anybody around, but it’d be nice, especially now. I just feel alone.

Two of the participants shared how they isolate themselves from the people of the small towns where they live. Both of the participants wandered into the small towns, escaping their life in larger metropolitan areas. Participant 7 shared:

Yes. I wanted somewhere where I knew I didn't have any contact with – I have lots and lots of friends. I have friends from one continent to the other. In Paris, Chicago, California, and I knew my mom knew most of my friends and I knew my wife, ex-wife, knew most of our friends because we traveled when the girls was younger, so I wanted to go somewhere completely off the grid. And so instead of putting myself out there and being stereotyped in a rural area, I pretty much just keep to myself about it. I mean, besides talking to (ASO) and, of course, you today, I pretty much keep it to myself. So I just really wanted to … I just… I do need a PPC, but I won’t do it here in (town). I’ll wait until I go back to (state),
(city), get with my old doctor who already knows me. Of course, they don’t know I have HIV, but I trust them enough that I know it’ll stay within… and in the big cities it’s, I mean, if you say something like this in the HIPPA law, you can get in a lot of trouble. Here, everybody knows each other. Who you going to tell? You go and tell the judge who’s probably related to the person who just did that to you? I mean, half the cops around here all cousins and related to each other.

Participant 12 and her family encountered difficulties while living in the small town. She and her family are afraid of encountering situations of violence and stigma in the future. She stated:

But you can't live like that either, because, just because, one person hurt you doesn't mean everybody gonna hurt you either. Not everybody's out to get you. But people, if they do get hurt, that's the first thing we think if anybody's out to get you. So it makes it harder to have a new relationship with anybody or any friendship with anybody 'cause you don't want to take the risk or take the chance to get hurt again. That’s just a fact. I’m happy, I might look happy on the outside, but in the inside, I’m really, really depressed and I try not to make it my life, trying to change my life. Sometimes my outside to me is like my shell for what really is going on inside of me.

Shadow of emptiness.

Participant 13 was the only participant to discuss the idea of “emptiness” that he experienced while living in a rural area.

Some people love gossip in a rural community. It’s an emptiness. In the city there’s more to keep you occupied. There’s always something to do. Yeah, and
that's when they put spin on things, embellish stories. Yeah, they can't tell it like a
friend got in a car accident. You have to, and then you pick up the paper; no one
got hurt. By the time it gets to the sixth person, you know that game we used to
play as children, whisper something. By the time it gets to the end, oh my God,
the embellishments and spins that go on this stuff. It's basically adults don't
emerge from that. The accuracy goes up in smoke. Empty lives, yeah. You know
the old saying, one my dad used to say, familiarity breeds contempt. That's like
telling my thing, that’s how someone say, my dad, would've said familiarity
breeds contempt. People know, and then they have contempt for me. That
emptiness thing's true. Empty lives, they need to fulfill something obviously.

**Shadow of small minds.**

Almost all the participants shared that they lived among rural people with small or closed
minds. Participant 10 observed that the people in the town were closed minded.

*(Town)* is very closed-minded. Here in *(town)* the stores that had some of the gay
magazines and what – oh, the church thumpers are right out on the sidewalk in
front of it and articles in the newspaper and everything else. That was just – that
was unheard of. You couldn't do that. *(Town)* didn't allow that. *(Town)* still back
in the 17th Century. They are so closed – well, *(Daughter)* said it right there – so
many closed-mind, old money families in *(town)* that still think everything has to
be their way. I'll call it “Bible Thumper Town” where if you don't fit their Bible
thumper category, you're out of the sync. Get out of here. There's some in this
town that still have the same mindset that they had clear back in the 1800s. The
family name goes back that far, and up through the generations, they're still the same way, [crosstalk] the old, old family names.

(Daughter) stated:

______ what I have seen, especially in this town, is that if the parents have those beliefs and the kids go differently or are starting to think differently, then they're ostracized by their family. Basically, then they're on the outs with their own family, so even if they do think that way, they usually leave town because they're not gonna have a relationship with their family [crosstalk] or ______ with their family. So, they move elsewhere ________.

Participant 11 found rural people are not open to change or personal growth. “I’ve not found a lot of people that do a lot of soul searching here.” He gave an example of an incident when a friend’s relative came out of the closet and the response of the town’s people.

But in the area there in (town), his daughter-in-law’s brother decided to come out of the closet. And all of the men throughout the area came up to (friend) saying, “Well, what are we going to do about this?” And (friend) had to say, “He’s the same person he was yesterday. There’s no difference. It’s just that now you know, another part of him is out there. But that will never have anything to do with you.” But, basically, a committee was put together about deciding what to do about this. And that’s an alien thought to me. But that emphasized – And I knew about that fairly quickly after the move back here. So, I knew things were different. I knew there was more at stake in that kind of knowledge. I couldn’t be as free with it and expect no adverse effects. I mean, being gay, you have to consider that always, anyways. But I wasn’t used to dealing with that around the HIV so much. Again,
people could turn against you. Sure. But there were so many people, there were so many places to go that you just knew you could avoid, if you needed to. There were good things. I’ve met wonderful people, completely accepting. But it’s not just them and it can’t be in a small area like this. You have your friends, but you can even drag them into things that are not good for them. Well, it’s like even with (partner), he’s a very open-minded person. Very knowledgeable. And does his best to be that. But it’s kind of like the difference between living something and reading about something. Yes, you’ve got the knowledge if you read it. If you haven’t lived it, you don’t have the experience, and certain things that would – living prunes away from you – certain preconceptions, ways of thinking – doesn’t happen. That’s the problem in finding them. Especially in small communities. And, see, that’s one other thing. I think being with him, he has surrounded himself with people very much like himself. Which we all tend to do. You know, that makes perfect sense. But that doesn’t leave any room for me to connect.

Participant 12 also used the phrase close-minded to describe the people in her town.

Yeah, that is a lot of what was here, close-minded. This place, oh, it has their good sides and it has a bad side. I mean, like I was saying, you know, some people look at you wrong when they find out you’re HIV positive. And in this kind of town like this one person you know they know you have HIV the whole town gonna know. The whole town gonna know. And they will know and one day, forget five, ten days, one day just go to Facebook the whole town will know. And so this little town like this is not very secret. You can't get away with being sick or live this kind of health like we do and be able to live the life you want to
live without people getting in your business 'cause they will get in your business.

You've just gotta learn to live with them and say, look, you don't have to live with this. I do, so put in my face, screw you and let me be. You don't have to be my friend just let me be. Just be your true self.

Participant 13 who has been infected since 1981, never told any of his family members because of their closed minds and religious beliefs that to him seemed to be hypocritical. His parents are deceased and never knew of his infection.

Even like my mom, she would, if she knew I was positive, she wouldn’t read up and research and see she had nothing to worry about, but she’d just go on believing that if I touch this lamp she could get, anybody in the family could get it. So that kind of thing, ignorance. The preachers here just love it in these country churches. I’m going; my mom and dad had a hell of a marriage. I had bleeding ulcers in 7th grade. It was horrendous. I mean terrible. Then you’d sit in church and never know and they’d take it (bad marriage) out on me. I was the oldest son. I was a pretty big kid. So I got some undeserved roughing up. Only time I thought about taking my life is that I thought is this how they think of me? They (the people of the rural town) embellish everything. I overheard her (his sister who works at a local medical center) and some of the girls talk of medical records and things. So it’s, not a secret you know. People will talk. Oh, and then also the jokes, honest to God, I’ll go out and have a drink with my friends or the guys at work in construction love to have a beer, so I’ll have a beer and then oh geez, the HIV jokes and the gay jokes which I feel bad with someone having to be gay in a bar or lesbian and they hear that. Some of them were pretty poor taste. They’re
horrible and I had to grin and bear it. I couldn’t say, gee, that’s a knife in my heart. You had to act like nothing, it was funny. I hate that. It’s kind of hard, very tortuous. There was one that was stupid, let me see. Oh, what do you call a guy with HIV in a wheelchair? Roll Aids. Just stupid but you’d have to grin and bear it. There’s a lot of them. I don’t hear them anymore as much. But that was a big thing. There’s some at my mom’s church that told everybody about it when someone was infected. An infected person was telling another one, just happened to see them somewhere, oh yeah, he has it too. So that went around.

Participant 14 called family members and the folks in the area backwoods. She shared that even her husband has difficulty embracing a wider view of the world.

They're just – they're very backwoods kind of people. They're very – they're stuck in the '80s. They don't know any different than their own close-knit unit, and that's how it is. That's all they know, and to go beyond that and learn something new, I think, terrifies them. We don't want to learn anything new because that's uncharted territory, and we don't want to go there. And even (husband), he knows what he knows, and for me to try and teach him something new, oh, my God. Oh, my God. He tries. You know what I mean? He's at least trying to expand his horizons. But he don't know nothing else about the way the world works. And that's just the way his family is, too. They're stuck in that.

Participant 15 felt that the closed minds were a result of the lack of diversity and therefore things stay the same. He missed the diversity he experienced in his earlier life.

There is not much diversity. Yeah, I think that's just the structure of society and geographic location. It's even from this town to a town six, seven miles away,
they're completely different towns, but you still get the same general themes. You hunt, you drink beer, you go to bars, you go to truck and tractor pulls. It's just – that's why there's one art museum in (town) and maybe 150 or 200 in (city). That's the way I look at it. There's just not enough of things that are open to keep me comfortable here.

Participant 7 described his experience with the nursing staff at the local hospital who were not open minded regarding his HIV infection.

Well, the thing about it is, and see, I sort of, again went through it at (local hospital) when they knew. It’s like their attitude is well, it’s your fault you got this anyway. They don’t say that, but you sort of sense, because like you said, the lack of compassion. Well, you know I have to go and get some blood work done. “Well, you’re just going to have to wait your turn. Well, they need this before I go see (HIV specialist). Well, you going to have to come back this day. They only do blood work for HIV Monday through Thursday.” They would always put me on Thursday, the last day. Always. And of course I was the only one when I went there, and I didn’t realize it then, but after she did that I started realizing why is it I’m the only one who’s on Thursday, every three months. Well, it dawned on me. Obviously she was telling people about it and only one nurse was there before she even came in the room. She would already have gloves and everything on her face. I didn’t think about it, it didn’t dawn on me until that day when she did that and I realized she’d probably been telling people. Yeah, the compassion. I just don’t understand the people that go into that line of work. If you’re not a people person, you shouldn’t be a nurse, you shouldn’t be a doctor. You shouldn’t go
into that line of work. You going to be dealing with people every single day. And most people you’re going to be dealing with, I would say at least out of the 100, at least 5% have HIV, you just don’t know it. I can see why… living here. Well, the thing about it is I’ve been a person that travels as much as I have, and then living in a town like this, one thing I’ve noticed about people in small towns like this, they haven’t been outside of (town). Farthest places they’ve been is what, (city) or (town). Other than that, they have not been outside of (town).

Participant 2 shared about experiencing closed mindness with a local psychologist.

I've been living in a small town, dealing with small minds, uneducated people, and I thought I was gonna be able to come to this session and speak openly. And obviously, I can't, and the people here are just as narrow-minded as they were in (state).

Participant 5 believed that the people in rural areas are not open to change. “They don't want change in their lives. They don't want to change. That's the key right there. They don't wanna change. They're happy in their little zone.”

Participant 6 shared how frustrated she was with the closed mindedness in the rural area that she believes is due to lack of diversity and isolation.

The closed-mindedness is the biggest issue I have. I don't know whether it's a rural area or – I don't know how to say this, whether it's just this rural area, just very closed-minded people, and that makes it – that is my biggest issue because I am so not – I mean, I'm so open-minded. I'm just so not in that direction that I have a hard time, sometimes, biting my tongue, and – whether it be about HIV or it be about people's religion or their ethnicity or – again, I'm just – I have a sister
who was in a relationship with another woman. I have a niece that is, also, as well. The family – my children are mixed race. I mean, you – there's just – I mean, my one – my ex-daughter-in-law was Hispanic. You know, there's just too much diversity for me to be able to be comfortable with living in an area with lack of diversity. Been very, very rough. And so that, I think – that's the biggest thing, because – and what goes along with that, too, was, again, the closed-mindedness about HIV. Even though this is a super high drug area, you know – I don't wanna keep saying rural areas, but there are so many people that are not up with what's going on in the world. I think what happens in a small town is they stay small towns because you don't get a large influx of new people. So they're small towns because these are the people that are born and raised here, have children that stayed, and so on and so forth. So the – you don't bring in any of the outside views. Everything is pretty much, you know – and I may have said it the last time, so – I remember somebody years ago, when I first moved here, an older man saying he had never been anywhere – and he – must've been in the '70s – never been any farther than 30 miles away. So, then, this is your world. This is your world. Not this is your world, you know? It's a little, tiny spot, and all you take in is what you want to 'cause you don't have to take in anything more. So I think this is where that just continues to breed small-mindedness. You don't need to, you don't – and you don't want to. So, I mean, that's kinda how I see it. If you're in a small town and it's closer to a big city, it kinda filters over every once in a while, but if you're in a small town like here, you take from it what you want, and so many people just don't want anything more than what they've taken. And they
don't – because they're afraid, you know? They like it. It's comfortable. They know. They know what to expect. They know what they've had all these years. They know what their grandparents had all these years. They don't have to worry about certain things. If you start letting things in, then you have to worry, you know? Like, now, all of a sudden, I see a difference in some of my customers. I think – my feeling is it's more the rural communities like this, again, because they're not dealing – they don't think they're dealing with it or they don't think they – that there's a need to or that it's happening in their communities, and no, that has not changed in 20 years. I mean, I remember, again, when I first started – so we're looking at 10, 12 years ago with the – with doing things with the (ASO) – we tried to put together, in this – in (county) with the – so when I did a bar and church outreach and we did a luncheon for the ministers, we had three that showed up from the whole area. Nobody wanted to hear it. We even had a couple of – I remember somebody from one of the bars saying, “oh, we don't have that kind of people come in here, so we don't need that information.” Okey dokey.

**Shadow of rejection.**

All the participants worry about living in the shadow of rejection. Participants shared experiences of rejection and how loved ones protected them from people who might reject them. The rejection was associated with their diagnosis or life style. Rejection was experienced by the participants as well as their family members.

Participant 12 shared:

People see you here, well, now it's getting better than it was but when I first moved here it was like if anybody knew you were HIV positive they didn't want
nothing to do with you. They didn't want your family, you know their family to do anything with you, or they didn't want to be around your kids, the kids. No, it’s not easy to feel pretty when you’re sick, because you know, I know I’m pretty, but in a relationship that’s the reason I don’t want to be in another relationship because I don’t want to have to tell the guy, you know, I’m HIV positive you know, and then have the rejection saying, well, don’t bother me with you, unless he’s an alcoholic or something to have to deal with something like that. I’m just better off just my little plastic toys and be happy with that and not have to worry about any of that anymore, because the only man that accepted me for who I was passed away. And I never going to find anybody like him. Ever.

Participant 11 shared that his partner has separated him from dangerous people who might reject him. “So he has already kind of weeded people out, so I’m not really confronted with a lot of people who weren’t accepting of the community in the first place.” A new individual within the participant’s social group, who relocated from a metropolitan area, voiced that he thought the gay community should be more out with their sexual orientation but met resistance with the group.

And he had come up and he was telling people, we have to be out there. We have to be in the community and make sure they understand who we are. And it just struck me as being so naïve and I confronted him on that. I said, there are people here who can’t do that. They don’t live in a safe place. It wasn’t me, at that point. But I knew people in the meeting that if they went out, they would be in danger. They live in small towns and those small towns are not open-minded and they would not be accepting. And that’s something that’s been hard. It’s still that way.
Participant 13 shared about a woman friend from his hometown that committed suicide because of the stigma she received by the people of the town.

(Friend). Oh this dude gave her AIDS and she killed herself. Took her own life, kids and all, but she couldn’t deal with it here. Fear of rejection if you tell them, as bad as you the feel… like an island, you know. It’s yeah, so, because I know I would have had rejection by my family... they were germophobia, mom would be running the bathroom with the Lysol, you know. I mean they’re just over the top with you know, germs. Especially my older sister and my younger brother, my mom. They were just crazy about germs. So it would have been, oh boy, impossible. I probably wouldn’t be welcome in their home any.

Participant 5 and his wife experienced rejection when they relocated to the wife’s birthplace. Most of the neighbors were members of her family.

But the (neighborhood family), they found out about you. They cut us off completely. I don’t know. I went to (physician) everybody in the office rejected me. Hostile ain’t the word for it. I never seen so much of a group of people with so much hate. None are love; none are love.

Participant 8 was alienated by his daughter, a nurse, when she learned he was HIV positive. She was accepting of the fact he was gay but then when she learned he was HIV positive she cut off their relationship. He shared about how many people hide their infection because they fear they will be rejected.

Everybody on these chats is negative. Yeah, right. There are a very few that are on there – I didn't put positive, either. You probably should, but then they wouldn't want to talk to you. That stigma is still there. But that’s the scary thing
‘cause you don’t know how people’s gonna react to you. She (daughter) just couldn't give the care the way she wanted to. This all came out with me being gay. That was okay for a few years. She told me, if I ever find out that you're positive, I will be mad if you don't tell me. I told her, and then she wouldn't let me see the kids. I wish I would have never told her. My counselors would just like to shake her for somebody who is a nurse.

Participant 15 feared rejection by individuals in his hometown if the word got out that he is gay and positive.

Of ridicule or being out in public and having a scene or something occur because information is disclosed. Just ridicule, maybe even physical violence in this area, especially the circles I run in, you know, at bars and things like that. Yeah, or just you know, it’s not going to make my day if somebody calls me a faggot or something to my face. It’s just a little constricting in this area for me. I mean I don’t let it bother me because I’m not trying to make a point or anything. I’m just trying to live day to day in a happy way if possible. But yeah, and it’s like a double whammy because living around here first of all you’re gay. Strike one. Second of all you’re positive, strike two. A lot of people in this area are not only afraid, but like you deserve it. If this is your choice, then you deserve what you get.

Participant 10 and his daughter shared what happens when individuals do not conform to the conservative culture of the small town where they reside. “Basically, then they're on the outs with their own family, so even if they do think that way, they usually leave town because they’re
not gonna have a relationship with their family [crosstalk] or _______ with their family. So, they move elsewhere ________.”

**Shadow of danger.**

Participants live in the shadow of danger. Several participants spoke of their ability to sense danger. Participants shared experiences when they were encountered dangerous situations or experienced physical harm as a result of their HIV diagnosis and/or life style.

Participant 2 and his partner shared experiences of physical violence while residing in their rural area.

We've had people throw stuff at us. I've been beat up before – a lot of discrimination when we moved to the country just being gay. Nobody knew I had HIV, but just from being gay, we had our windows shot out of our home. We had our house egged. Then, his mother got a letter, an anonymous letter, did she know that we were gay? And then, someone started leaving heterosexual pornographic magazines on our front doorstep. And condoms in our mailbox and driveway. Then, we started getting phone calls. We had heavy-breathing phone calls. Then, we had sexual phone calls. Then, we had people driving through our yard, and we ended up putting in a large hedge – a fence around it. But yeah, there was a lot of ‘prejudism’, and that was just over us being gay. Then, when someone found out I had –HIV, oooh.

Participant 9 shared that individuals living with HIV are afraid to attend support group for fear of others learning of their diagnosis. The participant believed that if attending a support group associated with HIV/AIDS is known to others in the community, one could be placed in
dangerous situation. Conversely, the participant felt that not attending support group leads to other dangers associated with lack of support and resources.

Yeah. It's enough of one that if you think of support group for a case manager with 50 clients that a lot of 'em wouldn't come and talk and maybe twenty percent of 'em show up. Even for – to talk to other people in their circle. Even that worries them. They don't want to do it [Laughs]. I don't know. That's what I'm guessing – my guess is that they're still afraid.

Participant 10 shared how he can sense danger while in the presence of others. “I'm a funny one. And she'll tell you and other people will, I can meet somebody and I have to talk to 'em five minutes, and I know whether I can trust 'em or not or whether I like 'em or not.”

Participant 11 shared how he felt vulnerable to danger.

Just because I felt very much more vulnerable. You know, that your whole community can find out. The whole community. Whereas, that just was never even possible before for me. Because I chose not to. I didn’t feel safe. There was nothing in my life that had prepared me for the idea that there would ever be a safe time, or place, or people. I guess the hardest thing is, unless you live in a community where you know you’ve been accepted, it feels dangerous. And that was something I was not used to. They (partner and a friend) went to the firemen’s, you know, barbecue thing. He felt, when they walked in, very unsafe. Everyone turned and looked, and it was not a happy look. And, you know, he’s had threats. He’s had to deal with police several times, so. Definitely not good.

Participant 12 described the violent and cruel experiences that she and her daughter encountered in the community and school.
My daughter did not have very good schooling up here because kids can be really, really cruel, you know what I'm saying. And it only takes one person, for them to hear a conversation it could be a comment that an adult made. And kids can be cruel and bring it back to the kids, because they don't know where it's coming from. There were kids really mean. I mean my daughter had to go to special classes and schools and stuff because of it. They tried to hurt her and they tried to burn my house down and all that stuff. So it wasn't that easy. I remember my daughter coming from school crying all the time and saying she didn't want to go school no more, because they would mess with her about me. And she would get into fights and would get sent to the principal all the time. I would be at school constantly getting called, your daughter got in fight, your daughter got to this or this happened to your daughter or you need to come to get your kid because every time they say something smart about me, my daughter always end up in a fight.

Participant 13 discussed the sense of danger residing in a rural community, even though it is his hometown.

There’s an uneasiness being a rural community if you want to compare the city. I felt more secure there. That’s one thing too. I have a fear of having to go out here and people talk and I know half the people who work at the hospital. My sister has done medical records for years. You can’t see her up at her house office. So she has… I know they’re sworn to secrecy and everything, but you know, but I have that fear all that time that oh god, I hope nothing happens if I have to go out there and disclosure.

Participant 14 shared how she is more cautious about who she discloses her HIV status.
Nobody – I got hurt at the beginning, but it all came to fruition. It all came for a good reason. And I’m cautious about who I tell. Like, my best friend, it took me like three years to tell her. She already knew because my mom told her. She was just waiting for me to tell her.

**Shadow of burdens.**

Other shadows hanging over the participants are the burdens of living with HIV. The burdens include financial burdens, compliance with treatment, end of life issues, past mistakes, and health care disparities. Several participants shared that if they had known they would live for years with HIV they would have handled their finances in a different manner. One participant shared how he developed creative ways he uses to lessen the burden of compliant. Another participant shared how he mentors younger individuals living with HIV/AIDS by stressing the importance of being compliant with treatment. Six participants shared experiences regarding how dealing with end of life issues have changed for them over time. Frequently participants struggle with the burden of regrets and past mistakes in multiple ways.

**Financial burdens.**

Participant 15 shared his desire for a place of his own. He has been living with his mother and has been unsuccessful in receiving housing assistance.

I’m still staying with her. I’m trying to look for a place of my own, because (ASO) has the program where they can help out with rent and bills and stuff. So I’ve been at the top of the list like twice now.

Although Participant 13 manages his own business he struggles with finances. Financially embarrassed or whatever. (Case manager) very nice and I thought these folks are here for me. To be honest if it weren’t for the (ASO) I don't know
when I’d get the creating done. I thought I’d sell it and move back to (city) or something, but I think I can tough it out here with them. They help me with my transportation. I get all these, my budget’s terrible. I don’t qualify for a medical card or anything. One of the most frustrating things financially over the years it’s been a terrible burden. And then there are always funding cuts like with the Boost. So you’ll hold your breath, gee, I hope you don’t take that little bit away. But, the (ASO) does the (grocery store) gift certificate. I point up there because it’s hidden in there. She sends me one every month and that’s how I buy toiletries and things at (grocery store) and it really helps me. You figure $25 a month that takes care of all of my supplies. Which I was not buying that stuff. Didn’t have any napkins in my napkin holder. I got one there. Anyhow, I’d buy stuff like that. It’s been a big help. It’s definitely life changing. I’m trying to think, over the years it’s cost me a lot of money, copays. But a lot of things, I’m just a working guy and I’m over the limit for any other kind of help. Just like, working class poor. When I learned I was HIV positive in 1981, I did something. I spent more money than I would have. I was a little more careless… went on some elaborate vacations and things and thought, OK, work your ass off. Yeah, that’s why I’m… luckily I didn’t blow it all, but I’d have it a lot better now if I didn’t have that effect on me too. Yeah, just thought, well, you know, might as well enjoy it. I didn’t think I’d need it later.

Participant 14 shared her appreciation of the financial assistant she and her family received from the ASO. Her husband works but she is unable to work due to her health. It is difficult making ends meet.
And then, every once in a while, they’ll help me pay some bills, which is very helpful especially now that I got the three of us. And it’s harder to make ends meet. And I don’t do it very often. I try not to take advantage of the system.

Participant 2 and his partner described why they left a metropolitan area years ago and came to live in the partner’s hometown. “So it's cheaper living here. And we wanted to cut our taxes. Our taxes were so high. We have our own well.”

Participant 4 was essentially without a home until recently. She struggled with limited finances and with challenging family relationships that kept her from having land she was entitled to possess. Just recently she was able to resolve the legal issues associated with obtaining the land.

And when I was trying to purchase this place, all I had going for me was in November would be my last payment on my vehicle. I had a couple hundred dollars in the bank and that was it. That was it.”

Participant 5 was working in a good job at the time he learned he was HIV positive. The company was helpful in keeping him on as an employee after his diagnosis. When his health began to fail he had to retire. The decrease in income due to the retirement created financial burdens for the participant and his wife.

So they knew I had AIDS. They worked with me. It got to the point that I couldn’t work no more so they gave me a partial retirement plan. Not my full-time – my full-time plan I miss it by a week. My full retirement plan was gonna be $4,600 a month and plus my Social Security. So they only gave me 60 percent of that. It was an option that I didn’t have much money and droppin’ off to $2,000 a month and down to $100 a month.
Participant 6 shared about the struggle she and her husband had in deciding where to live and then where she would live after her husband died of cancer while living with HIV infection. It was a little old trailer and it was cheap, and we went back and talked about it and worked some things out, and we moved here, and been here ever since. It – financially, financially easier, because at one point, I did go back to (home state) and I actually worked there for a while, and I was in services there with – through (medical Center), I think. They had a clinic, not at the center, but in the lower county, and so I was finding it easier to get services there again at the time, but just way too expensive to live. So…financially, I'm in a terrible situation, and had I known 20-something years ago that I was still gonna be here today, well, I would've done things very differently, you know? Well, 'cause I can't afford to live anyplace else. [Laughs] I've tried.

Participant 1 shared how he had to go off his HIV medications due to limited finances prior to receiving services through the ASO. “That’s why I went off my medication, because I couldn’t afford it. I had no clue what to do, I had nowhere else to go. I didn’t know what else to do until (HIV nurse consultant) come to the door.”

**Staying compliant with treatment.**

Many of the participants shared about their experiences with the daily burden of staying compliant with their HIV treatment and care.

Participant 12 shared:

I’m willing to admit when I first started taking the medication I was not really steady with my medication. I would take them for a while and they would make me sick and stuff like that. Then I’d like I can’t do this anymore and quit taking them. It got to a point that most of my medication became resistant and I couldn’t
take most of them because I kept, my body kept rejecting them, because I wasn’t really using them and not being responsible enough to take them like I was supposed to. Now I do. Medication what I used to hate, I still hate taking them, but if I don't take them I die and I don't want to die. You just survive in the best you can but you don't get any better. So learn to live that way and for people like, well now, in fact, people like me who don't eat very well and stuff like that, you have to take medication to make you eat. You have to take medication to keep you from throwing up to keep you healthy. It can get tiring. It gets boring sometimes. Sometimes you want to give up, at least I do, I don't know about anybody else, but sometimes I feel like oh my God, it's just too much for me to deal with. I take a lot of medications and I have like nothing but a whole bag of just medications that I have to take to stay alive. And it can be hard sometimes, well, it gets tiring, it drains you. You're just like, oh my God, how much longer do I have to take this? And you realize, forever. It's a never ending thing its forever. You either take it or you die. I become resistant. I have taken so many different kinds of medications that if you miss like one dose or you’re in a bad mood and you're like oh, screw you, I don't feel like taking that medication today, that dose could cost you to, your whole medication to become resistant and you cannot be able to take them again. Or they have the same, different medication they have some combination of the old medication but you'll still be resistant to the medication. So you gotta be like really careful with this medication. Stay away from drugs and take my medication like I’m supposed to and just maybe, just maybe I will see 110-years old.
Participant 13 described creative things he has done to stay compliant with his medications while working.

One thing that helped, I was missing doses all the time because a lot of them had to be refrigerated which is a real pain in the keister. I forget which one. I had refrigerated anti-viral. I go out and buy those key chain pill holders. Do you know, I never missed a dose after that? That changed everything, missing doses because I always had them right with me. So I still carry one so I always have my doses but it’s a little thing like that. I’m surprised (AIDS specialty clinic), in the suggestions many times they should make those available for people. I don't know if insurance would pay for them, it wouldn’t kill them. They have deep pockets, (urban health care system). I thought, yeah to keep people on any type of medicine. That’s the key to it, having it with you. It’s so simple, there missing doses for a few years and then, I didn’t know they had them. I stumbled across them at the drug store on a rack. Oh what’s this? A key ring with little barrel and that’s great. I didn’t even know about them. Doctors would know I was missing doses too. “How many doses did you miss?” I’d be at work and couldn’t get to them and they had to be refrigerated. I could take them, they could go a day without being refrigerated, so I had to keep taking the one that was in the container and change it every day. So that’s something so simple, but that’s 100% now. I learned how to take them without water too. I’m an expert on swallowing pills. Because for various things I take about 16 things a day. Well, I have a Prilosec and Lomotil and it goes on and on, cocktail drugs, the two for dementia, quite a few. So it’s no wonder I have stomach aches.
Participant 13 discussed how he attempts to mentor younger individuals living with HIV/AIDS especially stressing the importance of being compliant with taking medications.

Well I tell the young kids I said, “Look, HIV medicine, you have to take it every day even if you feel okay. You know, you just have to. I'm not used to taking pills. Like you're going to have to get in the habit because you – trust me because I went through it.” Like I had affected legs, lymph nodes and I, all I needed to do was take my pill. But I imagine that most people that run into trouble with AIDS is because they don't take the medication they're supposed to, not the medication itself. But AIDS is not that way. You take your pill and you'll be fine.

Participant 7 has done well with taking his HIV medications. He initially had side effects from the medications, but he struggled through the side effects until they stopped. He illustrated the impact staying compliant has on his daily life.

As long as I keep taking my Atripla there's no sign of disease in my bloodstream but I have to keep taking the Atripla every day. Yeah, it's just one pill. It's pretty large and I have to take that along with a vitamin pill. I just take it like once a day. I actually have a lunchbox that I keep all of my pills in and they actually have a timer on it so every morning at 8:00 when I get off of work, unless I have to work over I'll take it with me, but every morning I'll take it. Every morning the clock goes off at 8:00 and reminds me to take it. I haven't missed a dose in probably three years. I've taken them every single day. There was a lot going on. A lot going on, but again, it has come full circle, Renee. It really has. It was a lot of bumps and climbing and challenges but the main thing of having HIV is being able to deal with it and understand it. And knowing you're not going to die. Okay,
you take your medicine, you do what you need to do, and you’ll be just fine. It is a burden because it’s something that, it’s not like taking a vitamin, you can take it or not. You know, you have to take it. It’s just like a person, now I know how a person feels who has to take insulin or a person who has to take meds for their heart or something like that. It’s something that you, you don’t have a choice. It’s not a discussion. It’s not a choice. It’s a must. It has to. I mean, it’s part of your life now.

**End of life issues.**

The subject of end of life issues came up in several of the interviews. For the long-term survivors, the finality of death still exists, but in a different context from the earlier days of living with HIV/AIDS infection.

Participant 15 learned of his HIV infection in recent years. He shared that he dwelt on issues related to his death.

And I’m like a death obsessed person. I always think about it. I’m always negative thinking on certain things. I don't know why. I think about what stupid stuff like what’s going to be on TV when I’m lying in my bed dying or just like irrelevant things that have nothing to do with it. What will happen the day after I’m gone, you know? It’s like I’m not going to be here to see anything. But then I’ve got to think, well, maybe there’s something better that I’m going to. I know, the details is what I always think about, but it’s like I really shouldn’t be doing that. I should be worrying about living instead of what’s going to happen or could or maybe won’t. Who knows?
Participant 10 recalled his mother’s death and it is his hope that he dies a quick death and does not want an elaborate funeral. The expenses associated with funerals is a concern.

The only thing I can say is that when my time comes, I can go like my mother did. She had a heart attack at 11:00 in the morning, was dead at 8:00 at night. And the more I've thought about it through the years hearing that, I am down to the point where I hope they just do a one-hour viewing if they have to have a viewing of which I don't want 'em to even have. Just a private funeral period and put me in the ground. Have one hour before the funeral and bury me, cut way down on the cost of a funeral.

Participant 11 had his own brush with death several years ago due to an opportunistic infection. He is aware that death can approach without certainty.

Future’s still uncertain. But the only difference, really is that I’m made more aware of that than most people, because it is uncertain for everyone. It’s just I’ve got a better chance of something happening. And I had been sick before we left and ended up in the hospital with pneumonia that didn’t respond to the first medications they used on it. I was very weak and just understanding the new med doesn’t work. This is potentially – Yeah. And, at that point, I was okay. I had regrets, yeah. But, you know. It’s like, it’s all right. It wasn’t stressful. It helped me identify some things I needed to do when I got better, but I wasn’t thinking of it like that. It was just, oh, yeah. I wish I had. And that was all right. And, you know, if you had known you were going to live this long, there are things you would have done to have – be well on your way to somewhere. And now I’m here, and I’m still nowhere. You know, I did enjoy life. I made sure to do that, but
meaning of life. To accomplish something. To – you know, I’ve done things. I volunteer different places, things like this. But I move so often in my life that anything you did establish went away. Made some decisions based on thinking I didn’t have long to live that I would not have made under any other circumstances.

Participant 12 believes that you have to live each day to the fullest as you never know when death comes.

And just make the best of what God gave you 'cause you never know what you gonna get tomorrow. Be blessed for the time you go there or whatever with the family you have and if you don't have no relationship with your family and you're sick, try to make one, because you don’t want to die with regrets in your heart or regrets in your life. And you don't want your family to have regrets in their heart either. So you do the best you can with the life that God had gave you and that's how I see it now. That felt so, I don't know, weird saying it coming out of my mouth. Yeah, we came here to be some kind of a light and when he's ready to come, when he's ready for it he has a place set up for us in heaven. When he's ready for us and he thinks he really needs us by his side then you will get to meet him face to face. I look forward to that, but I don't think I'm gonna get that far now. Not because I couldn't, but because the disease is probably not going to let me now because there's a lot of complications that come with the disease. You get liver disease, kidney disease, you know.

Participant 4 worried about the financial aspect and logistics associated with death and burial.
Yeah, early on you mentioned about end of life situations and that’s something that I don’t stress about, but it’s on my mind a lot. As far as when you die, do you go to the morgue? Since I am on welfare and not the money, will the state cremate me? Is there a waiting time? You know, those kind of questions I haven’t asked anybody.

Participant 7 expressed concern about the care of his girls after his death. He also has discussed his funeral plans with his ex-wife and girls.

One of the first things I did was I took life insurance for myself and for my girls. My girls are beneficiary because I didn’t want to just not take care of them. But these are the type of things that you actually have thoughts about when you have this disease. They all say, “oh you sure? Yes, I’m sure.” My girls, my ex-wife knows that if anything happens to me, cremate me and bury me. I was born in (city), sprinkle my ashes over in (lake) at the house. That’s pretty much what I want. I thought about that.

*Past mistakes.*

Many of the participants have struggled with their past regrets and mistakes. Many of the mistakes were associated with the risks that led to acquiring the HIV infection. Many of the participants were aware that the past cannot be changed but the HIV infection reminds them daily of the past.

Participant 15 struggled with the guilt he placed upon himself while trying to make the best of an uncertain future.

But it’s behind me now. I mean there’s still in my mind it’s still there that I put myself in that situation, but life is strange. You just got to take it and do what you
can. You can’t just sit around and do nothing and complain about it. What’s done is done. I’m just happy I’m doing the right thing to stay alive. And to me it just seems like a bad dream. I still think about it a lot, but I’m glad it’s behind me that many years already. Well, that I lived and made such bad choices that it almost took my life. It’s like do I not cherish my life that much that I would just be like that. And I’m a Catholic and in my mind that’s always there too. The moral choices that I’ve poorly made you know, it’s like I’m always asking for forgiveness. Yeah, I guess everybody has something they’re sorry for I guess. Everyone wishes for things to happen in a better timeframe, but it never does [Laughs].

Participant 12 acknowledged her regrets but was aware that she could not undo the past and that her present situation is another chance to amend the past. She believed we make mistakes to learn and that mistakes strengthen us.

I do regret it now that I’m older and stuff and my kids are older. Do I regret it, yes, I do, but I can't change the past now. The past gotta be the past and if it wasn't for the past, I guess I wouldn't be here today, because I wouldn't know how nothing from the past. But I don't know, I just pray to God and give it to the Lord the best I can and his ability to do with my will as I would do with – I sure wasn't doing the right thing with my body, but I'm having my body be an instrument to him now. I just wish it would be a cleaner instrument than a dirty instrument but nothing I can do about that either. How did He create this world in seven days and we not perfect 'cause people say well, you're supposed to be perfect. No, because if you were meant to be perfect we would all be on the same level. God didn't
want us to be perfect. God made us to make mistakes and learn from those mistakes. God didn't make criminal, okay, killers and stuff those I think they were just born psycho like and mental problems. I just believe that God made this world for a reason and before we did it, whatever we did wrong, God already knew we were going to do it. I'm sorry, Lord, I'm sorry, well, he already knew you were going to fuck up anyway. Seriously. And you only learn from your mistakes. If you don't make no mistakes how can you learn from those mistakes, so you have to make mistakes in life to learn from it. And it makes you stronger. Your mistakes is what makes you stronger and your mistakes is what gives you the lie that you have now 'cause you learn from those mistakes. And then you learn not to make the same mistake to get the same results, pretty much is what I mean to say.

Participant 13 described a slightly different experience associated with regrets. He was involved in a motorcycle accident that led to the blood transfusion that infected him with HIV. He wished he would not have gotten on the motorcycle. All of his life dreams died.

All of this, so, yeah and self-pity. I just pretty much blamed myself and the motorcycle, if I had four wheels under me maybe it wouldn’t happen that way. I knew it was a result of what I did too. And it’s not … I had an epiphany here, but I mean, something I did caused me to have that technically. No one sexual, so what’s the difference? I brought it on myself. And I say others bring it on themselves a little different way, but technically I did. Like Ryan White, the poor guy was a hemophiliac. Well there’s total innocence. That guy didn’t…. me, I had an end result from an action, but his wasn’t that way. It was hemophilia. So I felt I
always had compassion for others that way. So that kept me strong. I don't know how to say… contracting it, like people throw someone away, like Ryan White or me who couldn’t help it, that if they do a sexual thing, or needles, now it’s intravenous drug users are getting it big time. But people who inflict it on themselves, it’s OK if they die, they did it themselves. But that attitude’s terrible. We all make mistakes. But those poor folks in one way or another make a deadly mistake or one they’ll regret all their life. I did cause it myself in a way. If I had had a car with four wheels I probably wouldn’t have gotten messed up. In a way, that’s due to my actions.

Participant 3 voiced his regrets about putting his mother through difficulties with his addictions. He shared that he regretted his violent behavior in the past that was associated with his drug addiction.

I put her through a lot. I put her through a lot and I became violent and I'm not a violent person. It was the drugs. I even surprised myself. I mean when I look back at the things I did I just like – that's not – I would never do that. It's not me; the addiction just – I'm a very strong person, very strong inside, very willful. And so I can control my environment. Well, yeah. I've learned to live past that. You know, people say you learn from their mistakes and –of course I've learned from mine, but I learned a while back that it's easier to watch other people make mistakes and just pretend that it was me and incorporate that into my wisdom so that I don't have to go through that.

Participant 4 admitted that her past behaviors led to her HIV Infection. She adamantly stated, “I did go out and get it, bottom line.”
Participant 5 described his past mistakes as old skeletons in the closet. He believed that skeletons haunt people throughout their lives. “And I got skeletons in the closet, but they're about 30 years old. Life itself follows you. You can't help it. You think things that happen 20 years ago. It does come back at you. And it did.”

Participant 6, a long time survivor, regretted she cannot do things differently. She shared various forms of regrets. She voiced regrets that she did not leave her husband who was an addict. She regretted the hurt she caused for her children, her difficult financial situations, and her unfilled dreams.

Yes, and there are so many – I – we can't go back and undo, but there's so many things that I wish I had done years ago. You know, years ago, I was very good at, I have this great idea, but I never followed through. Well, I couldn't, again, because financially, because of the lifestyle that I lived. When you live with an addict for that many years –I never should've stayed. I hurt my children badly. I hurt myself badly. But I wasn't a very strong person, and had I had the strength then that I have now, it would've been a whole different story. You know, but then I say, too, if I had strength then that I have now, I may not be positive and – so who knows? But with HIV, it's, you did something to acquire it. It's acquired. It's something that you went out and – you know, in some people's mind – purposely did. So that always separates it from any other disease because people say, well, you had a choice. You didn't have to get this, you know? So that always makes it hard. And in some cases, yeah, they're right, but it still – it is what it is. You have it.
Participant 7 did not know who infected him with HIV. He regretted he was not an intelligent responsible adult when he was sexually active with women. Since learning of his infection, he has moved forward by being responsible for protecting others.

I’m a grown adult. I should have been having having protective sex, but I didn’t. But I’ll be damned if I’m going to turn around and give it to someone else because it’s something I did to myself. Oh yeah, because you don’t know exactly, first of all you look at it like, just like everyone else, I looked at it like a gay disease. I’m like, I am way too macho and I know I ain’t lay down with no man. So how? I mean all these questions come up. How did I get this? Who was the person with that I caught it from? Did this person know that they had it and gave it to me on purpose? I mean all, you go through these over and over. The only regret that I have is that I didn’t use the brains that God gave me. I didn’t protect myself the way I should have. But, other than that, again, I can’t look back on yesterday. I only can go forward.

Participant 8 knew he was gay but married his high school sweetheart. He regretted he was not honest to himself or to his ex-wife by acknowledging he was gay. “We dated for 5-years. I played that double life, but it wasn't right. I don’t blame anybody but myself.”

Participant 9 voiced regrets about his relationship with his father. He shared that he felt he was not the son his father wished him to be.

I started thinking about my dad and our regretful relationship, because he didn't know what to do with me. I knew that he had gone to my aunt and said what am I going to do if he's gay, I don't know how to handle – what do I do with that? I think he's gay. This was when I was young, and I don't find out until years later.
But he knew there was something going on and he didn't know what to do with it. That made me feel like I wasn't the son that he wished he had, none of that was ever said. He wouldn't say that, he's my dad. But I knew that we just didn't have the relationship that you'd think we would want to have. It was strained and uncomfortable and not very – demonstrative, it was just – anyway, I started thinking about him and that song, because I used to play the piano for his men's Sunday school class, and they liked that song.

_Health care disparities._

All of the participants shared their experiences with receiving health care while residing in rural Northern Appalachia. The participants described experiences when they encountered difficulty accessing primary care physicians and specialists, experienced gaps in services, experienced difficulty locating health care providers who were knowledgeable about HIV, encountered health care providers who lacked compassion, and experienced a violation of ethics when health care providers inappropriately disclosed of their HIV infection to others. Women encountered lack of gender specific health care.

_Lack of access to health care providers._

Participant 15 shared concerns about accessing a physician with expertise in performing anal PAP smears.

With my doctor that I get the rectal pap smears every, twice a year, he moved back to (foreign country), so there’s nobody down there now to do that, no specialists. So I don't know, I'll hopefully wait for some news from (urban HIV clinic) saying if someone’s taking over that. There’s no one in this area that does it. So, hopefully nothing crops up between now and when they get a new person,
if they do. I’m hoping them do. You’re used to getting checked, and then when you don’t you wonder. Living in such a rural area, once again you have to go way out of town to get any kind of treatment.

Participant 1 spoke of the difficulty he had with accessing HIV services. “It wasn’t having the HIV, it was trying to find help to get it under control. Right, getting into the network. I think just getting into the network is the hardest thing.”

Participant 11 came to northern Appalachia to be near family. He and his mother came to northern Appalachia from the west coast.

Finding doctors back here, who actually know what they’re doing, is more difficult. There were two, but that’s two out of all the towns around here. I’m used to having options. I could find a GP anywhere, but that’s not who you want dealing with you on a regular basis because you do have special needs. So, I was very fortunate the doctor out here, who deals with the HIV patients, offered to take me on as my GP. Back here, you could be a doctor and you’d perhaps never see anyone or never know that you’ve seen somebody with HIV. So, it’s not relevant to them. They don’t invest the time when there are new diseases like Lyme that are going to be much more something that they need to know about – which I get. I understand, but that doesn’t help me. So, that and some of the hospitals are not the best, I’ve found. Watching other people go and the results that they’re getting – if they come out, for instance. [Laughs] And you don’t have a lot of other choices, either. It’s a long way to go for another hospital sometimes. Doctors not following up, not always understanding what’s going on, and not always having the best outcomes even when everything does go right. And things
are going downhill there. So, what had been a safe alternative is now not as much so. And they’re losing good doctors. That much I know for sure. So, I don’t know. That’s the only hospital around here I would have really trusted, and I don’t know that I can anymore. In fact, my doctor had made the comment to me that, if you have an emergency, you go there. But if you have elective, if you ever needed open-heart surgery or something, you will not go there. But that had been a very good one for that. It had a good reputation up until recently.

Participant 12 believed that physicians in the area don’t care if they have knowledge related to HIV care. She spoke of being unable to understand that after all the education physicians have they are not motivated to seek knowledge about caring for individuals with HIV but rather choose not to deal with issues related to HIV.

I don't think a lot of doctors in a rural area like this know much about it, or took the time to study about them. Not that they don't know about them, I think at some point they do have some idea of it, but they don’t want to deal with it. It's like they're better off not – they prefer to push you away and say, I don't deal with that kind of stuff, or I don't know what's going on with that stuff, because they don't want to deal with the fact that, you know, it's a contagious disease, but it's not as contagious as people think it is.

Participant 13 had considered changing to a local HIV clinic. Currently he travels two hours to receive his HIV care.

I’ll be honest why I chickened out. I thought about switching to this clinic, but then I got to thinking, well, I think it would be obvious and walking in there and saw people I knew from here. So that’s why, anonymity. So that’s why I have the
pain, kept going to (*urban clinic*) and the expense just for that, because people are terrible. I mean… and I know in the day around here if someone say, didn’t like another person, they would start that rumor about them and they travel fast. I know that cruel things happened before. I’d run into a few people from here that had gone to doctors here and felt they weren’t getting the support and care and went back to (*urban clinic*). This clinic, I’m still thinking about, but I can’t do both. I have to either or. So, I’m trying to think. Psychological support or whatever you call it is nil. I thought a therapist might help me a couple years ago. Oh my God, finding a therapist around here, I mean, they have them now, but even a dermatologist. Some skin reactions I have from some of my medicines, right, there’s not even a dermatologist here (*local town*). You have to drive to see a…. Yeah, so people without this burden, I mean regular health problems and dermatologist, a lot of people need a dermatologist, and yeah…

When Participant 4 relocated to the area where she was raised she found it difficult finding a physician. “Finding a doctor was kinda hard with an infectious disease specialist. It’s a big gap. That’s was a seven year gap.” She didn’t have a case manager in that time period. “We have gone through quite a few doctors through the years.”

Participant 5 shared the story of when he had an accident while working on restoring his house. He put a nail through his thumb. He first sought care at his local hospital.

They told me to go to another hospital. So for three hours I had a nail in my thumb from an air gun. So I had to go to (*town*) and they took it out. Yeah ten miles down the road. I still had to go to (*town*) and the emergency room took the nail out three hours later and they said, “why didn’t (*local town*) Hospital do it?”
They said they didn’t wanna deal with me ‘cause of blood and stuff so they rejected me. I couldn’t find a doctor up here, a family doctor. Nine of them shot me down. So there was one and only doctor (name of doctor) decided to take me in. Only person who had AIDS. I went to the pharmacy. They never knew anybody that had AIDS up there. They’re prejudice against me. That was just crazy. I had to go back and forth to the (city) family doctor and everything for years until I finally found a doctor. Then the (ASO) found Dr. (name) in (town). I was with him for 11 years and then they discharged him out of office and she didn’t wanna take me on. So what I did is trying to find a doctor now. Well I got an appointment down at (town) so I have a doctor the (ASO) hooked me up with ‘cause everybody else shot me down up here. I was too big a caseload for them because I had everything in the world thrown at me. I mean everything. You name it, I got it.

Participant 6 had difficulty finding a physician to treat her HIV infection and for gynecological care.

I couldn't find anybody, couldn't find – I don't know how – how did I get hooked up with Dr. (name)? I don't know, I – and I got a primary care doctor that I've been with ever since. And then, when I came back, I went to the clinic. I started – the clinic was up and running. So it's always been my primary care and the clinic, and that's pretty much it.

Participant 1 was diagnosed in a large urban medical center. He came back to his hometown to be with family. “I couldn’t find any HIV doctors within reason – you know, travel distance.”
All the participants shared experiences associated with their encounters with physicians. Some of the experiences were related to the time they learned they were infected with HIV. Other participants shared positive experiences of how their doctors made an effort to learn about HIV and learn about the participant in a holistic way.

Participant 1 shared his experience of learning he was infected with HIV. He was hospitalized in a large urban health center. He said the doctor walked into the room and said, “You’re positive,” and walked back out of the room.”

Participant 10 recalled the experience he had with an anesthesiologist in the local hospital prior to having surgery. “Anesthesiologist didn't want to touch me. Well, it's just like I said about the time I had to go to the hospital for surgery and the anesthesiologist acted like he was afraid of me.” Participant 10 told how his PCP made an effort to become educated about HIV. The local PCP was given the telephone number of another doctor who had been caring for Participant 10 in another town. Later the local PCP learned that the doctor in the other town was a former classmate in medical school.

And just like my own PCP. At first, you mean, he wasn't afraid to touch me or anything, like that, but he come out and said that he was not educated on any of that. Well, (case manager) went and talked to him and found out whether he still wanted to stay my doctor or wanted me to go somewhere. Anyway, he – after I told (physician), I said, all you gotta do is call (physician), 'cause at that time, he had a practice in (town). I said, “He's right up on it, and he told me to tell you hello, and anything you need, anything.” And he said, “I went to college with him.” He said, “I know him well.” My HIV doctor, the more we talked, and she
got to know me and I got to know her – now I've got all the confidence in her and whatnot.

Participant 11, who relocated to the area from the west coast, stated that finding a knowledgeable doctor was challenging.

Finding doctors back here, who actually know what they’re doing, is more difficult. There were two, but that’s two out of all the towns around here. I’m used to having options. I could find a GP anywhere, but that’s not who you want dealing with you on a regular basis because you do have special needs. So, I was very fortunate the doctor out here, who deals with the HIV patients, offered to take me on as my GP.

Participant 12 described her experiences with prejudice and subsequent discrimination while seeking care with local physicians.

People see you so different including doctors not just regular people. Some doctors are stupid and naïve too even though they've got a degree. They act like you're contagious and they don't even want to take care of you, same thing as the dental and stuff like that. You have to let those doctors know when you have it that you have that stuff. And sometimes when you do tell them and try to be honest with them it's like they look at you worse than if you didn't tell them. So they really – how do you call it – they have this stigma from the disease itself. It's a big stigma with the disease itself. I don't think a lot of doctors in a rural area like this know much about it or took the time to study about them. Not that they don't know about them, I think at some point they do have some idea of it, but they don’t want to deal with it. It's like they're better off not – they prefer to push you
away and say I don't deal with that kind of stuff or I don't know what's going on with that stuff, because they don't want to deal with the fact that, you know, it's a contagious disease, but it's not as contagious as people think it is. Well, why don't you know anything about that, you're supposed to be a doctor. You went to school for it, you took classes for it so how can you not know about one little thing out of all that you learned. You tell me you don't know nothing about HIV, nothing, but you've taken all this schooling. I didn't finish school and I think I know more about HIV than somebody who graduated from college. How come people who graduated from college don't know that part of everything else? They know about cancer. They know there's a cure for cancer and that stuff, but they don't know about HIV, come on. You know how many people in South Africa have full blown AIDS and that has been out there for a while now and you don't have no education on that, I don’t understand that.

Recently Participant 14 experienced the loss of her physician. The physician left the area to practice in a neighboring state. She now receives her care from another local physician who is not quite like her first physician. She described what she feels are important qualities of a physician who provides care to individuals living with HIV.

Dr. (former physician) is much more – was much more personable, much more – I mean, I took (son) to an appointment one time. And he came in the office and he said, “Is that your son?” And he said, “Hold on.” And he went out to the office to meet (son). You know? And doctors don’t do that. Dr. (former physician) went above and beyond – you know, I wasn’t just another number. I was a patient. I was a person. And Dr. (current physician) is very good about it, too. I just started
going to see her, I don’t know her very well. But she’s – you know, she’s – seems to be very much like that, too. But he was just – he was so nice, and like I said, he was so thorough. He would look into everything and make sure. You know? And he was just a really, really good doctor. (*Neighboring state*) is lucky to have him. She's still a good doctor. I don't have anything against her. It's just I think I have more love for him because he was my first doctor. He finally figured out what was wrong with me, and I was with him for so long. I just have more affection for him.

Participant 15 shared the frustrations he and support group members experienced regarding doctors not having the knowledge to care for him.

Yeah, the doctors just sort of do their job, and then it's up to you to find out what the next step is. Some of the group members said that the doctors really were sort of offset by the whole thing and hesitant to help them.

Participant 2 told of his experience when he first learned of his HIV infection in the local town.

It was a (*town*) clinic. I said to him, maybe you should give me an HIV test, and so they gave me a whole series of tests that day, and then, they, well, about two weeks later, they called me and said, “You need to come down. Your blood sugars were really high, and we need to do another blood test.” And I'm like, “Wow, that's really weird.” So I went down, and I went in, and it's like, Oh my. Everybody's like falling all over me, and the nurse is patting me on the hand. And I'm like, “What the hell is wrong with her?” And then, Dr. (*local physician*) walks in, you know, like, “Wow, you don't look so good. What is wrong with you?”
And he goes, “Your test came back positive for HIV.” And so I decided, Okay.

He goes, “I've never had an HIV client. I do not know what to do with you. I will be sending all my nurses and getting them educated on HIV because if you have HIV, then it is here, and other people in this community will also have it.” And he, then, had took classes himself. He said, “I'll be back in a few days.” And he came back to our house in a few days. He did not ask me to come to the clinic. He wanted to keep it quiet. And neither did I. Neither did I. So he came back about a week later, and he said, “I found you a doctor. Her name is Dr. (HIV specialist).

She's at the (urban health center) clinic, and she's the best there is.” And so I went down and seen her, and I just couldn't believe I had HIV. Even at the medical center, to draw my blood, it was like, in the beginning, major. They knew nothing about HIV. They were scared to death to draw blood from you. The dental department in (town) was afraid of me.

Participant 8 described his experience with the doctor who gave him the results of his HIV test.

The doctor got in the computer and said, “Come with me.” I knew what he was going to say. I had asked (friend) to step out. She kind of thought so. He told me, “Do you know you're positive?” I said, “I just found out.” The registered nurse was in there. She was her (friend’s) sister-in-law. She just felt so bad. The doctor was so rude to me. He probably didn't understand it, and he acted like he didn't want to touch me. The nurse kept on apologizing because her brother was HIV-positive, and he lived in (state). He was a twin. She felt so bad that she just started
crying. I said, “it’s okay I just found out. It will be fine.” He just kind of backed off. He acted like he didn't want to treat me.

*Gaps in health care services.*

Participant 11 told of the experience when his primary care physician provided him with instructions regarding where he should seek health care.

In fact, she had made the comment to me that, if you have an emergency, you go there. But if you have elective, if you ever needed open-heart surgery or something, you will not go there. But that had been a very good one for that. It had a good reputation up until recently. And they have a limited resource.

Describing the lack of services in his rural area, participant 15 stated, “It could be anything from just not getting the right medical attention or the right information to seek the attention. This is rural, but there's even more rural [laughs] places that are really – probably they get nothing.”

The gaps in services for women living with HIV infection were gender specific, as in the earlier days of the HIV/AIDS epidemic there was little information addressing HIV in women.

Participant 4 described her experiences in the early years of the epidemic. “In the beginning, care was very hard to find. I didn’t know about the (ASO) until ’99 – 1999. And I had some case workers helping early on, but there was very little information concerning women of any shade. That was kind of challenging.”

*Inappropriate disclosures.*

Six of the participants described experiences of inappropriate disclosure of their HIV infection. The inappropriate disclosures were made by health care providers, family members, and citizens in the rural towns.
Participant 12 experienced inappropriate disclosure of her HIV infection by a nurse.

Because I know that, the disease alone is a lot of people don't understand it. I have known a nurse, well, she's actually a nurse and she was supposed to keep my identity covered up and she went and told another patient that I had AIDS.

The sister of Participant 13 worked in a medical records office. Although Participant 13 is not aware that his HIV infection was inappropriately disclosed, he is aware of an inappropriate disclosure of another individual made by his sister and her other coworkers in the medical records office.

I have a fear of having to go out here and people talk and I know half the people who work at the hospital. My sister has done medical records for years. You can’t see her up at her house office. So she has… I know they’re sworn to secrecy and everything, but you know, but I have that fear all that time that oh God, I hope nothing happens if I have to go out there and there is disclosure. But I just know I overheard her and some of the girls talk of medical records and things. So it’s, not a secret you know. People will talk.

Participant 14 learned from her parents about inappropriate disclosure of her HIV infection by a local store clerk.

There was – somebody said something to me about having HIV, like they knew I had it. That they’d heard that I had it. And it’s like – Oh no! They said it to my parents. They said it to my parents that they knew I had it. And my parents were just like, “mmm”…and it’s like, how would she remotely find out about that? How is that even – how does that even come up? Because she watches everything. She works at (convenience store). So she knows everybody and everything. You

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know? So unless she’s watching my behaviors and my mannerisms and my illnesses and – I don’t know. She’s weird.

Two of the participants experienced inappropriate disclosure of their HIV infection while accessing care at the local hospitals in the towns where they resided. Participant 5 experienced inappropriate disclosure in his local hospital and in the local pharmacy. He said,

Then the doctor was in the emergency room, he got up and told everybody in the emergency room, all the patients, I had AIDS. Man, it’s unbelievable. The nurse in there makin’ a big thing. “Oh, he got AIDS.” Well, how can you stop the neighbors not knowin’ about it? They know about it. Can’t think of her name down the road. She worked for the hospital. She was a clerk. A real violation. I went to the drugstore. A guy's kid in there, his brother (name) had a temper fit and told all the employees in there I had AIDS in the open.

While Participant 7 was seated in a waiting room to have lab work drawn at the local hospital he experienced inappropriate disclosure of his HIV infection by a nurse.

I don’t want to have anyone in (city) to know because of that. It’s not that I’m afraid or anything else, if someone would approach me like that again I’m liable to slap them in the face and be in jail. It was unnecessary. It was inappropriate for her to do that in front of everybody like that. She was lucky that I didn’t hit her then. Though they fired her and they compensated me for what she did and everything else, it still makes me now not want to go to any doctors around here. I mean, it really, even when I only got my teeth done, they have on there, do you have any type of disease. I didn’t check HIV. They cover themselves anyway. But, I don’t want my landlords and all his kids knowing, because they could know
even though it is a HIPPA law you know they’re going to discuss it among family members. You know they are. Well, the thing about it is, and see, I sort of, again went through it at (local hospital) when they knew. It’s like their attitude is, well, it’s your fault you got this anyway. They don’t say that, but you sort of sense, because like you said, the lack of compassion. Well, you know I have to be, I have to go and get some blood work done. Well, you’re just going to have to wait your turn. Well, they need this (lab work) before I go see (HIV specialist). Well, you going to have to come back this day. They only do blood work for HIV on Monday through Thursday. They would always put me on Thursday, the last day. Always. And of course I was the only one when I went there, and I didn’t realize it then, but after she did that I started realizing why is it I’m the only who’s on Thursday, every three months. Well, it dawned on me. Obviously she was telling people about it and only one nurse was there before she even came in the room. She would already have gloves and everything on her face. I didn’t think about it, it didn’t dawn on me until that day when she did that and I realized she’d probably been telling people.

Living in a small town, Participant 8 was aware how news travels in his town.

You just never know. I went to (city) because up here in (town), everybody knows your business. I went to (city), and I was actually going to a doctor down there. I went to see him in (city). It was a very good doctor. Somebody leaked it out. Yeah. Well, one guy that did start telling, which I found out, somebody did tell me, and it got back to him. He talks to me if he sees me out, but he doesn’t want to be friends really like we were. I don’t know. Anyways, I told him I was gonna
sue him. I told somebody that if I hear it again I was gonna sue so I didn’t hear that anymore.

*Lack of compassion in health care providers.*

Three of the participants shared experiences associated with health care providers in the rural communities that lacked compassion towards their HIV infection. Participant 13 shared his thoughts related to his experiences where he encountered health care systems where providers that lacked compassion.

It’s a shame that we are… we see everything as parts to a machine instead of a living whole. We don’t – nobody expects the machine to be compassionate. And when you’re all about the profit and about producing a product, you don’t have – nobody expects you to be thinking of people. I think that – I mean, you can have – again, they’re just people. And some people aren’t big on empathy.

Participant 15 shared what he thought could be changed with health care providers who appeared to lack compassion. Upon learning he was infected with HIV his physician simply told him:

There's things you can do, but that was it. They didn't sit down, and I didn't have no counseling at the hospital or anything like that. Which would have been helpful had they done that. At least it would have –Yeah, doctors just sort of do their job, and then it's up to you to find out what the next step is.

Participant 8 was to the point about the lack of compassion he has experienced. “That there’s a lot of lack of compassion.”
Lack of education with health care providers.

Participants shared their thoughts and experiences related to the lack of education throughout the rural communities in which they reside. Participants spoke of their concern about lack of education to prevent the spread of HIV/AIDS. Some shared their experiences of providing education in schools. One participant described the need for education in bathhouses. Another participant expressed her concern that the state health department lacked educational materials in their local office. It was also discussed that there is a lack of education among nurses and dentists.

Participant 12 pointed out that all individuals living in rural areas are in need of education regarding the fact about HIV and about services that exist in the communities.

They should educate themselves better. If you don't know how to, find somebody out there, because there are services out there that knows. It might be just a little bit, but they know something about it and the little bit that somebody knows about it is better than knowing nothing at all. Because you take that little bit and hold on to that little bit that little bit becomes something bigger and you learn a lot more from it. When I first got it, I didn't know shit about it at all. I do know more about it now than I did before.

Participant 2 shared his experiences associated with lack of education of his dentist and his psychologist.

He (dentist) took – and my dental tools were all marked and kept separate from everybody else's and autoclaved and you know. He (counselor) was so afraid of me when I would go in to see him, he would open his door and put a brick in it so that the door wouldn't shut.
Participant 3 shared that he had to educate his health care provider while he was there to receive care. “The healthcare providers in the area don't know anything about it whatsoever. So I end up educating them and I'm not there for that.”

Participant 6 shared her concern about the lack of educational materials in the local state health department waiting room and doctors’ offices in the area.

I can't tell you – I've been in a few doctor's offices – excuse me. There's no – there are no HIV pamphlets. There's pamphlets on everything you could think of. I go to clinic at the health department in (town). There are no HIV pamphlets. There are no (ASO) pamphlets. Why? I don't get this, you know? I feel like there are a lot of people that really could – how do I – I don't know how to – there are so many people that could benefit from hearing about how people have to live with this, and I think that's why going out and speaking always made a difference, because it was kind of an in-your-face thing, you know? Okay, yeah, you've heard of it, but here, let me tell you. Let me show you. Yeah, and it's a shame, and I mean, even – there are some young people that still have some strange misconceptions, but again, it's lack of education, and this has always been the big thing. You know, when they cut education at the (ASO) – or the state cut education, I was furious. I mean, the state cuts education and there's no funding for this and there's no – but then you want it to just go away? I don't get this. Where does anybody think that this gonna end if it's swept under the rug or if it's not discussed or if education isn't out there, you know? And it's crazy, I mean, I remember – I can't remember which school it was. I think in (town) I went and spoke, and it was a health class, and we were already told, before we went in,
certain things we could not discuss. Well, we got in there and this teacher introduced us. She closed the door. She turned around, she said to me, “Say anything you want to say,” and she turned around to the class and she said, “Anything that's said in this class stays in this class.” And I was just so shocked, you know? But imagine having to say that. It just – it blows my mind. And again, that whole condom thing where you can't discuss condoms with kids – well, okay. All righty. And you think that little girl that's 14 over there or that 16-year-old that's running around with a baby carriage doesn't need to hear this kind of stuff? That's the big – I think that surprised me more, living here. You can always tell when spring comes. You go into (town) and the young girls with the baby carriages are all over the place, I mean, young – not 18 – 20 – 25 – young. It made a huge difference, and you know, you have to also stop and think the message that it sends because, again, when I was filling in for the educator at the time and I was going to all these places and doing education and speaking, what are these people now thinking, that – because there were some organizations that had us come in ongoing, to train staff. All of a sudden, it doesn't exist anymore. Well, to me, that sends a signal. Hey, nothing to worry about. Everything's good. You don't need to educate. You don't need – the word doesn't have to get out. And why nobody has picked upon that, you know, it just – it has sent a terrible message that there is no big deal anymore, and I think it's made a huge difference in a lot of different areas.
The daughter of Participate 8 was a nurse. Since learning of his HIV infection, the daughter became estranged from her father. Participant 8 stated he thinks nurses need more education regarding HIV infection.

I think they need to teach them in nursing more about it. I have two grandkids, and I haven't seen them for two or three years. Actually, I told her when I was positive, you can't get it. She said, “I don’t want my kids around that.”

Participant 8 also mentioned the need for education in bathhouses.

I just wish they could see – the men that go in the bath houses. The doctor could see too. They don’t take your information. They don’t tell nothin’ about ya’. They just take your name and your address and put it in the computer and you gotta pay, but they can just go in and see for them self. I’m tellin’ ya.

**Titles given to the experience of living with HIV/AIDS**

All participants were asked if they were given the opportunity to write a book or create a movie to tell others about their experience of living with HIV/AIDS, what would the title of the book or movie be. One participant stated that she had a title but was not willing to share it on tape and wanted it to be confidential. Other participants chose and shared the titles. The following titles were offered:

- "Living comfortably with HIV"
- "Major learning experience"
- "Wise man"
- "Live with AIDS, live day by day, and survive"
- "HIV and how it changed my life"
- "Second chance"
- "I get along with it"
- "ABC, 123, HIV baby you and me"
- "Keep your mouth shut"
- "Long road"
- "(Participant’s name) story"
- "Death sentence reprieve"
“Just another day”

The titles described the experiences in the data. The title were congruent with the major themes and common phrases. The titles appear to reflect the life of the participant after being given a second chance or rebirth and integrating HIV/AIDS into the life of their lives. Living in the shadows of isolation, adapting to living with HIV, and living out one’s legacy are depicted in the titles.

4.4 Summary

Six major themes were identified within the data. The major themes represented linkages between common phrases used by the participants and the meaning of the experience of living with HIV/AIDS across the data in the transcripts. The titles provided by the participants and the major themes were connected throughout the data.

The first major theme was surviving the predators. The experiences of surviving predators were associated with betrayal/infidelities, abuse, and abandonment.

The major theme walking the road to death referred to the struggles experienced by the participants related to high risk behaviors that led to their HIV infection, and the struggle associated with learning they were infected with HIV. All but one participant believed they had received their death sentence.

Encountering the brink depicted the place in time when the participants chose to live or die. The brink was the turning point where all the participants decided they needed to accept and integrate the HIV infection into their lives as they reached out to others for support.

The theme, second chance/rebirth was possible due to support. The support consisted of unconditional love and support from family, spirituality, and support services. With the
realization that they had a second chance or experienced a rebirth, the participants welcomed the opportunity to live meaningful lives.

The fifth major theme, creating the nest of safety, gave the participants a safe dwelling place to hide from the shadows, nurture and protect others, and live out their legacy. The importance of a dwelling place of safety was mentioned by all the participants.

The last major theme was living in the shadows. The shadows were representative the daily burdens carried by the participants. The shadows were comprised of financial burdens, staying compliant with treatment, end of life issues, living with past mistakes, and issues related to health care disparities.
CHAPTER 5
DISCUSSION OF FINDINGS, CONCLUSIONS, AND IMPLICATIONS

5.1 Introduction

An important component of the nursing discipline is to seek understanding of the human experience “in order to contribute to better practical nursing” (Benner, 1994, p. 4). Health care providers, particularly nurses, need to understand the lived experiences of their patients in order to provide compassionate, timely, and culturally appropriate quality care. Nurses are positioned to improve the quality of life for people living with HIV/AIDS (PLWHA) in rural Northern Appalachia. The aim of this study was to describe and understand the lived experiences of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia. One research question guided this study. The research question will be examined within the context of the identified themes. The major themes identified within the context of the data included 1) surviving the predators, 2) walking the road to death, 3) encountering the brink, 4) rebirth/second chance, 5) building the nest of safety, and 6) living in the shadows. The hermeneutic phenomenological perspective of the four lifeworld existentials; temporality, spatiality, corporeality, and relationality will be discussed as they interrelate to the findings (van Manen, 2007). Conclusions and implications for nursing practice, education, and policy will be discussed.

5.2 Interpretation of Findings

The research question guiding this study was: What is the lived experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia? The findings suggested that for the participants in this study, the experience of living with HIV/AIDS meant that they survived the predators prior to learning of their diagnosis. All but one participant
described experiences associated with living with predators. The participants felt the encroachments by the predators contributed to a lifestyle of high-risk behaviors that led to the HIV infection. Surviving the predators is consistent with other studies that suggest that high rates of psychosocial stressors contribute to high risk behaviors that contribute to acquiring HIV. Some of the psychosocial stressors include trauma exposure, post-traumatic stress disorder (PTSD), poverty, housing instability, and unemployment (Montgomery et al., 2015; Myers et al., 2009; Pearson et al., n.d.; Whetten et al., 2006; Whetten, Reif, Whetten, & Murphy-McMillan, 2008).

Studies have suggested that experiencing any form of violence is associated with participation in high risk behaviors that lead to acquiring HIV infection (Leserman et al., 2007; Maman, Campbell, Sweat, & Gielen, 2000; Montgomery et al., 2015; Whetten et al., 2006; Whetten et al., 2008). According to Pearson et al. (n.d.), women who experience post-traumatic stress disorder are more likely to participate in alcohol binge drinking and risky sexual behavior that increases the risk for HIV. One study suggested that the predator of betrayal was associated with vengefulness (Moskowitz & Roloff, 2008). The study suggested that vengefulness might have intrinsic properties that manifest as apathetic behavior toward others that leads to nondisclosure of HIV infection. The Moskowitz study found that disclosure of HIV infection decreased in men reporting higher vengefulness (Moskowitz & Roloff, 2008). A study by Fendrick, Avci, Johnson, and Mackesy-Amiti (2013) suggested that drug use and high levels of depression increased the odds of high risk sexual behavior by men who have sex with men.

In this study living with HIV/AIDS initially meant walking the road to death. Many of the participants in this study described a sense of victimization that manifested in personal feelings of helplessness, depression, and hopelessness that were present in the first 12 months
after the HIV infection diagnosis (Pellowski, Kalichman, Mattews, & Adler, 2013). As suggested by Pellowski et al. (2013), individuals living with HIV/AIDS reported self-destructive behavior and depression. As the participants in this study walked the road of death, several participants struggled with ongoing addictions. Many of the participants described the experiences of living with anxiety, depression, decreased quality of life, emotional distress, or grief, feared stigmatization and rejection. Some of the participants lacked social support systems and walked the road of death alone. With the onset of illness, many of the participants were unable to maintain their jobs, and due to the lack of finances, were forced into poverty. Some of the participants found themselves homeless.

Studies have suggested that affective disorders are experienced by PLWHA. As suggested in previous studies, individuals who experienced childhood trauma and substance abuse, similar to the experiences of the participants in this study, are more likely to exhibit depression, maladaptive coping, and re-victimization in adulthood (Pellowski et al., 2013). Anxiety prevalence is three times higher in HIV positive individuals than among HIV negative individuals (Clucas et al., 2011; Pellowski et al., 2013). The affective disorders are associated with negative HIV disease progression, poorer medication adherence, and delay in accessing health care (Clucas et al., 2011; Pellowski et al., 2013).

Prior to becoming infected with HIV, some participants in this study chose to leave their rural hometowns to pursue a life in urban centers where there were educational, cultural, and employment opportunities. The gay culture in the cities provided distance from family allowing pursuit of a lifestyle that could have created problems in rural towns (Verghese, Berk, & Sarubbi, 1989). Participants shared various reasons for relocating to rural Northern Appalachia during the journey on the road to death. Three of the 15 participants were residing in rural Northern
Appalachia at the time of diagnosis. The remaining 12 participants moved back to the region after being diagnosed with HIV. This is consistent with studies suggesting that upon learning of HIV infection, individuals migrate to rural areas (Ohl et al., 2010; Verghese et al., 1989). A study by Verghese et al. (1989) suggested that PLWHA migrate to rural areas in order to receive support from family members. However, moving back to rural areas is conditional depending upon the receptivity of the family. The study by Verghese et al. (1989) suggested that PLWHA migrated back to rural areas hoping that being back home would somehow protect them. Interestingly, as suggested by Ohl et al. (2010), participants in this study who relocated to rural Northern Appalachia experienced greater stigma. Stigma surrounding HIV infection in rural areas led to less disclosure and fewer individuals seeking testing and health care. The delays lead to poorer outcomes and increased mortality in rural areas (Chaudoir, Fisher, & Simoni, 2011; Ohl et al., 2010; Sood et al., 2014).

According to Carrico et al. (2006), infection with HIV presents unique challenges. Consistent with a study by Katz (1996), some of the participants experienced shock upon learning they were infected with HIV, while others expected to become infected with HIV due to their lifestyle decisions. Regardless, learning of their HIV infection forever changed participants’ lives.

Psychosocial adjustment and better health outcomes rest upon acceptance and integration of life change associated with living with HIV and maintaining a genuine sense of hope. Upon walking the road to death, many of the participants encountered the brink. The experience at the brink was similar to what Cutcliffe and Zinck (2011) described as losing the ontological self. During the loss of self, individuals experienced despair, possessed limiting attitudes, and went into hiding. Participants in this study described what it was like to be at the brink. At the brink
participants noted experiencing depression, thoughts of suicide, isolation, emptiness, loneliness, and hopelessness.

The significance of the brink, or loss of self, was described as the place where the participants experienced a conscious attitudinal shift regarding their life with HIV/AIDS. According to Perrett and Biley (2013), the positive adaptation of integrating HIV into life does not occur automatically, but is a conscious process of choice followed by action. The brink is consistent with findings from a study by Baumgartner (2012). Baumgartner found that individuals living with HIV/AIDS encountered a “turning point”. According to Baumgartner, the turning point is experienced six months to five years after being diagnosed with HIV infection. The turning point assisted in the integration of the HIV/AIDS identity into one’s self (Baumgartner, 2012).

Joseph (2011) posits that human beings constantly attempt to adapt to their environments. When confronted with trauma individuals attempt to resolve the tension between preexisting assumptions and traumatic events. With accommodation there is a death of the old self. During the process of accommodating traumatic events individuals need to modify their assumptions about the world to be more in line with reality. Assumptions are modified so they fit a new belief system of assumptions. When accommodation moves in a negative direction, individuals experience hopelessness and helplessness, believing the world is a bad place and they feel powerless over it. The process of new accommodation leads to what Joseph calls posttraumatic growth (Joseph, 2011). Tedeschi and Calhoun (1996) identified three main facets of posttraumatic growth; relationships are enhanced, individual perceptions of self are positively enhanced, and individuals have a change in their philosophy of life. This is consistent with the participants in this study who used the terms rebirth and second chance.
All the participants in this study described the experience of being diagnosed with HIV as a pivotal life event. In this study, it was at the brink where participants began the acceptance of self or becoming their authentic self. While at the brink, many of the participants in this study struggled with issues of past traumas or issues related to their identity and HIV infection. With the resolution of past issues, the participants experienced resilience at the brink. According to DeSantis, Florom-Smith, Vermeesch, Barroso, and DeLeon (2013), resilience is, “the process by which an individual accesses internal motivation (e.g., a desire to survive) and external motivation (e.g., psychosocial support) that provide a basis for him or her to learn to manage both the physical and psychological aspects” of HIV/AIDS. Individuals living with HIV/AIDS gain a sense of mastery that develops from advocacy and achieving better health outcomes (De Santis et al., 2013, p. 19)

Consistent with the study by Katz (1996), the participants began to look at themselves with honesty. They believed their personal growth would not have happened without the experience of being HIV infected. All of the participants in this study gained a new perspective that included self-care, living in the present, appreciating the positive, and seeking support. The participants in this study began to see their world with clarity, including acceptance of others and support that led to a second chance in life (Katz, 1996).

Rebirth/second chance occurred as the participants accepted support from family and AIDS service organizations, as well as practiced a personal spirituality. Participants shared experiences associated with acceptance by family and friends. Personal spirituality provided them with the courage to encounter difficulties while directing them toward purpose in life. Being connected to HIV services gave them ability to care for themselves and provided them
with social capital. Without acceptance and support they stated they would have died while enduring at the brink.

Resilience emerged as the participants accepted support from family and AIDS service organizations and fostered a personal spirituality. The support and spiritual experiences voiced by the participants in this study are consistent with the stage of finding acceptance and reconciliation, turning from death to life, and finding new meaning as described by Cutcliffe and Zinck (2011). Lee, Yamazaki, Harris, Harper, and Ellen (2015) found that social support and how to cope with and react to the impact of HIV needs to be integrated into resilience to enhance the quality of life for PLWHA. Cutcliffe and Zinck (2011) suggested that gaining acceptance from significant others is important to the re-emerging, or crossing over. Many of the participants in this study described the profound importance of positive relationships with their families. Participants shared stories of how they were extracted from their addictions, risky behaviors, and homelessness by their families. Families provided them with the safety of a home and embraced them with unconditional love. According to Grant, Vance, Keltner, White, and Raper (2013), the most common reasons for PLWHA to include individuals as family members were love and acceptance, support, blood and familial ties, and commonality. Participants describing experiences of being extracted from addictions, risky behaviors, and homelessness is consistent with the study by Serovich et al. (2001). The study found that family availability for support was instrumental in reducing risky behaviors.

As the participants embraced the rebirth or second chance, they recognized opportunities that linked them into avenues of support. Studies suggest that social support networks improved health behaviors, improved health outcomes, and more social capital (Webel & Holzemer, 2009; Webel, Sattar, Schreiner, & Phillips, 2016; Webel et al., 2015). A study by Kelly, Hartman,
Graham, Kallen, and Giordano (2014) found that greater social support at the time of HIV diagnosis was associated with earlier diagnosis and predicted successful access and retention in HIV, more HAART initiation, and greater adherence to HAART. Lee et al. (2015) found that HIV status disclosure was more likely to occur with a supportive circle of family and friends. This is consistent with a study by Chaudoir, Fisher, and Simoni (2001) suggesting that social support predicts greater disclosure of HIV infection. The significance of disclosure is that disclosure facilitates HAART adherence, physical well-being, provides opportunity for education, discussion, and increased awareness of HIV. DeSantis et al. (2013) found that disclosure improves mental health as well as promotes positive family communications.

All of the participants in this study felt that if it was not for the case managers and staff at the ASO they would have died. Many participants felt the ASO saved their life. AIDS service organizations, funded largely by Ran White HIV/AIDS Program funding, improve the health outcomes for low-income, uninsured, and underinsured PLWHA. Because of housing and lack of health care coverage, AIDS service organizations provide a wide range of support services designed to retain PLWHA in health care and reduce HIV transmission (Sood et al., 2014; Weiser et al., 2015). As suggested by Weiser et al. (2015), individuals living with HIV who receive health care and support services experience better clinical outcomes. Because of the AIDS service organizations, participants have available social capital such as assistance for food, housing, medical care, and transportation. This is consistent with the study by Webel et al. (2013) that found that social capital appeared to have the greatest influence of the ability of PLWHA to self-manage behaviors such as, diet, physical activity, maintain access to health care providers, and improve social relationships.
The resurrection of a personal spirituality was revealed when many of the participants in this study voiced that HIV/AIDS was a blessing. This is consistent with the study by Ironson et al. (2011) that suggested that a positive view of God was associated with more hope and reframed the HIV diagnosis as being chosen by God for a special purpose. According to Hall (1998), spirituality can frame the interpretation of the state of the body and mind. Pain or fear can provide the catalyst for heightened spiritual awareness that leads to spiritual meanings and helps to understand suffering. For individuals living with HIV who are stigmatized and ill, spirituality provides them a means to preserve the integrity of self. Consistent with the study by Hall (1998), the participants in his study found comfort and assurance in a spirituality that was personal and authentic. Spirituality attributed to the feeling that HIV infection provided purpose for their lives. Finding meaning in the experience of living with HIV began when the HIV infection provided the individuals with avenues to reconcile with family and reconnect. Many participants were surprised with the warmth and support they received from their families (Hall, 1998). Also consistent with the study by Hall, many of the participants became more aware and assertive about engaging in activities that fit with their new identity of self and letting go of or as one participant in this study stated “pruning” away old ways of self that no longer fit.

All of the participants felt having stable, safe housing, or “a nest of safety” was key in protecting them as well as family members and friends. Living in the refuge also provided them a place to nurture others and live out their legacy. This is consistent with the study by Webel et al. (2013) that suggested that stable safe housing was a key factor in improved health outcomes. Housing stability positively affected the social support domain and promoted positive HIV health outcomes. Having a nest of safety appeared to contribute to the participants’ quality of life.
Participants in this study believed that their life legacy rested upon protecting and nurturing others. Participants shared experiences where they reached out to the younger generation to advise them of ways to reduce their risk of becoming infected with HIV and to keep them from poor decision-making. Both male and female participants in the study shared how they attempted to protect, reconcile, and nurture children. This is consistent with studies that suggested individuals who experienced self-transcendence and a better quality of life while living with HIV/AIDS demonstrated a tendency to share their wisdom and experience with others and help other younger people in some way (Mellors, Riley, & Erlen, 1997). Like many of the participants in this study, many individuals living with HIV infection express altruistic concerns towards others and their community at large. One study suggested that PLWHA transcend external and internalized stigma through altruistic activities such as becoming HIV educators and becoming involved in HIV advocacy (Van der stratten, Vernon, Knight, Gomez, & Padian, 1998).

Participants in intimate sexual relationships shared concerns regarding infecting their significant other. Although the participants in this study did not shared specific details of sexual relationships, most expressed the burdens associated with protecting the uninfected partner. Research studies have suggested that the sex, sexuality, and HIV are complex with vary degrees of conflict. Strategies utilized between couples to lessen the tension between transmission concerns and maintaining a sexual relationship include denial or believing the couple were immune to transmitting the virus to always using condoms, gloves, and saran wrap during sexual activity (Van der stratten et al., 1998). Cusick and Rhodes (2000) suggested that couples that move from condom use to non-condom use coincided with the development of the emotional component of their relationship. HIV positive partners experience frustration when efforts to
practice safer sex were challenged. Like many couples in this study, the HIV positive partners feel the burden of responsibility for transmission prevention. Among some negative partners, not using a condom was viewed as an expression or a commitment to the relationship. It was the HIV negative partners who argued in favor of transition to unprotected sex (Cusick & Rhodes, 2000; Rhodes & Cusick, 2000).

In this study, participants used frequent phrases that indicated the experience of “living in the shadows”. Living in the shadows meant living a new life with burdens. The burdens, in the participants’ words included; isolation, financial burdens, staying compliant with treatment, end of life issues, living with past mistakes, and health care disparities. The shadows described by the participants in this study are similar to the social determinants that contributed to the experiences of African Americans living with HIV/AIDS in rural southeastern Appalachia (Abbott & Williams, 2015). The social determinants identified by Abbott and Williams included living in poverty, enduring unemployment, missing work, lacking transportation, sustaining stress, feeling social excluded, needing social support, battling substance use, and lacking adequate health care.

Loneliness is one of the most common stressors reported by individuals living with HIV/AIDS (Vance, 2006). The participants shared that they lived in secrecy or “under the radar” to protect themselves and their families. Conversely, McDowell and Serovich (2007) found that perception of having social support appears to have a positive impact on the mental health of those living with HIV. Some of the participants in this study participated in online chat rooms. This is consistent with the findings from the study that suggested that perception of social support can be found with the use of online support groups (Mo & Coulson, 2013). Higher levels of online support group participation was related to lower levels of depression and higher levels
of optimism. Optimism is more resistant to negative emotions such as depression, while loneliness contributes to maladjustment and lack of well-being (Mo & Coulson, 2013).

Many study participants expressed fears and anxiety about incidents of violence and stigma. Several of the participants shared experiences of physical violence and hostile communications from members of their communities. This is consistent with a study conducted by Williams, Bowen, and Horvath (2005) that explored the social sexual environment of gay men residing in a rural frontier state. The study suggested that hostility is imposed by rigid standards of social interaction where heterosexually dominated the social standards. In other studies conducted with women, researchers found that women were engaged in never ending work of making decisions whether to disclose or conceal their HIV infection to others due to fear of being harmed or family members being harmed (Grodensky et al., 2015; Sandelowski, Lambe, & Barroso, 2004).

Participants in this study were selective about disclosing their HIV infection. Many of the participants felt that members of the rural communities had “small minds” as a result of living in communities that lacked diversity. A study by Parker and Aggleton (2003) posits that stigma and stigmatization is a function between culture, power, and difference. Stigma is deployed by central members of a community to legitimize their dominant status with social structures of inequality. Two of the participants suggested emptiness, lack of diversity, and the loss of socioeconomic opportunities in rural Northern Appalachia contributed to the stigma and violence. According to Williams, Bowen and Horvath (2005), feelings of isolation can lead to hostile social environments and violence. Consistent with coping strategies identified in a study by Shandor-Miles, Roman-Isler, Banks, Sengupta, and Corbie-Smith (2011), participants in this study reduced their anxiety and distress with eliciting support from others, especially family
members and ASOs, practicing personal spirituality, and reaching out to others infected or affected by HIV/AIDS.

Many of the participants in this study shared concerns related to living in the shadows of financial burdens and their desire to be employed to lessen the financial burdens. Research findings suggested that being in paid employment was a positive contribution to the quality of life of individuals living with HIV (Webel et al., 2015). A study by Rueda et al. (2011) suggested that employed individuals living with HIV had a higher physical and mental quality of life. Employment was a positive predictor in decreased morality among former illicit drug users who are infected with HIV (Richardson et al., 2014). The benefits for women living with HIV and who were employed included a sense of self-worth, provided a way to balance the woman’s personal health needs with the needs of her family, and provided basic resources for the woman (Webel et al., 2013). Studies suggest that efforts should be made in assisting with job training and providing employment opportunities for individuals living with HIV to improve their quality of life (Martin et al., 2012; Rueda et al., 2011; Webel et al., 2013; Webel et al., 2015). Barriers to employment described by the participants in this study such as fatigue, low energy, and concerns regarding stigma and discrimination are consistent with findings suggested by other studies (Rodger et al., 2010; Wagener, Miedema, Keleijn, vanGrop, & Roelofs, 2015).

Many of the participants in this study described challenges associated with obtaining quality health care with compassionate and knowledgeable health care providers while living in rural Northern Appalachia. Some participants admitted that they were personally responsible for delaying their health care due to their denial or lack of acceptance of their HIV infection. Other participants voiced negative experiences associated with obtaining a health care provider that included a lack of quality health care in rural areas, limited access to health care services, limited
choices of health care providers, and health care providers who lacked compassion and appeared judgmental. All the participants in this study were established with a health care provider who provided care related to their HIV. All but two of the participants received their HIV care through local clinics funded through AIDS service organizations. Two of the participants traveled to urban health care centers to receive care from urban HIV specialists. The participants who traveled to urban health care centers feared stigma and discrimination from others in the rural areas. The experiences of the participants in this study are consistent with findings from other studies conducted with PLWHA in other rural areas of Appalachia. Studies have suggested that barriers associated with obtaining health care for individuals living with HIV included long distances to care, lack of HIV trained health professionals, lack of HIV specific services, lack of knowledge about available services, and issues associated with stigma and confidentiality (De Santis et al., 2013; Foster & Frazier, 2008; Konkle-Parker, Amico, & Henderson, 2011; Pellowski, 2013).

Inappropriate disclosure of HIV status by health care professionals experienced by the participants in this study was unsettling as well as being in violation of HIPAA and ethical guidelines. The inappropriate disclosure of their HIV/AIDS diagnosis contributed to the participants’ need to remain in the shadow of secrecy. One participant received monetary compensation due to the inappropriate disclosure of his HIV infection by a clinic nurse who was eventually relieved of her position. Perhaps health care providers in rural Northern Appalachia have limited experience with PLWHA and have not had the opportunity to discuss their feelings related to HIV disease and the associated risks (Earl & Penney, 2003). Studies have recommended that health care professionals must become more comfortable and knowledgeable regarding issues related to HIV infection (Hillman & Beiler, 2011; Relf et al., 2011; Siminoff,
Erlen, & Lidz, 1991; Volkow & Montaner, 2011). Nurses are in excellent positions to play a major role in advocating for PLWHA, such as developing interventions to decrease secrecy and stigma, creating support groups, community education programs, and edifying PLWHA through personal support measures (Vance, 2006).

The lived experience of living with HIV/AIDS while residing in rural Northern Appalachia meant living in the shadows. Although the participants acquired HIV infection in various ways, they described how the experiences affect the way they see the world and influence their behaviors and perspectives on life. The experiences of the participants illustrate that ethical issues and disparities exist in rural Northern Appalachia. Within the data, living with HIV infection in a rural region of Northern Appalachia was associated with resilience, living an authentic and purposeful life in a nest of safety, while utilizing support systems to lessen the burdens they encountered.

**Interpretation of the study findings related to the four lifeworld existentials.**

Temporality, or lived time, is experienced as the abstract concept of being in the world (van Manen, 2007). In this study the lived experience of living with HIV/AIDS while residing in a rural region of Northern Appalachia was created from the continuum of time as experienced in the past, present, future. The participants in this study valued the importance of the history of their life supported by their descriptions of surviving the predators in their life, the experience of learning of their HIV infection, walking the road toward death, experiencing a rebirth/second chance, and creating a nest of safety in order to continue their life legacy. According to Ricoeur, the self-narrative transforms contingent events into necessary episodes of life by providing a context or link with other events. Relation between character and narrated action is correlative to those in the narrative self (Reagan, 1996). The time continuum is evident in the data as the
participants often linked the past to the present and the future with phrases such as…”HIV led me down a path I would have never expected…making a difference in a positive way, being positive, because had I not been positive I would have never progressed to where I am today” and “looking for a new direction-an uplifting new direction, a new direction that would give us a purpose, having a legacy.”

Spatiality, or lived space refers to a place of being in the world, or space which is felt (van Manen, 2007). In this study the need for a safe place in which to live out their legacy is depicted by the passion of the participants to build a “nest of safety”. The nest of safety provided the participants with an opportunity to have control over their domain, such as finances, losses, as well as hiding their illness. Within the nest of safety, the participants created a beautiful peaceful world where they lived subdued lives as they blended into the background where they remained hidden and protected from the shadows of the outside world. The nest of safety was the place where the participants were free to be their authentic self. Within the nest of safety, the participants nurtured and vigilantly protected others, created their life legacy, and prepared for their eventual death.

Participants voiced that the rural areas in which they lived were much like impermeable membranes, where the participants felt they would never belong or be accepted by others in the rural communities. For one participant, living in rural areas seemed like “living outside an impermeable membrane” made up of community members and health care workers who embodied characteristics of “small minds”. Small minds meant “a lack of diversity”, “staying the same”, “not being open to personal growth”, “never changing”, and “not being open to learning a new way to see the world”. One participant viewed the people in the small towns as “living
empty” or “unfulfilled lives”. The “emptiness” provoked “embellished gossip” and the lack of diversity led to familiarity that bred “contempt toward others”.

Corporeality, or lived body, refers to one’s physical existence in the world (van Manen, 2007). For the participants in this study, the physical way of being in the world was reflected in their descriptions of nurturing and protecting others. Many participants reflected on early experiences with predators that led to the risky behaviors associated with acquiring HIV. The participants shared experiences illustrating the extensive efforts they made to nurture and protect others. For many of the participants, nurturing and protecting others offered them the opportunity for creating a life legacy for the future. For other participants being infected with HIV led to a more fulfilled life as they “pruned away” the negative aspects of their life. One participant shared that living “prunes away” negative ways of thinking that led to change, helping him to experience a more fulfilled life.

Relationality is the lived relation we maintain with others in the interpersonal space we share with them (van Manen, 2007). For one participant the legacy meant being that “one little string” that tied her to the family. Having family relationships, in the context of a bond that cannot be broken, provided a reason for the participants to embrace a second chance/rebirth to create a new life. A majority of participants depicted family support as the lifesaving power that helped them to embrace a second chance/rebirth to live out their life legacy. Families rescued participants from their death. Living in a nest of safety provided protection for the participants and their family members from dangers in outside world. Family support helped the participants realize they needed to move on. Family relationship helped participants to see life in a positive way. Nurturing family members gave participants a purpose and helped to create their legacy.
For some participants a new personal spiritual relationship with their higher power gave them purpose to live an authentic life. Participants felt their higher power allowed them to become infected with HIV so that they could help others find support and overcome the challenges associated with living with HIV infection. The ongoing relationship with their higher power gave the participants the courage to stand up to the injustice and unethical treatment experienced by individuals living with HIV. Many participants noted that the purpose for having HIV infection was to make a positive difference in the world.

5.3 Limitations

The findings of this study were limited by the self-selection of individuals living with HIV/AIDS. All of the participants were participating in various types of support services for individuals living with HIV. Missing from this study were individuals not participating in services. The meaning of the lived experience of individuals not participating in this study remain unknown and might be different from the individuals who participated in the study. Considering the findings of this study, one would wonder if there are individuals living with HIV/AIDS still existing at the brink. Due to the sensitive nature of the topic of HIV/AIDS and the perceptions of fear and danger held by the participants, experiences, intimate thoughts and feelings related to living with HIV/AIDS might not have been shared with the researcher.

The study was conducted in rural areas of Northern Appalachia. The Appalachian region is a vast region along the Appalachian mountain chain. The Appalachian region is diverse with many health disparities. The disparities are highly localized throughout the region (Haaga, 2004; Halverson & Bischak, 2008; Halverson et al., 2004).
5.4 Conclusions

The life journeys of the individuals living with HIV/AIDS while residing in rural Northern Appalachia were important in understanding the findings of this study. The individuals found meaning in sharing the history of surviving the predators, walking the road toward death as well as acquiring HIV/AIDS. As the participants survived at the brink, they recognized the opportunity to embrace a second chance/rebirth. Reaching out to others for support, the participants found resources to build a nest of safety where they nurtured and protected others and continued to live a purposeful life as they created a legacy for the future. The participants characterized the burdens they endure as living in the shadows. The findings of this study suggested that individuals living with HIV/AIDS in rural Northern Appalachia were living an experience not understood by the people of rural Northern Appalachia. Allowing the participants to share the narrative of their experiences was important in helping them to find meaning in their experiences.

5.5 Implications and Recommendations

Nursing Practice

One responsibility of nurses is to assist patients experiencing disequilibrium in returning to a more steady state. Nurses are continually present with persons who experience changes in their health and quality of life, and who live intense profound moments of struggling, questioning, and finding meaning in the process of human becoming (Naef, 2006). Therefore, understanding the meaning of living with HIV/AIDS while residing a rural region of Northern Appalachia is important for nurses and other health care providers as they encounter and provide care to individuals infected and affected by HIV/AIDS.
Throughout this study, patients described experiences where there was a lack of compassionate care and lack of knowledge among nurses and health care providers. Participants shared experiences of rejection and feeling betrayed with inappropriate disclosure of their HIV status by nurses and health care providers. According to Pellowski (2013), perceived provider stigma and discrimination by providers is a significant barrier to HIV/AIDS medical care. Negative health outcomes are correlated with discrimination and stigma. Patients who are not accepted into care perceived discrimination. Individuals who experienced discrimination were more likely not return to care. Perceived stigma led to poorer patient-provider relationships and impacted retention and engagement in health care. Also breach of confidentiality is a significant concern for PLWHA (Pellowski, 2013). Pellowski suggested the need for opportunities for nurses and health care professions to receive education, offer compassionate, confidential care regardless of their attitudes toward people living with HIV/AIDS.

Knowledge gained from this study exemplified the struggles, fears, and isolation of individuals living with HIV/AIDS in rural Northern Appalachia. According to Ricoeur, fear of judgement can bring the life narrative and self-identity to premature closure (Ricoeur, 1991). Ricoeur described loss of identity as a loss of configuration of the narrative of an individual, a crisis of closure (Ricoeur, 1991, p. 78). Edward Tick (2005), a psychologist who has conducted research studies exploring post-traumatic stress disorder (PTSD), defines PTSD as loss of identity. As nurses acquire new knowledge in the lived experiences of persons living with HIV/AIDS, it is critical that nurses foster a belief system reflective of the nurse’s role in patient/client advocacy.

According to the American Nurses Association code of ethics (American Nurses Association, 2015), the nurse practices with compassionate and respect while recognizing the
uniqueness of all individuals “regardless of the factors contributing to their health status” (p. v). Rendering commitment to the patient, the nurse “promotes, advocates for, and protects the right, health, and safety of all patients” (American Nurses Association, 2015, p. v). Congruent with the code of ethics, Mitchell and Bunkers (2003) posited that within a meaningful nurse-patient relationship cultivated through bearing witness, the nurse is given the opportunity to foster the well-being of the patient while forming social consciousness to be a change agent in society (Mitchell & Bunkers, 2003). Bearing witness, a way of being with others, is a valuable nursing practice in the development of a meaningful nurse-patient relationship (Mitchell & Bunkers, 2003; Naef, 2006). The nurse bears witness by being attentive to the person’s lived experiences and truths while honoring the person’s uniqueness, supporting the person’s choices, espousing the belief that persons know themselves best, and recognizing human interconnectedness (Naef, 2006). As the nurse witnesses the unfolding of the lived experiences of others, the nurse develops an understanding of the meaning of the lived experience (Letcher & Yancey, 2004).

The experiences described by the participants also point to the importance of being established in a support network. Prior to reaching out for support, the participants existed at the brink. At the moment when participants recognized a second chance at life, they sought medical treatment and socioeconomic support needed to continue life. With knowledge of local HIV/AIDS support networks, nurses will assist individuals living with HIV/AIDS in accessing support resources soon after being diagnosed with HIV infection.

**Nursing Education**

The findings from this study suggest that nursing education would benefit by focusing on enhancing ethical comportment within the design of curriculums. Over the past decade, Benner, Sutphen, Leonard, and Day (2010) suggested that nursing education programs incorporate the
three apprenticeships. The three components of the apprenticeships include cognitive-learning nursing knowledge and science; practical-learning skills and clinical reasoning; and ethical comportment- the development ethical standards, social roles, and responsibilities of the nursing profession (Benner et al., 2010; Noone, 2009). An ethical comportment is essential when working with PLWHA. The findings from this study indicate the importance of preparing nurses to enter practice with the knowledge skills, and attitudes to address individuals, families, and communities affected by HIV/AIDS (Earl & Penney, 2003; O'Sullivan, Preston, & Forti, 2000; Relf et al., 2011; Vance & Denham, 2008).

Findings from this study suggest that nurses and health care providers lack understanding regarding the experiences of PLWHA. Throughout the data, participants described experiences associated with the lack of compassion and understanding from nurses and health care provider. The participants shared that they wanted nurses and health care providers to provide compassionate care, as well as recognize and understand their daily struggles and life journeys. Curriculums developed around novel learning methods assist students in recognizing patients’ experiences, desires and goals, and life journeys (Bateman & Merryfeather, 2014). Appreciating the role and attributes of phenomenology as a research method, nurse educators assist students in understanding the experiences of patients and the meaning of the experiences of health and illness. The knowledge gained from phenomenology assist nurses and other health care providers in interacting with patients in ways that differ from individuals who do not understand the experience (Cohen et al., 2000).

Findings from this study indicate a lack of HIV-specific knowledge among nurses and other health care providers. Research studies suggest that lack of HIV-specific knowledge and inexperience with providing care to PLWHA negatively impacts patient care of PLWHA.
(Siminoff et al., 1991). Nurses are positioned to participate as active members of staff development committees and continuing education programs to create interdisciplinary education related to HIV/AIDS. Reflecting on the code of ethics (American Nurses Association, 2015) and as well as functioning as educators, the role of the nurse is to provide accurate and current knowledge pertaining to HIV/AIDS and to explore the beliefs and attitudes of health care providers across the disciplines (Siminoff et al., 1991). This research study supports Siminoff’s research. The findings from this study suggest that health care providers be provided with knowledge regarding the experiences of PLWHA in rural Northern Appalachia, the negative effects of isolation experienced by PLWHA, and the impact of delayed health care on the quality of life of PLWHA.

**Nursing Research**

Findings from this study suggest a number of topics for future research using qualitative and quantitative approaches. Many of the participants referred to members of the rural communities as “people with small minds”. In the review of literature no studies were found where the phrase “small minds” was revealed and described to such depth. Findings from this study suggest conducting focus groups to explore attitudes of community members towards individuals living with HIV/AIDS.

The experiences of women in this study portrayed unique challenges associated with differences in gender roles. All of the women in this study described experiences particular to women living with HIV/AIDS, such as accessing gender specific health care. The findings from this study suggest conducting a phenomenological study specific to describing the challenges associated with the lived experience of women residing in rural regions of Northern Appalachia.
The finding from this study indicate negative attitudes towards PLWHA by health care providers in rural Northern Appalachia. Conducting a mixed methods study, to describe and to measure the attitudes of health care providers in rural Northern Appalachia towards PLWHA is indicated. Research suggest that positive patient-health care provider relationships lead to positive outcomes (Boehme et al., 2012; Kempf et al., 2010). Additionally, with an increasing nationwide opioid epidemic, Williams and Bisaga (2016) suggested more research and education is needed for health care providers practicing in rural areas regarding issues that affect their ability to support and deliver care to populations associated with opioid use disorder as well as HIV/AIDS.

Based upon the experiences of PLWHA in rural Northern Appalachia, replication of this hermeneutic phenomenological study in other rural areas of Appalachia is suggested. Pellowski (2013) suggested that future research studies focus on the multiple barriers to care for HIV infected individuals. Although there is a wealth of knowledge regarding barriers to HIV/AIDS care in rural areas, the empirical knowledge and rural models for HIV/AIDS medical care have not been fully integrated into practice (Pellowski, 2013)

**Policy**

Participants in this study expressed the lack of knowledge of health care providers in linking them to networks of support in the communities. Research studies have suggested that being linked to health care and social support leads to better quality of life and improved health outcomes. Maintaining government funding for AIDS programs is imperative to enhancing the quality of life of PLWHA and improving health outcomes (Weiser et al., 2015).

The finding from this study suggest the necessity for educational efforts even though HIV infection has become a chronic illness. One participant in this study expressed concern
regarding the lack of educational pamphlets in offices of health care providers and the department of health. Education regarding risk reduction and early testing is crucial in reducing the transmission of HIV among individuals in high risk situations (Kelly et al., 2014).

The financial burdens and lack of employment opportunities was a concern for many of the participants. The exact number of job training programs or flexible employment programs available for PLWHA is unknown. The finding from this study indicate the creation of initiatives that support job training programs or flexible employment programs in rural regions.

Finding from this study suggest the necessity of raising awareness of the health disparities within Northern Appalachia, especially as it relates to HIV/AIDS. Health disparities associated with Appalachia seem to be focused in central and southern Appalachia. Findings from this study suggest the importance of keeping policy makers and key community leaders aware of the challenges experienced by PLWHA in rural Northern Appalachia in order to improve their quality of life.

5.6 Summary

Findings from this study contributed to nursing’s body of knowledge as well as the body of knowledge regarding living with HIV/AIDS while residing in a rural region of Northern Appalachia. The participants in this study shared their perspectives on the experience of living with HIV/AIDS while residing in a rural region of Northern Appalachia. They shared their experiences in order to give others hope, emphasize the need for obtaining support, and illustrated the existing challenges they face while living in the shadows. They were passionate about the need for others to understand their story and the need to be understood.
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APPENDICES
Revised Surveillance Case Definition for HIV Infection — United States, 2014
Recommendations and Reports

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Revised Surveillance Case Definition for HIV Infection — United States, 2014

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Summary
Following extensive consultation and peer review, CDC and the Council of State and Territorial Epidemiologists have revised and combined the surveillance case definitions for human immunodeficiency virus (HIV) infection into a single case definition for persons of all ages (i.e., adults and adolescents aged ≥13 years and children aged <13 years). The revisions were made to address multiple issues, the most important of which was the need to adapt to recent changes in diagnostic criteria. Laboratory criteria for defining a confirmed case now accommodate new multistart algorithms, including criteria for differentiating between HIV-1 and HIV-2 infection and for recognizing early HIV infection. A confirmed case can be classified in one of five HIV infection stages (0, 1, 2, 3, or unknown); early infection, recognized by a negative HIV test result by 6 months of diagnosis, is classified as stage 0; and acquired immunodeficiency syndrome (AIDS) is classified as stage 3. Criteria for stage 3 have been simplified by eliminating the need to differentiate between definitive and presumptive diagnoses of opportunistic illnesses. Clinical (nonlaboratory) criteria for defining a case for surveillance purposes have been made more practical by eliminating the requirement for information about laboratory tests. The surveillance case definition is intended primarily for monitoring the HIV infection burden and planning for prevention and care on a population level, not as a basis for clinical decisions for individual patients. CDC and the Council of State and Territorial Epidemiologists recommend that all states and territories conduct case surveillance of HIV infection using this revised surveillance case definition.

Introduction
Since the first cases of acquired immunodeficiency syndrome (AIDS) were reported in the United States in 1981, surveillance case definitions for human immunodeficiency virus (HIV) infection (the cause of AIDS) and AIDS have undergone several revisions to respond to diagnostic advances (1–5). This document updates the surveillance case definitions published in 2008 (5). It addresses multiple issues, the most important of which was the need to adapt to recent changes in diagnostic criteria. Other needs that prompted the revision included 1) recognition of early HIV infection, 2) differentiation between HIV-1 and HIV-2 infections, 3) consolidation of staging systems for adults/adolescents and children, 4) simplification of criteria for opportunistic illnesses indicative of AIDS, and 5) revision of criteria for reporting diagnoses without laboratory evidence.

Summary of Revisions to Surveillance Case Definition
The most important update is revision of the laboratory criteria for a confirmed case, which addresses the development of new diagnostic testing algorithms that do not use the Western blot or immunofluorescence HIV antibody assays. During 2009–2011, CDC and the Association of Public Health Laboratories proposed new diagnostic algorithms (6,7), and in June 2011 the Clinical and Laboratory Standards Institute (CLSI) published updated laboratory testing procedures for diagnosis of HIV infection (8). In these multistart algorithms, “supplemental” HIV tests (for confirming or verifying the presence of HIV infection after a positive [or “reactive”] result from an initial HIV test) can now include antibody immunoenzymes formerly used only as initial tests (e.g., conventional immunoenzyme tests or rapid tests) or can include nucleic acid tests (NAT). The 2008 surveillance case definition was not clearly consistent with the new algorithms because it specified that a test used for confirmation must be a “supplemental HIV antibody test,” e.g., Western blot or indirect
immunofluorescence assay test)" (5). This revised surveillance case definition explicitly allows these new testing algorithms.

Some new multistest algorithms lead to a conclusion that laboratories might classify as a "presumptive positive" result. Persons with a presumptive positive test result are expected to receive subsequent tests, such as a quantitative viral load, to confirm their HIV diagnosis, but results of those tests might not be immediately available to surveillance programs. To avoid unnecessary complexity for surveillance, the revised surveillance case definition, like the earlier definition, does not make a distinction between presumptive and definitive diagnoses. If subsequent test results reveal that the person is not infected, the case and previous test results should be deleted from the surveillance database.

Another important change is the addition of "stage 0" based on a sequence of negative and positive test results indicative of early HIV infection. This addition takes advantage of tests incorporated in the new algorithms that are more sensitive during early infection than previously used tests, and that together with a less sensitive antibody test, yield a combination of positive and negative results enabling diagnosis of acute (primary) HIV infection, which occurs before the antibody response has fully developed. The addition of stage 0 allows for routine monitoring of the number of cases diagnosed within several months after infection, which includes the most highly infectious period when viral loads are extremely high and intervention might be most effective in preventing further transmission. The definition of stage 0 also will reduce confusion between acute HIV infection (part of stage 0), when CD4+ T-lymphocyte counts can be transiently depressed, and stage 3 (AIDS), an advanced stage of HIV infection when CD4+ T-lymphocyte values are usually persistently depressed (9).

The revised case definition adds other criteria and eliminates several criteria that were impractical or difficult to implement uniformly across all states and territories. Specifically, the revised case definition:

- Classifies stages 1–3 of HIV infection on the basis of the CD4+ T-lymphocyte count unless persons have had a stage-3–defining opportunistic illness. The CD4+ T-lymphocyte percentage is used only when the corresponding CD4+ T-lymphocyte count is unknown. This avoids overestimating the proportion of cases in stage 3, which occurred when the stage was based on whichever CD4+ T-lymphocyte test result (count or percentage) indicated the more advanced stage. Clinical evidence suggests the percentage has little effect on prognosis after adjusting for the count (11,12).
- Removes the requirement that a "physician-documented" diagnosis must be based on laboratory evidence. This revision allows clinical evidence to be sufficient to define a case when it is impractical to retrieve laboratory test information regarding the initial diagnosis. The new definition also clarifies that the date of a physician-documented diagnosis is the diagnosis date recorded in a medical record note, rather than the date that the physician wrote the note.
- Combines the adult and pediatric criteria for a confirmed case of HIV infection and specifies different criteria for staging HIV infection among three age groups (<1 year, 1–5 years, and >6 years).
- Eliminates the distinction between definitive and presumptive diagnoses of HIV infection in children aged <18 months.
- Removes lymphoid interstitial pneumonia (pulmonary lymphoid hyperplasia) from the list of opportunistic illnesses indicative of stage 3 in children because this illness is associated with moderate rather than severe immunodeficiency (4).
- Eliminates the requirement that evidence of HIV infection in a child's biologic mother is needed to define a case of HIV infection in a child aged <18 months when laboratory testing of the infant independently confirms HIV infection. This change was recommended in a position statement approved at the June 2009 annual meeting of the Council of State and Territorial Epidemiologists (CSTE) (13).
- Extends the use of CD4+ T-lymphocyte counts and percentages for determining the stage of HIV infection to children as well as adults and adolescents, and now determines the stage in children aged 6–12 years the same way as in adults and adolescents. In the 2008 case definition, only the presence or absence of opportunistic illnesses was used as criteria for staging cases among children aged <13 years.
Scope and Applicability of the Surveillance Case Definition

This revised case definition, like the earlier one, is intended primarily for public health surveillance of HIV infection on a population level. Early diagnosis and viral suppression facilitate prevention of HIV transmission, morbidity, and mortality. This case definition’s staging system allows for health departments to evaluate prevention and care, which can be measured by analyzing cases by their stage at diagnosis and how rapidly they progress to more advanced stages. For various reasons, it would be inappropriate for clinicians to use the surveillance staging system as a guide to manage patients. United States national panels on antiretroviral guidelines recommend antiretroviral therapy for all HIV-infected adults, adolescents, and infants, and the staging system does not include criteria strongly recommended as indicators for more rapid initiation of therapy (e.g., HIV nephropathy, hepatitis B co-infection, viral load >100,000 copies/mL, and a decline in CD4+ T-lymphocyte count by >100 cells/μL per year) (14–16).

Methods

The revised case definition was developed in several stages. First, in 2010, HIV surveillance experts at CDC convened six work groups that included both CDC and external subject matter experts, including health-care providers, surveillance health department staff, and representatives from academic institutions and public health and commercial laboratories. The names of work group members are listed at the end of this report. The six topic areas were new HIV testing algorithms, acute HIV infection, HIV-2 infection, opportunistic illnesses, pediatric HIV infection, and physician-documented diagnosis. Each work group examined research and program information about the topic areas and elicited experience and expert opinion from federal, state, and local HIV surveillance programs: clinicians who diagnose HIV infection; and laboratories that report HIV test results.

Second, all work groups presented a summary of their reports at a consultation convened by CDC in February 2012. The consultation included additional experts in HIV surveillance, laboratory testing, and clinical care, including members of CSTE.

Third, most of the recommendations from the consultation were incorporated in a position statement developed in collaboration with CDC that was approved at the June 2012 annual meeting of CSTE (18). The revisions of the surveillance case definition in this document are based largely on that position statement. Finally, this document underwent peer review (described at http://www.cdc.gov/hiv/pdf/policies_PRP_Revised_HIV_Case_Def.pdf) by health-care professionals in compliance with the Office of Management and Budget requirements for the dissemination of influential scientific information.

Revised Surveillance Case Definition

Section 1: Criteria for a Confirmed Case

Criteria for a confirmed case can be met by either laboratory evidence or clinical evidence, as described below. Laboratory evidence is preferred over clinical evidence.

1.1: Persons Aged ≥18 Months and Children Aged <18 Months whose Mothers Were Not Infected

1.1.1: Laboratory Evidence

Laboratory criteria require reporting of the date of the specimen collection for positive test results in multistest algorithms or stand-alone virologic tests and enough information about the tests to determine that they meet any of the following criteria:

• A multistest algorithm consisting of
  – A positive (reactive) result from an initial HIV antibody or combination antigen/antibody test, and
  – An accompanying or subsequent positive result from a supplemental HIV test different from the initial test (8).

The initial HIV antibody or antigen/antibody test and the supplemental HIV test that is used to verify the result from the initial test can be of any type used as an aid to diagnose HIV infection. For surveillance purposes, supplemental tests can include some not approved by the Food and Drug Administration (FDA) for diagnosis (e.g., HIV-1 viral load test, HIV-2 Western blot/immunoblot antibody test, and HIV-2 NAT). However, the initial and supplemental tests must be “orthogonal” (i.e., have different antigenic constituents or use different principles) to minimize the possibility of concurrent nonspecific reactivity. Because the antigenic constituents and test principles are proprietary information that might not be publicly available for some tests, tests will be assumed to be orthogonal if they are of different types. For example:

– One test is a combination antigen/antibody test and the other an antibody-only test.
– One test is an antibody test and the other a NAT.
One test is a rapid immunoassay (a single-use analytical device that produces results in <30 minutes) and the other a conventional immunoassay.

Tests also will be assumed to be orthogonal if they are of the same type (e.g., two conventional immunoassays) but made by different manufacturers. The type of HIV antibody test that verifies the initial test might be one formerly used only as an initial test (e.g., conventional or rapid immunoassay, HIV-1/2 type-differentiating immunoassay), or it might be one traditionally used as a supplemental test for confirmation (e.g., Western blot, immunofluorescence assay).

A positive result of a multitest HIV antibody algorithm from which only the final result was reported, including a single positive result on a test used only as a supplemental test (e.g., HIV Western blot, immunofluorescence assay) or on a test that might be used as either an initial test or a supplemental test (e.g., HIV-1/2 type-differentiating rapid antibody immunoassay) when it might reasonably be assumed to have been used as a supplemental test (e.g., because the algorithm customarily used by the reporting laboratory is known).

A positive result or report of a detectable quantity (i.e., within the established limits of the laboratory test) from any of the following HIV virologic (i.e., nonantibody) tests:
- Qualitative HIV NAT (DNA or RNA)
- Quantitative HIV NAT (viral load assay)
- HIV-1 p24 antigen test
- HIV isolation (viral culture) or
- HIV nucleotide sequence (genotype).

### 1.2: Children Aged <18 Months Born to Mothers Who Have an Unknown Infection Status or Were Known to be Infected

#### 1.2.1: Laboratory Evidence

A child aged <18 months is categorized for surveillance purposes as HIV infected if all of the following criteria are met:
- Positive results on at least one specimen (not including cord blood) from any of the following HIV virologic tests:
  - HIV-1 NAT (DNA or RNA)
  - HIV-1 p24 antigen test, including neutralization assay for a child aged >1 month
  - HIV isolation (viral culture) or
  - HIV nucleotide sequence (genotype).
- The test date (at least the month and year) is known.
- One or both of the following:
  - Confirmation of the first positive result by another positive result on one of the above virologic tests from a specimen obtained on a different date or
  - No subsequent negative result on an HIV antibody test, and no subsequent negative result on an HIV NAT before age 18 months.

#### 1.2.2: Clinical Evidence

The same criteria as in section 1.1.2 or
- All three of the following alternative criteria:
  - Evidence of perinatal exposure to HIV infection before age 18 months
    - A mother with documented HIV infection or
    - A confirmed positive test for HIV antibody (e.g., a positive initial antibody test or antigen/antibody test, confirmed by a supplemental antibody test) and a mother whose infection status is unknown or undocumented.
  - Diagnosis of an opportunistic illness indicative of stage 3 (Appendix).
  - No subsequent negative result on an HIV antibody test.

### 1.3: Definition for Date of Diagnosis of a Confirmed Case for All Ages

#### 1.3.1: Laboratory Criteria

If the diagnosis is based on laboratory evidence, the diagnosis date is defined as the earliest date on which the specimen was obtained for a positive HIV test result.

#### 1.3.2: Clinical Criteria

If the diagnosis was based on clinical evidence (“physician-documented”) rather than laboratory evidence, the diagnosis
date is defined as the date (at least the year) of diagnosis reported in the content of the medical record. If the diagnosis date was not reported in the note, the date when the note was written can be used as a proxy.

Section 2: Criteria for Classifying the HIV Type as HIV-2

All HIV infections in the United States should be assumed to be type 1 (HIV-1) unless laboratory test results are sufficient to classify the infection as type 2 (HIV-2), dual HIV-1 and HIV-2 infections, or undifferentiated HIV infection, as described below. Clinical or epidemiologic evidence might lead to laboratory testing for HIV-2 but is insufficient for classifying the HIV type as HIV-2.

2.1: Persons Aged ≥18 Months and Children Aged <18 Months Not Perinatally Exposed

HIV-2 infection

For HIV-2 infection, one or more of the following laboratory criteria are necessary and sufficient:

- FDA-approved HIV1/2 type-differentiating antibody test result positive for HIV-2 and negative for HIV-1.
- Positive HIV-2 Western blot (WB) (or immunoblot or line assay) result and negative or indeterminate HIV-1 WB result.
- Positive qualitative HIV-2 NAT result.
- Detectable quantitative HIV-2 NAT (viral load).
- Laboratory results interpreted as consistent with HIV-2 infection by a laboratory expert experienced in differentiating HIV-2 from HIV-1 if laboratory evidence for HIV-2 is ambiguous.

Dual infection with HIV-1 and HIV-2

The HIV type is classified as “dual” infection (both HIV-1 and HIV-2) if both an HIV-1 NAT and an HIV-2 NAT are positive.

Undifferentiated HIV type

The HIV type is classified as “undifferentiated” if there is no positive or detectable result from an HIV-1 NAT and a laboratory expert cannot resolve ambiguous evidence for HIV-2, such as:

- HIV-2 WB is positive and HIV-1 WB is HIV positive or
- HIV-1/HIV-2 type-differentiating antibody test result interpretation is “undifferentiated” (positive for both HIV-1 and HIV-2).

2.2: Difficulty of Diagnosing HIV-2 Infection in Children Aged <18 Months Born to Mothers Known to be HIV-infected or whose HIV Infection Status is Unknown

In perinatally exposed children aged <18 months, antibody tests are not used to diagnose HIV infection because of the expectation that they might be false indicators of infection in the child due to passive transfer of maternal antibody. The HIV-1 NAT routinely used to diagnose HIV-1 infection in children of this age is likely to be negative in an HIV-2-infected child because it is insensitive to HIV-2. A positive HIV-2 NAT result would satisfy the criteria for a case. Otherwise, the diagnosis of HIV-2 infection in a child will need to wait until the child is aged 18 months, when it can be based on antibody test results.

Section 3: Criteria for Uninfected and Indeterminate HIV Infection Status of Perinatally Exposed Children Aged <18 Months

3.1: Uninfected

A child aged <18 months who was born to an HIV-infected mother or had a positive HIV antibody test result is classified for surveillance purposes as not infected with HIV if all three of the following criteria are met:

- Laboratory criteria for HIV infection are not met (see section 1.2.1)
- No diagnosis of a stage-3-defining opportunistic illness (Appendix) attributed to HIV infection and
- Either laboratory or clinical evidence of absence of HIV infection as described below.

3.1.1: Laboratory Evidence

Definitively Uninfected

- No positive HIV NAT (RNA or DNA) and
- At least one of the following criteria:
  - At least two negative HIV NATs from specimens obtained on different dates, both of which were at age ≥1 month and one of which was at age ≥4 months.
  - At least two negative HIV antibody tests from specimens obtained on different dates at age ≥6 months.

Presumptively Uninfected

- Criteria for definitively uninfected with HIV are not met
- At least one of the following four laboratory criteria are met:
  - At least two negative NATs from specimens obtained on different dates, both of which were at age ≥2 weeks and one of which was at age ≥4 weeks.
Recommendations and Reports

- One negative NAT (RNA or DNA) from a specimen obtained at age ≥ 8 weeks.
- One negative HIV antibody test from a specimen obtained at age ≥ 6 months.
- If criteria for HIV infection had initially been met by one positive HIV NAT test then it must have been followed by at least two negative test results from specimens obtained on different dates, one of which is:
  - A NAT test from a specimen obtained at age ≥ 8 weeks.
  - An HIV antibody test from a specimen obtained at age ≥ 6 months.
  - No subsequent positive NAT.

3.1.2: Clinical Evidence

A note in a medical record by a physician or other qualified medical-care provider states that the patient is not infected with HIV.

3.2: Indeterminate HIV infection status

A child aged < 18 months born to an HIV-infected mother is categorized as having perinatal exposure with an indeterminate HIV infection status if neither the criteria for being HIV-infected nor the criteria for being uninfected are met.

Section 4: Criteria for Classifying the Stage of HIV Infection

The stages of HIV infection defined in this document are for surveillance staging of disease and might not be appropriate for patient care, clinical research, or other purposes. A confirmed case that meets the criteria for diagnosis of HIV infection can be classified in one of five HIV infection stages (0, 1, 2, 3, or unknown). Stage 0 indicates early HIV infection, inferred from a negative or indeterminate HIV test result within 6 months of a confirmed positive result, and these criteria supersede and are independent of the criteria used for later stages. Stages 1, 2, and 3 are based on the CD4+ T-lymphocyte count. If the CD4+ count is missing or unknown, the CD4+ T-lymphocyte percentage of total lymphocytes can be used to assign the stage. Cases with no information on CD4+ T-lymphocyte count or percentage are classified as stage unknown. If a stage-3–defining opportunistic illness has been diagnosed, then the stage is 3 regardless of CD4 T-lymphocyte test results, unless the criteria described below for stage 0 are met. CD4+ T-lymphocyte counts or percentages at the time of diagnosis allow classification of cases by stage at diagnosis. Subsequent CD4+ T-lymphocyte counts or percentages help monitor disease progression and whether the person is receiving on-going care.

The stage characterizes the status of HIV disease at a particular point in time. Of primary interest to surveillance is the stage at initial diagnosis, but the stage can change in either direction after diagnosis and might be defined with reference to dates of interest such as the most advanced stage recorded through a particular date. The stages are defined as follows:

**Stage 0**

The criteria for stage 0 consist of a sequence of discordant test results indicative of early HIV infection in which a negative or indeterminate result was within 180 days of a positive result. The criteria for stage 0 supersede and are independent of the criteria used for other stages.

Stage 0 can be established either:

- Based on testing history (previous negative/indeterminate test results): a negative or indeterminate HIV test (antibody, combination antigen/antibody, or nucleic acid test) result within 180 days before the first confirmed positive HIV test result of any type. The first positive test result could be any time before the positive supplemental test result that confirms it;
- Based on a testing algorithm: a sequence of tests performed as part of a laboratory testing algorithm that demonstrate the presence of HIV-specific viral markers such as p24 antigen or nucleic acid (RNA or DNA) 0–180 days before or after an antibody test that had a negative or indeterminate result. Examples of algorithms that would fulfill this requirement include:
  - A positive initial HIV immunoassay result (e.g., antigen/antibody or antibody only) followed by a negative or indeterminate supplemental antibody test result (e.g., HIV-1/HIV-2 antibody differentiation assay or Western blot) and a positive NAT result. All three tests are usually performed as part of the same testing algorithm but time might elapse between tests if additional specimens must be obtained for definitive supplemental testing;
  - A negative initial HIV immunoassay result followed by a positive NAT result that might have been done to evaluate the presence of acute HIV infection (19, 20).

**Exception**

A confirmed case of HIV infection is not in stage 0 if the negative or indeterminate HIV test used as the criterion for it being a recent infection was preceded ≥ 60 days by evidence of HIV infection, such as a confirmed positive HIV test result, a clinical (physician-documented) diagnosis of HIV infection for which the surveillance staff have not found sufficient laboratory evidence, a CD4+ T-lymphocyte test result indicative of stage 3 (Table), or an opportunistic illness indicative of stage 3 (Appendix).
TABLE. HIV infection stage based on age-specific CD4+ T-lymphocyte count or CD4+ T-lymphocyte percentage of total lymphocytes

<table>
<thead>
<tr>
<th>Stage</th>
<th>Cells/μl. %</th>
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</tr>
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<tbody>
<tr>
<td>1</td>
<td>≥500</td>
<td>≥500</td>
<td>≥500</td>
</tr>
<tr>
<td>2</td>
<td>750–1,499</td>
<td>500–999</td>
<td>22–29</td>
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<tr>
<td>3</td>
<td>&lt;750</td>
<td>&lt;500</td>
<td>&lt;22</td>
</tr>
</tbody>
</table>

*The stage is based primarily on the CD4+ T-lymphocyte count; the CD4+ T-lymphocyte count takes precedence over the CD4+ T-lymphocyte percentage, and the percentage is considered only if the count is missing. There are three situations in which the stage is not based on this table: 1) if the criteria for stage 0 are met, the stage is 0 regardless of criteria for other stages (CD4+ T-lymphocyte test results and opportunistic illness diagnosed); 2) if the criteria for stage 0 are not met and a stage 3 defining opportunistic illness has been diagnosed (Appendix), then the stage is 3 regardless of CD4+ T-lymphocyte test results; or 3) if the criteria for stage 0 are not met and information on the above criteria for other stages is missing, then the stage is classified as unknown.*

Classifying a case as stage 0 depends on documenting negative HIV antibody test results in the specific situations described above. Negative test results from testing algorithms that have concluded that the person is not infected need not be reported to HIV surveillance programs.

Progression of Stage After Initial Diagnosis in Stage 0

Although the stage at diagnosis does not change, if >180 days have elapsed since the stage was 0 at diagnosis, the stage at the later date is classified as 1, 2, 3, or unknown, depending on CD4+ T-lymphocyte test results (Table) or whether an opportunistic illness had been diagnosed >180 days after HIV infection diagnosis.

Stages 1, 2, 3, and unknown

If the criteria for stage 0 are not met, the stage is classified as 1, 2, 3, or unknown, depending on CD4+ T-lymphocyte test results or whether an opportunistic illness was diagnosed (Table). Infection among children aged 6–12 years is staged with the same criteria as infection among adults and adolescents, including opportunistic illnesses indicative of stage 3 (Appendix) that formerly applied only to adults and adolescents (i.e., pulmonary tuberculosis, recurrent pneumonia, and cervical cancer). Multiple or recurrent bacterial infections (other than recurrent salmonella septicemia), which formerly applied only to children aged <13 years, now apply only to children aged <6 years. Lymphoid interstitial pneumonia is no longer classified as indicative of stage 3 in children because it is associated with moderate rather than severe immunodeficiency. The diagnosis of any of the opportunistic illnesses, irrespective of diagnostic method used, will meet the criteria for staging, thereby eliminating the requirement in the 2008 case definition for some of them to be "definitively" diagnosed.

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Disclosure of Competing Interests

The federal government employees who prepared this report have no conflict of interest with the manufacturers of the products discussed herein. Competing interests for non-CDC contributors were not assessed except for the five reports who reviewed a draft of this manuscript (external peer review described at http://www.cdc.gov/hiv/pdf/policies_PRF_Revised_HIV_Case_Def.pdf); they had no competing interests.
Appendix: Stage-3-Defining Opportunistic Illnesses in HIV Infection

Bacterial infections, multiple or recurrent*
Candidiasis of bronchi, trachea, or lungs
Candidiasis of esophagus
Cervical cancer, invasive†
Coccidioidomycosis, disseminated or extrapulmonary
Cryptococcosis, extrapulmonary
Cryptosporidiosis, chronic intestinal (>1 month’s duration)
Cytomegalovirus disease (other than liver, spleen, or nodes), onset at age >1 month
Cytomegalovirus retinitis (with loss of vision)
Encephalopathy attributed to HIV§
Herpes simplex: chronic ulcers (>1 month’s duration) or bronchitis, pneumonitis, or esophagitis (onset at age >1 month)
Histoplasmosis, disseminated or extrapulmonary
Isosporiasis, chronic intestinal (>1 month’s duration)
Kaposi sarcoma
Lymphoma, Burkitt (or equivalent term)
Lymphoma, immunoblastic (or equivalent term)
Lymphoma, primary, of brain
Mycobacterium avium complex or Mycobacterium kansasii, disseminated or extrapulmonary
Mycobacterium tuberculosis of any site, pulmonary†, disseminated, or extrapulmonary
Mycobacterium, other species or unidentified species, disseminated or extrapulmonary
Pneumocystis jiroveci (previously known as “Pneumocystis carinii”) pneumonia
Pneumonia, recurrent†
Progressive multifocal leukoencephalopathy
Salmonella septicemia, recurrent
Toxoplasmosis of brain, onset at age >1 month
Wasting syndrome attributed to HIV§

*Only among children aged <6 years.
†Only among adults, adolescents, and children aged ≥6 years.
§Suggested diagnostic criteria for these illnesses, which might be particularly important for HIV encephalopathy and HIV wasting syndrome, are described in the following references:
CDC. 1996 Revised classification system for human immunodeficiency virus infection in children less than 13 years of age. MMWR 1996;45(No. RR-12).
CDC. 1993 Revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. MMWR 1993;41(No. RR-17).
Figure 1. Subregions of Appalachia
https://www.arc.gov/research/MapsofAppalachia.asp?MAP_ID=31
Table 1. Health Disparities in Appalachia

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<tr>
<td>Bardach, S., Tarasenko, Y., Schoenberg, N. (2011)</td>
<td>Mixed methods: Cross-sectional descriptive study/semi-structured interviews.</td>
<td>Forty-one participants having 2-6 chronic health conditions that required self-management, lived in rural county in Appalachian Kentucky, average age 63 years</td>
<td>Explore how vulnerable resident described social support in the context of self-management for multiple chronic conditions.</td>
<td>Participants perceived great affection and positive interaction with health care provider. In a culture of self-reliance with medicalization lead to less reliance on family members. Participants attempted to meet their own self-management needs. Participants emphasized their self-reliance. Support services were available but participants did not want to utilize them until absolutely necessary.</td>
<td>Small sample size. The evaluation of overall disease burden, health trajectory, or specific disease type could have provided additional information.</td>
<td>None noted.</td>
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<tr>
<td>Chesson, H., Kent, C., Owusu-Edusei, K., Leichliter, J., &amp; Aral, S. (2012)</td>
<td>Cross sectional descriptive study to calculate the incidence of syphilis, gonorrhea, and chlamydia rates in eight regions of the United States</td>
<td>Surveillance data from eight race/ethnicity groups or geographical regions in the United States, including Appalachia.</td>
<td>Examine rates of three sexually transmitted diseases in areas of disparities.</td>
<td>Low-income whites in Appalachia and the Mississippi Valley had lower STI rates than the other seven groups. The highest groups for STIs were in Blacks living in middle America, southern low-income rural blacks and high-risk urban blacks.</td>
<td>Data was surveillance data that could be incomplete. Reported infections were only for those seeking treatment. Groups for the study were only race-county: other groups could have been considered. Rates were quantified across the eight groups but did not examine the reasons for the disparities.</td>
<td>None noted.</td>
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<tr>
<td>Christian, W., Hopenhayn, C., Christian, A.,</td>
<td>Survey study</td>
<td>Ninety-two health department</td>
<td>Identify correlates of exposure to</td>
<td>Those participating included: more</td>
<td>Used the HBsAg, as the marker for</td>
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<tr>
<td>McIntosh, D., Koch, A. (2010)</td>
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<td>clients from four health departments located in the Kentucky River Area Development District. The sample was screened serologically for the HCV antibody, Hepatitis B surface Antigen.</td>
<td>Hepatitis B and C viruses and investigate risk factors associated with transmission and the frequency of use of preventive measures.</td>
<td>men than women, those older than 30 years of age. Twelve out of 80 participants (15%) tested positive for previous exposure to Hepatitis C. No one was HIV positive. Positive test results were significantly associated with injecting drugs, having sex with injecting drug users (IDUs), having sex with someone known or suspected to have hepatitis, and having tattoos or body piercings from somewhere other than a tattoo parlor. Eight of the 14 IDUs were found to be</td>
<td>HBV, should have tested for the hepatitis B core total antibody. Twenty-five percent of those testing positive for HCV did not participate in the study. Small number of participants.</td>
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Table 1. Health Disparities in Appalachia

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<tbody>
<tr>
<td>Coyne, C., Demian-Popescu, C., &amp; Friend, D. (2006).</td>
<td>Qualitative study using ten focus groups</td>
<td>Purposive sample of 10 focus groups in southern West Virginia (five groups of men and five groups of women). Age 35 or older, lived most of their life in West Virginia, and have parents and grandparents born and reared in the state. Thirty-one women and 30 men participated in the study. Forty-five were White and 16</td>
<td>Examine social and cultural factors that may be associated with health and illness in the Appalachian region.</td>
<td>Both men and women in the focus groups have a sense of place, strong family ties, and strong spiritual belief for faith in God. Patriarchy as a cultural value was not a strong factor. Health beliefs are strongly related to religious beliefs and practices. Those living in the region have low levels of medical knowledge and many keep</td>
<td>Inclusion of participants from only a small region of Appalachia. Cannot reply on dated scholarly or popular literature that portray stereotyped Appalachian characteristics and culture or overgeneralize attitudes and beliefs that may apply to a subgroup of people.</td>
<td>West Virginia University Prevention Research Center.</td>
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<td></td>
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<td>were African American</td>
<td>discussions regarding physical and mental health issues within the family. Many health problems affecting the people in the region are related to health behaviors. Some folks distrust physicians and question the quality of care they receive. Expressed concern about a lack of Americanborn physicians in their geographic area and high turnover of physicians. Finding affordable health care is a barrier. Many do not have health insurance.</td>
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<tr>
<td>Denham S., Meyer, M., Toborg, M., Mande, M. (2006)</td>
<td>Qualitative study using focus groups</td>
<td>Fifty-two focus groups (469 individuals) from 24 Appalachian counties and one independent city in 10 states</td>
<td>Explore questions about culturally sensitive health education in Appalachia and use findings to develop health education materials</td>
<td>Family unit plays a central role in the health of family members. Women play a major role in maintaining health among family members. Men preferred succinct factual statements and pictures to words in conveying health messages. Children and youth preferred concrete to abstract messages. Talking about health problems was seen a valuable. Lack of recreational activities.</td>
<td>Findings cannot be generalized to other populations.</td>
<td>None noted</td>
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<tr>
<td>Fletcher, C., Slusher, I., &amp; Hauser-Whitaker, M. (2006)</td>
<td>Community assessment-conducted by Bureau Health Ministry Rural Health Clinic.</td>
<td>Nine counties in Appalachia Kentucky covering 2,180 square miles.</td>
<td>To assess the health care needs of individuals living in an area noted for health care disparities</td>
<td>Approximately 25% of the residents were living in poverty. Primarily Euro American and African American. 30,392 resident are without health insurance. Physician to patient ratio was 1:2500. High incidence of heart disease, cancer, diabetes, hypertension, COPD. Dental health is a significant contributor to unhealthy behaviors. Participants overall preferred one-on-one health information and preferred politeness.</td>
<td>Community assessment limited to 9 counties in Appalachian Kentucky. Assessment was done to support the establishment of a nurse managed rural primary care clinic in the designated area.</td>
<td>None noted.</td>
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<tr>
<td>Gebremarian, G., Gebremedhin, T., Schaeffer, P. (2011)</td>
<td>Used the Feasible Generalized Three Stage Least Squares estimator to analyze data for 418 Appalachian counties.</td>
<td>418 Appalachian counties using data from County Business Patterns, Bureau of Economic Analysis, Bureau of Labor Statistics, Current Population Survey Reports, County and City Data Book, US Census of Population and Housing, US Small Business Administration, and Department of Employment Security.</td>
<td>Examine the determinants of growth in Appalachia between 1990 and 2000.</td>
<td>Counties with high levels of immigration are favorable to employment and employment stimulates additional immigration. Counties with outmigration have characteristics that discourage employment. Increases in the demand for goods and services that result from increases in family income are associated with increases in employment that create opportunities for more people to</td>
<td>None noted</td>
<td>None noted.</td>
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<td>work and earn income. Besides labor, owners of capital and land will earn additional income, further increasing average regional income. There is an indication that the level of employment in one county has a positive spillover effects on neighboring counties but that an increase in income will delay or harm it. Random shocks into the system with respect to employment do not only affect the county but neighboring counties and but affects all of Appalachia.</td>
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## Appendix C

### Table 1. Health Disparities in Appalachia

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<td>Appalachian counties characterized by small-dispersed communities have been losing people during the study period. The outmigration of people mostly young and better educated resulted in the erosion of community income and the property tax bases that provide major sources of revenue to finance local public services. Outmigration of one county is associated with high levels of outmigration and employment in neighboring counties. Owning a house is expected to</td>
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decrease the propensity to migrate due to transaction costs and the illiquidity of real estate in locations of economic distress. Investing in a house may also reflect the decision to stay in the area. Home ownership in Appalachia was positively associated with the level of economic distress during the study period. Home ownership was higher in distressed counties and lower in attainment counties, higher in central Appalachia than in northern and...
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<td>souther sub regions. The average income of the immigrants is lower than the median income of the non-movers. Lower income counties are clustered in Central Appalachia whereas higher income counties are clustered around larger cities in the northern and southern Appalachian subregions. Families headed by female householder have greater opportunities for employment in higher income counties whereas poorer counties there would be</td>
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<tbody>
<tr>
<td>Griffith, B., Lovett, G., Pyle, D., Miller, W. (2011)</td>
<td>Cross-sectional descriptive study.</td>
<td>1, 576 adults from rural Appalachia who attended a West Virginia State Fair blood pressure screening booth.</td>
<td>Evaluate the self-rated health of Appalachian adults in relation to their objective health status and current health behaviors.</td>
<td>Seventy-four percent of the Appalachia adults described their health as good. Many demonstrated a high prevalence of hypertension, obesity, inactivity, and poor nutrition. Over half had multiple indicators of poor health.</td>
<td>Only individuals attending the state fair and visited the blood pressure screening booth were included in the study.</td>
<td>None noted.</td>
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<tr>
<td>Haaga, J. (2004).</td>
<td>Retrospective study examining demographic, social, and economic levels and trends in the Appalachian region</td>
<td>Data from the decennial censuses of 1990 and 2000.</td>
<td>Show how and why the age structure of the Appalachian population differs from the national average and varies within region. Discuss the implications for the region.</td>
<td>In 2000, 14.3 % of Appalachian residents were age 65+ compared with 12.4 % of all U.S. residents. Northern Appalachia had the oldest population. Pennsylvania and West Virginia ranked 2nd and 3rd with Florida.</td>
<td>found a disconnect existed between perceived health and actual health. Suggested that some health issues may not be perceived as poor health among those living in Appalachia until the conditions limit functional limitations.</td>
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<tbody>
<tr>
<td>Halverson, J., &amp; Bischak, G. (2008)</td>
<td>Retrospective descriptive study</td>
<td>Data analysis of death certificates, population count data, socioeconomic data from 1995-2001.</td>
<td>To investigate associations between measures of socioeconomic condition and rates of premature</td>
<td>Suggested statistically significant associations between socioeconomic indicators and premature heart</td>
<td>There was dependence on the overall mean in the distribution of socioeconomic measures and rates of</td>
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being 1st. The major reason for the difference in the age structure between Appalachian population and all of the U.S is the net out migration of young adults from Appalachia to other parts of the country and the low share of immigrants. High poverty rates among elderly people living alone are problematic in the Appalachian region.
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|       |        |        | mortality for leading causes of death in the United States, specifically focusing on the Appalachia region. | disease mortality in Southern Appalachia, Central Appalachia, and western U.S. counties in the western U.S. that share socioeconomic characteristics. Found that Southern and Central Appalachia do not experience comparable rates of mortality, except Southern Nevada. Suggested that national distribution of premature mortality rates are dominated by Southeastern U.S and Central Appalachia. Contributing factors include | premature mortality. More localized analyses with more constrained geographic areas is needed. Other key factors than socioeconomic factors need to be analyzed. Need to apply geographically weighted regression analysis to develop a multivariate analysis of health disparities to provide more complete geographic coverage to determine local levels of associations. | }
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<tr>
<td>Halverson, J., Ma, L., &amp; Harner, E. (2004)</td>
<td>Compile standardized, baseline information</td>
<td>Appalachian region</td>
<td>Compile standardized, baseline information regarding health disparities in</td>
<td>Variability across the regions of Appalachia. First analysis found in the</td>
<td>In general Appalachian</td>
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<td>regarding health disparities in the</td>
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<td>Aim of study</td>
<td>literature involving a regional review of mortality, morbidity, and</td>
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<td>Appalachian region</td>
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<td>behavioral risks in the approach to disparities research. There is a lack of</td>
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- low levels of income, high poverty rates, high unemployment, and high numbers of uninsured.
- Premature cancer mortality is principally in central and southern portions of Appalachia.
- Specific causes of death are heart disease, cancer, cerebrovascular disease, motor vehicle accidents, chronic obstructive pulmonary disease (COPD), diabetes, accidental deaths, suicide, and infant mortality.
- In general Appalachian
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<td>region lagged economically from other parts of the United States. Non-metropolitan areas of Appalachia less diversified economies, lower per capita incomes, and less access to medical care than metropolitan areas in Appalachia. Appalachian counties continue to lag behind much of the country in educational attainment. Appalachia has a higher prevalence of negative behavior risks: higher obesity, higher smoking rates, higher rates</td>
<td>morbidity data for more extensive analysis. The direct role of socioeconomic condition in influencing health disparities is not clear.</td>
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<tr>
<td>Hanson, M., &amp; Resick, L. (1990)</td>
<td>Ethnographic study (looking at the lifeways of a culture) using semistructed interviews.</td>
<td>Representative convenience sample of five mothers, less than 30 years of age from an Appalachian mountain community</td>
<td>Discover prevailing health beliefs of Appalachian mothers.</td>
<td>Mothers did not perceive themselves to be highly susceptible to common illnesses except colds, flu, cancer and complication of pregnancy. Seriousness of an illness was</td>
<td>None noted</td>
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<td>described in terms of varying degrees of dependency on others and how it affects the individual’s functioning. Mothers perceived benefits from action taken were contingent on the seriousness of the illness and the availability and personality of the health care provider. Preventive actions included keeping body strong, drinking fluids, and eating right. There were barriers to health care such as access to communications and transportation,</td>
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<tr>
<td>Havens, J., Lofwall, M., Frost, S., Oser, C., Leukefeld, C., Crosby, R. (2013)</td>
<td>Cross sectional correlation study.</td>
<td>Three hundred eighteen injecting drug users recruited using a respondent sampling that resided in Appalachian</td>
<td>Determine factors associated with Hepatitis C infection among rural Appalachian drug users. Interested in the</td>
<td>The prevalence of Hepatitis C infection (&gt;50%) in this cohort of Appalachian IDUs was greater than that of the general population.</td>
<td>Measured only exposure to hepatitis C virus. Data is cross-sectional and thus no conclusions can be made regarding the</td>
<td>National Institutes of Health, National Institute of Drug Abuse, National Institute of Nursing Research, and the Royal Society</td>
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<td>Kentucky and used one drug to get high in the prior 30 days. Over half were male and graduated from high school education. Ninety four percent were white with a median age of 31 years. Over half had HCV with 61.7% having injected prescription drugs.</td>
<td>correlates for HCV infection in Appalachian drug users.</td>
<td>Specialized medical treatment for HCV infection was limited in Appalachian Kentucky. The rural IDUs are at a higher risk for HIV/AIDS. Sharing of needles contributed to the being HCV positive. Those injecting for more than 5 years had 3 times the odds of being HCV infected. Two forms of lifetime substance injection were independently associated with HCV infection: injecting prescription opioids and injecting cocaine. Cocaine injectors</td>
<td>directionality of the reported associations.</td>
<td>Wolfson Research Merit Award.</td>
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<tr>
<td>Hendryx, M. (2008)</td>
<td>Non-experimental, retrospective analysis of Counties from all 13 states that constitute Appalachia.</td>
<td>Compare rural Appalachian counties to other rural areas of the same</td>
<td>Rural Appalachian counties were significantly more likely than non-cocaine injectors to have a longer duration of injecting behavior. None of the IDUs were HIV seropositive. Many of the IDUs were socially isolated that could have been the reason of not being HIV infected. PSTD decreased the odds of HCV infection by 65% suggesting that those with PTSD were more withdrawn from other drug users and drug using networks.</td>
<td>Reliance on countywide shortage designations.</td>
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<tr>
<td>Hutson, S., Dorgan, K., Phillips, A., Behringer, B. (2007)</td>
<td>Community based participatory approach that includes focus groups.</td>
<td>Twenty-two lay community members (12 in northeastern Tennessee and 10 in southwestern Virginia)</td>
<td>Review regional findings about cancer disparities in Appalachia</td>
<td>Four major themes: 1) Cancer storytelling: cancer stories appeared to be trapped in rural mountainous communities, spreading within and between families and influencing perceptions of health, healthcare and cancer in Appalachia, 2) Cancer collectivism: cancer experience affected everyone</td>
<td>Majority of work group members were white, middle class, English speaking individuals with high motivation for participating in research.</td>
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</table>
Table 1. Health Disparities in Appalachia

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<tr>
<th>Study</th>
<th>Design</th>
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<th>Aim of study</th>
<th>Findings</th>
<th>Limitations</th>
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<td>in the community especially the families. Rural families and communities rely on each other, 3) healthcare challenges: participants were doubtful about their abilities to access, navigate, or trust the health care system and felt invisible to the healthcare system, 4) cancer expectations—Appalachian communities have a lower expectation of the cancer care provided in the healthcare system—there was a sense of despondency within the communities regarding</td>
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<tr>
<td>Huttlinger, K., Schaller-Ayers, J., &amp; Lawson, T. (2004)</td>
<td>Descriptive survey</td>
<td>922 households (2,188 participants) in Southwest Virginia. Random sample from 16 rural and urban municipalities in coal producing counties. Average age was 54 years. 90% of participants had health coverage.</td>
<td>Survey households with regards to availability, need, and access to health care services</td>
<td>Participants voiced need for free or low cost primary health care, dental, vision, and specialty healthcare. Participants were generally satisfied with their health care provider. Many participants were dealing with depression at home, and were sharing</td>
<td>Difficult to generalize the findings in this study with other areas of Appalachia. Difficult to generalize the findings were related to the Appalachian culture.</td>
<td>Graduate Medical Education Consortium of southwest Virginia.</td>
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standard of care for cancer. There exists a traditional subculture in Appalachia that believes cancer and cancer treatment are always fatal.
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<tbody>
<tr>
<td>Kluhsman, B., Bencivenga, M., Ward, A., Lehman, E., Lengerich, E. (2006)</td>
<td>Quantitative retrospective study analyzing data collected through the Community Coalition Action Theory model.</td>
<td>Eleven rural Appalachian Cancer Coalitions in Pennsylvania and New York.</td>
<td>Describe a model based data system and the data of 11 rural cancer coalitions in Pennsylvania and New York collected from 2002-2004.</td>
<td>The partnership of coalitions and academic researchers greatly enhanced the potential to reduce the cancer burden in this rural Appalachian population. Combined resources and intervention strategies of the 11 coalition members and their partners can improve health outcomes and</td>
<td>Validity and reliability of the coalition data system have not been formally tested. Data system was developed from an established community based intervention model. Community change was infrequently reported. Possibly</td>
<td>Partially sponsored by grants from National Cancer Institute.</td>
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<td>Lane, N., et al (2012)</td>
<td>Indexes used: CMS Medicare Hospital Wage Index, 2005: Percentage of Persons under 65 who report having health</td>
<td>Development of an index that would consistently measure healthcare access and cost disparities of Appalachian counties have more healthcare cost, coverage, and access disparities than their respective states or the</td>
<td>lead to sustainable community change. The 11 coalitions and their academic partners were able to achieve more through their participatory partnership than any one coalition or research team alone.</td>
<td>underestimated the true number of community changes that resulted from the 11 rural coalitions. Cannot be generalized to other populations. Population was mostly rural and white. Need to establish external validity to non-rural and diverse racial and ethnic groups.</td>
<td>Appalachian Regional Commission</td>
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<td>Study Design</td>
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<td>insurance, 2007; Acute short term hospital bed, primary and specialty physician and dentist supply, 2007.</td>
<td>the Appalachian Region compared with the rest of the United States.</td>
<td>United States average. Health care payment and health care resources for counties in the Appalachian region are worse than all counties in the United States. Insurance coverage in the Appalachia region is slightly better due to high Medicare Disability enrollment and high Medicaid participation. Residents of Appalachian counties die younger from preventable causes. At the county level some areas with high insurance had low resource access and cost scores,</td>
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Table 1. Health Disparities in Appalachia

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<td>indicating that health insurance coverage alone is not the key to good care access, but access to healthcare resources may affect preventable mortality. Where there is economic distress, there is poor health and factors associated with less access to healthcare. Study suggested that there might be another factor beyond the combined impact of socioeconomic status and health system characteristics associated with access, cost and coverage that accounts for variations in preventable</td>
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<td>morality in Appalachia. Most of the Appalachian region had high Medicare expenditures per capita in 2009. In central and southern Appalachia as much as 15.6% of the population received Medicare Disability payments. Military veterans, particularly the central region and western Pennsylvania were among the highest users of the Veterans Health Association services.</td>
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<tr>
<td>Lengerich, E., et al. (2005)</td>
<td>Non experimental descriptive study</td>
<td>Using 1994-1998 data from central registries of Kentucky, Pennsylvania, and West Virginia (three contiguous states) age adjusted incidence rates were calculated for rural and non-rural regions of Appalachia. The state rates were compared to rates from the Surveillance, Epidemiology, and End Results (SEER) program for the same years.</td>
<td>Characterize cancer incidence in Appalachia, particularly in the rural region. Estimate Appalachian cancer incidence by stage and site and to determine if incidence was greater than in United States.</td>
<td>From 1994-1998 the incidence for all cancers in the Appalachian region was 471.7/100,000. The rural and non-rural regions of Appalachia had similar rates. Rural regions had a lower rate of local stage cancer but had a higher rate of unstaged cancer. Rural regions had a higher rate of lung cancer than non-rural regions. Rural regions had a lower rate of colon cancer, rectal cancer, breast cancer and cervical cancer than non-rural regions but had a higher rate of unstaged cancer. Compared to United States.</td>
<td>Designation of rural status was made at county level, which may introduce mis-classification of individual cases. Demographic differences were observed between the Appalachian population and the SEER reference population. Appalachia has a lower percentage of persons of other races. Analysis was conducted with data from three contiguous states. Age adjustment used the 2000 United States Census.</td>
<td>National Cancer Institute CA86096</td>
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<tr>
<td>McGarvey, E., Leon-Verdin, M., Killos, L., Guterbock, T., Cohn, W. (2011)</td>
<td>Telephone survey using a questionnaire that collected data regarding seven socio-demographic</td>
<td>Appalachian residents: 59.5 % were female, 90.5% were white, 31% had a high school</td>
<td>Investigate the health perceptions of community residents in Appalachian communities</td>
<td>SEER, the incidence of lung cancer, colon, rectal cancer, and cervical cancer were higher in Appalachia. The rate for each local stage and unstaged disease were higher in Appalachia than in SEER. Findings suggested that rural residents diagnosed with cancer might not have received comprehensive diagnostic or treatment services.</td>
<td>(U.S) population standard rather than 1970 population standard. The 2000 U.S. standard weights older age groups more than in the past.</td>
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<td>items, eight health related items, personal health status, health perceptions, and health care utilization.</td>
<td>education, 88.6% had health insurance, and 32.9% had an income of $15,000-$34,999. Non-Appalachian residents: 60% were female, 80% were white, 22.3% had at least a high school education, 86.9% had health insurance, 22.2% had an income of $50,000-$74,000. Conducted in the state of Virginia.</td>
<td>related to their health status and health care utilization compared to those who did not live in the Appalachian counties of the same state.</td>
<td>hypertension. The probability of having a chronic disease was not significantly higher for those living in Appalachia but it was higher for black residents overall. The Appalachian counties were not significantly more likely to report having a chronic disease than those living in non-Appalachian counties. No significant differences in the number of chronic diseases per person. Individuals living in the Appalachian counties reported their general age, while the stated median age is 36 years. Need a more diverse race/ethnic population. Those with fewer barriers with talking with strangers about health participated in the study.</td>
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<td>health as significantly worse, poor or fair. Perception of health was worse for those with a chronic disease. White respondents reported higher rates of good or excellent perception of health. Health care utilization depends on education level, race, having a chronic disease but not by living in Appalachian counties or other counties. Black respondents reported greater use of the emergency room for health care.</td>
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<tr>
<td>Tessaro, I., Mangone, C., Parkar, I., Pawar, V. (2006)</td>
<td>Twenty-three focus groups and a self administered survey</td>
<td>Two hundred five church members from 16 Appalachian churches in the Ohio Valley region of West Virginia that participated in 23 focus groups. 62% were women, 87%</td>
<td>Examine the knowledge about and barriers to colorectal cancer screening and predictors of screening adherence.</td>
<td>Age was found to predict colorectal screening with rates higher for individuals aged 65 to 74 years. Men were more likely to get screening, as some women participants felt that doctors were Study did not present all churches in West Virginia as churches with at least 100 active members were recruited for the study. The church members in the</td>
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<td>Grant U57/CCU320638 from the Centers for Disease Control.</td>
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<tbody>
<tr>
<td>Wewers, M., Katz, M.,</td>
<td>Descriptive study of the prevalence</td>
<td>The 29 counties of Ohio that are</td>
<td>Describe the prevalence of colorectal cancer screening</td>
<td>less attentive to older women’s health. More health conscious individuals and a family health history of colorectal cancer. Were more likely to be screened for colorectal cancer. Health care provider communication was shown to be an important predictor of screening. People knew little about screening recommendations. Many relied on their physician for advice about which test to have and when to have them.</td>
<td>study were the active members of their churches. The colorectal screening data was self reported and not verified by health records. Most individuals had health insurance to cover the cost of screening.</td>
<td>National Institutes of</td>
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<td>part of the Appalachian region. The 20 Ohio counties with the lowest median household incomes were all in the Appalachian region and 19 of the 20 counties have the highest poverty rates. Twenty-two percent of the Ohio Appalachian residents had no high school diploma, four of the 29 counties were classified as distressed counties, and another six were described as “at risk” counties. There were 32 hospitals in the region with 1723 physicians for risky behaviors (tobacco use, obesity, poor diet, physical inactivity, sexual behaviors) known to be associated with increased cancer morbidity and morality among Ohio Appalachian adults.</td>
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<td>proportion of current smokers in Ohio Appalachian counties was 31.5% compared with 26.2% of non-Appalachian Ohio counties. The Ohio Behavioral Risk Factor Surveillance System in 2003 found that 73.6% of Ohio residents participated in any type of physical activity during the past month compared with the national rate of 76.9%. Adults aged 18 years and older living in Appalachian Ohio had higher rates of obesity 23.4% compared with 22.3% of non-Appalachian Ohio counties.</td>
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<td>estimates were used in this study. Need to understand the role of social and contextual variables to understand the risky behaviors.</td>
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Appendix C

Health, National Cancer Institute, National Institute for Nursing Research and University of Kentucky.
Table 1. Health Disparities in Appalachia

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<th>Appendix C</th>
<th>Prevalence data on risky sexual behaviors in Ohio Appalachia is not readily available. The West Virginia 2003 Youth Risk Behavioral Surveillance System reported more female high school students in West Virginia reported having had sexual intercourse 54.9% vs. 43.6% nationally, having had sexual intercourse before age 13 years (W.V 4.3% vs. 3.5% nationally), having had sexual intercourse with 4+ partners (W.V 16.6% vs. 34.1% nationally), and having had sexual intercourse with 1+ partners within last 3 years.</th>
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more than 1.4 million residents. There were 200,000 uninsured Ohio Appalachian residents. Sixty-five percent of the Appalachian counties were designated as health professional shortage areas.
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<tbody>
<tr>
<td>Akers, T., Heckman, T., Hotgrave, D., Yarber, W. (2003)</td>
<td>Work group meeting</td>
<td>Seventy participants from 13 states that are within the geographic region known as Appalachia and other national organizations that have a vested interest in HIV/AIDS epidemic</td>
<td>Discuss with a diverse group of participants from 13 states within the geographic region known as Appalachia the HIV/AIDS epidemic in Appalachian region and to determine the unique characteristics in assessing the HIV/AIDS epidemic, surveillance needs, evaluation techniques, prevention strategies, creating organizational and community capacity and strengthening and integrating prevention, need to identify Appalachian cultural issues, identify geographical barriers within Appalachia, identify funding barriers and resources for Appalachia, generate quality data for HIV in the Appalachian regions, have more integrative HIV/AIDS prevention-care research in the Appalachian region, and identify the types of risk groups to consider within the Appalachian region. Need for</td>
<td>Need to identify Appalachian cultural issues, identify geographical barriers within Appalachia, identify funding barriers and resources for Appalachia, generate quality data for HIV in the Appalachian regions, have more integrative HIV/AIDS prevention-care research in the Appalachian region, and identify the types of risk groups to consider within the Appalachian region. Need for</td>
<td>No one story of AIDS in Appalachia, a diverse region. Data was generated from the participants in the work group meeting. Those with an interest HIV/AIDS attended the meeting and might not have been representative of those affected by HIV or living with HIV infection while residing in Appalachia</td>
<td>None noted.</td>
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<tr>
<td>Bletzer, K.</td>
<td>Dual case study analyzing life</td>
<td>Fifteen individuals living with HIV/AIDS in rural south. 10 individuals were African American.</td>
<td>Explore life reorganization and change in self-identity after receiving a reactive test for HIV/AIDS. Explore how HIV/AIDS differs from other medical conditions that can disrupt life.</td>
<td>The self was not weakened by HIV/AIDS. Adulthood was constructed in relation to family background. The world of their illicit drugs fell outside of their family. Both described their self-sufficiency. Orientation to time occurs through the outcome of their current activities. Each constructed a new life after their HIV/AIDS. Each reconstructed a sense of personhood living with HIV/AIDS by immersion in</td>
<td>None noted</td>
<td>Fieldwork-Wenner-Gren Foundation for Anthropological Research, College of Liberal Arts and Science, Arizona State University.</td>
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<tr>
<td>Boehme, A., Moneyham, L., McLeod, J., Walcott, M., Wright, L., Seal, P., Mugavero, M., Norton, W., &amp; Kempf, M. (2012)</td>
<td>Focus groups</td>
<td>Four focus groups of women living with HIV recruited from four HIV service organizations from 23 rural counties in south Alabama</td>
<td>Explore the patient/provider relationship from the perspective of women living with HIV</td>
<td>Attributes wanted in health care providers: caring, nonjudgmental, active listener, communicative, closeness, knowledge regarding HIV. Negative attributes: non-caring, disrespectful, lacked courtesy, lacked interest, judgmental or stigmatizing condescending attitude.</td>
<td>Limited to women living with HIV in rural south. Limited to women engaged in care. Need to include individuals living with HIV not in care.</td>
<td>None noted.</td>
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<tr>
<td>Foster, P., &amp; Gaskins, S. (2009)</td>
<td>Four focus groups. Participants completed Self Perception of HIV Stigma, Stigma Impact of</td>
<td>African American men and women over the age of 50 years with confirmed diagnosis of HIV/AIDS.</td>
<td>Explore stigma experiences of older African Americans living with HIV/AIDS.</td>
<td>Reported they rarely or did not experience stigma. They did experience stigma on the internalized shame scale.</td>
<td>Limited to sample of older African Americans living with HIV/AIDS. Stigmatized</td>
<td>Faculty Seed Grant from the Center for Mental Health and Aging; University of Alabama.</td>
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<td>HIV, and socio-demographic questionnaire</td>
<td>HIV/AIDS living in the deep south in the United States</td>
<td>Participants most likely to disclose HIV status to family members. Participants used non-disclosure or selective disclosure to manage and decrease experiencing stigma. Always worried about experiencing stigma, especially in rural areas. Many went to larger cities for treatment. Felt education decreased likelihood of experiencing stigma. Spirituality was part of embracing their disease and giving hope.</td>
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<td>individuals less likely to participate. Mode of transmission was not discussed and could influence perceived stigma. Wide range in time since diagnosis</td>
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<tr>
<td>Gaskins, S., Foster, P., Sowell, R., Lewis, T., Gardner, A., Parton, J. (2011)</td>
<td>Descriptive exploratory method using an interview for data collection</td>
<td>Forty men living with HIV/AIDS. Age 22 -49. Living in rural Alabama. 72.5% were high school graduates. Earned less than $10,000.</td>
<td>Explore reasons African American men living in a rural area of Alabama choose to disclose their infection with HIV</td>
<td>Reasons to disclose: relieve stress, need to tell, help others, to receive support. Disclosure strengthened family relationships. Disclosed to sexual partners but not to anonymous casual partners. Reasons to not disclose: fear of stigma, fear of others being told, belief that no one needed to be told, not ready to tell, didn’t want to burden others.</td>
<td>None noted</td>
<td>None noted</td>
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<tr>
<td>Hall, H., Li, J., McKenna, M. (2005)</td>
<td>Analysis of Centers for Disease Control (CDC) HIV/AIDS</td>
<td>Men and women reported to be living with HIV/AIDS living in areas</td>
<td>Determine the burden of HIV/AIDS in four rural or distressed geographic areas of United States.</td>
<td>Crude rate of new HIV diagnosis were higher for Mississippi Delta and lower for US-Mexican border</td>
<td>Data was limited to 29 states that had confidential reporting since 1999.</td>
<td>None noted</td>
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### Table 2 HIV/AIDS in Appalachia

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<tr>
<td>Reporting System</td>
<td>of Appalachia, Mississippi Delta, Southeast United States, and United States-Mexican Border.</td>
<td>and Appalachia. Majority diagnosed with HIV were men. A larger proportion of men in the Southeast region were exposed through heterosexual transmission. Most women were infected through heterosexual transmission however 1/3 of women at US-Mexican border were injecting drug users. Rates for new AIDS diagnosis were lower for rural areas. Rural residents less likely to seek HIV testing. 33%-50% of rural sexually active individual with HIV/AIDS</td>
<td>Completeness of AIDS reporting has been found to be 85% or greater. Potential differences in completeness of data by region are unknown. Possible misclassification of race/ethnicity of individuals.</td>
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<tr>
<td>Kempf, M., McLeod, J., Boehme, A.,</td>
<td>Descriptive qualitative study</td>
<td>Forty women: 37 African American and 3 Caucasian, age range of 29-69, living in Alabama. Average years living with HIV/AIDS was 8.8 years.</td>
<td>Generate detailed descriptions of HIV care experiences, described barriers and facilitators of adherence to clinic appointments.</td>
<td>Facilitators to care: patient-provider relationship, friendly faces, caring, respectful, women’s concern for their own health, appointment reminders, organized transportation, organization and management of clinic, empathy for peers, family relationships. Barriers to care: stigma, fear of being seen entering the clinic, childcare, work schedules, current health condition, legal matters.</td>
<td>One focus group had 16 women. Women in study were currently in care. Women lost to follow up were not included. 92% were African American and 77% were over age 40.</td>
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<tr>
<td>Walcott, M., Wright, L., Seal, P.,</td>
<td>Focus groups</td>
<td>Focus groups included</td>
<td>Describe various aspects of</td>
<td>Need for improved communications</td>
<td>None noted</td>
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<td>Norton, W., Schumaker, J., Mugavero,</td>
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<td>Study</td>
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<td>Woodman, D. (2008).</td>
<td>administrators of 7 regional HIV planning coalitions in Pennsylvania, state officials from the HIV/AIDS Bureau and the Pennsylvania Department of Health, and 20 states that were self-selected with similar characteristics to Pennsylvania, and referrals through exemplary programs from national experts</td>
<td>HIV/AIDS service delivery system in Pennsylvania and describe and categorize the perceptions of HIV/AIDS service providers, regional planners, and administrators.</td>
<td>between Pennsylvania Department of Health and the seven regional planning coalitions. Need for specialized HIV medical care and transportation for people living with HIV/AIDS. Improved access to mental health services in rural Pennsylvania. Need to adapt a continuum of care model that is sensitive to needs of rural Pennsylvanians living with HIV. Improved access to HIV data from Pennsylvania Department of Health. Need for the seven regional HIV planning coalitions, with</td>
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Table 2 HIV/AIDS in Appalachia

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<td>their dissimilarities, to adopt more comparable structures to achieve greater efficiency between coalitions. Need for non-governmental analysis of health related data. Interventions to reduce chronic disease should be community based and participatory because of the distinct, heterogeneous communities in Appalachia. Few evidence-based approaches have been developed or evaluated with the characteristics of the Appalachian populations in mind.</td>
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<tr>
<td>Lansky, A., &amp; Steinberg, S. (2003)</td>
<td>Cross sectional non-experimental study analysis of surveillance data of cumulative AIDS cases.</td>
<td>19, 222 persons aged &gt; 13 years from the Appalachian region diagnosed with AIDS between 1981 through December 2000.</td>
<td>Compare cumulative cases for Appalachia and the United States overall.</td>
<td>Incidence rate (cases per 100,000 population) for Appalachia was 6.0. The incidence rate per 100,000 for each subregion: South 8.4, Central 2.0, North 4.5. Largest proportion of cases was among men who had sex with men. Cases in women in the South and Central region were attributed to heterosexual contact (65% and 61% respectively). A large proportion of cases among women in the North subregion were attributed to injecting drug use (43%). Largest proportion of cases in each subregion was</td>
<td>The heterogeneity of the AIDS epidemic encompasses rural areas as well as urban areas (e.g., Pittsburgh). The epidemics in the rural and urban areas of Appalachian regions may have different demographic characteristics and different challenges in providing HIV care and treatment services. Need for information for risk behaviors cultural beliefs are important in addition to surveillance data.</td>
<td>None noted</td>
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<tr>
<td>Study Design</td>
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<tr>
<td>Exploratory study, non-experimental using interviews</td>
<td>Ninety-seven current and former methamphetamine users from the Cumberland Plateau area, a rural</td>
<td>To document the existence of known high-risk HIV related behaviors among rural methamphetamine users and to discern the perceptions of the</td>
<td>High-risk behaviors related to HIV/AIDS in a rural Tennessee. Meth-amphetamines were easier to obtain than</td>
<td>None noted. Conducted in Tennessee among individuals in treatment. Sample did not include</td>
<td>Professional Development Award, University of Tennessee Provost’s Office.</td>
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### Table 2 HIV/AIDS in Appalachia

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<td>mountainous region in Tennessee. 89% were Caucasian, 86.6% were heterosexual, 90.8% had household incomes below $30,000, 36% had full time employment, 55.7% were male. Average age was 30.8, 46.4% were married or living with a partner, 79% were native to Tennessee.</td>
<td>impact of methamphetamines and the needs for services among the population.</td>
<td>marijuana. Rural areas less equipped to handle meth epidemic. Impact of meth use in rural areas: ruined life, negative impact on children and families, and increase strain on law enforcement. 73.2% reported access to substance abuse treatment. Expressed need for targeted drug treatment for meth users. Need for education, HIV testing, and access to condoms and clean needles. 87.6% reported high-risk sexual behaviors and chose not use condoms. Reported trading bodies for meth</td>
<td>individual not in treatment.</td>
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<td>Moon, T., Vermund, S., Tong, T., &amp; Holmberg, S. (2001).</td>
<td>Interviews</td>
<td>211 women living with HIV/AIDS residing in rural Mississippi and Alabama. 67% were African American, mean age was 33 years, estimated mean age of HIV/AIDS was 28.5 years, 50% were single, 73% had a high school education, 80% were unemployed, 85% had an income of less than $12,000/year</td>
<td>Identify opportunities and the effectiveness of HIV prevention for rural women before HIV/AIDS and medical and social services offered to women.</td>
<td>Before HIV/AIDS 37% reported being seen at a HIV testing site. 30% received risk reduction counseling. When diagnosed with HIV/AIDS individuals were not directed to HIV treatment. Drugs of choice included crack/cocaine, High-risk behaviors injection drug use, sharing needles, and trading sex for drugs.</td>
<td>Some of the women might not have recalled being counseled or referred to services. Unable to determine “missed opportunities” in primary prevention.</td>
<td>None noted</td>
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<td>Phillips, K., Moneyham, L., Thomas, S., Vyavaharkar, M. (2001)</td>
<td>Phenomenological study</td>
<td>280 women living with HIV/AIDS living in rural areas of South Carolina, Georgia, and Alabama. 82% were single, 845 were African American. Age range was 18-66. Half lived in small towns and half lived in rural routes</td>
<td>Meaning of living with HIV/AIDS in isolated, impoverished circumstances in southeastern United States (U.S.)</td>
<td>Struggle with loss and depression related to HIV/AIDS. HIV/AIDS didn’t dominate their existence but places more demand of their efforts and energy. Instability is normal, stigma and hiding exist in their interpersonal relationships and social systems, experience loss of physical integrity and loved ones, strive for more independence and comfortable depending on others.</td>
<td>Data not obtained directly from women but through written notes of peer counselors during home visits.</td>
<td>None noted.</td>
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<tr>
<td>Preston, D., D’Augelli, A., Kassab, C., &amp; Starks, M. (2007)</td>
<td>Cross sectional study using a mailed questionnaire using mailing</td>
<td>Convenience sample 414 rural men who have sex with men (MSM) in rural areas</td>
<td>Explore the relationship between stigma and high risk</td>
<td>Inconsistent relationship between stigma and mental health variables to sexual</td>
<td>Able to access only men who are most social and who</td>
<td>None noted.</td>
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<td>lists of nonprofit political action group, social recreation group, two AIDS service organizations.</td>
<td>48 rural counties in Pennsylvania. Based on population density of fewer than 274 persons per square mile. 18-76 years of age, 78% had advanced education, 89% were white, 29% had one sexual partner, 52% had multiple sexual partners, and 26% were open regarding sexual orientation.</td>
<td>sexual behaviors of MSM</td>
<td>risk. Suggested risk taking may be a coping mechanism for rural MSM as a way of dealing with stress caused by intolerance.</td>
<td>identified as being gay.</td>
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<td>Sowell, R., Lowenstein, A., Moneyham, I., Demi, A., Mizuno, Y., &amp;</td>
<td>Focus groups and face-to-face interviews.</td>
<td>Eighty-two women identified as residing in rural areas of Georgia. 69% were African</td>
<td>Examine the characteristics of women living with HIV/AIDS in rural communities (demographics, needed resources, Fear of having HIV/AIDS, fear others would find out. Adequate resources, basic needs not always met. Women with</td>
<td>Finding were limited to rural women with access to HIV services</td>
<td>Funded by Centers for Disease Control.</td>
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### Appendix C

#### Table 2 HIV/AIDS in Appalachia

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<tr>
<td>Seals, B. (1997)</td>
<td>American, 72% were single, age range was 15-63 years, 47% did not complete high school, 85% were unemployed, 31.7% had no children, 17% were grandmothers, 21% lived with one other individual living with HIV/AIDS, 50% were infected through heterosexual transmission, 7% injecting drug use, and 17% did not know the source of their infection.</td>
<td>perceptions of stigmatization, and patterns of disclosure.</td>
<td>HIV/AIDS but not AIDS had greater difficulty obtaining resources. 50% of the women felt stigmatized. Reported using public sector entitlement programs but reported having inadequate resources in daily lives. Women with diagnosis of AIDS had great access to resources, but felt ashamed of their illness. Younger women feared blame by others and losing friends. Women feared rejection by their families and their family would be hurt if the community learned of their diagnosis.</td>
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### Table 2 HIV/AIDS in Appalachia

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<tr>
<td>Vyavaharkar, M., Moneyham, L., Murdaugh, C., &amp; Tavakoli, A. (2012)</td>
<td>Cross sectional, correlation study using variables of age, race, and time since HIV diagnosis, perceived stigma, internalized stigma, and depression.</td>
<td>299 rural women living in southeastern United States. Recruited from community based AIDS service organizations (ASOs) from rural areas of South Carolina, North Carolina, and Alabama.</td>
<td>Examine physical, psychological, and social factors associated with quality of life.</td>
<td>African American women reported higher quality of life compared to white women. Those diagnosed with HIV/AIDS after the development of HIV treatment reported lower quality of life scores than those diagnosed before the development of HIV treatment due to experiencing side effects of medication and pill burden. Older aged women had higher quality of life scores as they had less stress.</td>
<td>Cross sectional study limits ability to establish causality. Desirability response operating since all measures depended on self-report. Findings cannot be generalized</td>
<td>NIH-National Institute of Nursing Research.</td>
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Table 2 HIV/AIDS in Appalachia

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<td>Young, A., Jonas, A., Mullins, U., Halgin, D., &amp; Havens, J. (2013)</td>
<td>Cross sectional, non-experimental study using random network generation. Social network data was compiled and calculated using UCInet 6.36 and network visualization.</td>
<td>Respondent driven sampling was used for recruiting hard to reach drug users in a rural setting. Sample included 503 drug-users in a rural county located in Appalachian Kentucky county and having used at least one illicit drug in the past 30 days. 43% were female, 94% were</td>
<td>Describe the risk network structure among high-risk, rural drug users residing in Appalachia in order to determine the potential for HIV transmission as well as the amenability of the network to intervention.</td>
<td>Risk relationships within the network were bidirectional ties representing syringe-equipment sharing (18.7%) and unprotected sex (median number of unprotected sex acts 2-27). 89% of the participants were connected within one large main component of the network. The maximum number of steps between any two members of the main component</td>
<td>Cross sectional data limits ability to make causal inferences. Social networks are dynamic, therefore accounting for relationship timing in disease diffusion. Key network members might not have been captured in the current study due to potential recall and response bias.</td>
<td>National Institute on Drug Abuse.</td>
</tr>
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</table>
Table 2 HIV/AIDS in Appalachia

| White, median age 31 years, and median number of years residing in Appalachia was 29 years. 57% had graduated from high school, 58% were employed. 74% were not married. None were HIV positive. | of the network was 17. On average network members were approximately six steps from any other network member. There was more cohesiveness and centralization than would be expected at random. This could be a protective factor for acquiring HIV/AIDS. Conversely this could be facilitative for HIV/AIDS. | RDS sampling could influence the structural properties of the network. |
To: Renee Gilhousen  
From: Linda Goodfellow, IRB Chair  
Subject: Protocol #2015/08/9 - Approval Notification  
Date: 09/17/2015  

The protocol The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) while Residing in a Rural Region in Northern Appalachia, has been approved by the IRB Chair under the rules for expedited review on 09/17/2015.

The consent form, recruitment flier, demographic form and protocol summary are stamped with IRB approval and one year expiration date. You should use the stamped forms as originals for copies that you distribute or display.

The approval of your study is valid through 09/16/2016, by which time you must submit an annual report either closing the protocol or requesting permission to continue the protocol for another year. Please submit your report by 08/19/2016 so that the IRB has time to review and approve your report if you wish to continue it for another year.

If, prior to the annual review, you propose any changes in your procedure or consent process, you must complete an amendment form of those changes and submit it to the IRB Chair for approval. Please wait for the approval before implementing any changes to the original protocol. In addition, if any unanticipated problems or adverse effects on subjects are discovered before the annual review, you must immediately report them to the IRB Chair before proceeding with the study.

When the study is complete, please terminate the study via Mentor by completing the form under the Continual Renewal tab at the bottom of your protocol page and clicking on terminate. Please keep a copy of your research records, other than those you have agreed to destroy for confidentiality, over a period of five years after the study’s completion.

If you have any questions, feel free to contact me.

Linda Goodfellow, PhD, RN, FAAN  
IRB Chair  
goodfellow@duq.edu
Appendix E

October 29, 2015

RE: Renee Gilhousen IRB request

Dear Ms. Gilhousen:

The Institutional Review Board at Duquesne University has reviewed your approved protocol from Duquesne University (Protocol #2015-8-9, approved 9-17-2015), entitled “The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) while Residing in a Rural Region in Northern Appalachia.” The committee requested additional documentation regarding the length of time and location for storage of informed consents. We are in receipt of this additional documentation. With this additional documentation, the committee is in agreement with the IRB approval granted by Duquesne University. Any changes to your protocol should be reported to the IRB before proceeding with the study.

Good luck on your study.

Best regards,

Chair, IRB
Associate Professor of

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Appendix F
Recruitment Flyer

Invitation to Participate in a Research Study about Living with HIV in Rural Appalachia

You are being invited to participate in a study about what it is like to be living with HIV infection while residing in rural Appalachia. The purpose of this study is to explore and understand the lived experience of individuals living with HIV while residing in rural Appalachia. Finding of this study will add to the knowledge about living with HIV in a rural area with the goal to improve health care to individuals living with HIV in rural Appalachia.

Participants will be asked to allow me to interview you twice and to audiotape both interviews. One $15 gift card to a local convenience store will be provided to all participants as compensation for your time after the first interview.

Because face-to-face interviews will be conducted for this study, participants from this region are being recruited from this study. If you are interested in participating in this study, please contact me by email or phone:

Renée E. Gilhousen, PhD (c), MSN, CRNP, FNP-BC
Doctoral Student
Duquesne University School of Nursing
PhD Program
Appendix G
Protocol Amendment IRB

DUQUESNE UNIVERSITY – INSTITUTIONAL REVIEW BOARD

Protocol Amendment IRB Submission Form

Principal Investigator: Renee E. Gillhousen Protocol #: 2015/08/9

Type of Review Required for Original Submission (exempt, expedited, full board, program evaluation)

Expedited

Date: 4/18/2016

Phone: Home: Cell e-mail:

Protocol Title: The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) while Residing in a Rural Region in Northern Appalachia

Advisor

Lenore Resick, PhD, FNP-BC, FAANP, FAAN Phone:

(In order for the IRB to fully evaluate an amendment to your originally approved protocol, you will need to provide a summary of the modifications you propose below. In addition, please provide your Protocol Summary with any changes highlighted and original consent form if applicable. Note that any modifications to the protocol cannot be implemented until after final IRB Approval is received.)

1. Check all protocol amendments that apply:

☐ Change in Protocol
☐ Inclusion/Exclusion Criteria Change
☐ New Information Provided to Subjects
☐ Therapy Changes
☐ Scientific Changes
☐ Advertisement(s)/Recruitment Letter(s)
☐ HIPAA research authorization forms
☐ Instruments (e.g., questionnaires or surveys)
☐ Change in Title
☐ Change in Investigators (Submit CITI certificate for additional investigators)
II. Attach a description of amendments and anticipated effects on subjects and potential subjects

1. Describe the proposed amendments and explain how they differ from the original approved protocol.

2. Explain why you propose to make the amendments.

3. Describe any anticipated effects on subjects or potential subjects.

4. Include all documents in which wording will be changed in accordance with the amendments (such as consent form, recruitment materials, survey materials. All documents should be submitted in Word if possible).

Duquesne University Institutional Review Board

Title of Proposed Research Project
The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) while Residing in a Rural Region in Northern Appalachia.

Statement of the research questions
What is the lived experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia.

Purpose and significance of the study
The purpose of this research study will be to explore and understand the lived experience of individuals living with HIV/AIDS while residing in a rural region of Northern Appalachia. Past studies identified in a review of literature regarding people living with HIV/AIDS (PLWHA) in Appalachia were conducted in and prior to 2006. None of the studies explored the lived experience of PLWHA and none have explored the perspectives of people living with HIV/AIDS from an emic worldview in a focused rural region in Northern Appalachia. Using a hermeneutic phenomenological approach, the focus of this study will be on understanding the experiences of PLWHA in a rural region in Northern Appalachia. Previous research findings regarding health in the Appalachian region cannot be generalized to PLWHA in rural Northern Appalachia. By identifying themes based on the experiences of PLWHA in rural Northern Appalachia, strategies could be developed and implemented for culturally appropriate nursing interventions to mediate the impact of HIV/AIDS on PLWHA in rural Northern Appalachia. Newly identified knowledge can be used to improve access to specialized HIV/AIDS care and improve outcomes associated with HIV/AIDS disease in rural areas, particularly rural Northern Appalachia, a region known for health disparities. The research findings could lead to future research studies in the Northern Appalachian region.

Research design and procedures
Hermeneutic phenomenology will be used as the method of research to guide this study. Using the Utretch School approach, descriptive and interpretative phenomenology will guide this inquiry seeking to understand the lived experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia. The research will focus on the lived experience of the participants within the context of their experience and the meaning of their experience.

Instruments
A demographic questionnaire (Appendix A) and a semi-structured interview will be used for this study (Appendix B).

Sample selection and size
A regional AIDS service organization (ASO) in Northern Appalachia was identified as a potential setting for
this study because it is where PLWHA receive services. Purposeful sampling and snowballing will be used to
select volunteer participants for this study. Based on recommendations from other phenomenological
research studies, approximately 15 to 20 participants will be needed for this study or until saturation of data
is reached. Once the researcher determines that data saturation has occurred, the researcher will conduct two
more interviews to be assured that data saturation has occurred. Approximately 500 individuals are currently
receiving services at the regional ASO in rural Northern Appalachia. Inclusion criteria will include: an age
range of 18 years of age and older, self-identified as being HIV infected, male, female, or transgender,
unable to speak and understands English, inclusive of persons from all racial/ethnic groups, living in a rural area in
Northern Appalachia, and be willing to participate. The study will not include individuals under the age of 18
years, as the research topic is not related to children.

Recruitment of participants

Purposeful sampling and snowballing will be used to select volunteer participants for this study. Recruitment
will be conducted according to the following plan. Prior to distribution of recruitment flyers (Appendix C), the researcher will meet with the staff of the regional ASO and key individuals within the
HIV/AIDS community, such as consumers and advocates for PLWHA, to discuss the aim of the study and
the recruitment process. The researcher will stress to the staff and key individuals that the research study is
voluntary. The researcher will review the inclusion criteria, and will stress that participants may withdraw
from the study at any time, and will emphasize the need for confidentiality of participants. Written
recruitment flyers regarding the study will be distributed or posted by the researcher, staff members of the
regional ASO, and key individuals on bulletin boards, private offices, and private rest rooms within the
offices of the regional ASO, private meeting places of HIV/AIDS support groups, private offices and clinic
rooms of a rural HIV clinic, and a newsletter published and distributed by the regional ASO. Case managers,
employed at the regional ASO, will share information regarding the study to PLWHA. If interested in
volunteering for the study, the individual living with HIV/AIDS will be instructed to contact the researcher.
The interested participants will also have an option to sign a release of information consent form to allow the
staff at the ASO to share their preferred contact information with the researcher and allow the researcher to
contact the participant. Early participants in the study will be invited to share information regarding the study
to other PLWHA who might have an interest in participating in the study. Individuals living with HIV/AIDS
not receiving services at the regional ASO will also be invited to participate in the study. Consumers, who
access services at the regional ASO, will also have access to recruitment flyers if they are interested in
sharing information with PLWHA about the study. Potential eligible participants will be given a telephone
number to contact the researcher. A second option will allow the potential participant to sign a release of
information consent to allow the staff at the ASO to share their preferred contact information with the
researcher and allow the researcher to contact the participant. If the participant does not have a telephone, the
regional ASO assured the researcher that potential participants would have access to private telephones for
communication with the researcher. During the initial telephone call the researcher will explain the study
with the potential participant and determine if the inclusion criteria are met. The researcher will then
schedule a time and a private setting convenient for the participant to participate in the interview. The
interview will be conducted in a private setting such as a private office at the regional ASO or auxiliary
offices of the ASO, or at a private setting that provides confidentiality and convenience for the participant.
The interview will not be held in a public setting. The door of the private room will be kept closed until the
interview has ended. No information will be audible outside the confines of the private office room where
the interview is conducted.

As a token of appreciation for participating in the study, each participant will receive a token gift in
the form of a $10.00 gift card to a convenience store at the completion of each interview.

Informed consent procedures

Each participant will receive a consent form to read and sign if they agree to participate in the
research study (Appendix D). If unable to read the consent, the consent form will be read to the participant
by the researcher. Included in the consent form are the names of the researcher and her advisor. The
researcher will review with the participant the source of the study and the purpose of the study. The consent
form will provide the participant with the risks and benefits of participating in the study. The consent will
provide information regarding compensation, maintaining confidentiality, and the right to withdraw from the study at any time. The consent will explain how the participant will give consent. Contact information for the researcher and her advisor will be included in the consent form. After signing the consent form, each participant will be given a copy of the signed consent form. In addition to signing the consent to participate in the study, the participant will give verbal consent at the beginning of audiotaping of the interview permitting the researcher to audiotape the interview. If the participant does not give permission for audiotaping, the researcher will stop audiotaping the interview and will use paper and pencil to document the interview information. To maintain the confidentiality of the participants, the audiotapes will be transcribed by a professional transcriptionist who will sign a confidentiality statement (Appendix E).

**Collection of data and method of data analysis**

Data will be collected using a demographic questionnaire and a semi-structured interview conducted by the researcher. The first face-to-face interview will be approximately 1-1 ½ hours in length, being conducted in a private setting as previously described. After obtaining consent from the participant, the interview will be conducted. The participant will be asked to complete a demographic questionnaire (Appendix A). The interview questions will be open-ended to ensure the participant guides the interview. The research will focus on the research question: "What is the experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia?" Probe questions such as "Can you tell me more about that?" (Appendix B) will be used to clarify meaning and encourage conversation. The researcher and the professional transcriptionist will transcribe the interviews verbatim based on available time or availability to do the transcribing as soon as possible after the interview is completed. Following the transcription, the researcher will listen to the taped interview, de-identify the data, and compare it to the typed transcription. Once the researcher verifies the accuracy of the typed transcription, the researcher will begin the analysis of the data. The data will be managed using software NVivo10 and manually. The data analysis method will be congruent with the Utrecht School tradition (Barrett, Beckman, Bloeker, & Mulder, 1984; Cohen, Kahn, & Streeves, 2000, van Manen, 1978, 1984, 1997, 2007). A second interview with the participants will be conducted to clarify the interpretation of the data. The second interview will be conducted in a private setting as previously described. The second interview will be approximately 1-1 ½ hours.

To give fidelity to the study, the researcher will be reviewing the first 2-3 interviews with her dissertation chair to ensure accuracy of coding and identification of themes, clustering and analysis. Independent of each other, the chair and the researcher will review data, assign themes, and clustering of themes. Findings will be compared. Any disagreements will be discussed in person or by telephone. The dissertation chair will also critique the interview technique of the researcher to ensure the interview was conducted appropriately and without leading the participants’ responses.

**Emphasize issues relating to interactions with participants and participants rights.**

Participation in the study will be voluntary. The participants will not be obligated to participate in the study. The participant may withdraw from the study at any time. There is no physical risk from participating in the study outside the risks of normal everyday life. During the interview, if questions cause the participant discomfort, they have the option to not answer the questions or end the interview. If needed the participant will be given names of mental health care professionals in the community to access psychological services. Following the interview, confidentiality of all participants will be maintained by securely maintaining the data in a locked file cabinet in the researcher’s office until the data is destroyed. Participants’ names and identifiers will be encoded using pseudonyms. Upon defense of this dissertation the researcher will retain all de-identified data for any further research studies associated with the current study. The researcher will delete audio sound files and transcripts. Hard copies of the transcripts will be shredded by the researcher using a cross cut shredder in the researcher’s office upon successful defense of this dissertation. Demographic data will be presented in aggregate form only.
Appendix H

Institutional Review Board Annual Report Approval

To: Renee Gilhousen
From: David Delmonico, IRB Chair
Subject: Protocol #2015/08/9
Date: 08/26/2016

The annual report for 2015/08/9. The Lived Experience of Individuals Living with Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) while Residing in a Rural Region in Northern Appalachia. was approved on 08/26/2016.

This approval is valid through 09/16/2017. Please submit your next annual report by 08/19/2017.

If you have any questions, feel free to contact me.

David Delmonico, Ph.D.
Institutional Review Board, Chair
irb@duq.edu
CONSENT TO PARTICIPATE IN A RESEARCH STUDY

TITLE: The Lived Experience of Individuals Living with HIV/AIDS while Residing in a Rural Region in Northern Appalachia.

INVESTIGATOR:
Renée E Gilhousen, MSN, CRNP, FNP-BC
PhD Candidate Student
Duquesne University School of Nursing

ADVISOR:
Lenore Resick, PhD, FNP-BC, FAANP, FAAN
Professor Emerita
Duquesne University School of Nursing

SOURCE OF SUPPORT
This study is being conducted as partial fulfillment of the requirements for the degree of Doctor of Philosophy, Duquesne University School of Nursing.

STUDY TITLE: The Lived Experience of Living with HIV/AIDS while Residing in a Rural Region in Northern Appalachia.
- You are invited to participate in a research study.
- You do not have to participate in the study.
- If you say yes, you can quit the study at any time.
- Please take as much time as you need to make your choice.
- If you are unable to read, the form can be read to you.

PURPOSE: You are invited to participate in a research study that seeks to explore the lived experience of individuals living with HIV/AIDS while residing in a rural region in Northern Appalachia and what it means to you as a person living with HIV/AIDS. This study will provide an opportunity for research participants to verbalize the experience of living with HIV/AIDS while living in a rural region of northern Appalachia and the meaning of that experience to them.
What if I say yes, I want to participate in the study: If you say yes, you will

- Complete a Demographic Data Form
- Participate in two face-to-face interviews with the researcher. The purpose of the first interview is to learn about your experiences living with HIV/AIDS infection in a rural region in Northern Appalachia and what it means to you as a person. The second interview will be done a few weeks later. The second interview is to review the information from the first interview to be sure that the researcher has understood your information correctly. Each interview will last about 1-1½ hours.
- The interview will be audiotaped. I am asking you to allow audiotaping for the convenience of having a complete transcript to analyze the interview.
- These are the only requests that will be made of you.

CONFIDENTIALITY: Your name will never appear on any survey or research instruments. No identifiable information will be on any data related to this study. All written materials and consent forms will be stored in a locked file in the researcher’s home. All identifying information on the audiotapes will be deleted when the tapes are transcribed. There will be no way that you will be able to be identified from the information analyzed in the study. The transcribed interviews will be shared with my advisor in order to receive her guidance in identifying common themes across the interviews. The tapes and transcribed interviews will be kept in a locked file cabinet to assure that no one has access to the information until they are destroyed. When the tapes are transcribed, all sections that identify subjects or anyone subjects talk about will be deleted. Your responses will only appear in statistical data summaries. Upon successful completion of the dissertation defense the researcher will retain only de-identified information and de-identified transcripts indefinitely for future studies associated with this research. The researcher, upon completion of the PhD program, will shred hard copy transcripts. Demographic data will be presented in aggregate form only. The results of this study may be published in professional journals or presented at professional conferences, but you will not be identified in any of the information. All results will be summary results.

COMPENSATION: You will be compensated with a $10 gift card to a convenience store that will be given to you at the completion of each face-face interview. However participation in the project will require no monetary cost to you.

RISKS AND BENEFITS: There is no physical risk from participating in this study. During the interview if the questions cause you any discomfort you have the option to not answer the question or to end the interview. If needed, you will be referred to a health care professional in the community to refer you to psychological services.

Will being in the study help me in any way?
I cannot promise you will receive any direct benefit from participating in this study. The benefits of this study include increasing knowledge regarding what it is like living with HIV/AIDS in a rural region in Northern Appalachia.
What happens if I say no, I do not want to be in the study? No one will treat you differently. You will not be penalized.

What happens if I say yes, but change my mind later? You can stop participating in the study at any time. If you decide to participate you may stop and withdraw at any time. The data recorded up to that point will then be destroyed. You may also ask questions of the interviewer at the time of the interview.

What should I do if I want to be in the study? Sign this document. We will give you a copy of the document to keep. By signing the document you are saying:
- You agree to be in the study.
- We talked with you about the information in this document and answered all your questions.

You know that:
- You can skip interview questions you do not want to answer.
- You can stop answering my questions at any time and nothing will happen to you.

SUMMARY RESULTS: A summary of results of this research will be supplied to you at no cost, upon request.

VOLUNTARY CONSENT: I have read the above statements and understand what is being requested of me. I also understand that my participation is voluntary and that I am free to withdraw my consent at any time, for any reason. On these terms, I certify that I am willing to participate in this research project.

I understand that should I have any further questions about my participation in this study, I may call the principal investigator, Renée Gilhousen, MSN, CRNP, FNP-BC at [redacted] or [redacted] the advisor, Dr. Lenore Resick, Professor Emerita, Duquesne University School of Nursing or Dr. Linda Goodfellow, Chair of the Duquesne University Institutional Review Board at [redacted].

Participant’s signature ___________________________ Date ___________________________

Researcher’s signature ___________________________ Date ___________________________
The Lived Experience of Individuals Living with HIV while Residing in Rural Appalachia

Confidentiality Statement

As transcriptionist, I have direct access to study participant interview audiotapes. This information will be used only for the purpose of this research study under the protocol of the Duquesne University Internal Review Board and the university that provides administrative support for the regional AIDS service organization. By signing this document, I agree to maintain this information in a confidential manner at all times and that the information will not be disclosed to any non-authorized individuals. This includes but is not limited to:

- Disclosing confidential information or allowing physical access to research data other than the principal investigator
- Intentional or negligent mishandling of confidential information; or
- Leaving research data unattended

I acknowledge and agree to the above requirements. I understand that violation of this policy constitutes breach of participant confidentiality. I agree that if I have any questions, I will consult principal investigator, Renee Gillhausen, MSN, CRNP, FNP-BC at [redacted] or the dissertation chairman, Lenore Resick, PhD, CRNP, FNP-BC, FAANP [redacted].

Name: __________________________________________
(Please print)

Signature _________________________________________ Date __________________
(Please sign and date)
Appendix K

The Lived Experience of Individuals Living with HIV while Residing in Rural Appalachia

Confidentiality Statement

As transcriptionist, I have direct access to study participant interview audiotapes. This information will be used only for the purpose of this research study under the protocol of the Duquesne University Internal Review Board and the university that provides administrative support for the regional AIDS service organization. By signing this document, I agree to maintain this information in a confidential manner at all times and that the information will not be disclosed to any non-authorized individuals. This includes but is not limited to:

- Disclosing confidential information or allowing physical access to research data other than the principal investigator
- Intentional or negligent mishandling of confidential information; or
- Leaving research data unattended

I acknowledge and agree to the above requirements. I understand that violation of this policy constitutes breach of participant confidentiality. I agree that if I have any questions, I will consult principal investigator, Renée Gilhousen, MSN, CRNP, FNP-BC at [REDACTED] or the dissertation chair, Lenore Resick, PhD, CRNP, FNP-BC, FAAN. [REDACTED]

Name: [REDACTED]
(Please print)

Signature: [REDACTED]
(Please sign and date)

Date: 01/27/2016
Appendix L

Demographic Tool

The Lived Experience of Individuals with HIV/AIDS while Residing in a Rural Region in Northern Appalachia.

Demographic questions will be asked by the researcher using the following:

Thank you for agreeing to participate in this study. Before I ask you questions related to your experience of living with HIV/AIDS while residing in a rural region in Northern Appalachia, I would like to ask you some general questions about you. If there are questions you prefer not to answer, you do not have to answer them.

Gender: Male___________
Female___________
Transgender___________

What is your current age?
18-25 years___________
26-35 years___________
36-45 years___________
46-55 years___________
56-65 years___________}[
66-75 years___________
76-85 years___________}
What is your current marital status?

Single

Married

Divorced

Widowed

Domestic partner

How long have you lived with HIV/AIDS?

Less than one year

1-5 years

6-10 years

10-20 years

20-30 years

More than 30 years

Do you receive HIV/AIDS specialty services? Yes No

If Yes what types of services do you receive

From whom do you receive services?

How long have you been receiving services?
Appendix M

Semi-structured Interview Questions

We have talked a little bit about you. Now I am very interested in learning from you about the experience of living with HIV/AIDS while residing in a rural region in Northern Appalachia.

Can you tell about that?

Probes: Can you tell me more about that?

Tell me about when you first learned you were infected with HIV. What do you remember the most about the day?

Probes: Can you tell me more about that? What comes to your mind?

Tell me about the experiences you have had living with HIV/AIDS while residing in rural Northern Appalachia.

Probes: Can you give me an example of that?

Probes: What do you remember most?

If you were to give a title to your experience of living with HIV/AIDS, what would the title be?

Is there anything else you would like to tell me about your experience regarding this interview?

Is there anything else you would like me to know or feel it is important for me to know