EMERGING ADULTS' LIVED EXPERIENCE OF PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS

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EMERGING ADULTS' LIVED EXPERIENCE OF PERINATALLY ACQUIRED HUMAN IMMUNODEFICIENCY VIRUS

DISSERTATION

by

Angela Marie Wright

2018

Claudette R. Chin, PhD, APRN
Chairperson, Dissertation Committee

Jessie M. Colin, PhD, RN, FRE FAAN

Member, Dissertation Committee

Ronica Subramoney, PhD, RN Member, Dissertation Committee

Pegge L. Bell, PhD, RN
Program Director, College of Nursing and Health Sciences

John J. McFadden, PhD, CRNA Dean, College of Nursing and Health Sciences

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Abstract

Background: Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS) is a global problem, infecting over 70 million people worldwide. However, HIV has changed from being a terminal disease to a chronic one, resulting in approximately 10,000 perinatally acquired HIV (PAHIV) adolescents and emerging adults in the United States (U.S.). Little is known about this population because few studies have focused on them. They may encounter physiological, psychological, and sociological challenges that may affect their ability to meet the benchmarks of their developmental stage. Nursing may contribute to improving the health outcomes of individuals living with the disease through nursing education, nursing practice, and nursing research and health and public policy.

Purpose: The purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of PAHIV. The aim of this study was to determine if the emerging adults were meeting the benchmarks of their developmental stage as their unaffected peers and to elucidate their voices to understand their essence of the experience of PAHIV. This study answered the questions: What is the emerging adults' lived experience of perinatally acquired HIV (PAHIV)? What benchmarks of the developmental stage are the emerging adults with PAHIV meeting?

Philosophical Underpinnings: This study utilized the qualitative research approach with interpretivism and constructivism as the philosophic underpinnings.

Methods: The Heuristic research method of Clarke Moustakas (1990) guided the data collection and data analysis of the study. Convenience and purposive sampling strategies were utilized to select the sample of 15 emerging adults (18-25 years) with PAHIV from

private physicians' offices in South Florida. Data were collected via a researcher-designed questionnaire; face-to-face, semi-structured audiotaped interviews; member check meetings; participants' reflections; and the researcher's reflective journal.

Results: The emerging adults' essences of the experience of PAHIV were the emerged themes of *Panorama of Living With HIV; Consciousness* and sub-themes *Kinship, Concealing,* and *Paradox; Realities Of Living With HIV,* and *Affirming Milestones,* which were further connected to the principles of the human becoming theory for a philosophical perspective. Participants are extending time in post-secondary education focusing on career building, while developing intimate relationships and delaying childbearing and marriage, similar to their uninfected peers at the same developmental stage of emerging adulthood.

South Florida. Participants who volunteered received care at immunology clinics and

Conclusions: The study revealed that the emerging adults with PAHIV have structured meaning of *Panoramic Views of Living With HIV; Consciousness* of their HIV status, *Kinship* with parents and siblings, *Concealment* of their HIV status from close family members and friend, and medication (ART) *Paradox* through their images of those experiences that have influenced the values they ascribed to each. Participants have cocreated rhythmicity in *Realities of Living With HIV* through their relationships with their universe, by being actively involved in the processes of everyday living.

Participants are cotranscending *Affirming Milestones* towards a successful future. They are meeting the benchmarks of the emerging adulthood developmental stage (post-secondary education, career building, delayed marriage, delayed childbearing, and premarital sex) as their HIV uninfected peers.

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I would not have been successful at earning this degree without your patience, guidance, encouragement, support and sacrifice. Special thanks to your nieces who were literally the test subjects on emerging adulthood for this study and to your entire family for sharing you with me during your family time and sometimes deep into the hours of the night.

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Jackson – for always believing in me; Leslie Heslop; Gloria Weller – if you were still here with us, you would have been my loudest cheer leader. I can almost imagine you in the cheering stands being loud and proud, and taking a bow to your own credit. You instilled in me the belief that I can do and become anything that I wanted and that failure was not an option.

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experienced gained during that encounter has been influential and invaluable. Dr. Chin has remained an invaluable ally. Thank you for your friendship, support, and guidance. I would very much like to thank those who were supportive in the access and recruitment of participants for this study, Dr. Anna Puga; Dr. Olayemi Osiyemi and his staff member Glenda McDonald; Dr. Ramgopal and his staff; the staff at South Florida AIDS Network (SFAN)-Miami-Jackson including Valencia Davis and Candice Pinnock; Arlene Gurwich and Dr. Margaret Gorensek; John Marangio from the Ft. Lauderdale chapter of the Association of Nurses in AIDS Care (ANAC) and SFAN– Ft. Lauderdale; Jodie Reid who checked in on a regular basis and offered whatever resources she could find; and the many others who have given me advise or pointed me in a direction of some sort.

Ultimately, I would like to thank each participant for trusting me with their information and for helping me to accomplish this goal of completing the study and earning this degree. Each participant has left a unique impression on me, which I cannot shake.

Ahmazin:

It did not take much for you to agree to participate in this study. Thank you for your candidness, and for opening up and sharing your story of resilience, faith, and optimism. Continue making a difference in the lives of those you seek to help by sharing your story and through your volunteering efforts.

Ashley:

Thank you for sharing your story, and for trusting that I would keep your confidence and respect your privacy.

Blessed:

Thank you for making the effort to come out with your family and meet with me to share your story.

Brittany:

Your innocence, strength, and hopefulness are inspiring. I sincerely hope that you remain safe in your environment and that you are allowed to grow (slowly) into womanhood. Thank you for sharing your story and for the time and effort you put into creating such beautiful poetry for your member check submission.

Bryan:

You took me over the hump in this process by being the very first person to volunteer as a participant for this study. You were a novice researcher's dream come through because it was so easy having that conversation with you. You are such a remarkable and polite young man. Thank you for trusting me with your sensitive information.

Edward:

You inspired me. You had me interested and engaged in your story from the very moment I walked into the entrance of the library. You stood somewhat aloof, watching for my reaction, knowing that I would not have been able to pick you out of a crowd, because nothing about you fits the stereotype of someone who is HIV positive. You regaled me with your career path and goals, to the point that I had to refocus and remind myself of the objective of the interview. Your caring and tender personality shined through. Thank you for opening up and sharing your story, and for encouraging your cohorts to talk with me (yes, I know you did). Thank you.

Jamie:

At first you were guarded and hesitant to have a conversation with me; however, by the end, you were open, cooperative, and willing to share your private thoughts and experiences. You bolstered my confidence by divulging that our conversation was the very first time, that you had actually opened up and shared your HIV experiences with anyone. This was validation for me that this study was worth completing. I was honored by the confidence and trust you place in me by opening up in such a way. Thank you.

Loren:

Thank you for trusting me with your story and for the trust you place in me to tell your story in a responsible way. What you said, "this research allows our voices to be heard in a positive way" was very encouraging. I am hoping that you have accomplished your goal of finishing your degree as planned. Thank you.

Lovely:

You may have been the most impacted by this disease from this group, but you are no less fortunate than the others. Your resolve to succeed and to help others are inspiring. I am hoping that you were able to make the trip to Uganda and that everything went as planned. May God continue to bless you.

Kayden:

Our conversation was one of the most laid-back conversations of this process. Prior to transcribing the audiotape, I was concerned that I did not covered all the bases, but we did. Your story of beating the odds at longevity inspired me. What could be more poignant than being limited, yet you not just survive, but you thrive and you are living your best life. You are accomplishing dreams that you were never supposed to have and

being confident in who you are. Thank you for your efforts in creating the body mapping art for your member check submission. Thank you for sharing your story.

Keisha:

You walked into the interview a little guarded, almost skeptical, but you opened up, and shared your story anyway. You challenged me to think deeply about the reason why I chose this phenomenon to study as opposed to something more personal. Our frank discussion brought me to the realization that there is a distinction between grief and passion. Thank you for sharing your story and your dreams.

Margarita:

Thank you for trusting me and for inviting me into your home (your safe place) to conduct this interview. Your sadness breaks my heart, but your resolve gives me hope. Thank you for making that pencil drawing specifically for this study. I sincerely hope that you will use your talent to bring yourself some peace and possible economic gain.

Melissa:

Thank you for coming out and sharing your son and your story in this experience. Your need to be seen in a positive light was not lost on me. I sincerely hope that I did you justice. Thank you for taking this study seriously and for your contribution to its success.

Rashad:

You are so full of passion for life and hope in the future. It was very easy talking to you. As a novice researcher, I learned a valuable lesson from our encounter. I learnt that, to maintain my patient's privacy, I should always be aware of my surroundings and to pay close attention to my subjects' body language as much as I listen to what they have to say. When you invited me into your home to conduct the interview, I had no idea that

your other family members were not aware of your HIV status. Then, your cousin walked in and you became slightly distracted, but enough for me to want to move the meeting to my car. It was only after the recorded interview came to an end that you divulged that your mother and grandmother are the only family members who are aware of your HIV status. Thank you for trusting me by sharing your story with me and for your efforts in designing your member check submission. I am praying that your baby arrived safely and HIV negative as we all wished. Peace!

Travis:

Thank you for your insights and your willingness to share your story. I am listening out to hear your music, as you become successful in your music career.

I would also like to thank my coworkers at Jackson Memorial Hospital and South University. Your accommodation and encouragements have made this success possible. The list of people who have impacted my life significantly and others who have contributed to this success, does not end here by any measure. For those not mentioned, please know that your contribution in whatever form is no less appreciated or any less significant; neither is it forgotten nor is it taken for granted. I am eternally grateful, thank you.

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DEDICATION

Wilhel Jackson, my mother who taught me the values in hard work, respect for a job well done, and dedication to a task until it is completed. These lessons were learned from watching you. I remember in the 70's when you literally walked through hails of bullet every working day (in the wee hours of the mornings), to get to work on time. You never missed a day of work because of the dangers of getting to your place of work safely. I wish that you were here today to share and revel in this moment, which is as much your achievement as it is mine. Thank you for giving me life and for nurturing me. May your soul continue to rest in peace. Love you Mom.

Danielle A. J. E. Barrett, my daughter, friend and partner in life. My life has not been the same since you made your entrance. I am most fortunate to have the privilege of being your mother and to watch you evolve into such a remarkable human being. I am so proud of you, the woman you have become, and the successes that you have had. My only wish is that God will grant me the opportunity to watch you evolve even further. I love you with all of my being. Mom.

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CHAPTER ONE

PROBLEM AND DOMAIN OF THE INQUIRY

Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency

Syndrome (AIDS) is a global problem, infecting over 76.1 million people worldwide,
since it was first discovered in June 1980. Over 35.0 million of those infected have died

(World Health Organization [WHO], 2016a; WHO, 2016b; WHO, 2018; Joint United

Nations Program on HIV/AIDS [UNAIDS], 2018). Advancement in drug therapy,
research, development, and healthcare workers' preparation have decreased the incidence
of HIV infections and seroconversions among infants in high resourced countries
drastically. This has changed HIV/AIDS from being a terminal disease to a chronic one
(Levine, Aaron, & Foster, 2006). There are approximately 10,000 adolescents and
emerging adults with perinatally acquired HIV (PAHIV) in the United States (U.S.) about
whom much is not known. Not many studies have been completed about them, since
they were not expected to survive infancy (Hazra, Sidberry and Mofenson, 2010; Levine
et al., 2006; Phillips et al., 2011).

During emerging adulthood (18-25 years), parents exercise less influence than they did in childhood or adolescence, and most individuals have not yet entered the social or institutional roles of marriage, parenthood, and long-term employment that provide new constraints (Arnett, 2006). The PAHIV emerging adult, however, may encounter physiological, psychological, and sociological challenges that may affect their ability to achieve the benchmarks of this developmental stage. Nursing as a discipline may contribute to improving the health outcomes of these individuals through nursing education, nursing practice, and nursing research and by affecting health and public

policy. The purpose of this study was to explore the emerging adults' lived experience of PAHIV.

Background of the Study

Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome Pathway

The retrovirus that causes HIV infects cells of the immune system, thereby destroying or impairing their function (WHO, 2014). As the impaired immune system becomes weakened and the infection progresses, the infected individual becomes more susceptible to other infections. This results in the most advanced stage of HIV infection, AIDS, which can take up to 10-15 years to develop (WHO, 2014). However, the progression to AIDS can be further slowed down with antiretroviral therapy (ART) (WHO, 2014). HIV is transmitted through unprotected sexual intercourse (anal or vaginal), blood transfusion of contaminated blood products, sharing of contaminated needles, and from mother to infant during pregnancy, childbirth, and breastfeeding (WHO, 2014).

Perinatally acquired HIV (PAHIV) is the transmission of the virus from mother to infant, which may occur during pregnancy, delivery, or breastfeeding. Intrauterine HIV transmission (before 36 weeks of gestation) occurs in approximately 20% of cases, peripartum HIV-transmission (onset of placental separation, mother-to-fetus micro transfusions, labor and rupture of membranes) occurs in approximately 80% of cases, and most transmission occurs around labor and delivery (Centers for Disease Control and Prevention [CDC], 2014a). Factors influencing perinatal HIV-transmission are: high viral load (VL); low CD4+ count; co-infections (hepatitis C, cytomegalovirus, bacterial

vaginosis); maternal injection drug use; no ART or prophylaxis; length of ruptured membrane and/or chorioamnionitis; vaginal delivery when VL is > 1000 copies/mL; invasive procedures; prematurity; and breastfeeding (CDC, 2015a). Other risk factors that increase the likelihood of perinatal HIV transmission include mothers who did not know their HIV status prior to giving birth; inadequate prenatal care (adequate care is defined as five or more visits, starting by the fourth month of pregnancy or earlier); no neonatal anti-retroviral therapy; mothers who are substance abusers; mothers who acquired a sexually transmitted infection (STI) during pregnancy; and issues associated with poverty and limited access to health care (Florida Department of Health (FDH), 2013).

According to the WHO (2013), "an increasing proportion of children entering into adolescence has acquired HIV perinatally and remains undiagnosed" (p. 5). The late diagnosis of HIV infection in adolescence results in delayed initiation of ART, which is increasingly being recognized as a significant problem (WHO, 2013). These slow progressors (those who have survived into adolescence without being diagnosed and started on ART) often have chronic medical and developmental problems and would benefit from early diagnosis and initiation of treatment, as well as long-term care and support (WHO, 2013). Antiretroviral drugs, other factors such as access to services to prevent mother to child transmission (PMTCT), and improved clinician training and preparedness have slowed the progression of HIV (Levine et al., 2006). This has resulted in a change in the face of HIV/AIDS from being a terminal disease to a chronic disease. There is a growing cohort of PAHIV positive adolescents and emerging adults who were not expected to survive into adulthood (Hazra et al., 2010; Levine et al., 2006; Phillips et

al., 2011). According to the UNAIDS (2016), "antiretroviral medicines have averted 1.6 million new HIV infections among children since 2000" (p. 3).

Emerging Adulthood (18-25 Years): Theory of Development from Late Teens Through the Twenties

The term emerging adulthood was coined by Jeffery Arnett (2000), regarding the age period between 18 and 25 years, which is theoretically and empirically distinct from adolescence and young adulthood. According to Arnett (2000), emerging adulthood is a period of life that is culturally constructed and not universal or immutable, applying only to industrialized societies where the period of adolescence is prolonged. This is largely attributed to the drastic changes related to this age period in the past half a century which features:

- A change from an industrialized to an information-based economy, which
 has resulted in the need for post-secondary education which causes a delay
 in transitions to career, marriage, and parenthood;
- An increase in educational and occupational opportunities for women,
 which has resulted in an increase in the number of women obtaining postsecondary education and developing their careers, while delaying marriage
 and child bearing; and
- 3. Greater tolerance for premarital sex, which has allowed young people to become sexually active at an earlier age, long before they contemplate marriage (Tanner & Arnett, 2009).

Contrary to Arnett's earlier assertion that emerging adulthood is "not a universal period, but a period that exists only in cultures that postpone the entry into adult roles and

responsibilities until well past the late teens" (Arnett, 2000, p. 478); there is evidence of emerging adulthood worldwide. The historical changes that characterize this developmental stage are now occurring in many developed and developing economies (Tanner & Arnett, 2009). There is worldwide evidence of increased rate of post-secondary education, although educational systems vary from one economy to the next; increased age at first marriage; increased age at first birth; increased roles and opportunity for women; and increased acceptance of premarital sex, although there are varying degrees of acceptance from culture to culture (Tanner & Arnett, 2009). In addition to variations of emerging adulthood between cultures, there is also evidence of variations within societies where emerging adulthood may be evident in some aspects of the middle class but nonexistent in the working class. This variation within society is attributed to society's role in structuring and shaping emerging adulthood (Tanney & Arnett, 2009).

According to Arnett (2000), emerging adulthood is distinguished by relative independence from social roles and normative expectations, having left the dependency of childhood and adolescence, yet not having entered the enduring responsibilities that are normative in adulthood. Emerging adulthood is a period when a variety of possible life directions in love, work, and worldviews are explored and is considered the most volitional years of life. There are five features to this developmental phase: (a) the age of identity exploration; (b) the age of instability; (c) the self-focused stage of development where people perceive that they have the most control over significant events in their lives as parents exercises less influence and they are most likely to have the freedom to make choices as they wish; (d) the age of feeling in between because they have not yet

entered into the social or institutional roles of marriage, parenthood, and long-term employment which provide new constraints; and (e) the age of possibilities (Arnett, 2006; Tanner & Arnett, 2009).

Emerging adulthood is focused on two processes: recentering and ego development. According to Tanner and Arnett (2009), recentering is the primary psychosocial task of emerging adulthood, which can be achieved in three stages: (a) transitioning into emerging adulthood, where individual relationships and roles would formally identify them as dependent; recipient of guidance and support; and resources in adolescence shifts towards relationships where "power is shared, mutual and responsibility for care and support gain in reciprocity" (Tanner & Arnett, 2009, p. 40); (b) emerging adulthood where "commitment to roles and relationships are temporary and transitory in nature ... individuals explore a series of commitments to inform themselves of the available opportunities in love and work (Tanner & Arnett, 2009; p. 40); and (c) adulthood where the individual make commitments to enduring roles and responsibilities in careers, marriage and partnerships, and parenthood (Tanner & Arnett, 2009).

According to Tanner and Arnett (2009), studies have shown that:

Emerging adult renegotiate relationships with parents by relinquishing residential and financial support and moving towards commitment to others such as life partners and children ... Salient tasks of emerging adulthood includes friendships, academics, and conduct goals, giving way to occupational and romantic goals as emerging adults move into young adulthood (p. 41)

Cognition, emotion, and behavior are other distinguishing features of the 18-25-year-old as an emerging adult, which set them apart from younger and older individuals.

Cognitive capacities, strategies, and organization shifts during emerging adulthood where maximum levels are achieved across multiple measures of aptitude, numerical ability, verbal attitude, clerical perception, finger dexterity, and general intelligence (Tanner & Arnett, 2009). Physical health and mental health are complex and diverse in emerging adulthood; however, risky behaviors including sexual risk-taking and substance use and psychiatric disorders among this group is high, which puts them at risk for unintended, sub-optimal health outcomes including sexually transmitted infections (STIs), unintended pregnancies, and abortion (Tanner & Arnett, 2009). According to Arnett (2000), "emerging adulthood is a distinct period demographically, subjectively and in terms of identity exploration" (p. 470).

Demographic variability. There is a great deal of demographic variability, which reflects the wide scope of individual volition during emerging adulthood. This diversity and unpredictability make it difficult to predict an individual's demographic status based on age alone, because the period is characterized by an emphasis on change and exploration, which reflects the experimental and exploratory quality of the period. The emerging adult has a wider scope of possible activities from which to choose than persons from any other age period. According to Arnett (2000), this occurs because:

They are less likely to be constrained by role requirement ... It is only in the transition from emerging adulthood to young adulthood in the late twenties that the diversity narrows and the instability eases, as young people make more enduring choices in love and work (p. 471).

The emerging adult enjoys great variability in residential status and school attendance:

Residential status. Approximately one-third of emerging adults are going off to college after high school; 40% move out of their parents' home for independent living and full-time work; two-thirds experience a period of cohabitation with a romantic partner; others remain at home while attending college, working, or a combination of both; and only approximately 10% remain at home until marriage (Arnett, 2000). The instability in residential status is the unifying feature, as "emerging adults have the highest rates of residential change of any age group" (Arnett, 2000, p. 471). This frequent change in residential status often reflects its exploratory quality because they often occur at the end of one period or the beginning of an exploratory period.

School attendance. "College education is often pursued in a nonlinear way, frequently combined with work and punctuated by periods of nonattendance" (Arnett, 2000, p. 471). For graduates with a 4-year degree, the likelihood of attending graduate school increases (Arnett, 2000).

Subjective sense. Most emerging adults see themselves as having left adolescence but not having completely entered young adulthood. Their difficulty in associating with young adulthood arises from not having established a stable residence, finished school, settled in a career, and married or committed to a long-term love relationship (Arnett, 2000). The characteristics that matter most to their subjective sense of attaining adulthood is their ability to accept responsibility for themselves; to make independent decisions; and to be financially independent (Arnett, 2000). Although not an essential criterion for adulthood, becoming a parent is the most important marker of the

transition to adulthood, as the explorations that occur in emerging adulthood becomes sharply restricted, and "the focus of concern shifts inexorably from responsibility for one's self to responsibility for others" (Arnett, 2000, p. 473).

Identity exploration. "Emerging adulthood is the period of life that offers the most opportunity for identity exploration in the areas of love, work and worldview" (Arnett, 2000, p. 473). According to Arnett (2000), the process of identity exploration starts in adolescence, but most of it takes place in emerging adulthood. Explorations in love tend to involve a deeper level of intimacy, and the implicit question is more identity focused, answering such questions as, "What kind of person do I wish to have as a partner through life?" (Arnett, 2000, p. 473). "Work experiences become more focused on preparation for adult work roles" (Arnett, 2000, p. 474), which lays the foundation for jobs they may have through adulthood. Emerging adults may have examined and considered a variety of possible worldviews, eventually committing to worldviews that may be different from the ones they entered the developmental stage with, including those of their parents, yet they remain open to further modifications.

Arnett's (2000) emerging adulthood developmental phase is informed by the lifespan theory and developmental sciences of Erik Erikson's (1950, 1968) theory of human development across the lifespan; Daniel Levinson's (1978) theory of development in the late teens and the 20s, which includes the Novice Phase of Development (17-33 years); and Kenneth Keniston's (1971) theory of youth; among others.

Erik Erikson (1982) Theory of Human Development Across the Life Span

Erikson's eight stages of psychosocial development ranges from infancy to adulthood. During each developmental stage, the individual may experience a

psychosocial crisis, which may have a positive or negative outcome (McLeod, 2013). Erikson, an ego psychologist, emphasized the role of culture and society and the conflict that may take place within the ego. Emerging adulthood (18-25 years) falls within two of Erikson's stages of development: identity versus role confusion (adolescent) and intimacy versus isolation (young adulthood). During the identity versus role confusion (adolescent) stage, conflicts from earlier life periods are revisited and resolved, as the individual integrates all the earlier identifications while they struggle to meet the challenges of gaining occupational identity (Bergen, 2008). A strong resolution of crisis in this stage results in the adolescent having a strong sense of self, which allows them "to accept their abilities and uniqueness and to have goals for change and further growth" (Bergen, 2008, p. 47). However, an unsuccessful resolution may result in a lack of direction, feeling of being unproductive, and being unsure of their strengths (Bergen, 2008).

The intimacy versus isolation (young adulthood) stage covers a wide age period. Having a strong sense of identity is important for intimacy, which requires sharing and commitment to a partnership. According to Erikson (1982), young adults emerge from adolescence in search of a sense of identity and are eager and willing to fuse their identities in mutual intimacy with individuals (work, sexuality, and friendship), which proves complementary. Erikson (1982) further stated that, from the resolution of the antithesis between intimacy and isolation emerges love, which is "a mutuality of mature devotion that promises to resolve the antagonisms inherent in divided functions ... The antipathic counterforce to young adult intimacy and love is exclusivity" (p. 7), which may emerge in later adulthood.

Daniel Levinson's (1986) Theory of Development in the Late Teens and the Twenties (The Novice Phase of Development)

Levinson's theory of development was formulated in 1978 and further expanded in 1987. There are three concepts to this theory: (a) the concepts of life course and life cycle; (b) the individual life structure; and (c) a conception of adult development.

According to Levinson (1986), life structures are developed through an orderly sequence of age-linked periods, with alternating structure-building and structure-changing (transitional) processes (Levinson, 1986) during the adult years. The primary task of the developing adult being to form life structure to enhance life. A transitional period, which occurs between structures, terminates the existing life structure, and creates the possibility for a new structure (Levinson, 1986). Levinson's (1986) life structure periods that corresponds with Arnett's emerging adulthood developmental stage are as follows:

- 1. Early adult transition (17-22 years): a developmental bridge between preadult hood and early adulthood; and
- 2. Entry life structure for early adulthood (22-28 years): a time for building and maintaining an initial mode of adult living.

The first three periods of early adulthood (17-33 years) in Levinson's (1986) theory, constitute the Novice Phase, where an individual can move beyond adolescence, build an entry life structure, and learn the limitations to that structure (Levinson, 1986).

Kenneth Keniston (1970) Youth a "New" Stage of Life

According to Keniston (1970), youth is a transitional stage in the life course of human development, which cannot be equated with any particular age range, although most Americans enter the stage between the ages of 18 and 30 years. As a developmental

stage, youth is emergent and is based on psychohistory, which is the relationship between historical and psychological change and their effect(s) on each other. This change in functioning is irreversible, in that, regression to a previous level may occur, but the second experience with the previous level is different from the first experience. As with Erickson (1982), development progresses through stages, of which each stage is a prerequisite for the next. Each stage builds on the preceding stage, which is the building block for the one that follows.

Keniston (1971) also articulated that those social transformations such as rising prosperity; further prolongation of education; high educational demands of a postindustrial society; and other less quantifiable factors are responsible for the emergence of "the problem of youth." Youth as a post-adolescent stage is characterized by the individual's inability to answer the questions of relationship to existing society, vocation, and social role and life-style (Keniston, 1970). The definition of youth involves three related tasks: major themes or issues that dominate consciousness, development, and behavior; transformation or changes in thoughts and behavior that can be observed in each "line" of development (moral, sexual, intellectual, interpersonal); and clarification of what youth is not (Keniston, 1970).

Major themes or issues that dominate consciousness, development, and behavior in youth are addressed below.

1) **Tension between self and society** is the focus of concern as "the youth" begins to sense who they are, as they recognize the possibility of conflict and disparity between their emerging selfhood and their social order (Keniston, 1970).

- 2) Pervasive ambivalence toward self and society: "how the two can be made more congruent is often experienced as a central problem in youth ... where the conflict between the maintenance of personal integrity and the achievement of effectiveness in society ... are experienced for the first time" (Keniston, 1970, pps. 636-637).
- 3) Estrangement and omnipotentiality is the feelings of isolation, unreality, and absurdity and disconnectedness from the interpersonal, social, and phenomenological world. These arise from the disengagement of youth from society and the psychological incongruence between self and the world. On the other hand, youth may experience the:

 Feeling of absolute freedom, of living in a world of pure possibilities, of being able to change or achieve anything ... The same sense of freedom and possibility that may come from casting off old inhibitions, values, and constraints may also lead directly to a feeling of absurdity, disconnectedness and estrangement (Keniston, 1970, p. 637).
- 4) **Refusal of socialization and acculturation** occurs when the individual becomes aware of the effects of their society and culture on their personality and may attempt to break out of their prescribed role.
- 5) **Emergence of youth-specific identity roles** includes the contrast between the ephemeral enthusiasms of adolescent and the more established commitment of adulthood.

- 6) Values placed on change, transformation and movement represent the psychological problems of youth become overwhelming when they seem to block change.
- 7) **Heightened valuation of development** occurs when change becomes a conscious goal and ideologies of "transformation and the telos of human life may be developed" (Keniston, 1970, p. 639).
- 8) **The fear of death takes a special form** where the loss of an individual's essential vitality is merely to stop.
- 9) Youthful view of adulthood that to grow up, "is in a sense ceasing to be alive" (Keniston, 1970, p.640).
- 10) **Youthful counter-cultures** where individuals deliberately distance themselves culturally from existing social order.

The psychological and interpersonal transformations in youth. According to Keniston (1970), psychological and interpersonal transformations that occur in youth are related to the self-society relationship; sexual development; and relationships with elders. The self-society relationship is a central issue in youth; consequently, as the youth achieve greater emancipation from the family, the tension between the self and society comes to constitute a major area of development and change. Sexual development issues are related to identicality, parity, complementarity, and mutuality. Relationship with elders may undergo characteristic youthful changes. Cognitive changes occur in youth as the individual breaks away from the phenomenological ego and passes beyond the simplistic views of right and wrong; truth and falsehood, and good and evil to a more complex and relativistic view (Keniston, 1970). The achievement of this highest level of

moral reasoning is the personal principled stage of development, which occurs in the 20s, as the individual begins to experience the tension between themselves and society, and questions the absolutism of conventional moral judgment (Keniston, 1970).

What youth is not. According to Keniston (1970), "youth is not the end of development ... but a preface for further transformation that may (or may not) occur later in life" (p. 648). Youth is a transitional stage, where some lines of development may be completed, while others continue throughout adulthood. Youth is not:

The adoption of youthful causes, fashions, rhetoric, or postures ... [which give rise to] pseudo youth – preadolescents, adolescents, and frustrated adults masquerade as youths, adopt youthful manners and disguise (even to themselves) their real concerns with the use of youthful rhetoric (Keniston, 1970, p. 650).

According to Keniston (1970), in youth, "adolescent themes and levels of development are relatively outgrown, while adult concerns have not yet assumed full prominence" (p. 651).

A comparison of the emerging adulthood developmental stage with the developmental theories of Erikson (1950, 1968), Levinson (1978), and Keniston (1970) is illustrated in Figure 1.

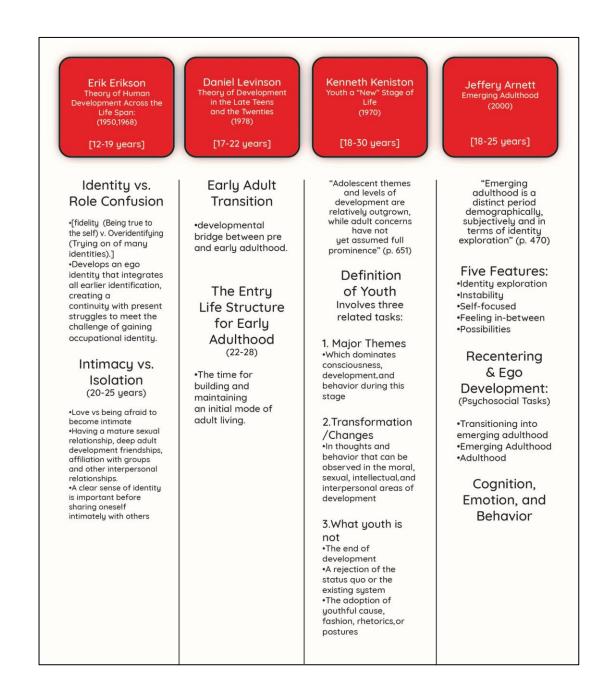


Figure 1. Erikson's, Levinson's, Keniston's and Arnett's (18-25 years) developmental stage comparison (Wright, 2018, partially adapted from Erickson (1982), Levinson (1986), Keniston (1970, 1971), and Arnett (2000, 2004, 2006, 2009).

Jeffery Arnett (2000) Emerging Adulthood

According to Arnett (2000), Erikson's theory did not propose a separate stage of development that is analogous to emerging adulthood, but he wrote of development in adolescence and young adulthood and commented on the prolonged adolescence that is typical of industrialized societies and the psychosocial moratorium granted to young people in those societies, during which they were free to role experiment and find their niche. Arnett (2000) stated that Levinson argued that the overriding task of the novice phase of development was the move into the adult world, where "the young person experiences a considerable amount of change and instability while sorting through various possibilities in love and work in the course of establishing a life structure" (p. 470). Arnett (2000) also stated that in his theory of youth, Keniston (1971) "conceptualized youth as a period of continued role experimentation between adolescence and young adulthood" (p. 470). From a developmental perspective, Tanner and Arnett (2009) argued that emerging adulthood is a distinct and critical juncture in human life development, when events occurring during that stage of development are integrated into the individuals' identities and memories, more so than events occurring in any other stage of life development.

Perinatally Acquired Human Immunodeficiency Virus and Emerging Adulthood

According to UNAIDS (2016), over the past 10 years, there has been a threefold increase in the number of adolescents who were infected with HIV as children. However, at the end of 2015, the number of PAHIV ages 15-19 years were estimated because there were no direct data collection measures in the reporting systems globally or nationally, that accounted for this population. Therefore, the estimates were based on the current

number of youths (15-19 years) living with HIV, minus those who were known to be infected with the virus behaviorally (sexual intercourse, injected-related transmission) (UNAIDS, 2016). This increase in the number of PAHIV adolescents has also increased the challenges faced by treatment programs to prevent and treat HIV/AIDS because adherence to ART and treatment failure were high among adolescence living with HIV. This made the transition to adulthood a dangerous time for the population.

The inconsistency in the data collection and reporting on children through emerging adulthood globally have led to overlapping in age categories and different definitions of "child," "adolescence," "young person," "young adult," and "emerging adult" (WHO, 2013). The WHO (2013) regards adolescence as 10-19 years of age; however, most reporting reference youth as age 15-24 years. For this study, adolescence is 15-24 years; youths 15-19 years, and emerging adults is 18-25 years as determined by the emerging adult developmental stage. These distinctions are necessary to capture the global impact of HIV on the emerging adult (18-25 years) group, which is the focus of this study.

Global Human Immunodeficiency Virus Epidemic

Globally, HIV/AIDS continues to be a major public health issue with its greatest effect in Sub-Saharan Africa, which bears the greatest burden. Figure 2 illustrates the global HIV/AIDS epidemic for 2015.

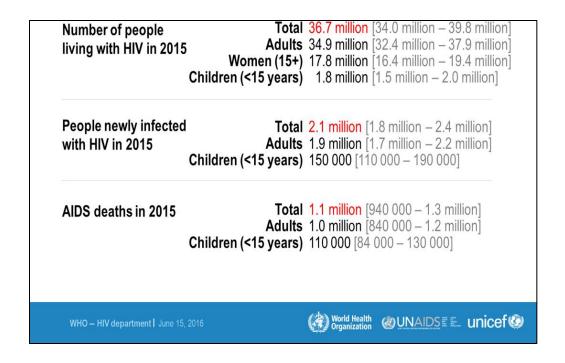
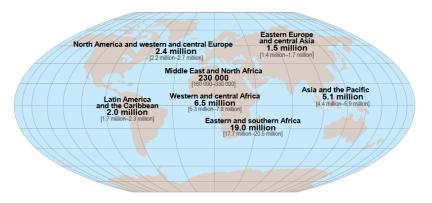


Figure 2. Global summary of the AIDS epidemic for 2015 (Wright, 2018, adapted from WHO, 2016).

In 2015, there were 2.1 million new cases of HIV/AIDS, an estimated 36.7 million people were living with the disease, and 1.1 million people died from the disease around the world (WHO, 2016a; WHO, 2016b). Globally, there were 1.8 million children (<15 years) living with HIV, of which 150,000 were newly infected. Most new infections occurred mostly among those infected by their mothers. The number of youths (15-24 years) newly infected with HIV globally in 2015 were 670,000, and 110,000 children (< 15 years) died from the disease (WHO, 2016a; WHO, 2016b; United Nations Children's Fund [UNICEF], 2016a).

Figure 3 presents the regional distribution of adults and children affected by HIV/AIDS in 2015.



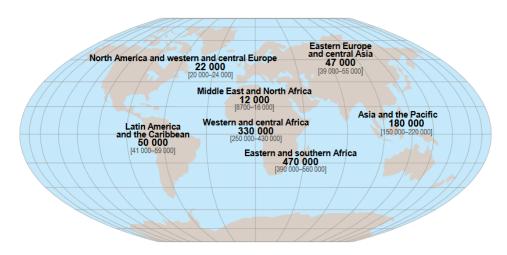
Total: 36.7 million [34.0 million—39.8 million]



Figure 3. The number of adults and children estimated to be living with HIV in 2015 (Wright, 2018, adapted from The Joint United Nations Program on HIV/AIDS [UNAIDS], 2016).

Figure 3 illustrates that of the 36.7 million people living with HIV/AIDS globally in 2015, approximately 25.7 million (70 %) were in Sub-Saharan Africa (Eastern, Southern, Western, and Central), which also accounted for approximately two-thirds of all new HIV infections globally in 2015 (WHO, 2016b). Approximately 19 million (52%) people were from Eastern and Southern Africa, 5.1 million (14%) from Asia and the Pacific, 2.4 million (6.5%) from West and Central Europe and North America, 2 million (5%) from Latin America and the Caribbean, 1.5 million (4%) from East Europe and Central Asia, and 230,000 (0.5%) from the Middle East and North Africa.

It was estimated that only approximately 60% of people who were living with HIV knew their status, and the remaining 40% (14 million people) who did not know their status needed to access HIV testing services (WHO, 2016b). Figure 4 illustrates the estimated number of adults and children who died from AIDS globally in 2015.



Total: 1.1 million [940 000–1.3 million]



Figure 4. Estimated adult and children deaths from AIDS globally in 2015 (Wright, 2018, adapted from UNAIDS, 2016).

Figure 4 demonstrates that 812,000 (74%) or over two-thirds of the approximately 1.1 million people who died from the disease globally in 2015 lived in Africa. Asia and the Pacific accounted for 180,000 (16%); Latin America and the Caribbean 50,000 (4.5%); North America and Western and Central Europe 22,000 (2%); and Eastern Europe and Central Asia 47,000 (4%).

Global Perinatally Acquired Human Immunodeficiency Virus Epidemic

The largest known multi-regional global epidemiological analysis of adolescents (10-15 years) infected perinatally with HIV was compiled by The Collaborative Initiative for Pediatric HIV Education and Research (CIPHER) Global Cohort Collaboration

between May 2016 and January 2017 (The Collaborative Initiative for Pediatric HIV Education and Research (CIPHER) Global Cohort Collaboration, Slogrove, Schomaker, Davies, Williams, Balkan, et al. [CIPHER, et al], 2018). These data, which were pooled from observational pediatric HIV cohorts and cohort networks among multiple settings across multiple regions of the world, accounted for 183,119 adolescents (CIPHER et al., 2018). The analysis included data on "all children infected with HIV who entered care before age 10 years, were not known to have horizontally acquired HIV, and were followed up beyond age 10 years" (CIPHER et al., 2018). The data set were adjusted for known non-perinatal transmission (222); data discrepancies (13); first observable age greater than 10 years (1989); and last observable age less than 10 years (142,701). Of the remaining 38,187 adolescents, 51% were female; they came from 51 different countries of which 79% (30,296) were from sub-Saharan Africa; and 65% lived in low-income countries (CIPHER, et al., 2018).

Human Immunodeficiency Virus Epidemic in the United States

In 2015, the total number of people in the U.S. who were newly diagnosed with HIV were 39,513; more than 1.2 million people were living with HIV/AIDS infection, and almost 12.8% or 1 in 8 were unaware of their HIV status (CDC, 2015a; CDC, 2017). The incidence of HIV/AIDS is disproportionately distributed among subpopulations because the burden is not evenly distributed culturally, ethnically, or geographically. This was illustrated in the total number of gay and bisexual men who were diagnosed with HIV (26,375), accounting for approximately 67% of the total number of people diagnosed with HIV in the U.S. in 2015. This occurred particularly among young African American gay and bisexual men who accounted for 26% (10,315) and white gay

and bisexual men accounting for the second highest incidence of 7,570 (19%) (CDC, 2017). Ethnically, African Americans and Hispanic/Latinos continue to bear the greatest burden of the HIV epidemic in the U.S., accounting for 17,670 (45%) and 9,290 (24%) respectively in 2015 (CDC, 2017). Geographically, 16.8 cases per 100,000 people occurred in the South where HIV care and treatment indicators are generally behind; 11.6 cases per 100,000 people occurred in the Northeast; 9.8 cases per 100,000 people occurred in the West; and 7.6 cases per 100,000 people occurred in the Midwest (CDC, 2017).

Perinatally Acquired Human Immunodeficiency Virus in the United States

At the end of 2015, there were 11,847 PAHIV individuals living in the U.S. and six U.S. dependent areas (CDC, 2018).

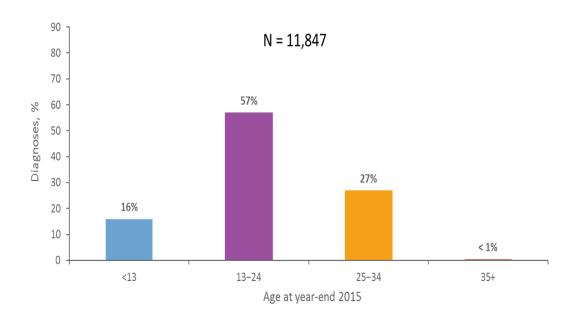


Figure 5. Age distribution of Perinatally Acquired HIV (PAHIV) population in the U.S. and 6 dependent areas at the end of 2015 (Wright, 2018, adapted from CDC, 2018).

Figure 5 shows the age distribution of the PAHIV population in the United States and its 6 dependent areas, at the end of 2015. The majority (57%) of the PAHIV were aged 13-24 years, 27% who were aged 25-34 years, 16% who were less than 13 years, and less than 1% were 35 years of age or older (CDC, 2018).

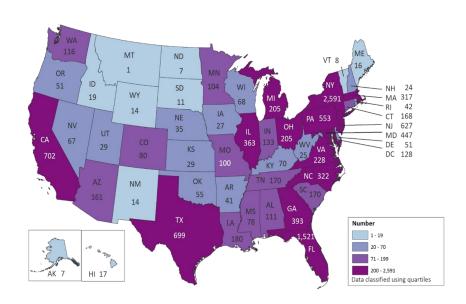


Figure 6. Geographic distribution of PAHIV population in the U.S. in 2015 (Wright, 2018, adapted from CDC, 2018).

Figure 6 illustrates the geographic distribution of the PAHIV population (11,847) in the U.S. and its six dependent areas at the end of 2015, regardless of their age. The number of persons living with PAHIV ranged from zero in American Samoa, the Northern Mariana Islands, and the Republic of Palau to 2,591 in New York (CDC, 2018). At the end of 2015, there were 5,667 PAHIV individuals who ever classified as stage 3 (AIDS) in the United States and its 6 dependent areas (CDC, 2018).

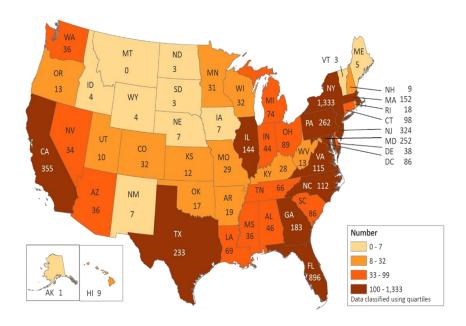


Figure 7. Geographical distribution of PAHIV individuals who were ever classified as stage 3 (AIDS) and were alive at the end of 2015 (Wright, 2018, adapted from CDC, 2018).

Figure 7 shows the geographical distribution of PAHIV individuals who were ever classified as stage 3 (AIDS) and were alive at the end of 2015, regardless of their age.

The number ranged from zero in American Samoa, the Northern Mariana Islands, the Republic of Palau, and Montana to 1,333 in New York (CDC, 2018).

HIV/AIDS continues to be a U.S. government priority, as demonstrated in their commitment to decreasing the incidence and improving the health and well-being of people living with HIV (PLWHIV) globally and domestically. This was evident in their investments and collaborative support with other partners. For fiscal year (FY) 2017, a total of \$34 billion was requested from Congress towards these efforts. Of the total amount requested, \$6.6 billion (19%) was targeted towards the global effort and the

remaining \$27.4 billion (81%) towards the U.S. domestic efforts. The domestic provisions had specific targets: Domestic prevention – \$0.9 billion (3%); Domestic research – \$2.7 billion (8%); Domestic cash and housing assistance – \$3.1 billion (9%); and the vast amount to domestic care and treatment – \$20.8 billion (61%). Other U.S. initiatives supporting the fight against HIV/AIDS include the National HIV/AIDS Strategy for the United States, which was released in July 2010, and updated to 2020. To date, this is the most comprehensive national effort. It has four overreaching goals: (a) to reduce new HIV infections; (b) to increase access to care and improve health outcomes for PLWHIV; (c) to reduce HIV-related disparities and health inequalities; and (d) to achieve a more coordinated national response to the HIV epidemic.

Human Immunodeficiency Virus Epidemic in Florida by County

Florida covers a geographic region of 53,927 square miles and comprises 67 counties (FDH-HIV/AIDS, 2016). In 2015, the incidence of HIV in Florida was 4,868 or 24.5 cases per 100,000 people, while in Broward County, there were 657 or 36.06 cases per 100,000 people; in Miami-Dade County there were 1,368 or 51.60 cases per 100,000; and in Palm Beach County there were 290 or 20.99 cases per 100,000 (FDH, 2016). Figure 5 below illustrates the HIV infection rate (per 100,000 of population) by county in Florida in 2015.

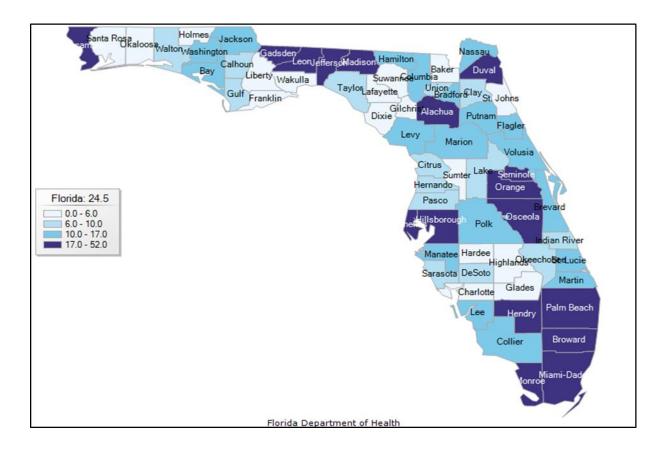


Figure 8. HIV infection rate (per 100,000 of population) by country in Florida for 2015 (Wright, 2018, adapted from Florida Department of Health, 2016).

Figure 8 illustrates that South Florida (Monroe, Miami-Dade, Broward, Palm Beach and Henry counties) bears a high infection rate of 17.0 - 52.0 cases per 100,000 of population while the state of Florida's overall rate was only 24.5 cases per 100,000 of population. Other counties in Florida (Hillsborough, Osceola, Seminole, Alachua, Duval, Madison, Jeffers, Leon, Gadsden) also bears a high HIV infection rate (17.0 - 52.0 cases per 100,000 population).

In 2015, of the 4,868 people in Florida who were newly diagnosed with HIV, 83% had HIV- related care within 3 months of diagnosis; 96% of those in care were on ART; and 81% of PLWHIV in care had a suppressed viral load (FDH, 2015b). Of the

111,768 people in Florida who were living with HIV, 101,932 (91%) were linked to care; 81,316 (74%) were in care; 73,632 (66%) were retained in care; and 66,172 (59%) had suppressed viral loads (< 200 copies/mL). Florida estimated that an additional 15,821 (12.4%) people were living with the virus and were not aware of their HIV status (FDH, 2015b). The number of PAHIV individual in Florida at the end of 2015 was documented as 1521, representing 12.83% of the population in the U.S and its six dependent areas. Additionally, at the end of 2015 there were 896 PAHIV individuals who were ever classified as Stage 3 (AIDS) in Florida. This accounts for 15.81% of the population of those who were ever classified as stage 3 in the U.S. and its six dependent areas (FDH, 2015b).

In 2015, HIV was the most distinctive cause of death in Florida, by being the state with the most HIV- related deaths in the nation. There were no geographic or economic reasons for this occurrence. However, factors that attributed to the incidence and prevalence of HIV/AIDS in Florida included the amount of HIV already in the community; the late diagnosis of HIV or AIDS; access to and/or acceptance of care; stigma and/or denial; discrimination and homophobia; HIV/AIDS complacency; and poverty and unemployment (FDH, 2015a). Some factors were not controllable and others were addressed through initiatives which Florida had implemented. In 2016, the Integrated Prevention and Care Plan 2017-2021 was developed in collaboration with stakeholders and community partners to eliminate HIV transmission and reduce HIV related death in Florida. This plan has four components:

 Implement a test and treat model of care that provides medication as soon as possible after diagnosis.

- Incorporate antiviral pre-exposure prophylaxis (PrEP) and nonoccupational post-exposure prophylaxis (nPEP) as a risk reduction strategy.
- 3. Include routine HIV and STD screening in healthcare settings and targeted testing in non-health care settings.
- 4. Implement community outreach and messaging to target communities (FDH-HIV/AIDS, 2016).

Low income Floridians with HIV/AIDS who are not covered under Medicare, Medicaid, or other public assistance programs are provided care and support through this initiative. These supports are provided throughout the state in six Part A areas where HIV/AIDS service coordination and delivery occur at the local levels in 14 area consortia, according to the state HIV Integrative Prevention and Care Plan as illustrated in Table 1.

Table 1

Florida HIV Integrative Prevention and Care Plan (Wright, 2018, adapted from Florida Department of Health - HIV/AIDS, 2016)

Part A Areas	Local Service & Delivery Area Consortia
	(Counties)
1. Ft. Lauderdale	Broward
2. Jacksonville	Clay, Duval, Nassau, and St. Johns
3. Miami	Miami-Dade
4. Orlando	Lake, Orange, Osceola, & Seminole
5. Tampa/St. Petersburg	Hernando, Hillsborough; Pasco; and
	Pinellas
6. West Palm Beach	Palm Beach

The success in the prevention and treatment of pediatric HIV in high-resource countries has resulted in a change in PAHIV-infection from a progressive fatal disease to

a chronic disease (Hazra, et al., 2010). During emerging adulthood, parents exercises less influence than they did in childhood or adolescence, and most people have not yet "entered into the social or institutional roles of marriage, parenthood, and long-term employment, that provide new constraints" (Arnett, 2006, p. 304). The PAHIV emerging adults have defied the odds and are now enjoying a longer and improved quality of life, yet little information exists about them because few studies have been done since they were not expected to survive into emerging adulthood. The purpose of this study was to explore the emerging adults' lived experience of perinatally acquired HIV.

Statement of the Problem

The perinatally acquired HIV (PAHIV) emerging adults are in the self-focusing stage of development, when individuals are most likely to have the freedom to make life-affirming decisions as they wish, yet not having "entered into the social or institutional roles of marriage, parenthood, and long-term employment that provide new constraints" (Arnett, 2006, p. 304). There was a paucity of data to indicate whether these adults can achieve the benchmarks of the development stage because not many studies have been done to determine the effects of the physiological, psychological, and sociological challenges they encounter. It was important to understand the transition to emerging adulthood for the individual with PAHIV. This study was needed to provide information on the care and wellness needs of this population to inform nursing and to ensure that these needs are addressed.

Purpose of the Study

The purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of perinatally acquired HIV (PAHIV). The aim of the study was to

determine if the PAHIV emerging adults are meeting the benchmarks of their developmental stage as their unaffected peers and to elucidate their voices to understand their essence of the experience of perinatally acquired HIV.

Research Questions

The following research questions were used to guide the study: What is the emerging adults' lived experience of perinatally acquired HIV (PAHIV)? What benchmarks of the developmental stage are the emerging adults with PAHIV meeting?

Philosophical Underpinnings

Interpretivism

Kuhn (2012) asserted that research, which is based on one or more past scientific achievements that a particular scientific community acknowledges as supplying the foundation for further practice, is in the realm of normal science. He further stated that when these achievements are unprecedented and open-ended and further the research process, they are paradigms. According to Kuhn (2012), research based on alternative methodologies are developed based on a shared paradigm, which shares the same rules and standards of the scientific practice and helps the researcher or students of a scientific community create avenues of inquiry; formulate questions; select methods with which to examine questions; define relevance; and establish or create meaning (Kuhn, 2012; Pajares, n.d; San Diego State University [SDSU], n.d.). This study about the PAHIV emerging adult could have been approached from either the quantitative or the qualitative research paradigm perspective. The qualitative research approach was selected to guide the study because it was the better approach to elucidate the emerging adults' essence of the lived experience of PAHIV.

According to Munhall (1994), the philosophical underpinnings of the qualitative research approach reflects beliefs, values, and assumptions about the nature of human being, the nature of the environment, and the interaction between the two. During the research process, the truth that was sought was that of the participants. The researcher was immersed in the project and brought prior knowledge, biases, and experience to the study, which the researcher bracketed out. The study report is in words, not numbers and statistics (SDSU, n.d.). The qualitative research process is supported by the interpretive, constructionist, and constructivist philosophical stance. The research process allowed the researcher to identify gaps in knowledge and the significance of the study to nursing.

Interpretivism emerged in opposition to positivism to understand and explain human and social realities (Creswell, 2013). It was often linked to the thoughts of Max Weber (1864-1920), who suggested that the human sciences were concerned with Verstehen (understanding). Weber's Verstehen sociology was "the study of society in the context of human beings acting and interacting" (Crotty, 1998, pps. 67- 68). Weber also believed that at any given time, both the natural sciences and the human and social sciences can be concerned with either the nomothetic (nature-law) and the idiographic (human-individual) and that one scientific method should be applied to both forms (Crotty, 1998). According to Weber (1968), sociology is a science that attempts to interpret the understanding of social action to arrive at a casual explanation of its cause and effects (as cited in Crotty, 1998, p. 3).

In an attempt to reject empiricism (natural science) and the sociology (Verstehen) of Weber, Wilhelm Dilthey (1833-1911) proposed that natural reality and social reality are different kinds of realities, and, therefore, their investigation required different

methods (Crotty, 1998). Dilthey believed in the human science (Geisteswissenschaften), which is inclusive of any inquiry about human being, and he described life as a unity—a living nexus; the individual as a whole; and the human life as interconnected with others and with history (Mitchell & Cody, 2013). Dilthey proposed that the lived experience should be the basic empirical datum of the human science and that the researcher is a living being inexorably and unequivocally in and of what is being investigated (Mitchell & Cody, 2013). According to Dilthey, life is a continuous process that manifests itself in the dynamic unity of experience; human beings are individual whole with intrinsic value; and the self is a 'life-unit' that is free yet also determined by history (Dilthey, 1976, 1977b, as cited in Cody, 2013).

Amedeo Giorgi (1932-) and Dilthey (1971) maintained that the person is not "a passive receiver of energy, but rather that his/her behavior reflects intentionality" (as cited in Cody, 2011, p. 225). Giorgi proposed the study of human beings as a person or experiencing participants by contending that the human experience must be understood in the way that it reveals itself and that "understanding life experience requires a focus on meaning within the context of the person's experience of the phenomenon" (Mitchell & Cody, 2013, p. 225). The goal of interpretivism, therefore, is to provide a "culturally derived and historically situated interpretation of the social life-world" (Crotty, 1998, p. 67). O'Reilly (2009) also stated that interpretivism relies on the interpretation or the understanding of the meanings humans attribute to actions.

Constructivism

Constructivism is a worldview, which is often described as interpretivism, where individuals seek understanding of the world in which they live and work. The

constructivist focuses on individual knowledge construction (natural dimension), which describes the individual "engaging with objects in the world and making sense of them" (Crotty, 1998, p. 79; Raskin, 2008). According to Creswell (2013), the individual develops subjective meanings of their experiences, which can be "varied and multiple, leading the researcher to look for the complexity of the views rather than narrowing the meanings into a few categories or ideas" (p. 25). Constructivism is deeply rooted in the evolutionary perspectives and principles, which posit that organisms evolve over time by adapting to their environments (Darwin, 1985, as cited in Raskin, 2008; Raskin, 2008). Organisms develop different features depending on the evolutionary "soup" in which they exist, where both gene and environment shapes that evolutionary development (Raskin, 2008). According to Raskin (2008), evolutionary theory can help constructivism address the issues of realism, cognitivism, relativism, dualism, and social constructionism. The evolutionary epistemology is the knowledge process, which is not limited to the physiological realm but also includes the biological, psychological, and social constitutes of knowledge, which serves to help people make sense of and navigate their surroundings (Campbell 1974, as cited in Raskin, 2008).

Constructivism "describes the individual human subject engaging with objects in the world and making sense of them" (Crotty, 1998, p. 79). The goal of research based on this worldview relies on the participants' views of the situation because their subjective meanings are negotiated socially and historically, being formed through interaction with others (social construction) and through historical and cultural norms (Creswell, 2012). The constructivist researcher addresses the process of interaction among individuals, focuses on the specific context in which people live and work to

understand the historical and cultural setting of the participants, and recognizes that their own background (personal, cultural, historical experiences) shape their interpretation.

The researcher's intent, therefore, is to make sense (interpret) of the meaning others have about a world (Creswell, 2013). According to Crotty (1998), the constructivist "emphasizes the instrumental and practical function of theory construction and knowing ... focuses exclusively on the meaning-making activities of the individual mind" (pp. 57-58). This suggests that everyone's' way of making sense of the world is valid and worthy of respect (Crotty, 1998). Therefore, the qualitative research paradigm and the constructivist underpinning were construed to be most appropriate to guide this study to elucidate the emerging adults' essence of the lived experience of PAHIV.

Constructionism

The constructionist sees knowledge as emanating from relationships (social dimension) being influenced by the cultures and sub-cultures into which one is born and that which provides the meanings that the individual is taught and how they learn through enculturation (Crotty, 1998; Raskin, 2008). Constructionism as an epistemology is a way of understanding how we know what we know, which "embraces the whole gamut of meaningful realities" (Crotty, 1998, p. 54), including those that are socially constructed. It focuses on the collective generation [and transmission] of meaning or on the effect our culture has on us, by shaping the way we see and feel things, which, effectively, shapes our worldview (Crotty, 1998).

Social construction is about the mode of generating meaning as opposed to the kind of object that has meaning. Therefore, the object may not involve a person, as it could be natural (as in the sunset). It is through interaction with human communities that

culture teaches individuals how to see it or whether to see it. Hence, meaningful realities are socially constructed through the process of interpretation and reinterpretation (Crotty 1998). Constructionism is embedded in many theoretical perspectives except for positivism and post-positivism. It is more generally found in symbolic interaction (SI), which often informs methodologies such as ethnography and grounded theory (Crotty, 1998).

Qualitative Research

The qualitative research paradigm was the appropriate approach for this study to elucidate the PAHIV emerging adults' essence of the lived experience of having HIV since conception. Qualitative research is:

A form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live...used to explore the behavior, feelings and experiences of people and what lies at the core of their lives.

(Holloway & Wheeler, 2010, p. 3)

It lends itself to the study of complex human issues that have previously been understood only by way of assumption and focuses on the quality of something rather than the quantity, amount or frequency (Scott Tilley, 2011, pp. 206-207). Qualitative research is an inductive approach where the subjective perspective of the participants provides the meaning for the study as opposed to the perspective of the researcher in quantitative studies (Holloway & Wheeler, 2011, p. 3l). The data in qualitative research have priority; therefore, theoretical frameworks are not predetermined. According to Holloway and Wheeler (2011), qualitative research is context-bound; therefore, researchers need to be context sensitive, often immersing themselves in the natural

setting of the people whose behavior and thoughts they explore, as they develop close relationships based on a position of equality as human beings. This close association with the people and the setting allows the researcher to use "thick descriptions" as they describe, analyze, and interpret the data, giving detailed portrayals of the participants' experiences by uncovering their feelings and the meaning of their actions (Holloway & Wheeler, 2011). The stance of the researcher is the main research tool, which must be made explicit in relation to the study, as a form of self-monitoring (Holloway & Wheeler, 2011).

Scientific assumptions of qualitative research. The major philosophical assumptions regarding scientific knowledge development in qualitative research are ontological, epistemological, axiological, methodological, and rhetorical (Creswell, 2013). These assumptions are based on how humans create social networks and are able to describe retrospective and prospective life events, which allow patterns and themes to surface through intense study of the phenomena (Parse, 2001). These assumptions shape the formulation of the research problem; the research question; and how the information to answer the question are acquired. They are also deeply rooted in the researcher's training and are reinforced by the scientific community that the researcher represents (Creswell, 2013).

Ontological assumption. Ontological assumption refers to the nature of reality and its characteristics. This can be presented as realism, which, "claims that an external world made up of structures and objects exist independently of our representation of it" (Chen, Shek, & Bu, 2011, p. 133). This claim is consistent with the objectivist perspective and relativism, which "suspects the 'out-there-ness' of the world and

highlights the diverse interpretations of it" (Chen, et al., 2011), which is consistent with the constructionist/constructivist perspective. According to Chen et al. (2011), with relativism:

Even if a reality described by the realist position exists, it is impossible for us to access it ... the only thing accessible are our different representations of the world, and none of them is more 'true' than the other (p. 133).

The ontological assumption of human science and invariably constructivism, as explicated by Dilthey and Giorgi, considers "human beings as a unitary whole in continuous interrelationship with their dynamic, temporal, historical, and cultural world" (Mitchell & Cody, 2013, p. 226). From the realist perspective, ontological assumptions consider human experience as preeminent and fundamental, and reality as a complex of experiences (thinking, feeling, and willing). In qualitative research, multiple realities are embraced (the researcher, the participants, and the readers of the research), and each has different realities (Mitchell & Cody, 2013). In this study, the participants' account of their experience of PAHIV were taken and reported as expressed by the participants, because it was their essence of the experience that were being sought and not that of the researcher or what was present in the literature as expected norms.

Epistemological assumption. Epistemological assumption refers to assumptions about knowledge and how it can be obtained. The focus is "on the relationship between the 'knower' (research participants) and the 'would-be knower' (researcher)" (Chen et al., 2011, p. 133). From the relativist perspective, there is no pure experience, and the aim of the research is to explore the relationship of culture and other resources in the construction of different versions of experiences within varied contexts (Chen et al.,

2011). Subjectivism is the epistemological view that knowledge is generated from the mind without reference to reality. It holds that the metaphysical world is a figment of our imagination; and because reality is an aspect of our mind, our mind is affected by our reality (Landauer & Rowlands, 2010). Chen et al. (2011) reported that "reality is not independent of human perceptions and beliefs" (p. 133); therefore, the inquiry cannot avoid being influenced by the investigator's value(s).

Knowledge is known through the subjective experience of people; therefore, the focus is "on the specific context in which people live and work, in order to understand the historical and cultural settings of the participants" (Creswell, 2009, p. 8; Creswell, 2013). According to Parse (2001), the epistemological assumptions are "the nature of the research for the qualitative descriptive method which focuses on social connections, interrelationships, life events, and other matters concerned with the social sciences" (p. 58). The epistemological assumption was observed in this study by the researcher respecting, acknowledging, allowing, and accepting the participant's description of their experience of PAHIV, without having to give reference or qualification of their experience. Such information was the basis on which new knowledge regarding the lived experience of perinatal HIV was generated in this study.

Axiological assumption. Axiological assumption refers to the value-laden nature of the information gathered from the field by researcher and the participants. In heuristic research, the researcher must make disciplined and systematic efforts to set aside their prejudgments (epoche) to launch the study "free of preconceptions, beliefs, and knowledge of the phenomenon from prior experiences and professional studies" (Moustakas, 1994, p. 22). Qualitative researchers need to be reflective in their writings

by being conscious of the biases, values, and experiences that they bring to the study, thereby satisfying one of the characteristics of a qualitative research, of making their position explicit (Hamersley & Atkinson, 1995). In reflexivity, the researcher give details of their experience with the phenomena being explored and discusses how their past experiences may potentially shape the findings, the conclusions, and the interpretations of the study (Creswell, 2013). In this study, the researcher discussed prior experience with or knowledge of the phenomenon in an experiential context section in the literature review and maintained a reflexive journal that documented and tracked experiences, thoughts, and values that was brought to the study, to bracket self and maintain the integrity of the research process.

Rhetorical assumption. Rhetorical assumptions are sometimes informational, evolving decisions, or personal voice. According to Creswell (2013), the writing of a qualitative text cannot be separated from the author, how readers receive it, and how it impacts the participants and the site under study. The researcher shapes the writing that emerges, as it reflects their own interpretation, based on their cultural, social, gender, class, and personal politics, which they bring to the research (Creswell, 2013).

According to Tierney (1995), all writers write for an audience, and in the case of a qualitative researcher, that audience may be a colleague, those involved in the interviews and observations, policymakers, and the public (as cited in Creswell, 2013). Gilgun (2005) also stated that, [writings] "are co-constructions, representations of interactive processes between the researchers and researched" (p. 258; Creswell, 2013). This may also impact the reader whose interpretation of the account may be different from both the author and/or the participants (Creswell, 2013).

In contrast to quantitative inquiry where the findings from studies are reported in numerical values, charts, tables and graphs, in qualitative research, the rhetorical assumption exhorts the researcher to write and report the study in the language and style of a qualitative study, which includes text, split page writing, "theatre, poetry, photography, music, collage, drawing, sculpture, quilting, stained glass, performance and dance" (Creswell, 2013; Gilgun, 2005, p. 259). Research findings may also be presented in the form of a general structure or a case synopsis, but the language shapes the qualitative text, as the words used reveal how we perceive the needs of our audience (Creswell, 2013). The research is often written in the first person, indicating an involved, even passionate researcher, and possibly an appeal is made for action to correct a social ill (SDSU, n.d). The findings of this study were determined by the essences derived from the participants' expressions, in the forms of pencil drawing, song, poetry, picture, music, continuous prose, inspirational Bible verse tattoo, body mapping art, or similar art forms.

Methodological assumption. Methodological assumptions are the procedures of qualitative research, which are characterized as inductive from the ground up, emerging, and shaped by the researcher's experience in the collection and analysis of data. The research question may change in the middle of the study to better understand the research problem. This requires a modification of the data analysis strategy to accompany the new question. The data analysis follows a path to develop detailed knowledge of the phenomenon being studied (Creswell, 2013). According to Parse (2001), two qualitative descriptive approaches exist: (a) the exploratory study, which is an investigation of the meaning of a life event for a group of people and (b) the case study, which is an

investigation of one social unit. This study took the form of an exploratory descriptive study that explored the emerging adults' lived experience of perinatally acquired HIV.

Phenomenological Research

Phenomenology is the study of the individual's lifeworld, which is aimed at gaining a deeper understanding of the nature or meaning of everyday experiences, or the essence of the experience, which is attentive practice of thoughtfulness (van Manen, 1990; Munhall, 2007). It is an experience rather than a concept, category, or theory. It is the science of examples that permits the reader to see the deeper significance or structure of the lived experience as described by the participants (van Manen, 1990; Munhall, 2007). The history of phenomenological research is characterized by changes in the scientific process related to the changing views of its leaders, which occurred in different phases (preparatory, Germany, France, others). Phenomenology can be traced back to the Buddhist philosopher and to Immanuel Kant. The preparatory phase involved Franz Brentano (188-1917) and his student Carl Strumpf (1848-196). Brentano's goal was to reform philosophy to provide answers that organized religion was not able to answer and to make psychology scientific by basing it on descriptive psychology (Cohen, Kahn & Steeves, 2000).

Strumpf was the founder of experimental phenomenology, which uses experimentation to discover the connections between the elements of what is being perceived (Munhall, 1994; Strumpf, 1890/1912, as cited in Cohen et al., 2000). Strumpf introduced phenomenology in the last half of the 19th century and was considered the forerunner of the movement. Strumpf also introduced the idea of inner perception

(immediate awareness of psychological phenomena: emotions; infallible self-evidence) versus unreliable introspection (self-observation; intentionality) (Munhall, 1994).

Later in the 1900s, many activities were generated in the German Phase of the history of phenomenology, at the University of Gottingen. These activities occurred among a group of academic philosophers, as a reaction to the sociocultural and political forces in Germany. This phase included philosophers such as Edmund Husserl (1859-1938); his student and assistant Martin Heidegger (1889-1976), and Hans-George Gadamer (1900-2002). They argued against the concept of science and scientific methods as the answer to all questions of the natural world; human problems; and the only route to truth. Phenomenology was a search for a methodology that would put human science (Geisteswissenschaften) on the same footings as the science of nature (Natrwissenschaften) (De Chesnay, 2015).

Edmund Husserl (1859-1938)

Husserl is considered the central figure in the development of the phenomenological movement, which represented a change in ideas involved in the philosophy both across and within philosophers (Cohen, Kahn, & Steeves, 2000). Husserl's real or realist phenomenology is descriptive psychology that is based on the first edition of his book *Logical Investigations*, which is an analysis of the intentional structures of mental acts as they are directed towards real and ideal objects (Cohen et al., 2000). Husserl's ideas also included the concept of things or phenomena as acts of consciousness, transcendental, or constitutive phenomenology.

According to Husserl, phenomenology can only begin after the transcendentalphenomenological reduction (TPR) has occurred, which is different from all other phenomenology (Schmitt, 1959). Consequently, before the phenomenological method can be employed, the phenomenologist must first understand and practice the transcendental-phenomenological reduction (Schmitt, 1959, p. 238). According to Schmitt (1959), Husserl's description of TPR was not straightforward and was left open to different interpretations. In TPR, "one is led to question what had previously seemed self-evident ... what we had previously taken for granted ... what seems most familiar?" (Schmitt, 1959, p. 238). This involves a change in attitude, which requires the individual to view the phenomena through new lens. Husserl described this process in many ways, including "bracket the objective world" (Schmitt, 1959, p. 239).

Transcendental and eidetic science of consciousness, also called eidetic reduction or bracketing, was generated from Husserl's 1913 *Ideas*, which took the intuitive experience of phenomena as the starting point and tries to extract the generalized essential features of experience and the essence of what is experienced from it (Mastin, 2008). Eidetic is the adjective of eidos the alternative form for ideas, which Husserl used to designate universal essences (Cohen et al., 2000). Bracketing means to bracket out an individual's prejudices and personal commitments to understand the meaning as they are for those describing the experience. This was based on Husserl's mathematics background where an expression was placed in brackets with a plus or minus sign before it, giving it a different value (Schmitt, 1959). Hence, phenomenologists who have bracketed themselves becomes a disinterested spectator by changing their attitude from a previously experienced reality to a phenomenon (Schmitt, 1959). Husserl called this a "naive" attitude, where an individual believes that the perceived objects are real and that one lives in a real world. That belief is further placed into suspension and not used,

leaving the individual with a world of phenomenon (Schmitt, 1959). The "I" that transforms this world into a phenomenon is the transcendental ego, which is aware of itself transforming the world, yet not being subjected to the same transformation, being devoid of any content that could be studied or explicated (Schmitt, 1959).

According to Schmitt (1959), transcendental-phenomenological reduction does not limit experience. Consequently, the phenomenologist is not required to turn away from the whole experienced reality or actuality; they are only required to suspend judgment regarding the reality and validity of what is experienced (Schmitt, 1959). Therefore, transcendental "uncovers the ego for which everything has meaning and existence ... phenomenology transforms the world into mere phenomenon ... and reduction leads us back to the source of meaning and existence of the experienced world in so far as it is experienced" (Schmitt, 1959, p. 240).

Epoche first appeared as a synonym for reduction; however, in his last writings Husserl differentiated between the two terms: epoche is the change of attitude i.e., the suspension of all natural beliefs in the objects of experience; which is a precondition for reducing the natural world to a world of phenomena (Schmitt, 1959). "Transcendental-phenomenological reduction covers both the epoche and the reduction" (Schmitt, 1959, p. 240). Husserl's phenomenology is a reflective enterprise, where reflection may occur in the mind as well as outside of the mind. Reflection occurring in the mind involves the scope of reflection about oneself, which includes "facts about one's relations to others and about oneself which had before remained unnoticed or had appeared irrelevant" (Schmitt, 1959, p. 240). Reflection occurring outside of the mind, as in the case of a successful revolutionary who is required to think but not necessarily to reflect (Schmitt,

1959). Husserl also introduced the notion of intersubjectivity, which refers to a plurality of subjectivities that make up a community sharing a common world. The lifeworld as, "The world of the everyday experience is not immediately accessible to us in our 'natural attitude.' The natural is what is original and prior to critical and theoretical reflection" (Cohen et al., 2000).

Martin Heidegger (1889-1976)

Heidegger criticized and expanded on Husserl's phenomenology. Heidegger was primarily concerned with being and time and he is considered the prime instigator of modern Hermeneutics. His expansion on the definition of hermeneutics included three different ideas: the basic structure of being; the working out of the conditions on which the possibility of any ontological investigation begins; and an interpretation of dasein being (the human capacity to comprehend our own existence; the non-dualistic human being engaged in the world) (Heidegger, 1962, p. 7-38, as cited in Cohen et al., 2000; Mastin, 2008). According to Heidegger, philosophy is not a scientific discipline—it is more fundamental than science, which is one way among many of knowing the world with no specialized access to knowing the truth (Mastin, 2008). Heidegger viewed phenomenology as a metaphysical ontology rather than the epistemological focus of Husserl. Heidegger introduced hermeneutic, interpretive, existential phenomenology, which is a combination of phenomenological method with the importance of understanding man in his existential world. According to Heidegger, the observer cannot separate himself or herself from the world and therefore cannot have the detached viewpoint of Husserl (Mastin, 2008).

The French phase (third phase) of the development of phenomenology began with the movement of Heidegger's papers to the Louvain shortly after his death. During this time, Dasein analysis or the existential-analysis movement was being developed among therapists (Cohen et al., 2000). The key figures were Gabriel Marcel (1889-197), Jean-Paul Sartre (1905-1980), and Maurice Merleau-Ponty (1908-1961). Marcel believed that phenomenology provides the avenue to explore the ontological or existential questions of being in the world. Sartre, the existential philosopher, believed that individuals are condemned to freedom; and Merleau-Ponty believed in the primacy of perception, which purports that individuals are condemned to meaning (De Chesnay, 2015). These philosophic views of phenomenology have since been used to develop research traditions in several disciplines including nursing (Cohen et al., 2000).

The major constructs of phenomenology are consciousness, embodiment, natural attitude, and experience and perception. Consciousness is a "sensory awareness of and response to the environment" (Munhall, 1994, p. 14). It is a unity of the mind and body in acquiring knowledge, where the subjective (body) [being in the world] and the objective (mind) [quest for reliability & validity] equates consciousness. Therefore, the unity of the mind and the body becomes a means of experiencing the world (Munhall, 1994; Merleau-Ponty, 1962-1964, as cited in De Chesnay, 2015). Embodiment is an awareness of being in the world, where the individual's perception or consciousness is based on their history; knowledge of the world; and their openness to the world (Munhall, 1994). According to De Chesnay (2015), it is through consciousness that we are aware of being in the world, but it is through the body that we gain access to the world. Natural attitude is "a mode of consciousness that espouses interpreted experience" (Munhall,

1994, p.15), such as the influence of others (proceeding generations) on our perception (Schutz, 1970, as cited in De Chesnay, 2015). Experience and perception are our original modes of consciousness, which gives an individual access to experience the world. Perception depends on the context in which the experience occurred. It is not what is happening but what is perceived as happening because it is the perception of the experience that matters and not what may appear to be more truthful (Munhall, 1994).

Heuristic Research Approach of Clarke Moustakas (1923-2012)

The qualitative, descriptive, and heuristic approach are fitting philosophies to explore the PAHIV emerging adults' experience of having HIV since birth because it allows the researcher an understanding of the life world of the PAHIV emerging adults as they experience it. Heuristic comes from the word *heuriskein*, meaning to discover or to find (Moustakas, 1990). According to Moustakas (1990), "Heuristic is a way of engaging in scientific search through methods and processes aimed at discovery" (p. 15). The heuristic scientific process of discovery is a process of self-search, self-dialogue, and self-discovery between the researcher others, which is aimed at finding the underlying meanings of important human experiences. This process leads to new images and meaning regarding the human phenomena, as well as the realizations relevant to the researcher's own experience and life (Moustakas (1990). The heuristic research process is a way of being informed as well as a way of knowing, which begins with a question or problem that creates a personal challenge or puzzlement to the researcher, to understand themselves and the world in which the phenomenon occurs (Moustakas, 1990).

The heuristic research design and methodology embraces belief, values, theory concepts, processes, and methods that are essential to the understanding and conducting

of heuristic research discovery (Moustakas, 1990). The concepts are: (a) identifying with the focus of the inquiry; (b) tacit knowing which underlies all other concepts in heuristic research; (c) focusing which enables the researcher to determine the core themes that constitute an experience; (d) indwelling which is turning inward to seek a deeper, more extended comprehension of the nature or meaning of a quality or theme of the human experience; (e) intuition which is an internal capacity to make inference about immediate knowledge without logic or reasoning; (f) self-dialogue where the researcher allows the phenomenon to speak directly to his experience and unfold its multiple meanings; (g) internal frame of reference which is the basis of the knowledge attained through tacit, intuitive, or observed phenomena or the knowledge deepened through indwelling, focusing, self-searching, or dialogue with others (Moustakas, 1990).

The heuristic research processes or method of data analysis has six phases: (a) the initial engagement where the researcher develops a passionate concern for a phenomenon and gathers all the data from one participant; (b) immersion during which the researcher enters into timeless immersion with the data of an individual participant until it is fully understood; (c) incubation where the researcher set aside the data and engages in other unrelated activities to facilitate the awakening of fresh energy and perspectives; (d) illumination when the researcher returns to the original data of the individual participant to verify that the individual depiction of the experience fits the data and that if it contains the quality and themes essential to the experience, he or she may then share this depiction with the participant for affirmation; (e) explication where the researcher again enters into an immersion process with intervals of rest until the universal qualities and themes of the experience are thoroughly internalized and understood; (f) develops a composite

depiction that represents the common qualities and themes that embrace the experience of the participants; and (g) creative synthesis where the researcher develops an esthetic rendition of the themes and essential meanings of the phenomenon and new knowledge are specified and recommended for further studies (Moustakas, 1990; Parse, 2001).

Relationship of Phenomenology (Heuristic Research Approach) to this Study

The phenomenological research process facilitates a deeper understanding of the nature or meaning of the everyday experiences of the perinatally acquired HIV (PAHIV) emerging adult, or the essence of their experience of having HIV since birth. According to Douglas and Moustakas (1985), phenomenology "attempts to reveal the actual nature and meaning of an event, perception, or occurrence, just as it appears" (p. 43). Subjective data are transformed into objective accounts of reality; and phenomenology requires an initial stepping back from various suppositions and prior beliefs that the researcher may hold (Douglas & Moustakas, 1985). The authors further stated that heuristic research shares some similarities (revelation of meaning and intense scrutiny of data) with phenomenology but differs in a number of ways as follows:

- Phenomenology encourages detachment from the phenomena being investigated, while heuristics encourages connectedness and relationship.
- 2. Phenomenology permits the conclusion of the study with definitive descriptions of the structure of experiences, while "heuristics leads to depictions of essential meaning and portrayal of the intrigue and personal significance that imbue the search to know" (Douglas & Moustakas, 1985).
- "Phenomenological research generally concludes with a presentation of the distilled structures of experience, heuristics may involve reintegration of

derived knowledge that itself is an act of creative discovery, a synthesis that includes intuition and tactic understanding" (Douglas & Moustakas, 1985, p. 43).

4. "Phenomenology loses the person in the process of descriptive analysis; in heuristic, the research participants remain visible in the examination of the data and continue to be portrayed as whole persons. Phenomenology ends with the essence of experience, heuristic retains the essence of the person in experience" (Douglas & Moustakas, 1985, p. 43).

The organized and systematic feature of the heuristic research process was appropriate for the investigation of the emerging adults' essence of the experience of living with HIV since birth because it is an organized and systematic form for the investigation of the human experiences. This allowed the researcher to interact with the participants in their personal space (cognitive, home, library, physician's office, etc.) to gain an understanding of their life world as they experienced it (Moustakas, 1990). Heuristic research emphasizes connectedness and relationship between the researcher and the phenomenon, which leads the researcher to "a depiction of essential meanings and portrayal of the intrigues and personal significance" (Douglas & Moustakas, 1985) that ties them to the study. This process involved the reintegration of derived knowledge, incorporating intuition and tacit understanding (Moustakas & Douglas, 1985).

Throughout this heuristic research process, the participants remained visible in the examination of the data, continually being portrayed as a whole person, and retaining their essence of the experience (Moustakas & Douglas, 1985).

Significance of the Study

There is paucity of information in the literature regarding the perinatally acquired HIV (PAHIV) population, the developmental stage of emerging adulthood and invariably, the PAHIV emerging adult. A significant number of the PAHIV emerging adults were exposed to ART in utero, and the effects of such exposure are not well understood. Hence, the essence of their experience with HIV exposure since in utero and the challenges that they may encounter needed further investigation, to determine if they were meeting the benchmarks of their developmental stage and to provide evidence-based, developmentally appropriate opportunities to make their lives as academically, economically, and socially comparable to their unaffected peers. This study gives voice to the PAHIV emerging adult by providing a perspective on their essence of the lived experience of having HIV since birth.

Significance of the Study to Nursing

HIV/AIDS and perinatally acquired HIV (PAHIV) is a global problem, and nursing as a discipline with its global reach can affect global health outcomes because nursing plays a vital role in the health and well-being of people living with HIV (PLWHIV) globally, particularly the PAHIV emerging adult. Nurses have been at the forefront of providing care and often have been the most consistent care provider to this population since the disease first emerged. Consequently, nursing should be invested in the health outcomes of this population. This may be achieved by nursing taking a major role in strengthening the global health workforce in accordance with the WHO's 2030 goals as outlined in The Global Strategy on Human Resources for Health (HRH):

this HRH; the health outcomes of people living with HIV/AIDS (PLWHIV) in general; and more specifically the PAHIV emerging adult, through nursing education, nursing practice, nursing research, and public health policy. The implications for nursing involvement are explained below.

Implications for Nursing Education

The availability of science and tools for prevention, diagnosis, and treatment of the disease has not only decreased the rate of transmission of the virus (UNAIDS, 2016); but it has also allowed those affected to be living longer with what is now considered a chronic disease. Consequently, more PLWHIV will access healthcare services, and therefore, the average nurse will be required to provide care to patients with the disease at some point in their career. Nursing may also become instrumental in meeting the projected needs of approximately 40 million new health and social care jobs globally by 2030. These may be accomplished by increasing the nurse workforce to bridge the gap in the over 18 million additional health workers which will be needed, primarily in low-resource settings, to cover the broad range of health services required to ensure healthy lives for all (WHO, 2016, p. 12).

Nursing should be prepared to meet these challenges through nursing education. The education and preparation of nurses to function at their full potential at all levels of nursing care, may be accomplished through the inclusion of HIV/AIDS care in all nursing curriculum and the requirement of HIV/AIDS care continuing nursing education on an intermittent basis for already established nurses. These measures would prepare new nurses and make all available nurses qualified to provide HIV/AIDS specific care and to meet the HRH 2030 targets in part. Additionally, the availability of a larger and more

adequately prepared nursing workforce is important because of the significant role nursing plays in the health and wellbeing outcomes of PLWHIV and others globally.

Implications for Nursing Practice

The results of this study may inform the implementation or improvement of nursing protocols of care to assess the social needs of the perinatally acquired HIV (PAHIV) emerging adult. The successful implementation of such would ultimately improve their health outcomes, their self-efficacy, and their access to social services. Changing nursing protocols of care to assess social needs may require designing questions to incorporate in the patient history and physical assessment. These questions should address the PAHIV emerging adults' involvement in their community, extracurricular activities, life goals, plans for achieving such goals, and their state of mind in relation to achieving such goals. The social history assessment should also require frequent updating.

Nursing practice may also develop and implement educational programs for the PAHIV emerging adult, to empower members of this population, by improving their health knowledge and self-efficacy for limiting health risk behaviors. According to UNAIDS (2013), access to comprehensive sex education has been effective in delaying sexual debut and increasing condom use among young people who are sexually active. Absence of such educational programs undermines the efforts to protect young people from acquiring HIV. The results of this study may provide the background on which developmentally appropriate educational programs are designed to address the challenges that the PAHIV emerging adult may encounter.

Implications for Nursing Research

The paucity of information related to this population and phenomenon requires that further studies utilizing various methodologies be conducted to gain a broader perspective of the challenges that the perinatally acquired HIV (PAHIV) emerging adult encounters and to provide the information on which evidence-based interventions are developed. The results of this study may provide new knowledge on the PAHIV emerging adult; their essence of the experience of PAHIV; and the perspective of a new researcher. These may be the catalyst for further studies addressing the challenges that the PAHIV emerging adult may encounter; and informing such evidence-based interventions.

Implications for Health and Public Policy

Nursing may influence global health and the health of the perinatally acquired HIV (PAHIV) emerging adult through public policy by translating the findings of this research study and others into language that policy makers may understand to facilitate policy decisions. Nursing may also lobby local, state, and federal representatives for their support in efforts that may improve the health outcomes of this population. One such effort is the Patient Protection and Affordable Care Act [PPACA] (2010), also known as The Affordable Care Act [ACA], which requires healthcare coverage for all Americans. The benefits of universal healthcare coverage for all Americans are consistent with the Healthy People 2020 vision of "a society in which all people live long, healthy lives" (USDHHS, 2014), and the Global Strategy on Health Workforce, which is "part of the broader concept of universal access to health care" (WHO, 2016b, p. 7), in improving the health and wellbeing of the global population.

There are states, including Florida, that have not taken full advantage of the provisions of the ACA (2010), and therefore, they are not qualified for federal funding, which leaves millions of residents without adequate health care coverage. Additionally, the ACA (2010) is in jeopardy of being repealed without replacement with adequate health insurance coverage. Repealing the ACA (2010) without adequate replacement would be a setback for many Americans, including PAHIV emerging adults, who require healthcare coverage to maintain treatment and care coverages to sustain their overall health and well-being. Moreover, universal healthcare in all nations is one of the mandates of the Global Strategy on Human Resources for Health initiative to improve global health outcomes (WHO, 2016). These are opportunities for nursing to influence policy decisions on health insurance coverage, locally, nationally, and globally, in the effort to improve the health outcomes and wellbeing of people with chronic illnesses including the PAHIV emerging adult. The results of this study provide information that may allow nursing to collaborate with other partners to inform policy decisions in the many efforts against HIV/AIDS transmission and treatment, locally, in the U.S., and globally.

Scope and Limitations of the Study

This study explored the emerging adults' lived experience of perinatally acquired HIV (PAHIV), to gain an understanding of their essence of the experience of living with HIV since birth. This was achieved by gaining the perspective of 15 emerging adults (participants) from the South Florida region. The sample methods employed were purposive and snowball sampling. The information obtained was self-reported by participants. Limitations of this study related to the sampling method, which may

contribute to the results of the study not being transferable to other populations and potential bias from the participant selection process, included participants' self-reporting, which may result in selective memory, and the researcher's inexperience with the research process. Consequently, frequent communication with committee chair, who is experienced in research, was made to ensure the trustworthiness of the research process.

Chapter Summary

This chapter discussed the background of HIV/AIDS; PAHIV; emerging adulthood; and the HIV/AIDS epidemic from a global, national (U.S.), and local (Florida) perspective. The statement of the problem facing the PAHIV emerging adults, which give rise to the purpose of this study and the research questions, were presented. The philosophical underpinnings of the research paradigm and method chosen to guide the study and the related concepts and scientific assumptions were explored. The importance of conducting the study to the PAHIV emerging adult, the significance of the study to the discipline of nursing and the study's implications for nursing education, nursing practice, nursing research, and public health policy, as well as the scope and limitations of the study were discussed. Chapter Two will follow with a review of the literature.

CHAPTER TWO

REVIEW OF LITERATURE

The purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of perinatally acquired HIV. A literature review in a qualitative study assists the researcher in identifying works already completed and to further highlight the gap in knowledge related to the phenomena being studied. To achieve this purpose, a search of relevant literature across disciplines was conducted to explore the phenomenon of perinatally acquired HIV. Using PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Science Direct databases, the following search terms were used: perinatal HIV-infection, emerging adult, and perinatally acquired HIV (PAHIV) emerging adult. Citations were limited by language to English and by subject to exploration of the concept. A limitation was further imposed to find literature published since 2012, with classics sort by reviewing citations in the published works. Additionally, 23 research studies were reviewed in which the PAHIV emerging adult was explored. As a result of the literature review, the following content areas were identified: historical context, physiological challenges, psychological challenges, and sociological challenges that the PAHIV emerging adult may encounter. Finally, the experiential context is discussed.

Historical Context

Global Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome

Epidemic

The first cases of HIV infections in the United States were diagnosed in June 1980 (KFF, 2013). It has become a global problem, affecting individuals from every

developmental stage across the life span, gender, social, and economic strata. As of 2017, over 76.1 million people worldwide have been infected with the virus, since it was first discovered, of which over 35.0 million have died (WHO, 2016a; WHO, 2016b; WHO, 2017, UNAIDS, 2017). The first meeting of global significance to HIV/AIDS, was held on November 22, 1983, by the World Health Organization (WHO) in collaboration with other partners, to assess the global AIDS situation and to begin international surveillance (AIDS.Gov, 2016). Subsequent to this first meeting, the WHO launched the Global Program on AIDS on February 1, 1987. This program was the global strategy on the prevention and control of AIDS, which marshaled the support of every nation in the world, including the developing and industrialized world. Every country is required to have a national AIDS program (Mann, 1987). Globally, HIV/AIDS continues to be a major public health issue. In 2016, there were 1.8 million new cases; an estimated 36.7 million people were living with the disease; and 1.0 million people died from the disease or its complications (WHO, 2016a; WHO, 2016b; UNAIDS, 2017). Sub-Saharan Africa (Eastern, Southern, Western, and Central), which bears the greatest burden, accounted for 25.5 million people (69%), which is approximately two-thirds of all new HIV infections globally (WHO, 2016b; UNAIDS, 2017).

In 1997, the global number of new HIV infections peaked at 34.7 million people and then decreased steadily to its lowest levels at 1.8 million people in 2016, while the number of people living with HIV (PLWHIV) continued to increase steadily to its peak of 36.7 million people in 2016, and AIDS-related death peaked between 2004 to 2005 and then decreased steadily to its lowest level at 1.0 million people in 2016 (WHO, 2016b; UNAIDS, 2017). According to the WHO (2016b), between 2000 and 2015, new

HIV infections fell by 35% and in 2016 there was a further decrease of 0.1 million (0.5%) (UNAIDS, 2017). For the corresponding period. In 2015, AIDS-related deaths fell by 28% globally (WHO, 2016b) and further decreased by 0.1 million (0.9%) in 2016 (UNAIDS, 2017). In all regions of the world, there was an increase in the number of PLWHIV in 2015 when compared with 2010, and the number of new cases either decreased or remained the same except in the Middle East and North Africa where the number of new cases in 2010 and 2015 were 20,000 and 21,000, respectively. However, in 2016, there were only 18,000 new cases of HIV in this region, which represented a 14% decline in new HIV cases (UNAIDS, 2017).

Globally, there are inconsistencies in the data collection and reporting systems which combines most children who were perinatally infected "with behaviorally infected adolescents and youths, making it difficult to keep track their outcomes" (Sohn & Hazra, 2013). However, the global incidence of new infections among youths (< 15 years) has decreased significantly from 2008 when 430,000 children were born with HIV (WHO, 2016b), compared to 2012, when there were only an estimated 260,000 new infections in children worldwide (WHO, 2013). In 2016, there were 160,000 new cases of HIV among the 0-14 age group (UNAIDS, 2017). In 2015, there were 1.8 million youths (< 15 years) living with the disease, which declined from 2012 when approximately 2.1 million adolescents worldwide were living with HIV/AIDS globally (WHO, 2013; 2016c). This trend may be attributed to a decline in the number of HIV transmission from mother to child combined with an increase in the life expectancy of the PAHIV infant.

The number of youths (15-19 years) living with HIV globally steadily increased between 1985 and 1998, when the total number of youths (15-19 years) living with HIV

peaked at approximately 1,050,000 youths. During this time, the number of PAHIV youths (15-19 years) remained steady. Since then, there have been a significant increase in the number of PAHIV youths (15-19), although the total number of youths (15-19) living with HIV declined from 1998 to approximately 800,000 in 2006. After 2006, there was a steady increase in the total number of PAHIV youths (15-19 years), while the number of youths (15-19 years) who acquired HIV other than perinatally declined. Hence, the PAHIV youths accounted for a larger proportion of the increase with the larger percentage increase and number of PAHIV youths (15-19) occurring in 2015 (UNAIDS, 2016).

Between 2005 and 2012, HIV-related death among adolescents increased by 50%, while the global number of HIV-related deaths decreased by 30% (WHO, 2013). This increase in HIV-related death among adolescents was "attributed to poor prioritization of adolescent in national HIV plan; inadequate provision of accessible and acceptable HIV testing and counseling (HTC) and treatment services, and lack of support for adolescents to remain in care and adhere to ART" (WHO, 2013, p. viii). According to the WHO (2013), "access to and uptake of HTC by adolescents (especially those who are members of key populations) is lower than for many other groups," which leaves them at a disadvantage in terms of seeking and being linked to HIV prevention, treatment, and care services (WHO, 2013).

Antiretroviral therapy (ART) was introduced in 2003, at which point AIDS-related deaths were still increasing, peaking between 2004 and 2005, after which these rates started to decline in 2006. Consequently, as the number of PLWHIV and on ART increases, the number of AIDS-related death decreases. These trends began after several

initiatives were put in place. Examples of these initiatives include the introduction of highly active antiretroviral therapy (HAART) in 1996, which was funded by UNAIDS; The United Nations General Assembly Special Session on HIV/AIDS in 2001; The Global Fund to Fight AIDS, Tuberculosis, and Malaria, which was established in 2002; The President's Emergency Plan for AIDS Relief (PREPFAR) founded by then President George Bush in 2003 and renewed by President Barack Obama in 2008; and the HIV Prevention Network (HPTN) 052 trial in 2011, which shows that drug treatment also prevents transmission. Additionally, in 2011, the United Nations Political Declaration on HIV and AIDS set its target of 15 million people on ART globally by 2015. The target was reached in 2014 and exceeded in 2015 by over 2 million people, recording over 17 million people on ART at the end of 2015 (WHO, 2016a).

According to UNAIDS (2016), scientific knowledge and experience exists globally to tailor options for people with HIV according to their lives and the communities in which they live. This, in part, can be attributed to low and middle-income countries taking the challenge to invest in the AIDS response in their communities. There was an increase in domestic investment of over 46% between 2010 and 2015, reaching a total of \$10.8 billion in 2015. The total annual investment globally was approximately \$19.0 billion from all sources, including the U.S. contribution through PEPFAR; the Global Fund to Fight AIDS, Tuberculosis, and Malaria; and other bilateral and multilateral donors (UNAIDS, 2016). These sources of funding to low and middle-income countries demonstrates the shared efforts in the fight against HIV/AIDS in these countries between 2000 and 2015. Domestic investments (public and private) accounted for the largest portion of investments in these countries each year, in addition to

investments from the United States (Bilateral); the Global fund to Fight AIDS, Tuberculosis, and Malaria; other bilateral governments; and other multilaterals and foundations. The total investments by all partners have increased progressively from US\$4.9 billion in 2000 to its largest amount of US\$19 billion in 2015. Other global efforts to end new HIV/AIDS infection and improve the quality of life of those who already have the virus include *Get on the Fast-Track; The Lifecycle Approach to HIV/AIDS; The Global Strategy on Human Resources for Health (HRH): Workforce 2030; The ALL IN! To End Adolescence AIDS; and The Sustainable Development Goals (SDG) – 2020, among other programs.*

According to the WHO (2016a), the international community's commitment to end the AIDS epidemic as a public health threat by 2030, is an ambitious target of the 2030 Agenda for Sustainable Development, which was adopted by the United Nations General Assembly in September 2015. At the 69th World Health Assembly; on December 1, 2017 (World AIDS Day); the new Global Health Sector Strategy on HIV for 2016-2021 was adopted (WHO, 2018). This new strategy includes five strategic directions to guide priority actions that each country and the WHO should undertake over the next six years (WHO, 2018). The five strategic directions were: (a) information for focused action – know your epidemic and response; (b) interventions for impact – covering the range of services needed; (c) delivering for quality – covering the populations in need of services; (d) financing for sustainability – covering the cost of services and; (e) innovation for acceleration – looking towards the future (WHO, 2018).

United States Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome Epidemic

The first cases of HIV infections in the United States were diagnosed in 1980. Since then an estimated, 1.8 million people in the U.S. have been diagnosed with the disease, and 658,992 have died from the virus or other related diseases (Kaiser Family Foundation [KFF], 2013). Although the incidence of HIV in the U.S. has decreased, it has remained steady at approximately 50,000 new cases each year (CDC, 2014b; CDC, 2015a; 2015b). Presently, more than 1.2 million people in the United States are living with HIV (CDC, 2015a, p. 1). In 2009, an estimated 10,834 persons who were diagnosed when they were under the age of 13 were living within 46 of the U.S. territories. Of this amount, 9,522 (88%) were infected perinatally (CDC, 2015b). There has been a 90% decline in the number of PAHIV infections in the United States since the 1990s (CDC. 2014b); however, in 2010, 162 or 75% of children under the age of 13 who were diagnosed with HIV were infected perinatally (CDC, 2014b). At the end of 2012, an estimated 7,300 adolescents and 33,334 emerging adults were living with HIV in the U.S. (Florida Department of Health, 2015).

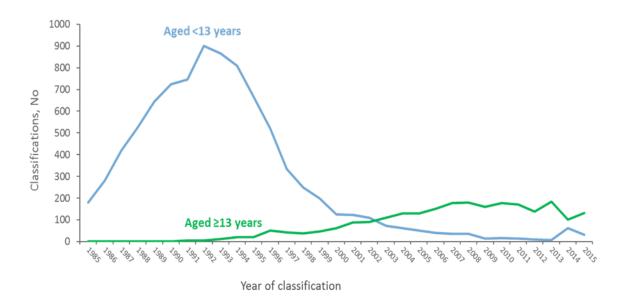


Figure 9. The number of persons with PAHIV infection in the U.S. and six dependent areas 1985-2015 (Wright, 2018, adapted from UNAIDS, 2016).

From 1985 through 2015 the number of persons with PAHIV infection in the U.S. and six dependent areas, who were classified as stage 3 (AIDS) is illustrated in Figure 9 above. The annual numbers of PAHIV children, who were classified as stage 3 (AIDS) when they were less than 13 years of age is represented by the blue line (CDC, 2018). This indicates that the number of children less than 13 years of age with PAHIV and classified as stage 3 (AIDS) has been decreasing since 1992. However, in 2014, there was an increase to 61, which has been attributed to a revision to the HIV surveillance case definition in 2014. The green line represents the annual numbers of PAHIV adolescents who were classified as stage 3 (AIDS) at the age of 13 or older. It shows that there have been gradual increases in stage 3 (AIDS) classifications among this population after they have aged to adolescence or adulthood.

The fight against the transmission of HIV and improving the lives of those affected by the disease remains a high priority for the U.S. as demonstrated in their efforts to decrease the impact of HIV/AIDS both domestically and globally. The first bill

passed in the U. S. Congress targeting AIDS research and treatment was on May 18, 1983, where \$12 million (U.S.) was set aside for agencies within the U.S. Department of Health and Human Services (AIDS.Gov, 2016). On May 31, 1987, President Ronald Reagan made "his first public speech about AIDS and established a Presidential Commission on HIV" (AIDS.Gov, 2016). The first comprehensive federal AIDS bill was The Health Omnibus Programs Extension (HOPE) (November 4, 1988). This bill authorized the use of federal funds for AIDS prevention, education, and testing and established the National Commission on AIDS and the Office of AIDS Research at the National Institutes of Health (NIH) (AIDS.Gov. 2016).

The national strategy to combat HIV/AIDS was developed in 2010 by the Office of National AIDS Policy (ONAP) and revised in 2015, in collaboration with "people living with HIV (PLWHIV); community groups and national organizations; providers from various disciplines; researchers and other individuals working with Federal Agencies; Tribal; and local governments" (Whitehouse Office of National AIDS Policy [WHONAP], 2015, p. A4). The strategy has four overreaching goals and 10 indicators. The four goals are to "reduce HIV infections; increase access to care and improve health outcomes for people living with HIV; reduce HIV-related disparities and health inequities; and to achieve a more coordinated national response to the HIV epidemic" (WHONAP, 2015, pp. 4-6).

Subsequently, other programs and partners such as the Ryan White Foundation have emerged in the fight against HIV/AIDS. The U.S. commitment to the fight against HIV/AIDS is also demonstrated in the amount of funds requested (including amounts for the Global Fund) from the U.S Congress from fiscal years 2010 to 2016. These amounts

have increased steadily from \$26.2 billion in 2010 to \$31.7 billion in 2016. The highest increase was from 2013 to 2014 when an increased amount of \$1.4 billion (5%), representing the largest percent increase from 2010 to 2016, was requested.

Florida Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome Epidemic

In 1981, after the first cases of Kaposi's sarcoma and Pneumocystis Carinii were discovered in New York and Florida, the Florida Department of Health began surveillance of AIDS cases. However, an AIDS surveillance program was not established until 1983, with active surveillance commencing in 1984. The first governor's task force on AIDS was established in 1985 by then Governor Bob Graham, and the first patient care network began in 1986 at Jackson Memorial Regional Medical Center. In 1987, Florida became the first state to establish voluntary confidential HIV counseling and testing in all counties, and funding was designated specifically for expanding HIV prevention and education, and community-based groups. The Azidothymidine (AZT) patient care program was also established in 1987. In 1991, the first Ryan White planning group was established; and in 1992, The Red Ribbon Panel on AIDS was commissioned by then Governor Lawton Chiles, to address HIV/AIDS treatment and prevention.

In 1991, the Business Response to AIDS Program was established to educate employees, their families, and the community about HIV/AIDS. In 1994, Florida AIDS Health Fraud Task Force was established, and the state received funding from the CDC to initiate community planning. In 1995, additional funding was received for the AIDS Drug Assistance Program (ADAP). In 1996, the Florida Legislature mandated

counseling and HIV testing to all pregnant women in the state; and in 1998, the State Legislature created the Targeted Outreach for Pregnant Women Act (TOPWA).

Preliminary planning of the Florida HIV/AIDS Minority network also began in 1998. In 2000, Florida received the Ryan White CARE Act Title II grant, and Florida mandated HIV testing of all inmates prior to release. In 2004, rapid testing for pregnant women was initiated and expanded to 24 sites, and behavioral surveillance also began. In 2005, the Florida State Legislature required HIV testing as part of routine prenatal care for all pregnant women. In 2007, the CDC funded Florida African American Testing Initiative was established; the first decline in HIV resident deaths since 1999 (13% decrease) occurred; and *Out in the Open, The Continuing Crisis of HIV/AIDS, Among Florida's Men Who Have Sex with Men* was released (FDH, 2016).

In 2010, Florida accounted for the third largest incidence (98,530 or 0.5-0.6% of Florida's population) of new AIDS cases in the U.S. In 2012, Florida had the fourth largest population in the nation with 19.1 million people, and HIV was the sixth leading cause of death among those aged 24-44 years. In 2012, the number of AIDS-related deaths were 923, a decrease of 8.2% from 2011, and the first time that the annual HIV-related death fell below 1000 people in one year (FDH, 2013). In 2013, Florida was first in the nation for incidence of new HIV and AIDS cases and, in 2014, they had the third largest population in the U.S. at 19.6 million people.

In 2014, there were 4613 (23.6) people per 100,000 new HIV cases in Florida, of which 3380 (73%) occurred in seven counties (Broward: 694; Duval: 275; Hillsborough: 340; Miami-Dade: 1198; Orange: 382; Palm Beach 320; and Pinellas 171), of which Miami-Dade, Broward, Orange, and Hillsborough alone accounted for 2614 (57%). The

number of AIDS cases in Florida in 2014 was 2,370 with the greatest number of cases 766 (32%) occurring in Broward (322) and Miami-Dade (444) counties (FDH-HIV/AIDS, 2016). Through 2014, Florida reported a cumulative total of 2619 HIV/AIDS cases of people who were infected prior to the age of 13. Of this amount, 95% were infected perinatally (FDH, 2014), while the number of infants known to be born to an HIV-infected mother in Florida was 506, of which only six (1%) were found to be infected with the virus (FDH, 2014; FDH-DCHP, 2013). The number of PAHIV-infected babies born in Florida from 1979 through 2014 was 1,220. There has been a steady decline (95%) from a peak number of 109 cases in 1993 to the lowest number of six cases in 2014 (Florida Department of Health, 2013, 2014, 2015; Florida Department of Health, Division of Disease Control and Health Protection [FDH-DCHP], 2013). Florida ranked second (N = 1,553) behind New York (N = 2,447) in the number of pediatric AIDS cases diagnosed through 2013. In 2011, the cumulative pediatric cases in Florida were second in the nation with 1544 cases (FDH, 2015).

Physiological Challenges

The physiological challenges that the PAHIV emerging adult may encounter can influence their ability to achieve the benchmarks of their developmental stage. These challenges are associated with neurocognitive development and sexual and reproductive health issues. The paucity of data on the PAHIV young adult and emerging adult has resulted in data related to children and adolescent being used as baseline data to address the development of the PAHIV emerging adult in some areas. This was the experience of Laughton, Cornell, Boivin, and Rie (2013), who conducted a literature review about the evidence on neurodevelopmental outcomes among PAHIV adolescents. The authors

reported that, when coupled with the high risk for psychiatric difficulties in PAHIV adolescents, the relationship between impaired executive function (EF), and risk-taking behavior could be compounded by factors including the risk of substance use, risky sexual and other risk-taking behaviors, and poor ART adherence. Laughton et al. (2013) concluded that overall, HIV positive children and adolescents have poorer neurodevelopmental outcomes than their uninfected peers, particularly those with more advanced HIV disease, and poorer psychiatric outcomes and executive functioning.

According to Laughton et al. (2013), other important variables have been shown to affect neurodevelopmental outcomes. These include caregivers' mental health or substance problems; orphan status and chronic illness; nutritional status; having a biological caregiver; higher family income level; and higher caregiver cognitive functioning. Cohorts initiating ART earlier report better outcomes; however, evidence is inadequate on the effect of long-term ART on the developing brain. They recommended that more longitudinal research studies should be conducted to assess the long-term effect of ART and timing of ART initiation on neurodevelopmental outcomes of PAHIV adolescents by gender, particularly in resource-constrained settings.

Cattie, Doyle, Weber, Grant, Woods, and the HIV Neurobehavioral Research Program (HNRP) Group (2012) conducted a quantitative study to investigate the relationship between the component processes of planning in HIV-infected persons with and without HIV-associated neurocognitive disorders (HAND) as compared to seronegative individuals, using a standardized test of higher order problem-solving ability (i.e., the Tower of London DX). The authors hypothesized that HAND would be associated with lower scores on planning indices of efficiency, speed, and impulsivity,

which in turn would be associated with executive dysfunction, more severe HIV disease, and poorer everyday functioning. The sample of 162 persons infected with HIV and 82 seronegative comparison participants was chosen from a population of 244 volunteers. The volunteers were recruited from a San Diego community and local HIV clinics. Participants from the HIV+ group were classified as either HAND– (N = 109) or HAND+ (N = 53).

Data were collected using the following tools: Tower of London-Drexel version (TOLDX); Trail Making Test (TMT) –Part B (1985); Action Fluency Test (2005); California Verbal Learning Test–Second Edition (CVLT–II) (2000); Logical Memory I subtest of the Wechsler Memory Scale–Third Edition (WMS–III) (1997); Grooved Pegboard (1963); CVLT–II Trial 1; Digit Span subtest of the Wechsler Adult Intelligence Scale (WAIS–III) (1997); TMT–Part A (1985); Wechsler Test of Adult Reading (2001); Diagnostic and Statistical Manual–Fourth Edition (DSM–IV((1994); Composite International Diagnostic Interview - Version 2.1 (1997). Data analysis utilized nonparametric tests; post hoc analyses; Wilcoxon ranked sum tests and Cohen's d statistics; regressions; z scores; logistic regressions; Spearman's nonparametric correlations (ρ); critical value of .01; and the critical alpha was set to .05.

The results of the study indicated evidence of difficulties in multiple aspects of planning among the HAND+ group. They were found to be less accurate (solved fewer problems), less efficient (excess moves), flexible (rule violations), and slower (reflected by task execution time) in solving complex visuomotor problems. Planning deficits among the HAND+ group were characterized by decreased efficiency and accuracy in problem solving; and deficient rule-bound control. Both groups spent the same amounts

of time in initial planning, however, the HAND+ group took much longer to complete the task, made more total moves, and solved fewer problems (Cattie, et. al., 2012).

The authors concluded that less accurate and efficient planners were more likely to be unemployed and to report declines in other instrumental activities of daily living. They recommended that future study design may include additional neuropsychology measures; replicate the procedures in The parameters and predictors of problem difficulty on the Tower of London task (Berg, Byrd, McNamara & Case, 2010); incorporate maze or measures of social and activity planning; recruit gender-balanced samples; inform theory-driven hypothesis generation and testing using modern models of planning; incorporate associations between planning and neurobehavioral symptoms, HIV-related pathology in prefrontal region, and the temporal course after infection; and address medication nonadherence effects (high viral load, increased HIV transmission risk, high risk behaviors) through intervention.

Croucher, Jose, McDonald, Foster, and Fidler (2013) conducted a retrospective case note review that was designed to assess the sexual health and behavior outcomes of PAHIV young adults and to audit sexual health interventions afforded them against public standard of care. The sample was collected in London between January 2005 and January 2011, consisted of 83 PAHIV-infected young adults (16-25 years). The mean age of transition was 17 years or up to 25 years of age for stable patients. Fifty-two PAHIV-infected young adults were already transferred to adult care. Data were collected from medical records and included all consultations over the audit period. The information evaluated were related to reported sexual behavior (age of coitarche; number of lifetime partners; non-consensual sex [NCS]; STI screen; documented STI; pregnancy;

cervical smear testing; Hepatitis B vaccination [HBV] and serology results; and contraception and condom use). Data were analyzed using the SAS V.9.2, univariate test, Fisher's exact or X2 test, and Wilcoxon Rank Sum test. Crude incidence rates were calculated, and a significance level of 5% was used.

Croucher et al. (2013) reported that 41 participants were sexually active; the mean age of first intercourse was 16 years; the mean interval from first sexual intercourse to the STI screen was 2 years; and the mean number of lifetime partners was 3.5. Croucher et al. (2013) also disclosed that most sexually active PAHIV were unprotected from HBV; mean age of first pregnancy was 17.5 years; and eight pregnancies occurred among six participants, which resulted in three live births of which none were HIV+. Six participants were diagnosed with an STI, of which Human Papilloma Virus (HPV) was the most common occurring. The incidence of non-consensual sex (NCS) was higher in this cohort (9.6%) and another UK study cohort of HIV infected youth (12%) than the UK national survey of the general population. Croucher et al. (2013) recommended that HBV be administered while under pediatric care; cervical screening and baseline colposcopy to be initiated earlier; and that future studies should be conducted to identify age-specific outcome incidence as the cohort expands.

Phillips et al. (2011) conducted at retrospective comparative study to compare the risk of disease progression of pregnant women with PAHIV-infection and behaviorally acquired HIV (BAHIV)-infection. The family-centered care model was utilized as a guiding theoretical framework. The sample which was obtained between January 2000 and January 2009, consisted of 11 PAHIV-infected adolescent and young adults and a comparison group of 27 BAHIV-infected women. The participation ratio of almost 2:1

PAHIV to BAHIV was used to identify contrasting differences between the two groups.

Data for the study was abstracted from medical records. For statistical analysis, the

Anderson Darling normality test, bivariate comparisons using the Mann-Whitney U test;

Fisher's exact 2-tailed test using Minitab; and statistical software were utilized.

Phillips et al. (2011) determined that among the participants, there were 15 live births (PAHIV) and 33 live births (BAHIV) and a mean age of 20.8 and 30.3 years, respectively. Three (27%) of the PAHIV-infected participants died—one each at 2, 3, and 4 years after giving birth. They found the outcome measures for the PAHIV-infected group to be significantly worse. Phillips et al. (2011) concluded that the challenge in caring for the PAHIV-infected pregnant women is a result of their extensive treatment regimen and long-term exposure to ART. Multi-drug resistant strain of the virus and an increasingly complex medication regimen with potential for greater toxicity and medication non-adherence related to toxic side effects were more common among the PAHIV group (Phillips et al., 2011). The authors recommended that multi-center studies addressing pregnancy management, monitoring, and long-term pediatric follow-up interventions be adapted and implemented in resource poor settings.

Cooper, Mantell, Moodley, and Mall (2015) conducted a qualitative study to explore South African policymakers' perspectives on public sector sexual and reproductive health (SRH)-HIV policy integration, with a special focus on the need for national and regional policies on safer conception for people living with HIV (PLWHIV) and contraceptive guidelines implementation. The purposive sample of 42 South African policymakers were recruited from the public and civil society sectors on HIV and SRH, at both the national and provincial levels. Data were collected in English between

January 2008 and June 2009, late 2011, and early 2012 until saturation was achieved; via semi-structured interviews and demographic questionnaire.

Data analysis included initial coding informed by the researcher's field notes of the interviews; NVivo 9 was used to facilitate data sorting and management; inductive thematic analysis; descriptive themes and sub-themes; and extraction of illustrative quotations. Rigor and trustworthiness of the research process was achieved by member checking; informed consent; IRB approval; permission for access; anonymity and confidentiality. Four themes emerged from the study:

- Inadequacy of current policy, guidelines and services for SRH-HIV integration
- Integration advantages and disadvantages and support in principle for improved SRH-HIV service integration but caution and challenges
- Lessons to be learned for SRH-HIV integration policies from other integration initiatives
- Specific views on childbearing in PLWH and integration of safer conception for PLWH into policy

The authors concluded that a strengthened health system could promote effective SRH-HIV care integration efforts for PLWHIV. The emphasis on training and quality of care by the National Health Insurance program could be used as a motivation for values clarification training, to counter healthcare providers' judgmental attitudes towards PLWHIV childbearing. Cooper et al. (2015) recommended a comprehensive and integrated approach to HIV and SRH that includes preventing unintended pregnancies and promoting safer conception; attending to women who seroconvert during pregnancy;

identifying women with AIDS and other illnesses during pregnancy and childbirth; and implementing tailored cervical screening for WLWHIV, which is crucial for respecting the SRH rights and choices of PLWHIV and combatting the global HIV epidemic.

A review of the literature on the physiological challenges of neurocognitive development and reproductive and sexual health issues that the PAHIV emerging adult may encounter indicates that the PAHIV emerging adult have poorer neurodevelopment and psychiatric outcomes; executive functioning; and severe developmental delays than their uninfected peers, which may prevent them from understanding their disease process (Laughton et al., 2013). Furthermore, the impact of HIV on the developing adolescent brain was found to be highly complex and being influenced by factors that are not well understood. Additionally, the long-term effect of early initiation of ART on the developing brain has not been determined (Laughton et al., 2013). HIV-associated neurocognitive disorders (HAND) may render the PAHIV emerging adult less accurate and efficient planners, more likely to be unemployed, and decline in functional activities of daily living (Cattie et al., 2012), which may affect their development and function in activities of daily living.

The mean age of first intercourse was found to be 16 years, which may expose the PAHIV emerging adults to STIs, the likelihood of multiple lifetime sexual partners, and the possibility of becoming pregnant at an early age. Caring for the PAHIV-infected pregnant women was found to be challenging because of their extensive treatment regimen and long-term ART exposure. Furthermore, a high incidence of NCS was reported among the study population, and most participants were found to be unprotected from HBV (Croucher et al., 2013; Philips et al., 2011). The authors recommended the

introduction of routine cervical screening, baseline colposcopy, hepatitis B vaccination in pediatric care settings, and screening for nonconsensual sex (NCS) and sexual abuse during routine office/clinic visits for this vulnerable population; and for multi-center studies to address pregnancy management, monitoring, and long-term pediatric follow-up (Croucher et al, 2013; Phillips et al., 2011). Respecting the reproductive rights of PLWHIV and providing services to promote their health and well-being are important and should be addressed from a policy perspective and integrated into care guidelines (Cooper et al., 2015). This study will satisfy the need for further studies of different (qualitative) methodologies exploring the essence of the emerging adults' experience of perinatally acquired HIV to facilitate developmentally appropriate evidence-based care and services.

Psychological Challenges

The PAHIV emerging adult may encounter psychological challenges of mental health disorders, disclosure of HIV status, and self-efficacy for limiting HIV risk behaviors; which will be covered in this section. Mellins, Brackis-Cott, Leu, Elkington, Dolezal, Wiznia, ... Abrams (2009) conducted a descriptive quantitative study to examine the rate and types of psychiatric and substance abuse disorders in HIV positive (9-16 year old) youths and the association between HIV infection and these mental health outcomes by comparing HIV positive youths to seroconverters. The sample consisted of 340 caregiver/youth dyads (206 PAHIV+ and 134 PAHIV- youths) and their primary adult caregiver. They were recruited from four family-focused medical centers in NYC that provides primary and tertiary care to HIV- affected families.

Variables assessed and instruments used included: (a) Child psychiatric disorder using the Diagnostic Interview Schedule for Children [DISC-IV] (1996) generic parent and child version – an extensively used, well validated instrument; (b) History of mental health treatment – caregiver report on child's treatment; (c) Health variables for HIV positive youths from medical records; (d) Demographics. Data collections were from caregivers and adolescents' interviews and medical chart abstraction. Baseline interviews were conducted over two sessions within 4 weeks of each other where children and caregivers were interviewed separately but simultaneously. Data analysis was via descriptive analysis to ensure group compatibility on demographic variables (*t*-test for continuous variables and chi-square tests for categorical variables); and logistic regression was used to examine the association between youth's HIV status and types of disorder; the odds ratio the *p*-value, and 95% confidence interval were determined for all significant results; and the *p*-value of less than .05 was determined to be statistically significant.

Mellins et al. (2009) found that a high percentage of HIV-positive and HIV-negative youths met the criteria for a non-substance use psychiatric disorder, with significantly higher rates among the HIV-positive youths (61% vs. 49%). The most prevalent diagnoses in both groups were anxiety disorders (46% for total sample), which included social phobia, separation anxiety, agoraphobia, generalized anxiety disorder, panic disorder, obsessive-compulsive disorder, and specific phobias. One quarter of the sample met criteria for a behavioral disorder (ADHD, conduct disorders, and oppositional defiant disorders), with ADHD being the most prevalent. HIV-positive youths had significantly higher rates of ADHD, 7% of youths met the criteria for a mood disorder,

and 4% for a substance abuse disorder. HIV-positive youths are at high risk for mental health disorders. The authors recommended larger longitudinal studies to examine the contribution of familial variables to child mental health and studies of the drug-to-drug interaction between psychotherapeutic medications and ART to ensure that neither treatment is compromised by the other.

Gillard and Roark (2012) used observational dialogue to utilize the Basic Needs
Theory (sub-theory of Self-determination Theory), to understand older youth's perception
of support for their basic needs of autonomy, relatedness, and competence in the context
of disclosing their HIV status. The sample consisted of nine youths (17-19 years old,
four women and five men) and two adult staff from a group of 41 program participants in
a 1-week life skill residential program, which was conducted in a large Southern city in
2010. Data collection was completed by semi-structured interviews lasting 10-15
minutes and observation. Data were coded until categorical saturation was achieved and
author's contemplative dialogue to establish inter-rater reliability was used to analyze the
data. Member checking was used to improve the credibility of the findings.

Gillard and Roark (2012) indicated that when participants perceive more support for their basic psychological needs for autonomy, relatedness, and competence, they reported more self-determined motivation to disclose their status and better satisfaction with their decisions. The authors concluded that basic needs theory is useful for understanding how the basic psychological needs of autonomy, relatedness, and competence are satisfied or thwarted in the context of HIV disclosure for older youths. They recommended that more research should be done to quantitatively measure the three basic needs and assess their prevalence in the context of HIV disclosure and correlation

to life satisfaction. In addition, the authors suggested that longitudinal studies should be conducted to explore if and how perception of support of basic needs changes over time. Moreover, research should be conducted with groups that are older and younger than adolescents to further establish operational constructs of the basic needs theory in the context of HIV disclosure (Gillard & Roark, 2012).

Fernet, Wong, Richard, Otis, Levy, Lapointe, ... Trottier (2011) mixed method embedded strategy relied predominantly on a qualitative design while supported with quantitative methods. The purpose of the study was to describe the participants' perspectives related to romantic involvement and sexuality, risk management, and partner serostatus disclosure. The sample from Canada consisted of 18 PAHIV-infected adolescents and young adults with an average age of 17.5 years and prior participation in a primary qualitative interview. Data collection were completed via a 90-minute semistructured interviews and self-report questionnaires. Recorded interview tapes were transcribed verbatim and revised by the interviewer for accordance. Data analysis utilized a mixed coding approach on romantic relationships, sexuality, risk management, and disclosure management supported by ATLAS/ti V.5 software. For each theme, three of the authors identified meaning units in the coded text related to experience; meanings/significance; difficulties/facilitating elements; coping strategies; or changes overtime. Patterns were then identified and regrouped into conceptual categories, and suggested revisions were made to ensure reliability and validity of the results. Descriptive analysis on quantitative data using of SPSS 16.0 was also done.

The following themes emerged from the data analysis: intimate and sexual experiences; sexual partners, at-risk behavior, condom use and partner disclosure;

abstaining from romantic relationships for now; contemplating sexual relations with the condition that the partner must be informed; protecting one's partner and oneself from rejection; not using a condom is tempting; transgressing and repeating; and dealing with the risk of losing one's lover. Fernet et al. (2011) stated, "in the context of a significant romantic relationship, risk taking becomes more tempting and condom use acts as a reminder of HIV and a barrier to intimacy" (p. 399). In addition, fear of infecting the partner gradually dissipates when the viral load is undetectable or when past experiences suggest that partners might not become infected. The authors also communicated that risk was not only related to the transmission of the HIV virus but also the risk of getting rejected. Youths initiate their romantic and sexual lives, but they are filled with the anxiety and fear of rejection. The authors recommended that sexual health programs designed for youths living with HIV must adapt the message about risk management according to relative context.

Fair and Albright (2012) utilized a grounded theory research method to provide a qualitative exploration of challenges confronted by adolescents and young adults with PAHIV in forming and maintaining intimate, romantic relationships. The sample of 35 adolescent and young adults with PAHIV was taken from a total of 42 who were invited to participate in the study. Participants were over 14 years old and aware of their HIV status, did not have cognitive impairment, and understood English. The sample was acquired from two pediatric infectious disease clinics in the Southeast U.S. where data were collected from July 2011 to April 2012. Data collection were by semi-structured interviews (in person and over the phone) by trained interviewers. The recorded interviews were later transcribed, and data coding supported by ATLAS/ti 6.0.

Fair and Albright (2012) noted that relationships were desired and sought by all participants. Conceptual themes that emerged were: (a) relationship experiences – experience with relationship – rejection, support, and other HIV-related challenges; (b) delay dating, termination of relationships, and taking it slow; and (c) advice to peers – to be safe, establish trust, go slowly, protect yourself and partner; physical health, emotional health, you can do it, normalizing HIV, and self-respect and patience. Although there were no disclosure-related violence reported, most participants feared rejection. The authors recommended that the focus of education in HIV care settings for adolescence and young adults living with PAHIV must include transmission risk factors as well as other strategies to develop and maintain healthy relationships in the context of a highly stigmatized illness.

Chaudior, Jose, McDonald, Foster, and Fidler (2011) cross-sectional study aimed to review the current literature and assess the applicability of the new Disclosure Process Model (DPM) in the context of HIV/AIDS disclosure. The sample included 210 articles that were written in English and obtained through literature search of PubMed, PsycInfo, and an HIV-related list serv through November 2009. The articles obtained provided a quantitative assessment of at least one main component of the DPM which assessed interpersonal and verbal disclosure of HIV status by people living with HIV/AIDS (PLWHA). The articles were reviewed in a two-step process. In the first step, the abstracts were reviewed for inclusion criteria. In the second step, the first author read and vetted the remaining articles and then coded for country of origin, research design, components of the DPM assessed, population, and types of confidants examined. Five main antecedent factors were assessed across this literature: disclosure motivations,

stigma, disease progression, confidant serostatus, and confidant relationship. Three aspects of the disclosure event were assessed across this literature: disclosure positivity, content of communication, and whether confidants were disclosed to directly or indirectly. Nine types of outcomes were assessed across the literature: individual psychological well-being, social support, ARV adherence; physical well-being; dyadic sexual risk behavior; confidant well-being; social contextual knowledge of HIV; prejudice; and HIV preventative behaviors.

Chaudior et al. (2011) concluded that motivations for disclosure, confidant's serostatus and relationship, and some measure of disease progression predict greater disclosure likelihood, whereas motivation against disclosure and stigma predicts lower disclosure likelihood. Limitations to this study included the fact that the literature obtained was drawn mainly from U.S. studies and did not include information that explains how the factors that bring PLWHA to disclosure might ultimately affect their disclosure outcome; and the design of the study does not allow causal relationships to be established. The authors recommended that additional research is needed to understand how contextual factors (the degree of social devaluation or cultural stigma) affect the disclosure process.

Greenhalgh, Evangeli, Frize, Foster, and Fidler (2013) qualitative cross-sectional design study utilized Interpretive Phenomenological Analysis (IPA). This entailed an indepth examination of the experiences of intimate relationships in PAHIV-infected young adults and how they perceive having grown up with HIV to affect such relationships; the aim of which was to (a) focus on how perinatally infected participants felt that growing up with HIV impacted on intimate relationships and (b) to describe the experience of

intimate relationships in an older cohort they previously studied. The purposive sample of seven participants (five females and two males) 18-23 years of age, were from the NHS Clinic in London where multi-disciplinary HIV medical care is provided to PAHIV young adults 16-25 years of age. The participants were either in an intimate relationship or had been in one previously and had their HIV status disclosed to them by age 16. Data for the study were acquired via semi-structured interviews, which were developed in association with the UK Children HIV Association (CHIVA) youth committee. In the IPA analysis of data, three themes emerged: (a) HIV viewed by partners linked to AIDS and sexual transmission, (b) discrepancy between young people and their partner's view of HIV, and (c) partners view of risk of transmission.

Greenhalgh et al. (2013) determined that there appears to be a link between participants' response to finding out about their own HIV status and concerns about how their partners would respond to disclosure of their HIV status. Participants were concerned that HIV would be associated solely with sexual transmission because of a lack of understanding about perinatal transmission on the view of the partner. The authors found a discrepancy between the participant's view of HIV and the partner's view, where the participant may see HIV as a manageable disease, and the partner may view it as a death sentence. How the information is disclosed influences the response to the disclosure. Greenhalgh et al. (2013) also found that when participants disclosed their HIV status to partners, some partners were very committed to the use of condoms, while others dealt passively with the risk of transmission of the virus. The authors recommended that ongoing attempts should be made by clinicians to advise (and model) disclosing patients' HIV status to partners in a way that is balanced and accurate. The

authors also recommended future studies with the PAHIV youths and their partners to explore the experience of being in an HIV-affected relationship.

Chariyeva, Golin, Earp, and Suchindran (2012) conducted a descriptive analysis to understand the effect that dose of motivational interview (MI) counseling had on self-efficacy to practice safer sex, among a sample of people living with HIV (PLWH). Social cognitive theory provided the theoretical framework that guided the study. The study used 490 participants from the Safe Talk Study from 2006 to 2009. The participants were HIV positive, aged 18 years of age and over, had sex within the previous 12 months, and spoke and understood English. Master's-level trained counselors were used to conduct face-to-face and telephone interviews and complete evaluation surveys at baseline, and at 4-, 8-, and 12-month visits. Data were collected using audio-computer assisted self-interview (ACSI), and the self-efficacy to practice safer sex 16-item scale was used to measure the variable. Statistical analysis was conducted via logistic regression analysis for longitudinal data using SAS 9.2 and PRAC MI.

Chariyeva et al. (2012) found that building patients' self- efficacy for practicing safer sex has been successful at changing sexual risky behaviors and that self-efficacy increased as the number of counseling session and the number of minutes of counseling increased. The authors also observed that people with lower educational levels have lower self-efficacy to practice safe sex and that there is a positive association between drug use and unsafe sex behavior. The authors recommended that practitioners working with HIV-infected patients should pay attention to the amount of time they devote to these patients because investing more time with clients to build their self-efficacy through

gradual steps, will enable them to make sustainable change, thereby avoiding the need to spend more time in clinic later.

Mahat, Scoloveno, and Ayers (2012) conducted a quantitative study to develop and test the effectiveness of an HIV/AIDS peer education program to improve Nepalese adolescent's HIV/AIDS knowledge and self-efficacy among students in one of the schools in Nepal. The convenience sample of 118 students came from 121 students at a private Nepal high school. Social learning theory (SLT) was the theoretical framework that was used to guide the study. The peer education program used was a modified version of the Teen for AIDS Prevention (TAP) program. The peer educators were 10thgrade volunteers who were trained by the researcher. The education intervention consisted of five 45-minute counseling sessions given by peer educators to adolescents in health education classes, after which students were asked to complete a three-section questionnaire (demographic, HIV knowledge, and self-efficacy for limiting HIV risk behaviors). The instruments used were the 39-item Youth Risk Behavior Surveillance System (YRBSS), which was developed by The Health and Human Services, Centers for Disease Control and Prevention (CDC, 2000, as cited in Mahat et al., 2012), and the nineitem Self-Efficacy for Limiting HIV Risk Behavior (LHRB) scale. Statistical analysis utilized SPSS 17.0 for descriptive analysis of the variables. A paired t-test was used to determine differences in pre-intervention and post intervention HIV knowledge and selfefficacy scores (Mahat et al., 2012).

The results demonstrated a significant positive relationship between HIV/AIDS knowledge and self-efficacy. The authors detected that the mean score for adolescence self-efficacy for limiting sexual behavior improve from 26.4 to 29.5 after the peer

education program and that the higher the self-efficacy scores of the adolescent, the less likely they were to participate in sexual risk behaviors. Mahat et al.(2012) concluded that a culturally appropriate HIV peer education program was effective in improving HIV/AIDS knowledge, attitudes, beliefs, and self-efficacy for limiting sexual behaviors among Nepal adolescents. The authors recommended that educators, health care providers, and policy makers develop and implement evidence-based educational interventions that focuses on increasing HIV/AIDS awareness and self-efficacy among adolescents.

Weiner, Battles, and Wood (2007) prospective exploratory study (longitudinal) examined the sexual behavior, self-efficacy for risk reduction, sexual behavior attitudes, and levels of sexual knowledge of PAHIV-positive youths. The sample consisted of 40 participants (13-24 years) who were also enrolled in an active treatment protocol at the National Cancer Institute (NCI) for the previous 5 years and had participated in clinical trials between 2001 and 2003. Data collection included two interviews (T1, T2) approximately 21.2 months apart at mean age 16.6 and 18.3 years at T1 and T2, respectively; chart abstraction; questionnaires utilizing the Youth Risk Behavior Survey (YRBS), New York State Department of Health (NYSDOH) AIDS Institute Survey, and adolescent questionnaire; and risk reduction self-efficacy and condom use self-efficacy instruments. Statistical analysis was done using a *t*-test and chi-square analysis.

Weiner et al. (2007) stated that there were no differences between perinatally and transfusion-acquired HIV participants in whether they had ever had sex. Low knowledge of HIV sexual transmission risk behavior was associated with low self-efficacy for limiting HIV risk behaviors. The authors recommended that programs and future studies

be designed to help this emerging population successfully address the issues of managing their chronic illness, adjust to living independently, make decisions about initiating sexual relationships, and disclose potentially damaging information to the sexual and romantic partners while acquiring the knowledge and skills to engage in risk reduction practices (Weiner et al., 2007).

Elkington, Bauermeister, Brackis-Cott, Dolezal, and Mellins (2009) conducted a cross-sectional study to examine the relationship between sexual risk behaviors and substance use. The sample consisted of 340 (134 PEHIV exposed but uninfected and 206 PAHIV infected) 9 – 16 year-olds with perinatal exposure to HIV. They were selected from a population of 443 recruited from four Medical Centers in New York City that provides primary care to HIV-affected families. Data were acquired from chart review, audio computer-assisted self-interview (ACASI), and face-to-face interviews. Variables were measured using the Adolescent Sexual Behavior Assessment (ASBA) (2006); Diagnostic Interview Schedule for children IV (DISC IV), which is extensively used and well validated; and the Parent Child Relationship Inventory (PCRI). Statistical analysis was achieved by using subjective norms, hierarchical logistic regression, *t*-test, and X2 test.

Elkington et al. (2009) determined that cigarette, alcohol, and marijuana use were significantly associated with HIV sex risk behavior; that caregiver relationship characteristics had no effect on the association between substance use and risky sexual behavior; and regardless of HIV status, perinatally exposed youths who use substances are more likely to engage in sexual risk behaviors. The study concluded that PAHIV infected and exposed youths are at risk for both substance use and engaging in risky

sexual behavior; and substance use increases the likelihood that they will engage in risky sexual behaviors. The authors recommended that both groups in the study are in need of HIV prevention measures from a young age and that family and peer-based interventions for non-PAHIV adolescents may be suitable for this population. They also recommended that HIV prevention measures to be adapted should address parental infection, PAHIV+ youth, and the youth's own HIV infection.

The PAHIV emerging adults may experience psychological challenges related to disclosure of their HIV status to romantic partners, mental health disorders, and selfefficacy for limiting HIV risk behaviors. Ten recent articles were reviewed, and an almost equal amount of qualitative and quantitative studies were represented. This indicates that more studies of varied approaches are being conducted about the psychological challenges affecting the PAHIV emerging adults than the physiological challenges they may experience. The problems addressed by these studies were: (a) psychiatric substance abuse disorders and the association between HIV infection and these disorders; (b) youths' perceptions of their basic needs of autonomy, relatedness, and competence; (c) perspectives on romantic involvement, sexuality, and risk management and partner's serostatus disclosure; (d) challenges in forming and maintaining romantic relationships; (e) the Disclosure Process Model in the context of HIV disclosure; (f) the experience of intimate relationships and the perceived effect of having grown up with HIV on such relationships; (g) the effect of motivational interview counseling on selfefficacy to practice safer sex; (h) the use of peer education programs to improve HIV/AIDS knowledge and self-efficacy; (i) the sexual behavior, self-efficacy for risk

reduction, sexual behavior attitudes and levels of sexual knowledge; and (j) the relationship between behavior and substance use.

A number of recommendations were made from these studies: (a) mental health service providers and sexual health programs to incorporate and adopt HIV risk reduction and or family-based mental health strategies into ongoing treatment or traditional sexual and drug risk reduction efforts according to relative context (Chariyeva et al., 2012; Elkington et al., 2009; Fernet et al., 2011; Mellins et al., 2009); (b) larger longitudinal studies (Gillard & Roark, 2012; Mellins et, al., 2009); (c) the development and implementation of evidence-based educational interventions and programs in HIV care settings (Fair & Albright, 2012); and (d) additional research to understand the degree of social devaluation or cultural stigma youth and their partners experience when in an HIVaffected relationship; management of their chronic illness; independent living; decision making about relationships; disclosure to intimate partners; and acquisition of skills to engage in risk reduction practices (Chaudior et al., 2011; Greenhalgh et al., 2013; Mahat et al., 2012; Weiner et al., 2007). The phenomena also need new voices, as the authors of the sources reviewed were frequently the same, some of whom developed studies based on their previous works. This study will provide such new voice in the form of a new researcher with a new and open perspective on the HIV/AIDS epidemic, PAHIV emerging adult, and the global HIV/AIDS response.

Sociological Challenges

The PAHIV emerging adults may encounter sociological challenges that may affect their ability to achieve the benchmarks of their developmental stage. The sociological challenges addressed in this section are stigma; transition of health care; and

medication adherence. Fielden, Chapman, and Cadell's (2011) constructivist qualitative inquiry aimed to explore the Health Service Provider's (HSP's) understandings of the stigma experienced by HIV-positive young people and how this stigma is managed as part of programs and services targeted towards this population. The purposive sample consisted of 15 service providers from four countries (U.S., Canada, Australia, & UK). Semi-structured telephone interviews with open-ended questions and reflexive journaling were used to collect the data, followed by memoing of interviews and chunking of the data. Data was input into NVivo 7.0 (QRS international software). Fielden et al. (2011) found that managing stigma entails managing silence in the context of the social world of the young person. Silence exists in three social worlds of the young person with HIVinfection (the young person themselves, the family, and the HSP). Internalized or felt stigma is associated with silence from the individual, family, and HSP/setting. T here are strong relationships between silence and power, silence and space, and silence and secrecy in the lives of HIV+ young people. The authors recommended that healthcare providers work collaboratively with young people and their significant others to develop successful health promotion program models and interventions to create a safe place in which young people feel comfortable voicing their concerns and naming HIV.

Tanney, Naar-King, and McDonnel (2012) conducted a quantitative study to explore the relationship between depression, stigma, and risk behavior, using baseline data from a randomized control trial among high-risk youths living with HIV in the U.S. The study examined the efficacy of a motivational intervention addressing multiple risk behaviors. There were 186 participants from four adolescent clinic sites (Ft. Lauderdale, Philadelphia, Baltimore, and Los Angeles) in the Adolescent Trial Network and Detroit a

Non-ATN clinic site. They were HIV-infected youths with either problem level substance use, current sexual risk, and/or suboptimal HIV medication adherence. They were also participants in an ATN-randomized clinical trial measuring the efficacy of motivational intervention addressing multiple risk behaviors.

Tanney et al. (2012) used the car, relax, alone, forget, friend, and trouble (CRAFFT) six-item adolescent screening tool to screen for problem level substance abuse. The 10-item Berger stigma scale, which measures personal stigma, disclosure concerns, negative self-image, and public attitudes, and the Brief Symptom Inventory (BSI), which measures symptom patterns of depression, were data collection tools by computer-assisted personal interview (CAPI). The instruments were found to be reliable. Statistical analysis of the data utilized the t-test. Tanney et al. (2012) indicated that more than half of the participants scored at or above the clinical cutoff for depression (p < .10), with higher depression scores predicted among adolescents with behaviorally acquired infection (p < .05), older age, more problem behavior, and greater stigma (p < .01). Sixty-five percent (65.6%) of the participants had problem level substance use, 53.8% has sexual risk factor, 44.1% had medication non-adherence issues, and both stigma and risk behavior independently contributed to a variance in depression (p < .01). The authors recommended that youths with high level of stigma should be evaluated for depression, as this could assist with decreasing some of the barriers to healthy behaviors (treatment adherence and safer sex behavior) and alleviate the negative consequences from the impact of stigma and depression (Tanney et al., 2012). They also recommended that studies should be conducted to address stigma and depression to reduce HIV stigma in urban U.S. communities.

Sharma, Willen, Garcia, and Sharma (2014) conducted a qualitative study aimed to determine if patients and family caregivers shared similar views about the transition of health care process and what they felt that they would gain or lose from transitioning from pediatric health care to adult health care. The study also aimed to obtain participants' advice on additional services that they might benefit from while undergoing transition and their suggestions on developing a transition protocol. The sample consisted of 15 PAHIV-infection young adults (15-24 years old) (eight Haitians, four African Americans, and three Hispanics and Caribbean) and eight caregivers. They received care since birth at the Pediatric Special Immunology Program at the University of Miami. Recorded structured interviews with a series of open-ended questions were used to collect data in small groups with the same interviewer. Analyses of the recordings were guided by grounded theory.

From the analysis of the data, three themes emerged: (a) perceived lack of transition preparedness related to their ability to manage the complexities of healthcare and perceived lack of knowledge; (b) fear and anxiety related to having to change providers and navigating the new healthcare system; and (c) the personal responsibility that comes with getting older. Other findings that emerged were as follows: (a) preparation or information for transition should start as early as age 13; (b) fear of losing their medical home; and (c) trust was built through a comprehensive care model. The authors recommended that future studies should shift towards assessment of best practices, such as the inclusion of life skills courses and the development of specific outcome measures. They also suggested that the lessons learned could apply to other populations in need of transitioning.

In a qualitative study, Gilliam, Ellen, Leonard, Kingsman, Jevitt, & Straub (2011) aimed to describe the characteristics and current practices surrounding the transition of adolescents from the clinics of the Adolescent Trial Network (ATN) for HIV/AIDS interventions to adult medical care. The study was a multi-center collaboration of ATN sites that provided HIV-infection care and service to adolescents and young adults 13-25 years of age. The purposive sample consisted of 19 representatives of knowledgeable individuals from 14 ATN qualifying centers within the ATN network. The 19 representatives managed a total of 1775 patients of which 31-266 patients within the targeted age group were at each site. Between January 2007 and July 2007, one member of the research team conducted a 39-item semi-structured interview using open-ended questions. Data were analyzed by developing an a priori list of content and contextual topics into a preliminary code, from which a coding matrix was developed guided by the methods of Miles and Huberman (1994). The data was organized using Microsoft Excel and ATLAS.ti. Transcripts were analyzed using content analysis from which themes were copied and transported into a Word document. Clinic documents were reviewed and coded. Rigor in the summary and reporting was achieved by triangulation in both method and analysis. Gilliam et al. (2011) reported that six of the ATN sites had developed a formalized approach to healthcare transition, utilizing a collaborative transition team. The formalized approach included a developmental approach and planned activities to facilitate patient education and skill building. They recommended that future studies should include young adults who had either recently transitioned or are in the process of transitioning and for the identification of additional factors that affect (positive or negative) the transitioning process. They also recommended that clinical

care-based delivery system be designed, implemented, and evaluated from which an evidence-based transition plan can be established.

Naar-King, Montepiedra, Garvie, Kammerer, Malee, Sirois, ... Nichols (2012) conducted a longitudinal cohort study using the Social Ecological Model to explore the psychosocial factors prospectively associated with longitudinal adherence to ART in PAHIV-infected youths. The sample consisted of a random selection of 138 PAHIV individuals (8-19 years old) from the Pediatric AIDS Clinical Trial Group protocol (PACTG) 1042 and sub study 219C enrollees. Participants were on ART treatment for the duration of study without plan for treatment adjustment. Naar-King et al. (2012) used baseline cogitative testing and psychosocial questionnaires, which were completed by youths and caregivers in separate rooms and a validated caregiver report measure of adherence completed at baseline, 24, and 48 weeks. The following instruments were used to collect and analyze the data: Wechlser Intelligence Scale, Behavioral Assessment System for Children (BASC) Relations with Parents Scale, Diabetes Family Responsibility Questionnaire, Belief about Medication Scale, 10-item Quality of Life Questionnaire, and the Belief Self Report. Statistical analysis was conducted using Fisher's exact test, Pearson's Chi-square test, Kruskal-Wallis test, Generalized Estimating Equations (GEEs), Markov Chain Monte Carlo method, and linear regression. SAS version 9.0 was utilized to enter the data.

Naar-King et al. (2012) exploratory analysis showed that caregivers were not fully responsible for medication administration. They also determined that (a) there was evidence of low caregiver well-being; (b) adolescents had perception of poor youth-caregiver relations; (c) caregiver had perception of low social support; (d) African

American ethnicity was associated with low medication adherence over 48 weeks; and (e) youth were aware of HIV status. Although lower income and single-family households often occurs in African American households, they were not evaluated in this study. Assuming responsibility of medication administration and adhering to the medication regimen are important to the success of therapy to maintain and prolong quality of life and to prevent resistant strains of the virus. This readiness needs to be evaluated using evidenced-based measures (Naar-King et al., 2012).

The sociological challenges of stigma, transition of health care, and medication adherence, as discussed, may impact the PAHIV emerging adults' ability to achieve the benchmarks of their developmental stage. HIV-related stigma may prevent the PAHIV emerging adult from seeking care and support, effectively silencing them; therefore, managing stigma should also entail managing silence. They should also be evaluated for depression to alleviate some of the negative consequences from the impact of stigma and depression. Healthcare providers should work collaboratively with young people and their significant others to develop successful health promotion program, models and interventions; and to evaluate for depression in youths with high level of stigma (Fielden et al., 2011; Tanney et al., 2012).

The need for a formalized healthcare transition approach, utilizing a collaborative transition team was identified; consequently, recommendations were made for further studies to assess for best transition of care practices, and for studies to include youths who were either in the transitioning process or who had transitioned recently (Gilliam et al., 2011; Sharma et al., 2014). Assuming responsibility for medication administration and adhering to the medication regimen are important to the success of ART in

maintaining and prolonging quality of life and preventing resistant strains of the virus. This readiness should be evaluated using evidence-based methods (Naar-King et al., 2012). Lower income and single-family households should be addressed because of the high occurrence of HIV/AIDS that exists in African American households, which accounts for a significant proportion of the HIV/AIDS population. The sociological challenges addressed are significant to the PAHIV emerging adults because they are at the developmental stage where they are expected to leave home, often have multiple types of residential arrangements, be involved in post-secondary education, and set the stage for professional careers, significant relationships, and parenthood.

Experiential Context

The extent of this researcher's nursing career spans over 18 years. During this time, the researcher worked mainly at a large community teaching hospital, in a major metropolitan city with one of the largest HIV/AIDS populations in the nation.

Consequently, this researcher has provided different levels of care to patients at different stages of the HIV/AIDS health continuum. The researcher first provided care to a patient with HIV/AIDS while being a nursing student in a medical-surgical clinical rotation. The researcher's reflection of that initial experience: "Today I was assigned a 51-year-old Caucasian male who had leukemia and a history of HIV+. I was a bit cautious at the idea of working with this individual but thought that I needed to do it because soon I will be a nurse and will not be able to pick and choose my patients. My hesitation was not from prejudice but from fear and lack of experience. This I hope to successfully deal with before I put myself out as a professional nurse" (Personal note, September 16, 1999).

That first experience left the researcher reflective on the meaning of life (life's journey); her ability to provide care to patients who were critically ill and unstable; and her ability to provide care to patients who have HIV/AIDS. The researcher was in doubt of her ability to provide care to these categories of patients which required nurses with expert knowledge and nursing skills. Those thoughts left the researcher anxious about the choice of nursing as a career. Although the researcher's reactions were without judgment, the fear of providing care to patients with HIV/AIDS and possibly contracting the virus, as a result, was a thought that was present in an era when acquiring the virus needle stick injury and other exposures were still probable.

During that first encounter, the researcher paused for more than a moment to observe the patient in his condition. She observed how frail and sick the patient was and that he was not able to help himself even if he wanted to. The patient was totally dependent on others for care and his presentation was not encouraging for others (especially the naïve and inexperience nursing student) to willingly help. While observing the patient, the researcher's thoughts were occupied with images of the patient at a better time in his life when he was able to take care of himself and before he was in such poor state of health. Clearly, the patient was very handsome, and his life experiences were quite different from his condition at the time. He was about to die; if not that day, then soon, and he was alone and in a state of suffering. That experience left the researcher with an overwhelming feeling of sadness; the realization that life is fragile and will not always be on the upside; and a question as to whether providing care to a person in such state was the job for her. Fortunately, that question has been answered in the affirmative.

Throughout the researcher's nursing career, she has provided a single standard of care to numerous patients including those at different stages on the HIV/AIDS health continuum and has done so professionally, with compassion, care, and without reservation. Her interest in this phenomenon was triggered by her response to the behavior of several PAHIV adolescents and young adults whom she had observed in 2011. This observation occurred at a dedicated PAHIV clinic in a County Health Department, while orienting with a physician during the pediatric rotation of a Family Nurse Practitioner program. The clinic catered to infants, children, adolescents, and young adults who acquired HIV from their parents and often included clients from different generations. The physician had been providing care to this population from the disease first started affecting infants and children in Florida and had developed a bond with the patients and their caregivers.

In the student nurse practitioner role, the researcher was privy to a conversation in which a PAHIV young woman (22 years) was the mother to an infant whose father did not know that the mother was HIV positive or that the child was exposed to the virus. On the day in question, the mother had brought the infant to the clinic for the infant's 6-month wellness check. The mother stated that the father of the infant (who also lives in the same household with the mother and the infant) did not know of their HIV status. She communicated that she was careful to administer the antiviral medication to the infant on schedule, but not in the presence of the father, to prevent the father from becoming suspicious. That experience left the researcher highly incensed, emotional and concerned. There were other incidents that also sparked an emotional response from the researcher because there were adolescents in the program whose behaviors were also of

concern. Their social lives and appearance were no different from their uninfected peers. Some were sexually active and even working towards getting pregnant the conventional way, without the guidance of a healthcare professional. Yet, they were not ready for the responsibility of disclosure of their status to others, safe sexual contact (condoms; PrEP, viral load), or parenthood.

These are personal experiences and biases that the researcher brought to the study. According to Munhall (2007), an individual should be able to suspend such judgment and prior knowledge, to understand the experience of others, by adopting a position or stance of "unknowing." The fear, anxiety, concern, anger, and rage that the researcher experienced from her association with this population have now dissipated into the proper perspective. This change in perspective began in part with an encounter and discussion with an experienced nurse researcher about this researcher's proposed research trajectory. The researcher was advised to not get angry but to find out why—why do they do what they do? In the experienced nurse researcher's opinion, it is only by understanding why the patient does what they do that others can be of help to them.

This researcher is energized and optimistic about her role in improving the health outcomes and well-being of this population; consistent with the goals of the *Healthy People 2020* initiatives, especially in resource-poor regions where the incidence of HIV in general and PAHIV are still above the Healthy People 2015 target. This researcher brought a sense of urgency, passion, and disciplined sensitivity to the study, which facilitated the revelation of shadings and subtleties in the stories that the participants shared. The researcher was able to dispel all prior knowledge and biases and engage in

reflexive journaling throughout the research process, documenting all thoughts or ideas that may have impacted the outcomes of this study.

Chapter Summary

This chapter presented a review of the literature, which covered the historical perspective of HIV including the state of HIV/AIDS globally, nationally (the U.S.), and at the state level (Florida). In addition, content headings that covered the PAHIV included the physiological (neurocognitive development and sexual and reproductive health issues), psychological (mental health disorders; disclosure of HIV status to intimate partners; and self-efficacy for limiting HIV risk behaviors), and sociological (stigma, transition of care, and medication adherence) challenges that the PAHIV emerging adult may encounter. An experiential context is also covered. Chapter Three follows with the methodology that was applied to this study.

CHAPTER THREE

METHODS

The purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of perinatally acquired HIV (PAHIV). The aim of this study was to give voice to the emerging adults with PAHIV by gaining an understanding of their essence of the lived experience of PAHIV and to add to the body of nursing knowledge in part. This chapter discussed the heuristic research methodology of Clark Moustakas (1990), which was applied to this study, giving details of the seven concepts and the six phases of data collection and data analysis processes of the method. An overview of the qualitative characteristics of the method was also given. Additionally, the sample and setting, access and recruitment of sample, inclusion and exclusion criteria, ethical considerations/ protection of human subjects, data collection procedures, interview questions, demographic data, and research rigor were also presented.

Research Design

Research design are types of inquiries that provides specific directions for procedures in a research study. In designing a research study, a quantitative, qualitative or mixed method (Creswell & Creswell, 2018) approach may provide such directions. The quantitative research design's philosophical approach is embedded in the positivist perspective of empirical verification and mathematics as the basis of all science. In this approach, all ideas must be empirically verifiable or have the possibility of verification, and the concepts of hypothesis and prepositions and their testing are used to prove them false (Crotty, 1998; Welch, 1999). According to Creswell and Creswell (2018), the quantitative approach is used for testing objective theories by examining the relationships

among variables which can be measured with instruments that facilitates the analysis of data using statistical procedures. The mixed method approach involves the collection and integration of both quantitative and qualitative data. This approach has its own distinct designs (convergent, explanatory sequential, and exploratory sequential), which may include philosophical assumptions from the qualitative perspective and theoretical framework from the quantitative perspective. The core assumption for this integration of approaches allows additional insights into the phenomenon being investigated beyond that provided by either approach on their own (Creswell & Creswell, 2018). The qualitative approach is a form of social inquiry that focuses on the way people make sense of their experiences and the world in which they live (Holloway & Wheeler, 2010). It lends itself to the study of complex human issues (Scott Tilley, 2011, as cited in Boswell & Cannon).

In the qualitative research approach, the data have priority; therefore, theoretical frameworks are derived directly from the data. The research is context-bound, which allows the researcher to use "thick description" to describe, analyze, and interpret the data; and the stance of the researcher is the main research tool (Holloway & Wheeler, 2011). The qualitative, constructivist philosophical approach and the heuristic method are fitting philosophies and research method to understand the emerging adults' experience of perinatally acquired HIV (PAHIV). Interacting with participants in their personal space (cognitive, home, school, etc.) and the close and intense interaction with the interview transcripts allows the researcher an understanding of the lifeworld of the participants as they experience it. The Heuristic research method further allowed the researcher to explore the participants' experience of living with HIV from birth because it

is an organized and systematic form for the investigation of the human experiences (Douglas & Moustakas, 1985; Moustakas, 1990).

Heuristic comes from the word *heuriskein*, meaning to discover or to find (Moustakas, 1990). Although Heuristic research is not guided by rules or mechanics, it is not a casual process (Douglas & Moustakas, 1985). According to Douglas and Moustakas (1985), each heuristic study presents a unique and creative challenge to reveal the intimate nature of reality, and therefore, requires methods that fit the particular investigation. The researcher's passion and energy towards the phenomenon creates and maintains the urgency needed to reveal and explore the shadings and subtleties of meaning inherent in the phenomenon being explored (Douglas & Moustakas, 1985). Douglas and Moustakas (1985) further reported that:

Heuristics is concerned with meaning, not measurements; with essence, not appearance; with quality, not quantity; with experience, not behavior. Formal hypotheses play no part, though the researcher may have initial beliefs or convictions regarding the theme or question, based on intuition and or prior knowledge and experience (p. 42).

The heuristic design embraces belief, values, theory concepts, processes, and methods that are essential to the understanding and conducting of Heuristic research (Moustakas, 1990). This process began with a problem giving rise to a question that created a personal and emotional challenge or puzzlement to the researcher to understand the emerging adults with PAHIV and the world in which they exists (Moustakas, 1990). Throughout the research process, the researcher experienced self-awareness and self-knowledge by being an integral part of the process of discovery that led to new images

and meaning regarding the emerging adults' lived experience of PAHIV and the researcher's own experiences with the phenomenon (Moustakas, 1990). There are seven concepts embedded in Heuristic research, which are also qualities that the heuristic researcher possesses. They are illustrated below.

Identifying With the Focus of the Inquiry

Identifying with the focus of the inquiry was accomplished through open-ended inquiry, self-directed search, and immersion in active experience which allowed the researcher to get inside the question and became one with it (Moustakas, 1990). This was facilitated by the interview process of the study, the researcher journaling, and transcription of the voice-recorded interviews.

Tacit Knowing

This concept underlies all the other concepts in heuristic research (Moustakas, 1990). Polanyi (2009) explained human knowledge in the tacit dimension as knowledge which one is unable to explain. He stated, "we know more than we can tell ... it is not easy to say exactly what it means ... most of this knowledge cannot be put into words" (Polanyi, 2009, p. 4). According to Moustakas (1990) "Such knowledge is possible through tacit capacity that allows one to sense the unity or wholeness of something from an understanding of the individual qualities or parts" (pp. 20-21).

Focusing

Focusing is an inner attention or sustained process of systematically contacting the more central meaning of an experience. This allows the researcher to identify qualities of an experience that have remained out of their conscious reach; determine the core themes that constitute an experience; identify and assess connecting feelings and

thoughts; and achieve cognitive knowledge (Moustakas, 1990). Focusing was achieved in this study by the creation of an individual depiction from the recorded interview for each participant and mode creation with the assistance of NVIVO 11 data management system.

Indwelling

Indwelling is the heuristic process of turning inward to seek a deeper, more extended comprehension of the nature or meaning of the quality or theme of a human experience. Indwelling was achieved in this study by the creation of a composite depiction from the individual depictions; exemplary portraits for three participants; and the creative synthesis.

Intuition

Intuition is an internal capacity to make inference, which makes immediate knowledge possible without logic or reasoning. This is considered a bridge between the implicit knowledge associated with tactic and the explicit knowledge associated with the observable or discernible. The bridge between the implicit and the explicit knowledge in this study was achieved by the researcher identifying new or conflicting information and using follow-up questions to explore the deeper, richer, and clearer meaning of the information that participants shared during the interview.

Self-Dialogue

Self-dialogue allows the phenomenon to speak directly to the researcher's experience by examining it and unfolding its multiple meanings. Self-discovery through self-dialogue is the initial step of the heuristic process, which requires the researcher to be open, receptive, and attuned to all facets of their experience of the phenomenon. In

this study, the researcher remained open, professional, and attentive to the information that each participant imparted, seeking congruence with body language, appearance, and consistency in the information shared during each interview.

Internal Frame of Reference

Internal frame of reference is the base, consisting of the knowledge attained through tactic, intuitive, or observed phenomena or the knowledge deepened through indwelling, focusing, self-searching or dialogue with others (Moustakas, 1990).

Sample and Setting

A sample is a small subset of a population that is chosen to be studied, which must demonstrate characteristics that represents the entire population (Lunsford & Lunsford, 1995). Sampling is the process of defining the representative of a population, including the method, criteria, and procedures used to select subjects for a study (Lunsford & Lunsford, 1995). There are two overreaching strategies that could have been employed in this study: probability and non-probability sampling. The choice of strategy is determined by the research paradigm being used for the study. Probability sampling is related to the quantitative research paradigm and includes random, stratified, and cluster sampling techniques among others. Non-probability sampling is related to the qualitative research paradigm and includes convenience, purposive, and snowball sampling techniques (Lunsford & Lunsford, 1995). In convenience sampling, "subjects are selected because of their convenient accessibility to the researcher" (Lunsford & Lunsford, 1995, p. 110). In purposive sampling "subjects are handpicked from the accessible population using judgmental sampling because ... the researcher believes that certain subjects are likely to benefit or be more compliant" (Lunsford & Lunsford, 1995,

p. 110). Snowball sampling may be used when an adequate number of subjects are not available for a study and an identified member of the target population recommends others with similar characteristics to participate in the study (Lunsford & Lunsford, 1995).

In qualitative research, sample size is determined by saturation (Mason, 2010). The requirement for saturation is that the qualitative sample must be large enough to ensure that all the important perceptions are captured or "the collection of new data does not shed any further light on the issue under investigation" (Mason, 2010, para 2). According to Mason (2010), more data does not necessarily lead to more information in qualitative research because only one code is necessary to ensure that an entry is a part of the analysis, and not the frequency of its occurrence. Saturation is the standard or governing principle for achieving sample size; however, others have suggested, an actual number or range in sample size. Creswell (2013) suggested that a phenomenological study should have between five and 25 participants. Moustakas (1990), the author whose research design was used in this study, stated, "It is possible to conduct heuristic research with only one participant, a study will achieve richer, deeper, more profound, and more varied meanings when it includes depictions of the experience of others—perhaps as many as 10 - 15 co-researchers" (p. 47). This qualitative study targeted the emerging adults (18-25 years) with PAHIV residing in South Florida by employing the nonprobability sampling strategies of convenience, purposive, and snowball sampling techniques to select the 15 participants of this study. Saturation was achieved at the 12th participant; however, the researcher continued the recruitment process to gain additional data for a richer analysis.

Access and Recruitment Procedures

Barry University Institutional Review Board (IRB) approval (see Appendix A) was received on October 30, 2017, and recruitment of study participants commenced in November 2017. Access to potential participants and permission to place flyers were obtained from medical directors or persons in charge of immunology clinics, private physicians' offices where emerging adults with PAHIV have access to health care services, and places of worship in South Florida (see Appendix C). Flyers (see Appendix D) announcing the study were posted in visible locations approved by administrators or persons in charge of immunology clinics, physicians' offices, and places of worship. Flyers announcing the study were also posted on social media sites where potential participants visits. Convenience, purposive, and snowball sampling techniques were employed to acquire the sample population. Recruitment was limited to the first 20 volunteers who contacts the researcher and met all the inclusion criteria. Twenty (20) volunteers contacted the researcher; five of whom did not schedule an interview appointment for the following reasons: (a) one was married and needed his wife's approval; (b) one was fearful of her privacy being breached; (c) two were 28 and 34 years of age, which did not meet the inclusion criteria; and (d) one was not comfortable participating in a study outside of her health care setting. The other 15 volunteers, which reflects the study sample, consented to participate in the study.

Inclusion Criteria

The inclusion criteria included:

- Self-identified as having contracted HIV from their mother
- Between 18 and 25 years of age

- Spoke and understood English
- Currently resided in South Florida
- Had access to a telephone
- Was willing to be audiotaped

Exclusion Criteria

The exclusion criteria included:

- Did not self-identify as having contracted HIV from their mother
- Under the age 18 years or older than 25 years of age
- Did not speak or understand English
- Did not currently reside in South Florida
- Did not have access to a telephone
- Was not willing to be audiotaped

Ethical Considerations

Institutional Review Board (IRB) approval was obtained (see Appendix A), and the researcher complied with requirements by completing the National Institute of Health (NIH) training course on protecting human research participants. Procedures to protect the confidentiality of participants were implemented to the extent required by the laws governing the protection of human participants. Each participant selected a pseudonym, or one was assigned by the researcher. The pseudonyms are not traceable to the participants' identity. Confidentiality was further assured by using these pseudonyms on all records including digital audio recordings, transcriptions, scanned documents, demographic data sheets, and published results. These will be held securely and separately in a locked file in the researcher's home office. Signed informed consent forms

are stored in a locked file in the researcher's home office, separate from other study records. Electronic records of digital recordings, transcriptions, scanned demographic forms, and consents are stored on the researcher's secured password-protected personal computer in the researcher's home office.

Participants were informed that the findings of the study will be reported in aggregate format to protect their privacy and that no identifiable traits that can reveal their identity will be used. Aggregate findings from the study will be disseminated through poster and podium presentations, newspaper, and journal articles. Participants were advised that they could decline to participate in the study at any point or that they could withdraw at any time without any penalties. They could also decline to answer any question(s) during the interview. There were no known risks associated with this study. There were no known benefits associated with this study either. A \$20 Publix gift card was given to each participant, as a token of appreciation for their participation in the study. They were allowed to keep the token even if they withdrew from the study or they did not keep their follow-up appointment.

Data Collection Procedures

Following Barry University's IRB approval, recruitment of participants began by gaining access to participants via immunology clinics; private physician's offices; and places of worship in South Florida, after which recruitment flyers were posted in the approved locations. Flyers announcing the study were also posted on social media sites. Emerging adults with PAHIV who were interested in participating in the study, met the inclusion criteria, and contacted the researcher were screened to ensure that the inclusion criteria were met, and they were provided with information about the study. Eligible

volunteers were recruited, and an interview was arranged at a mutually convenient time and place in person for data collection. The sources of data collection included a demographic questionnaire (see Appendix E), which lasted approximately 10 minutes; a face-to-face, semi-structured conversational audiotaped interview lasting approximately 30 minutes; participants' reflection of the interview which lasted a maximum of 15 minutes each; a follow-up meeting for member checking and collection of reflection lasting approximately 15 minutes. The total time commitment for each participant was approximately 70 minutes.

The researcher assured each participant privacy and protection of their data, beginning with finding a quiet, convenient, and safe place to conduct the interview, and giving participants an option to choose their safe place for the interview. Interviews were conducted in private study rooms in libraries, the researcher's car, and participants' homes. The assurance of privacy and security of identity/information allowed the participants to feel more comfortable and to be more open and trusting in sharing their experience with HIV since birth. Each interview was opened with a welcome and thank you to the participant from the researcher. The study protocol, audiotape recordings, and clarification of the purpose of the study were reviewed, and all questions were answered.

Once the preliminary procedures were completed, the researcher again explained the purpose of the study, procedures for the interview, and the method of audiotape recording. The participants were then advised that they could decline to participate in the study at any point or that they may withdraw at any time or decline to answer any question(s) during the interview without being penalized. Each participant then selected a pseudonym, or the researcher assigned one. These pseudonyms are untraceable to the

participant's identity to maintain the confidentiality of the participant's information.

Informed consent (see Appendix B) was obtained. All signed consents were held securely and separately in a locked file in the researcher's home office. Each participant was given a \$20 Publix gift card at the interview, as a token of appreciation for participation in the study. They were informed that they may keep the promised gift card even if they withdrew from the study at any point.

The participants were asked to complete the demographic questionnaire (see Appendix E), which were then labeled with the pseudonym and subsequently held securely and separately in a locked file in the researcher's home office. It took each participant approximately 10 minutes to complete the demographic questionnaire. The face-to-face, semi-structured conversational audiotaped interview, using open-ended questions (see Appendix F) that followed, lasted an average of approximately 30 minutes. The digital audiotape recorder and the backup recorder were visibly located for participants to request pausing or for it to be turned off at any time. However, none of the 15 participants had made such a request. The researcher used follow-up questions to elicit, a richer, thicker description of the participants' experience, and to clarify or expound on specific expression of their experience of living with HIV since birth.

At the conclusion of each interview, the participants were offered the opportunity to ask questions and make any additional comments. They were also asked by the researcher to reflect on the interview and document their thoughts for a maximum of 15 minutes within the 3 weeks following the interview. Their thoughts were reflected in song, drawing, poems, body map art, and reflections, which were presented at follow-up meetings. The follow-up meetings were scheduled for 3 weeks after the initial interview

to facilitate member checking and the collection of reflections. The researcher thanked each participant for trusting the researcher with their private information and for their cooperation and participation.

After each audio-recorded interview, the researcher transcribed verbatim the recordings in an individual depiction within 1 week of the interview. Each individual depiction was reviewed multiple times by the researcher to ensure the accuracy and completeness of the transcription. All transcribed data are maintained on the researcher's secured, password-protected personal computer in the researcher's home office. At the follow-up meetings, the individual depictions were presented to each of the 13 participants who made themselves available for their follow-up meeting. They reviewed, clarified, and confirmed the transcribed data.

Two participants did not make themselves available for the follow-up meeting as scheduled. The researcher made numerous unsuccessful attempts to reschedule those meetings. Member checking is a significant step in the research process. It ensures credibility of the data by allowing the participant to review the transcribed data in the individual depiction and verify that it correlates with their intended statements. The audiotape recordings were deleted by the researcher after each participant verified the transcription presented in the individual depiction. Member checking lasted for approximately 15 minutes. Throughout the research process, the researcher recorded her reflexive thoughts. The data were useful during data analysis because the researcher is an instrument of the research process.

The guiding interview questions (see Appendix F) included a primary (grand tour) question and follow-up questions. The primary (grand tour) question gave the

participants an opportunity to express the meaning of their experience in their own words and gave direction to the interview process (Brenner, 2006, as cited in Green, Camilli, & Elmore). The follow-up questions were used when necessary to engage in in-depth probing of the participant to elicit a rich, thick descriptions of their experience and to clarify or expound on specific expressions of their experience of living with HIV since birth.

Demographic Data

Demographic data were collected from each study participant using a researcherdesigned demographic questionnaire (see Appendix E). The participants were asked to enter their selected or assigned pseudonym on their demographic questionnaire. The demographic questionnaire requested information from each participant regarding their age, gender, ethnicity, educational level achieved, employment information, living arrangements, relationship status, plans for marriage and family, sexual activity, involvement in community activities/organizations, and disclosure of HIV status. The data were used to describe the participants' characteristics and social activities that contributed to the interpretation of their lived experience. These data were reported in aggregate form. Completion of the demographic questionnaire took approximately 10 minutes. The face-to-face interview took approximately 30 additional minutes to complete. The demographic questionnaires are securely and separately held in a locked file in the researcher's home office. They were scanned and will be stored on the researcher's secured, password-protected personal computer for a minimum of 5 years upon completion of the study and then indefinitely.

Data Analysis

Moustakas' (1990) heuristic approach to data analysis, as illustrated in Figure 10, Heuristic Research, was used to guide this study. In heuristic research, the data collection and data analysis processes are continuous, occurring simultaneously, and without delimits of time or structure.

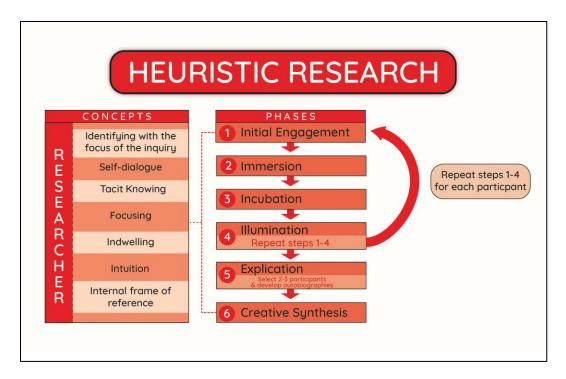


Figure 10. Heuristic research (Wright, 2018, adapted from Moustakas, 1990).

Phases of the Heuristic Data Analysis Process

The six phases of the data analysis process, as described by Moustakas (1990), are explained below.

Initial Engagement

The researcher discovers an intense interest or a passionate concern for an area of research that has important social and personal meaning, and compelling implications.

During this process, the researcher "reaches inward for tactic awareness and knowledge, permits intuition to run freely, and elucidates the context from which the question takes

form and significance" (Moustakas, 1990, p. 27). According to Moustakas (1990), the researcher gathers all the data from one participant (recording, transcript, notes, journal, personal documents, poems, artwork, etc.). The initial engagement phase of the data analysis process in this study involved, obtaining Barry University Institutional Review Board (IRB) approval (see Appendix A); and recruitment and access of participants by obtaining permission from medical directors or persons in charge of immunology clinics, private physicians' offices, and places of worship in South Florida (see Appendix C). Flyers (see Appendix D) announcing the study were posted in visible locations approved by administrators or persons in charge at immunology clinics, physicians' offices, and places of worship. Flyers announcing the study were also posted on HIV/AIDS related social media sites. The sampling procedure employed convenience, purposive, and snowball sampling techniques to select prospective participants. Recruitment was limited to the 15 volunteers who contact the researcher and who met all the inclusion criteria.

The researcher obtained informed consent (see Appendix B) from each participant. All signed consents are held securely and separately in a locked file in the researcher's home office. Participants were given a \$20 Publix gift card as a token of appreciation for participating in the study. Each participant was allowed to keep the gift cards even if they were to withdraw from the study at any point. Participants then selected a pseudonym or was assigned one by the researcher. Pseudonyms are not traceable to the participants' identity to maintain confidentiality. Each participant then completed the demographic questionnaire (see Appendix E), which was labeled with the pseudonym and has subsequently be held securely and separately in a locked file in the researcher's home office. Completion of the demographic questionnaire took a

maximum of approximately 10 minutes. The face-to-face semi-structured conversational audiotaped interview, using open-ended questions (see Appendix F), which lasted approximately 30 minutes, followed immediately after.

Immersion

Having identified the research question, the researcher lives and grows with the knowledge and understanding of the question. According to Moustakas (1990), the researcher comprehends knowledge of the individual participants' experience and its details by entering into timeless emersion with the data until it is understood. Moustakas (1990) further stated that, "primary concepts for facilitating the immersion process include spontaneous self-dialogue, self-searching, pursuing intuitive clues or hunches, and drawing from the mystery sources of energy and knowledge within the tacit dimension" (p. 28).

The immersion phase of the data analysis process in this study was satisfied through the data transcription process, for which the researcher transcribed verbatim the recordings (see Appendix G) into an individual depiction, within 1 week of the interview. All transcriptions were reviewed multiple times by the researcher to ensure accuracy and completeness of the transcription. This close, intense, and time-consuming relationship with the data permitted the researcher an understanding of the "participants' experience as a whole and in its detail" (Moustakas 1990, p. 51). The individual depictions are maintained on the researcher's secured, password-protected personal computer in the researcher's home office.

Incubation

During this phase, "the researcher retreats from the intense, concentrated focus of the question ... detached from the involvement with the question and removed from awareness of its nature and meanings" (Moustakas, 1990, p. 28). This separateness allows another level of knowledge to take place, as the inner workings of the tacit dimension and intuition continues. "The heuristic researcher through the incubation process gives birth to a new understanding or perspective that reveals additional qualities of the phenomenon or a vision of its unity" (Moustakas, 1990, pp. 28-29). Moustakas (1990) further advised that setting aside the data for a while encourages an interval of rest and return to the data, which facilitates the awakening of fresh energy and perspectives. The researcher then reviews all the data for that participant, making "notes, identifying the qualities and themes manifested in the data" (Moustakas, 1990, p. 51). This allows:

The heuristic researcher to construct an individual depiction of the experience ... which retains the language and includes examples drawn from the individual coresearcher's experience of the phenomenon ... It includes qualities and themes that encompass the research participants' experience (Moustakas, 1990, p. 51).

During the incubation phase of the data analysis process of this study, the researcher set aside the data and all related activities pertaining to each participant for 3 days. The researcher then returned to the data for that participant, made further notes, and developed and organized nodes in the NVIVO 11 data management system, from which themes for that participant were derived, thereby constructing an individual depiction of that participant.

Illumination

According to Moustakas (1990):

The illumination process occurs naturally when the researcher is open and receptive to tacit knowledge and intuition.... [it] is a breakthrough into conscious awareness of qualities and a clustering of qualities into themes inherent in the question ... [which] opens the door to a new awareness, a modification of an old understanding, a synthesis of fragmented knowledge, or an altogether new discovery of something that has been present for some time yet beyond immediate awareness. (pp. 29-30)

Moustakas (1990) further posited that the researcher returns to the original data of the individual participant to verify that the individual depiction of the experience fits the data and that it contains the quality and themes essential to the experience. If they are present, the researcher may move on to the next participant; however, if they are not present, the researcher must revise the individual depiction to include what was omitted. The researcher may also share the individual depictions with the "participant for affirmation of its comprehensiveness and accuracy and for suggested deletions and additions" (Moustakas, 1990, p. 51). During the illumination phase of the data analysis process of this study, the researcher returned to the data in the individual depiction for the participant, in search of new perspectives from the data, in preparation for the follow-up meeting where member checking and collection of reflections occurred. Member check was not done for two participants who did not make themselves available for the follow-up meeting. However, their individual depictions were given additional scrutiny to ensure the accuracy of the transcription.

Repeat the Process for Each Participant

At this point, the researcher repeated the previous four steps of the data analysis process for each of the following participants to the maximum of 15 participants who volunteered to participate in the study.

Explication

The explication phase facilitated the examination of what was:

Awakened in consciousness, in order to understand its various layers of meaning ... the recognition of new constituents and themes ... and the researcher attends to their own awareness, feelings, thoughts, beliefs, and judgments as a prelude to the understanding that is derived from conversations and dialogues with others (Moustakas, 1990, p. 31).

According to Moustakas (1990), "the heuristic researcher utilizes focusing, indwelling, self-searching, and self-disclosure ... the most significant concepts in explicating the phenomenon are focusing and indwelling" (p. 31). A more comprehensive depiction of the themes and sub-themes were developed consistent with Moustakas (1990) instructions which stated, "the researcher brings together discoveries of meaning and organizes them into a comprehensive depiction of the essence of the experience ... the researcher explicates the major components of the phenomenon, in detail" (31).

According to Moustakas (1990), the composite depiction may include exemplary narrative, descriptive accounts, conversations, illustrations, and verbatim excerpts that accentuate the flow, spirit, and life inherent in the experience and includes all of the core meanings of the phenomenon as experienced by the individual participants and by the

group as a whole. In this study, during the explication phase the collected data were further concentrated into major themes in a composite depiction.

Select Two to Three Participants and Develop Autobiographies

According to Moustakas (1990), the researcher will now return to the raw (data) material from each participants' experience and the individual depictions derived from the raw material and select two to three participants who exemplify the group. The researcher developed individual portraits for all 15 participants, depicting both the phenomenon being investigated and the individual person that emerged. In this study, the researcher returned to the raw data for each of the 15 participants and selected three participants (Melissa, Keisha, and Kayden) whose experiences exemplified the researcher's portrait (concentrated themes) of the emerging adults' essences of the experience of perinatally acquired HIV, and the images of the persons that emerged from such experiences.

Creative Synthesis

This is the final phase of the heuristic research process, Moustakas (1990) stated: [the researcher is]

Thoroughly familiar with all the data in its major constituent, qualities, and themes ... the researcher is challenged to put the components and core themes into a creative synthesis ... usually takes the form of a narrative depiction utilizing verbatim material and examples ... expressed as poem, story, drawing, painting, or by some other creative form (pps. 31-32).

This familiarity can only be achieved through tacit and intuitive powers ... of which the tacit dimension, intuition, and self-searching are the major concepts. Moustakas (1990) further stated:

The researcher, as a scientist-artist, develops an esthetic rendition of the themes and essential meanings of the phenomenon ... taps into their imaginative and contemplative sources of knowledge and insight to synthesize the experience in presenting the discovery of essences (p. 52).

The researcher is allowed a free reign of thoughts and feelings that supports their knowledge, passion, and presence, thus providing a personal yet professional and literary value that can be expressed through a narrative, story, poem, work of art, metaphor, analogy, or tale (Moustakas, 1990). Interpretation of the findings is the creative synthesis about the phenomenon in light of the reference of the researcher and is discipline-specific to enhance knowledge. New knowledge should be specified and recommended for further studies (Moustakas, 1990).

In this study, the creative synthesis of the data analysis process explicated the emerging adults' essences of the experience of having HIV since birth, through the interpretations of the themes and sub-themes; the participants' artistic association of their experience; and the researcher's best representation of their understanding (including the connection to a nursing theory), from which the final artistic presentation of the emerging adults' essence of living with HIV was determined. During the entire research process, the researcher set aside all prejudgments, biases, and preconceived ideas about emerging adulthood and perinatally acquired HIV, retaining only the natural attitude and the biases of everyday knowledge by maintaining a reflexive journal throughout the research

process. The researcher set aside the scientific "facts" and knowledge of things in advance (Moustakas, 1994). Reflexive journaling assisted the researcher to keep track of their thoughts, experiences, biases, and prejudgments, while leaving a trail from which the integrality of the research process can be judged.

Research Rigor

Rigor in qualitative research is the way of establishing trust or confidence in the results or findings of a research study. It launches consistency of the study method and provides an accurate representation of the population being studied with enough details to facilitate replication of the study with a different research sample (Thomas & Magilvy, 2011). According to Moustakas (1990), this is a question of meaning: "Does the ultimate depiction of the experience derived from one's own rigorous, exhaustive self-searching and from the explications of others present comprehensively, vividly, and accurately the meanings and essences of the experience?" (p. 32). Therefore, the scientific rigor with which this study was conducted was evaluated in terms of trustworthiness or the methodological soundness and adequacy of the data analysis (Holloway & Wheeler, 2010); through the processes of credibility, dependability, confirmability, and transferability.

Credibility

According to Shenton (2004), credibility has to do with how congruent the findings of the study are with reality. To promote confidence in the accuracy of the information provided in this study, tactics were used to ensure honesty in participants, when contributing data that was employed in this study. Each volunteer was informed that they may withdraw from the study at any time or refuse to answer any question(s),

without fear of reprisal (they can keep the Publix gift card) or changes in the quality of care they receive at any of the facilities that they were recruited from. In-depth probing and/or iterative questioning into matters raised by participants during their interview were also used to extract related data through rephrasing of indicated questions (Shenton, 2004).

The researcher used frequent briefing sessions with the dissertation chair to draw attention to flaws in the research process; discussed alternative approaches; and drew on the chair's experience and expertise. The dissertation chair was also used as a sounding board on which the researcher discussed developing ideas and interpretations to help recognize personal biases and preferences (Shenton, 2004). Adequate representations of the construction of the social world of the emerging adult with PAHIV (Bradley, 1993) were facilitated through the data analysis process in the illumination phase, where the researcher returned to the original data for verification of the individual depiction and accuracy and quality of the transcribed data and revised them where necessary. The researcher further consulted with participants through the member-check process at the follow-up meeting, on the accuracy of the interpretation of their statements in the initial interview and made corrections where necessary.

Dependability

According to Shenton (2004), to address dependability:

The process within the study should be reported in detail, thereby enabling a future researcher to repeat the work, if not necessary to gain the same result ...

This allows the reader to assess the extent to which proper research practices have been followed. (p. 71)

The coherence of the internal process of this study was facilitated through the consistent and accurate evaluation of the decision-making process of the study method. The context of this study was described in detail including changes in the study methods or procedures, arising from a change in conditions of the phenomena (Bradley, 1993). This was evident in the in-depth description of the study design and implementation; the operational details of the data collection process; and the reflective appraisal of the study by the researcher in a reflexive journal (Shenton, 2004).

Confirmability

Confirmability is the extent to which the characteristics of the data presented can be confirmed by others (Bradley, 1993). According to Shenton (2004), confirmability is:

The manner in which the concepts inherent in the research question give rise to the work to follow may be tracked ... detailed methodological description enables the reader to determine how far the data and constructs emerging from it may be accepted ... which allows any observer to trace the course of the research step-by-step via the decisions made and the procedures described (p. 72).

Confirmability was accomplished by preserving the collected data which facilitated the linking of the participants' voice to the findings of the study. The transcribed data were further presented to each participant at the scheduled follow-up meeting for their review, clarification, and confirmation; to ensure that the transcribed data correlated with the information they intended to share. Additionally, Holloway and Wheeler (2010) concurred that the findings and conclusions of the study should not be affected by the researcher's prior assumptions and preconceptions (EPOCHE) because the data should be traceable to its original source. To this end, an experiential context was presented in the

literature review, giving details of the researcher's experience with the phenomenon. The researcher maintained a reflexive journal throughout the research process.

Transferability

Transferability refers to the extent to which a researcher's working problem statement about one context and the knowledge acquired are relevant to other situations and to other researchers conducting research in another related context. Depending on the research paradigm, the findings of the study should be transferable to similar situations or participants (Bradley, 1993; Holloway & Wheeler, 2010). Shenton (2004) further stated that, in qualitative research, the transferability of the study finding to other situations or setting is not the responsibility of the researcher; that burden lies on those who wish to make the comparison. According to Bradley (1993), [the researcher's] "responsibility is to provide enough data, through rich, ample description, to allow these judgments to be made" (p. 497). In this study, a thorough description of the research process is documented, thereby providing a paper trail from which others may determine the accuracy of the findings, which is consistent with qualitative research.

Chapter Summary

This chapter provided details of the methods applied to this study. These include the heuristic research design; sample and setting; access and recruitment procedures; inclusion criteria; exclusion criteria; ethical considerations; data collection procedures; demographic data; data analysis; and research rigor. Chapter Four follows with the findings for the inquiry.

CHAPTER FOUR

FINDINGS OF THE INQUIRY

The emerging adults with perinatally acquired HIV (PAHIV) are in the selffocusing stage of development when individuals are most likely to have the freedom to make life-affirming decisions as they wish, yet not having "entered into the social or institutional roles of marriage, parenthood, and long-term employment that provide new constraints" (Arnett, 2006, p. 304). A paucity of data exists that indicates whether they can achieve the benchmarks of this developmental stage because few studies have been conducted to determine the effects of the physiological, psychological, and sociological challenges they often encounter. It is important to understand the transition to emerging adulthood for the individual with PAHIV; therefore, studies are needed to inform nursing and to ensure that the health and wellness needs of this population are met. Nursing needs to conduct more studies to gain that understanding to ensure the health and wellbeing of the PAHIV emerging adult and to give them a voice. Consequently, the purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of perinatally acquired HIV, with the specific aim to determine if the PAHIV emerging adults are meeting the benchmarks of their developmental stage as their unaffected peers, and to elucidate their voices to understand their essence of the experience of perinatally acquired HIV.

A total of 15 interviews were conducted between January 3, 2018 and June 17, 2018. Data saturation was achieved at interview number 12 with study participant **Rashad**; however, the researcher continued the recruitment process to facilitate a richer analysis of the data. This chapter describes the characteristics of the sample participants,

giving details of the demographic characteristics; an individual depiction of each participant; and the explication phase where a composite depiction is composed from the individual depictions. The composite depiction elucidates the major themes and subthemes emerging from the study. This chapter also includes exemplary portraits (autobiography) for three participants, whose stories reflects both the individual participants' essence of the emerging adults' lived experience of PAHIV as well as the collective or universal portrayal of the essence of that experience; a creative synthesis which explicates the meanings and details of the experience as a whole; an aesthetic rendition; connection of the themes and sub-themes to the Human Becoming Theory; and a chapter summary.

Sample Description

Access and recruitment of participants for this study was the most challenging aspect of the study because of the potential threat of violation to the Health Insurance Portability and Accountability Act [HIPPA] (1996); the protectiveness of health care providers (HCPs) toward this population; and the stigma associated with HIV. Healthcare providers were reluctant to place flyers in their facilities citing the potential for HIPPA violation, and in some cases additional Institutional Review Board (IRB) approval were required from their institution and/or from the state of Florida. In addition, HCPs were reluctant to have their patients participate in such a study being conducted outside of their establishment. Access to the population of emerging adults with perinatally acquired HIV (PAHIV) was achieved by gaining permission to post flyers in approved places in physicians' offices, immunology clinics, and churches; the creation of a Facebook page; and the use of other social media to advertise the study. This process

facilitated purposive and convenience sampling techniques to achieve the study sample of 15 emerging adults (age 18-25 years) who acquired HIV perinatally.

A total of 20 volunteers contacted the researcher, of which 15 consented to and were among the sample population. One female volunteer who met the inclusion criteria and already had a child ultimately decided not to participate in the study because she was afraid that others in her community would find out about her HIV status. Another female activist who also met the inclusion criteria was not comfortable participating in a study outside of her health care network, although she was actively involved in the community representing the PAHIV population. Two volunteers, a female and a male, did not meet all the inclusion criteria because they were 28 and 34 years of age, respectively. One male volunteer needed permission from his wife before he could agree to participate. He did not follow up with the researcher to participate in the study.

The selection of the sample population of 15 participants was based on the inclusion criteria of the study. Each participant self-identified as having contracted HIV from their mothers; that they were between 18 and 25 years of age; and that they lived in South Florida (Miami, Dade, Broward, and Palm Beach counties). All participants spoke and understood English; had a personal cell phone; and consented to be audio-taped. Each participant signed the consent form giving permission to participate in the research after the study was fully explained. Each participant was then given a \$20 Publix gift card as a token of appreciation for participating in the study, and they were informed that the gift cards were theirs to keep even if they decided at any point to withdraw from the study or refused to answer any question(s). Participants were asked to select a pseudonym to maintain confidentiality. Allowing the participants to select their own

pseudonym also facilitated the participants' further description of themselves. The names chosen were based on either how they regarded themselves as defined by their experiences or names that they would have given themselves if they had the option of choosing their own names. The pseudonyms were placed on the demographic questionnaires and all other documentation and audiotaped recordings related to the study. Each audiotaped recording was destroyed by the researcher after each follow-up meeting, where the participant verified the correctness of the data, which were transcribed from the audio recording.

Characteristics of Sample Demographics

The demographic composition of the sample population represented a diverse group of emerging adults (18-25 years) who contracted HIV perinatally. Table 2 presents a summary of the characteristics of the sample demographics: age, gender, ethnicity, education, employment status, area of preference to work as an adult, residency status, geographic location (county), relationship (intimate) status, partner aware of HIV status; disclosure of HIV status to partner, good age to start having sex, sexually active, age first became sexually active, HIV sero-status of intimate partners, marriage, children, and volunteer activity.

Table 2
Summary of Characteristics of Sample Demographics (Wright, 2018)

Demographic Data	N = 15	Percentage
Age		
18 – 20 years	2	13.33%
21 – 23 years	6	40%
24 – 25 years	7	46.67%
Gender		
Male	5	33.33%
Female	10	66.67%
Ethnicity		
Black – African or American	13	87%
Hispanic	2	13%
White Non-Hispanic	0	0
Education		
High School Diploma (Only)	5	33.33%
Associates/Technical Degree	1	6.67%
Bachelor's Degree	2	13.33%
Master's Degree	1	6.67%
Registered in Bachelor's Degree Program	2	13.33%
Registered in Associate/Technical Degree Program	4	26.67%
Employment Status		
Unemployed	6	40%
Part-time	5	33.33%
Full-time	4	26.67%
Is This an Area You Want to Work as An Adult?		
Not Applicable	4	26.67%
No	6	40%
Yes	5	33.33%
Residency Status		
Lives at Home with Parents/Family	12	80%
Lives with Intimate Partner	1	6.67%
Shares Living Space	1	6.67%
Lives Independently	1	6.67%

(Table 2 continues)

(Table 2 continued)

Demographic Data	N = 15	Percentage
Geographic Location (County)		
Broward	10	66.67%
Palm Beach	2	13.33%
Miami Dade	3	20%
Relationship (Intimate) Status		
Never been in an intimate relationship	4	26.67%
Not in an intimate relationship presently	2	13.33%
In an Intimate relationship	9	60%
Partner Aware of HIV Status		
Not Applicable	6	40%
No	0	0%
Yes	9	60%
Good Time to Start Having Sex		
No Opinion	1	6.67%
18 years or before	1	6.67%
19-20 years	9	60%
21-22 years	3	20%
23-24	0	0%
25-26	1	6.66%
Sexually Active		
No	6	40%
Yes	9	60%
Age of First Sexual Experience		
Never Been Sexually Involved	4	26.67%
13 - 15 Years	1	6.67%
16 - 18 Years	8	53.33%
19 - 21 Years	2	13.33%
HIV Sero-Status of Intimate partner(s)		
Never had sex	4	26.67%
Have had sex with HIV negative partner	10	66.67%
Have had sex with HIV positive partner(s) ONLY	1	6.67%

(Table 2 continues)

(Table 2 continued)

<i>N</i> = 15	Percentage
2	13.33%
12	80%
1	6.67%
2	13.33%
9	60%
3	20%
1	6.67%
8	53.33%
3	20%
3	20%
1	6.67%
	2 12 1 2 9 3 1 1

Age and Gender

The population sample consisted of 15 participants between the age of 18 to 25 years. The age distribution groups were as follows: 18 to 20 years n = 2 (13.66%); 21 to 23 years n = 6 (40%); and 24 to 25 years n = 7 (46.66%). The gender distribution among the population sample were females n = 10 (66.67%), and males n = 5 (33.33%). Females 24 to 25 years represented n = 5 (33.33%), accounting for the largest group; 21 to 23 years represented n = 4 (26.66%); and 18 to 20 years included n = 1 (6.66%). Males between 24 to 25 years were n = 2 (13.33%); 21 to 23 years were n = 2 (13.33%); and 18 - 20 years was n = 1 (6.67%). The sample consisted of more Black Africans or Black Americans n = 13 (87%) than Hispanics n = 2 (13.33%); and Whites-Non-Hispanics n = 0 (0%).

Education

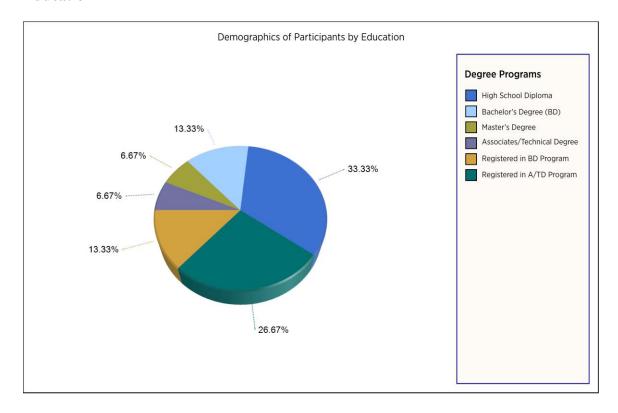


Figure 11. Demographics of participants by education (Wright, 2018).

Figure 11 illustrated that all 15 participants have obtained a minimum of a High School Diploma (HSD) of which 33.33% (n = 5) remained with an HSD as the highest degree earned and not presently enrolled in a program of study. Of those five participants, 60% (n = 3) have indicated a desire or plan to further their education; 20% (n = 1) did not believe that college was for them, and 20% (n = 1) did not have the mental capacity for higher education. Figure 11 also demonstrates that 6.67% (n = 1) have already earned an Associate Degree (AD); 13.33% (n = 2) have already earned a Bachelor's Degree (BD); 6.67% (n = 1) have already earned a Master's Degree (MD); 26.67% (n = 4) are presently enrolled in either an Associates or a Technical Degree (A/TD) program and are focused with a high possibility of completing these programs successfully; and 13.33% (n = 2) are presently enrolled in Bachelor's Degree programs.

Employment Status

The employment status of the sample population indicated that 40% (n = 6) of the sample population were employed part time; 33.33% (n = 5) were unemployed; and 26.67% (n = 4) were employed full time.

Residency Status

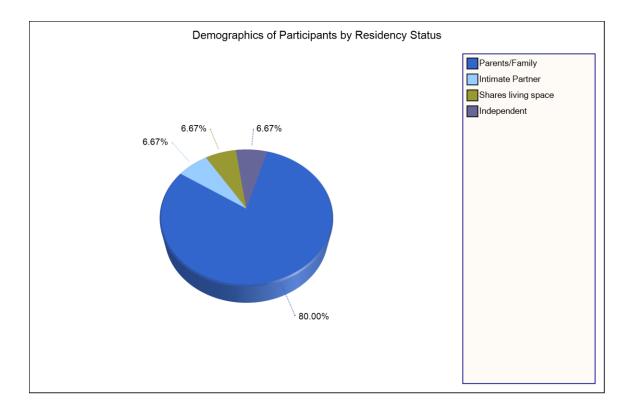


Figure 12. Demographics of participants by residency status (Wright, 2018). Figure 12 demonstrated that 80% (n = 12) of all participants were still living at home with their parents or family; 6.67% (n = 1) were living with an intimate partner; 6.67% (n = 1) were sharing living space; and 6.67% (n = 1) lived independently. Geographically, all participants resided in South Florida (Broward, Miami-Dade, and Palm Beach counties). Most participants, n = 10 (66.67%) resided in Broward County; n = 3 (20%) resided in Miami-Dade County; and n = 2 (13.33%) resided in Palm Beach County.

HIV Sero-Status of Intimate Partners Compared with Participants' Relationship Status

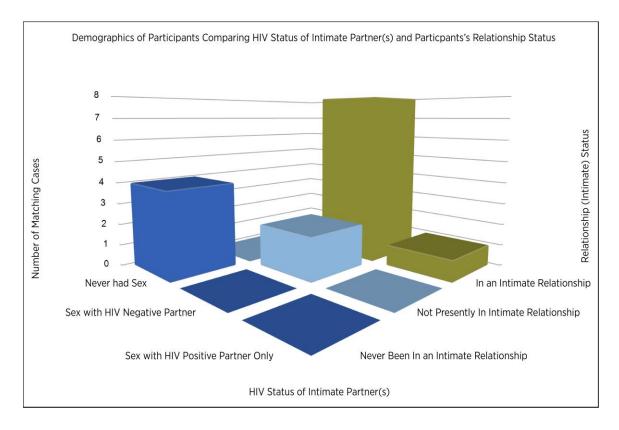


Figure 13. Demographics of participants comparing HIV sero-status of intimate partner(s) and participants' relationship (intimate) status (Wright, 2018).

Figure 13 illustrated that n = 9 (60%) of sample population were involved in an intimate relationship of which n = 8 (53%) of the sample population were involved in an intimate relationship with an HIV negative partner; n = 1 (6.67%) of the sample population have had sexual encounters with HIV positive partners only; and n = 10 (66.67%) of the 15 study participants have had sexual encounter with a HIV negative partners at some point. Figure 13 also illustrated that, of the remaining six participants who were not involved in an intimate relationship, n = 2 (13.33%) have been involved in intimate relationships with a HIV negative partner(s) in the past; and n = 4 (26.66%) have never been involved in an intimate relationship nor have ever had a sexual encounter. All participants who reported

that they have been involved in sexual relationships, have also reported that they had informed their intimate partners of their HIV status before they became sexually involved. Of the 15 participants, 53.33% (n = 8) reported that they had their first sexual encounter between 16-18 years of age; 13.33% (n = 2) had their first experience between the age of 18-21 years of age; 26.67% (n = 4) have not had a sexual encounter; and 6.67% (n = 1) first sexual encounter was between 14-15 years of age.

Plan for Marriage and Having Children

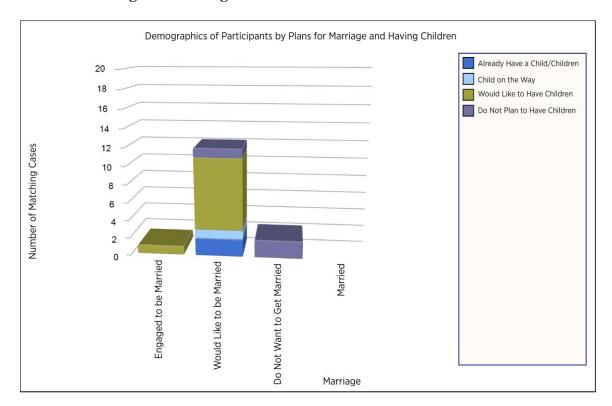


Figure 14. Demographics of participants comparing participant's plan for marriage and having children (Wright, 2018).

Figure 14 indicated that n = 1 (6.67%) of the sample population is already engaged to be married and plans to have children in the future; n = 12 (80%) would like to get married, of which n = 2 (16.66%) already have a child; n = 1 (8.34%) has a child on the way; n = 8 (66.66%) would like to have children; n = 1 (8.34%) does not want to have children;

and n = 2 (13.33%) of the sample population does not want to either get married or to have children.

Volunteer Activity

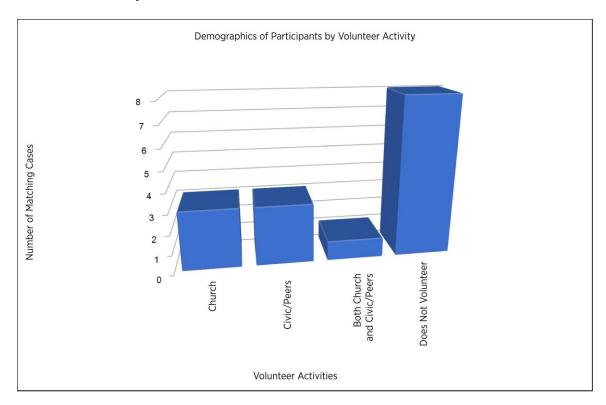


Figure 15. Demographics of participants by volunteer activity (Wright, 2018).

Figure 15 illustrated that n = 3 (20%) of the sample population volunteered in church groups; n = 3 (20%) volunteered in civic/peer groups; n = 1 (6.67%) volunteered in both church and civic/peer groups; and n = 8 (53.33%) did not volunteer.

Characteristics of Sample

Each participant was described using data obtained from the demographic questionnaires, interview transcripts, and the researcher's reflections. Those characterizations included: age; gender; ethnicity; education; employment status; is this where they wanted to work as an adult; residency status; geographic location (county);

relationship (intimate) status; partners aware of HIV status; good age to start having sex; sexually active; age at first sexual experience; HIV sero-status of intimate partner(s); marriage, children and volunteer activity. Those characterizations of each participant are presented in the order that the interviews were conducted as follows:

Bryan

Bryan is a 19-year-old male of Black/Non-Hispanic descent. He graduated from high school and has completed two semesters in a 4-year college program, from which he had to transfer. Bryan is presently enrolled in a 2-year college program. He is employed part time managing beach equipment, which is what he would like to be doing in the future. Bryan presently lives at home with his biological father in Broward County. He is involved in an intimate relationship and his girlfriend who is HIV negative and aware of his HIV status. Bryan believes that a good time to start having sex is between 19 and 20 years of age. He is sexually active. Bryan's first sexual experience was between 16-18 years of age. He would like to get married and have children in the future. Bryan thinks that he will be ready to start having children between 24-26 years of age. He is not involved in any organized sporting or recreational activities, religious, civic or community organization, or peer programs.

Jamie

Jamie is a 24-year-old female of African American descent. She has earned an associate degree in medical technology but presently works full time in retail. Jamie's career goal is to become a nurse, and she has plans to return to college to earn the qualifications. She presently shares accommodation with her sister and her niece in Broward County. Jamie reported that she is not involved in an intimate relationship.

She believes that a good time to start having sex is between 25 and 26 years of age. **Jamie** is not sexually active. She would like to get married, but she is not planning to have children. **Jamie** is not involved in any organized sporting or recreational activities, religious, civic, or community organizations or peer programs.

Blessed

Blessed is a 22-year-old female of Black/Non-Hispanic origin. In addition to being born with HIV, she was also born with cystic fibrosis. Blessed has graduated from high school. She plans to go to college in the future to prepare herself to become a professional photographer. Blessed is presently unemployed. She currently lives at home with her mother, stepfather, brothers, and stepbrother in Broward County. Blessed is presently involved in an intimate relationship with her HIV negative partner, who is aware of her HIV status. She believes that between 21 to 22 years of age is a good time to start having sex. Blessed's first sexual encounter was at 16 years of age, when she was raped by a schoolmate, who was unaware of her HIV status. She is planning to get married and have more children in the future. Blessed is not involved in any organized sporting or recreational activities, religious, civic, or community organization or peer programs. She shares a daughter, who is HIV negative, with her HIV negative partner.

Margarita

Margarita is a 22-year-old female of Black/Non-Hispanic origin. She has already earned a high school diploma and is in the process of registering for a program to continue her studies. Margarita is not presently employed, but she is actively seeking employment. She lives with her brother in Miami Dade County. Margarita is not presently involved in a romantic relationship, but she has been involved in the past and

each of her former partners were HIV negative. Her last two partners were aware of her HIV status. Margarita believes that between 19 and 20 years of age is a good time to start having sex. Her first sexual encounter was between 16-18 years of age. Margarita would like to get married. She has suffered miscarriages in the past, however, she is looking forward to having children in the future. Margarita thinks that she will be ready to have children when she is between 24 and 26 years of age. She is not involved in any organized sporting or recreational activities, religious, civic or community organization, or peer programs. Margarita was informed of her HIV status when she was 14 years of age, which was after her mother died of complications from HIV/AIDS. She has since been diagnosed with depression, for which she has been hospitalized on multiple occasions. Margarita's father was incarcerated for most of her life and he was recently released from prison. She is presently waiting on her mother's death certificate to proceed with her application to a program of study.

Ashley

Ashley is a 24-year-old female of Hispanic origin. She was adopted by her foster parents at 6 years old. Ashley will earn a bachelor's degree in sociology and a minor in psychology May 2018. She is presently employed full time while working on her degree. Ashley lives with her HIV negative partner in Broward County. He is aware of her HIV status. She believes that between 19 and 20 years of age is a good time to start having sex. Her first sexual encounter was between 16-18 years of age. Ashley would like to get married and she plans to have children in the future. She thinks that she will be ready to have children when she is between 24 and 26 years of age. Ashley is not involved in

any organized sporting or recreational activities, religious, civic or community organization, or peer programs.

Ahmazin

Ahmazin is a 25-year-old female of Black/Non-Hispanic origin. She was not diagnosed with HIV until after she became ill, at about 15 years of age. Ahmazin already has an associate degree and a bachelor's degree. She will earn a master's degree in Business Administration in June 2018. **Ahmazin** is presently employed fulltime at an HIV/AIDS Prevention and Awareness Organization. She resides with her mother and grandmother in Miami-Dade County. **Ahmazin** is currently involved in an intimate relationship with her HIV negative partner. She reported that she disclosed her HIV status to him, 3 weeks into their relationship. **Ahmazin** believes that between 19 and 20 years is a good time to start having sex. Her first sexual experience was between 19-21 years of age. Ahmazin is planning to get married and have children in the future. She thinks that she will be ready to start having children between 27 and 29 years of age. **Ahmazin** is not involved in any organized sporting or recreational activities. She is involved in religious, civic, and community organizations where she plays active roles. Additionally, **Ahmazin** volunteers at a family foundation, and she participates in peer programs. She is also in the process of establishing her own non-profit foundation.

Loren

Loren is a 24-year-old female of Black/Non-Hispanic origin. She is enrolled in a 2-year college degree program, where she has made several changes in her major. Loren pledges to complete her degree by the end of 2018, while she continues to work part-time. She presently lives at home with her mother. Loren is not currently involved in

an intimate relationship, but she has been involved in the past, and all her sexual partners have been HIV negative. She believes that a good time to start having sex is between 19 and 20 years of age. Her first sexual encounter was between 19-21 years of age. **Loren** hopes to get married and have children in the future. She thinks that she will be ready to start having children when she is between 27 and 29 years of age. **Loren** attends church and participate in a woman's group, but she does not volunteer.

Edward

Edward is a 22-year-old male, of Hispanic origin. He has an associate degree and he is a full-time student, pursuing a bachelor's degree in mechanical engineering. Edward is presently employed as a research assistant. His career goal is to obtain his Doctor of Philosophy (PhD) degree and become a researcher and professor in his field of study. Edward lives with his mother in Broward County. He is presently involved in an intimate relationship with his HIV negative partner, who is aware of his HIV status. Edward believes that 18 years of age or before is a good time to start having sex. His first sexual encounter occurred when he was between 16 and 18 years of age. Edward would like to get married and have children in the future. He believes that he will be ready to have children between 24 and 26 years of age. Edward volunteers in peer groups on his college campus. His career choice will allow him to mentor and support other aspiring researchers.

Melissa

Melissa is a 24-year-old female of Black/Non-Hispanic origin. She is a high school graduate who is presently unemployed. **Melissa** has several career ideas in mind, including being a nurse and an entrepreneur. She continues to live at home with her

sisters in Broward County. **Melissa** is in a romantic relation with her HIV negative partner. She reported that he is aware of her HIV status, which she disclosed to him. They share a son, whom she reported as being HIV negative. **Melissa** believes that between 19 and 20 years of age is a good time to start having sex. Her first sexual encounter was between 16 and 18 years of age. **Melissa** would like to get married and have more children in the future. She volunteers at her doctor's office when they have events, however she is not involved in any organized sporting or recreational activities; religious; civic or community organization; or peer programs. **Melissa's** mother died when she was only 10 years of age, after which her sister assumed responsibility for her.

Keisha

Keisha is a 22-year-old female of Black/Non-Hispanic origin. She graduated from high school and is presently a full-time student in a 4-year undergraduate college program. Keisha is unemployed, but she aspires to become a medical doctor. She lives at home in Broward County with her aunt who has been her primary caregiver since she was a child. Keisha's biological mother lived in Haiti and would travel to the U.S to see her from time to time. However, she has since died of complications from HIV/AIDS. Keisha is engaged to be married to her fiancé who is HIV negative. She reported that he is aware of her HIV status, which she disclosed to him in June 2015. Keisha believes that between 19 and 20 years of age is a good time to start having sex. She is sexually active, and her first sexual encounter was between the age of 16 and 18 years of age. They plan to get married within the next year and to start having children when she is between 24 and 26 years of age. Keisha attends church; otherwise, she is not involved in any organized sporting or recreational activities, civic or community organization, or peer

programs. However, she would be interested in becoming involved in the destignatization of HIV.

Kayden

Kayden is a 25-year-old male of Black/Non-Hispanic origin. He has a bachelor's degree in criminal justice with a minor in psychology. **Kayden** planned to return to college in the fall 2018 semester to earn a master's degree in public administration or criminal justice. He is employed full-time as a teller/customer service representative. Kayden would like to become a Transportation Safety Administration (TSA) custom and border patrol agent. He lives at home with his mother's cousin who took on the responsibility for him and his two brothers, providing parental and emotional support after his parents died. Both of **Kayden's** parents died of complications from HIV/AIDS when he was only 5 years of age. At the time of his parent's death, a burial plot was also purchased for him, in preparation for his death. **Kayden** and his family reside in Broward County. He is currently involved in his first serious intimate relationship, with an HIV positive partner, who acquired the virus behaviorally. **Kayden** reported that he disclosed his HIV status to his partner. He believes that it is a good time to start having sex between 19 and 20 years of age. **Kayden's** first sexual experience occurred when he was between 16 and 18 years of age. He hopes to get married in the future and has only recently started to consider the possibility of having children. **Kayden** provides support to individuals who are newly diagnosed with HIV by reassuring them and pointing them in the direction of available resources, that they might not have been aware of. He also volunteers in a youth program at his doctor's office; and every year he attends the

summer camp for children with HIV and other chronic illnesses. **Kayden** cannot recall not knowing that he is HIV positive.

Rashad

Rashad is a 25-year-old male of Black/Non-Hispanic origin. He was recently enrolled in a 2-year college degree program, from which he has taken some time off to prepare for the birth of his first child. **Rashad** is employed full-time in the school system. He aspires to become an occupational therapy technician. Rashad resides independently in Broward County. He is presently involved in an intimate relationship with the mother of the child he is expecting. She is aware of his HIV status because they have known each other since they were children, as part of the same medical program. **Rashad** believes that between the age of 19 and 20 years is a good time for an individual to start having sex. His first sexual experience occurred when he was between 14 and 15 years of age. **Rashad** reported that all his sexual partners have been his peers who also acquired the virus perinatally. He thinks that marriage is "nice," but he has no immediate plans to get married, although he would like to get married when the time is right. **Rashad** thinks that he will be ready between 24 and 26 years of age. He volunteers every year at the summer camp, for children with HIV/AIDS and other chronic diseases, that he also attended when he was younger. **Rashad** does not participate in any other organized sporting or recreational activities, religious, civic, or community organization or peer groups.

Brittany

Brittany is a 19-year-old female, Black/Non-Hispanic. She has graduated from high school and is presently attending a full-time technical training program where she is

learning cosmetology. **Brittany** is unemployed, but she would like to own a cosmetology business in the future. She lives with her sister who is her primary care giver, in Miami Dade County. **Brittany** reported that she is not presently involved in a romantic relationship and that she has never had sex. She believes that a good time to start having sex is between 21 and 22 years of age. **Brittany** would like to get married and have children in the future. She thinks that she will be ready to have children between 27-29 years of age. **Brittany** attends church every Sunday; however, she does not play any active role. She does not participate in any other organized sporting or recreational activities, civic or community organization, or peer programs. **Brittany** was not informed of her HIV status until she was 11 years of age. She lost both of her parents within a short time of each other, to complications from HIV/AIDS.

Travis

Travis is a 23-year-old male of Black/Non-Hispanic origin. He graduated from high school and started college briefly. However, about 2 months into the program, he realized that college was not for him and withdrew from the program. Travis has no plans of going back to college because he does not believe that he needs a college degree to become a successful musician. However, he is willing to reconsider that decision if it ever becomes necessary for him to have a degree to become successful in his career.

Travis is presently working multiple jobs as a music therapist, social work and online marketing. He aspires to become a musician. Travis resides with his adoptive mother in Palm Beach County. He is not involved in a romantic relationship. Travis thinks that between 21 and 22 years of age is a good time to start having sex. He would like to get married, but he has absolutely no desire to have children. Travis is not involved in any

organized sporting or recreational activities, civic or community organization, or peer program.

Lovely

Lovely is a 22-year-old female, of Black/Non-Hispanic origin. She graduated from high school in 2011. **Lovely** is presently unemployed and attends a day program at Goodwill, where she is being prepared for job interviews. She lives at home in Palm Beach County with her adoptive mother but, she has plans to move into a group home in a few weeks. **Lovely** is not involved in an intimate relationship. She has never had sex and is not planning to get married nor to have children. Lovely attends Church regularly and participates in church activities; however, she does not hold any position. She is enthusiastically looking forward to a mission trip to Uganda, where she hopes to share with the children about herself and the Love of Jesus. Lovely is not involved in any other organized sporting or recreational activities, civic or community organization, or peer programs. She was born prematurely at 23 weeks gestation, with multiple birth defects including cognitive and developmental deficits. Lovely stutters and sometimes have difficulty expressing her thoughts; however, she was alert and responded to the questions in context. When she was not certain of how to respond, she simply stated, "I don't know."

Individual Depictions of Sample Participants

The individual depictions retained the language and included examples drawn from the individual participant's experience as an emerging adult living with HIV since birth. They were generated from the transcribed interview, information gathered from the demographic information sheet, and the researcher's reflection of the meeting. The

individual depictions included the qualities and themes that surrounded the participants' experience. In constructing the depictions, the researcher entered into timeless immersion in the data from the tape recordings of the interviews with the participants, listening multiple times while transcribing the data until the participants' experiences were fully understood (Moustakas, 1990). The data was then set aside for 3 days to facilitate the awakening of fresh energy and perspective (Moustakas, 1990). The researcher then returned to the data (the transcribed interview, which was read several times for accuracy; the demographic questionnaire; and the researcher's reflection of the interview), utilizing tactic dimension and intuition to identify nodes. The NVIVO 11 data management system was then utilized to organize the nodes, from which the individual depiction of the experience as an emerging adult with PAHIV was constructed. The individual depiction was presented to the participant during member check, for their corroboration of the accuracy of the depiction, and for corrections to be made where necessary (Moustakas, 1990, 2001).

All 15 participants of the study self-identified as having contracted HIV from their mothers; that they were between the age of 18-25 years; and that they lived in South Florida (Miami-Dade, Broward and Palm Beach counties). All participants spoke and understood English and had a personal cell phone. Confidentiality was maintained by each participant selecting a pseudonym after signing the informed consent. The pseudonyms were subsequently used on all documentations and recordings, and participants' were subsequently referred to by the pseudonym at all points and mode of contact (phone calls, text messages, emails, and meetings) throughout the study. Participants received medical care at physicians' offices and immunology clinics and

participated in social groups. Interviews were conducted in physicians' office, private study room in libraries and participants' homes. Interview recordings lasted from a minimum (**Keisha**) of 14.54 minutes to a maximum (**Ahmazin**) of 38.03 minutes for a sample average of 24.15 minutes.

Bryan

Bryan explained his perception of his life with HIV:

At first when you are a child you don't really know until your parents actually tell you, you think you are normal ... it was now that just that we the short percentage of us who surpass that rough stage ... we just look back and it's like we were meant to be here for something, whether it's we ... live to see the cure or not, were er to, were here, we are here for something. We may not know what is for, we are meant to teach somebody something, whether is one person were here to raise awareness of what's going on with this ... it not our fault, ok were just born with it unfortunately.

When asked by the researcher if he thought that his life would be different if he did not have HIV, **Bryan** responded:

The only thing different I think, it would be I would be, playing football because, when my mother passes I had a lot of anger build up in me and when I got introduced to football, that's what was able to let me release it out. And in middle school my guardian at the time was my aunt, I asked her Hey! "can I play football?" and she said yes. When high school came she changed her mind and said no, and I would play football with my [physical education] PE class and during the time I was in high school and kinda still now I good at it and the coach

would go to the school and call my aunt on her phone and ask her like if can he play? And like we need help in such and such a position and he could help. She was like [pause] so, the only thing in my life that I think would be different? The sport that I love and that's that really it yeh! Honestly! If I would stay with it, maybe I wouldn't be here, I may have been in a different state maybe have gotten a scholarship but just because I had that I couldn't play. I wouldn't let it hinder me from my academic.

Bryan believed that his life was normal and not any different from his HIV negative peers. He said, "the only thing different I think, it would be I would be playing football." When asked by the researcher about his vision of the future as a person with HIV, **Bryan** responded:

Normal life! I would like to get married, I would like to have children, have my own house. Have my own stable job. I don't see myself as, Oh! I got to keep going to the hospital for this and that, I can't have a wife, I am not gonna love you because of this, I am not gonna have children because I don't wanna be a risk of my children having this, and I may feel that I am going to mess up there life as well.

Bryan learned of his HIV status when he was in the fifth grade. He explained:

I found out how I got it, I found [out] I had it when I was in the fifth grade, when I was living with my father at the time ... I think what happened was I keep asking him why I was taking the medication and he didn't tell me, so I refused to take them ... So, he felt like "I have to tell him so, he can start take the medication" ... So that when he decided to tell me ... I can't exactly remember

what happened, but I am pretty sure knowing myself back then, that's what mostly what happened.

Bryan disclosed the following about his knowledge of HIV at the time he was told of his diagnosis:

The only person I ever spoke to about that was my father ... I didn't feel comfortable going to my mom about it; he didn't think that I was gonna figure it out; I was like probably 14 when I figured that out.

Prior to being told that he had HIV, **Bryan** questioned having to take medication as frequently as he did. He explained, "you always wonder like, why do I take this liquid medication at night, why do I have to take a pill or three pills at morning or night? Until you actually find out..." **Bryan** explained that even after his dad told him of his diagnosis, he had other questions:

So, one day I was like, ok? You can only contract HIV through blood and semen. She couldn't have gotten it through semen, because from what I know my mother wasn't cheating, and my father my father was negative, and if she is [in] Rehab, that means she got it through blood and the only drug of choice you can get blood from, is if you are sharing needles through crack or heroine or things of that nature.

The researcher asked **Bryan** what it was like growing up with HIV, and he responded:

Until your parent or your guardian actually tells you what's going on, you don't really know, you actually have this thing, you just think that you are a normal kid, and you, but you, sometimes if your imagination is wild enough you actually wonder why am I taking this liquid medication, once, twice, three times a day, or whichever the case may be.

When asked about his response to his HIV diagnosis, **Bryan** said:

I never shamed my mother for it I'll never thought it was her fault ... I never was like you ruin my life. I was like it's fine, something always happen to everybody, somebody's life but you can't blame somebody for it. You have to embrace and live with it.

When his biological mother died, **Bryan** assumed that it was from complications of HIV/AIDS. His aunt, who is also his godmother and adoptive mother, has been his main source of care, support, and guidance. **Bryan** reported:

I would consider her a parent because I lived with her from when I was 3 years old till I was, until I was until I was 10 or 11 So, I always consider her as, even though she is not my mother I always consider her my mom especially consider that she is already my godmother, and the fact that she is my mother's biological sister and I never saw anything different of her ... When I was a younger age, I used to call her my mom, even her husband, like me and him may never have gotten along, we may never talked but at the end of the day I saw him as a second dad as well.

At the time of the interview, **Bryan** was living at home with his biological father who was HIV negative. Bryan graduated from high school and started a full-time 4-year college degree program for which he had earned a scholarship. However, he later transferred to a part-time 2-year college program. **Bryan** explained:

I got pass my first year, I did my fall and spring semester of my freshman year at STT aahm I switched over to BDD doing that part time so that I can work and maintain a job and maintain financial stability while I am in school, instead of me

going to school five days a week and then working only on the weekends, but I need, I need my weekends, I need my weekend to study and things of that nature. So, I decided to make the sacrifice for me to get my associated degree later, so I may wanna maintain everything and keep the grades up because that was my situation at STT. I ended up failing one class, twice because of the fact that I am always in school and I have to go to work on the weekend. I wouldn't have any time to put aside to study or do my homework or anything of that nature.

Bryan was adamant that the disease played no part in his ability to study. He said, "No, not at all ... The disease takes up 30 seconds of my time if I am studying, because all I've got, all I've got to do is take my medication. That's it." Bryan worked part time at the beach on weekends, where he managed beach equipment. He was looking forward to finishing college and finding more stable employment, to facilitate renting an apartment and going out on his own. Bryan was involved in an intimate relationship with his 18-year-old girlfriend who was HIV negative. He said the following about their relationship:

I have been in a committed relationship for a year and nine months starting today, and she is known since [pause] my first day talking to her that, at first, she had no problem with it yet of course we haven't told her family yet. Sorry, I met her at my church, aahm ever since that day, we start dating. It's been good ever since. She's met, she's met most of my family. I have met most of her family, we go, she goes to my family gatherings. I go out to hers. Me and her spend Christmas, thanksgiving, family birthday parties, personal birthday parties together. Her family from what I know loves me, I know my family loves her. She sees nothing

different towards me, she doesn't look at me different because of it. She, sometimes if we are hanging out late she was like hey did you take your medication, is everything ok, how are you feeling? So, on and so forth. But ... She sees nothing different.

Bryan explained how having HIV may have affected their intimate relationship:

At first, I told her Hey! I know that you may feel some way towards it, because I am your first boyfriend and everything, you may not know too much about the disease and everything like that, but after we got pass that, it doesn't affect it at all.

Bryan shared how his family were able to maintain the secret of his diagnosis:

My family told me that they were an incident with my mom had a aahm, it was a hospital accident, because she was a nurse ... my aunt was always like... Oh aahm, don't spread it around, don't let people know. It's just like what's the point in me hiding it?

However, he had other experiences with friends that he also shared:

If you told somebody in the beginning, nobody wanna talk to you, no body wonna affiliate with you. But as I experience through my high school life, if I don't tell them up front, that when they will cut me off.

Bryan explained how he and his family guarded his secret from his girlfriend's family:

My family knows that, most of them knows that she is aware of my status, so they understand. They kinda had a conversation with me, to tell her. To make sure like "Hey, don't go and tell your parents" or anything. I had that conversation with her from the first day I told her, so it just like more of a reiteration towards

her. We haven't come to the time we think it's safe to talk to her family about it ... we haven't told her family yet.

Bryan's reflection of the interview is depicted in the song, "We Rise."



Figure 16. Bryan's reflection of living with HIV (Wright, 2018, partially adopted from San Halo, 2015).

Figure 16 documents lyrics from the song "We Rise," which reminded Bryan of the interview. He explained what the song meant to him from that perspective:

Because when we first find out yet of course we like, we fall, we think that our life is over but then we would all just come together just by ourselves we just rise up to what's going on and the tone like, I don't just look at the song for words because it don't really have that many words, but the tone and the beat the song gives just try to get everybody up, get everybody up to realize, like, you can live with this, it is not a big issue, it's not the end of the world or anything like that.

Jamie

Jamie described what her life has been like living with HIV:

Aaw, it has its pros and its cons, like, you feel like, sometimes you feel like you don't wanna like be bothered because of the condition that you're in. You feel different sometimes, like you feel like you can't do things like you could do, like other people can do, like for instance like, like some people can live with each other like without secrets, like sometimes, like couples they can live with each other without like secret and you have this secret that you wanna tell your partner, if you have a partner, and it's like you don't wanna [pause] tell them because you are scared of their reaction. So, it has it's, it's had its pros and cons but at the end of the day you can' let it get to you, you can't let it beat you because you're bigger than what it is, it's just a disease it's not something that like, you can, you like it's the end of the world, it's something that you can really [pause] learn from and just embrace it and just deal with it, and live a normal life, a lot of people think that just because you have it, oh it's this and that Oh it's a people just to have it. Yes, it

is! but it's not like it's the end of the world, people live with its people have kids with it, a whole family with it and it's like people live normal life with it, and some people just like, they misjudge you, just like, not educated about it more, so I just feel like people should be more educated about it before they judge [pause]. Yes! basically, the disease itself do not bother me, it bothers me but it don't, I don't let it affect me. Like! I don't let it get to me.

Jamie discussed when she became aware of her HIV status, how she responded to the diagnosis, and her opinion of the disease:

I was twelve years old when I found out I had it, I asked my cousin. I used to always ask myself, why do I always take medicine, why do I take medicine? I finally asked my cousin, why did I take medicine? and she told me, it hurted me, yeh! Like I was very shocked, but I took that, and I embraced it and I just dealt with it because I know, it's like, I can't let it beat me. People live long with HIV, and I feel just like, some people just take that and just think it's like, it's crazy ... I feel like cancer kills you faster than HIV, aahm hepatitis kills you faster than HIV, like it's so much stuff that kills you faster, and I feel like some people just take this one disease, and take it and just like, that's the only disease out there, when there is other diseases out there that's killing people real faster, aahm I just got to know a lot about, and it's, I got to be, I got to be knowledgeable about it, because you know, I am in a situation, and aahm, like, I mean it, its position of where I have to know about this disease too [pause] you know? Pass it on.

Jamie shared her thoughts on what her life would be like if she did not have HIV:

I see my life would be more happier but I wouldn't be more depressed, wouldn't be like sad [pause] sometime I have my moments when I don't like wanna be messed with or I feel like I am different you know? I feel like [pause] I just can't do like [pause] stuff that normal people do, as in like ... [pause] like certain stuff I just like, yoou know, like, I just feel like something is wrong with me, just because I take medication and like [pause], I don't know, it's a lot, it's just a lot, it's a lot of things that [I] did with myself and I just feel like I weren't have like this disease, I feel like I would be more free because sometimes I feel trap [pause], and if I didn't have this disease I feel like my life would more like, like freeable like I won't have to go to the doctor like every three months and two months, I wouldn't have to take medication, [pause] every day for the rest of my life, I won't have to worry about, Oh! What I have to tell this person, if I am dealing with this person, I don't have to tell this person such and such and such, what is going on with me that I have HIV. I have to let my partner know this, aahm [pause] my kids, if I wanna have kids I wouldn't have to worry about, you know, you know how pregnancies have their difficulties, but as far as you won't, I won't have to worry about like [pause] giving it to my child as in due birth or I just have a normal child birth without giving it to them, that child so, it [pause] it, a mean, some people just I just feel like I would be more like relaxed, more suitable, more [pause], I just feel more free, I just don't know the other word to say it, like I just feel more free about it.

Jamie shared her hopes of what her life would be like if she did not have HIV:

I vision it to be a normal [pause] life! ... Yeh ... as in ... I don't wanna take medicine every day! [laughing] ... Just living life, trying to get myself, [pause]

working in the field that I want to work in, which is medical, aahm, going back to school to be a nurse, aahm, helping people, as in homeless people, anybody, helping anybody aahm, playing sports doing [pause] like working a better job [pause], and just living, being happy.

Jamie's biological mother died when she was 6 years old, after which her aunt assumed the responsibility of primary caregiver for her and her siblings. **Jamie** described her caregiver dynamics while growing up:

When, I was staying at my mom's house, when my mom passed, we stayed with my grandma, when my grandma passed we stayed with my aunt and my aunt used to always [emphasis and pause], I think I was 7 or 8 years old, she used to always make, have me drink out of a different cup, she use to always have me drink out of like, eat out of different spoon, like dishes completely. And I use to always ask why, why, why I had to eat different from everybody else? ... and she use to always do that so, as I got older I asked my cousin, that when everything came together, like Oh! this is why she used to do this, this is why she used to do that and it's just like [pause], why you used to treat me that way, you know? [pause] ... When I would stay with my aunt, I was going through so much stuff ... she would be having me miss doctor's appointment. I was not eating right, not going to school ... walking in the cold, like I was sick, so, I mean I am better [pause], that's all that matters. I was living with my brother. Then I went to live with my brother, he took care of me until I was 18? That's when me and my sister got our own place. And we are living on our own since then. Now I am ready to get my own place [laughter].

Jamie explained her relationship with her siblings:

Well, my present situation is different, my brothers and sister don't treat me no different ... I have 2 brothers and my sister ... Yehem! I am the baby ...they don't treat me no different they all treat me like I don't have nothing. All they want me to do is just [pause] take my medicine, go to my doctor's, appointments and that's it. They don't treat, they don't see me different, that's it ... me and my sister we stay together, and [pause] my niece, her daughter, that's it.

Jamie further described her relationship with her sister:

Me and my sister were close, were pretty close, we're pretty close but we buck heads a lot because we both two strong [pause] headed people. You're not gonna talk to me like this. That's how, like we goona say what we are gonna say and it's to the point like, [pause] she is like she is like very strong headed and I am very strong headed, and it like, I feel like when she is coming and the way she talks to me [pause] she still feels like aahm like, I am suppose to ... right life a baby, like I am still that little girl, when I am 24 years old and you like just keep doing the things that I used to do. [pause] I know I am not and she feel like I am growing it, it hurts her, [pause] to her heart that I am growing up and she can't see that [pause], so it's like that's why we always bumping heads. It's like the littlest thing she would sit there and argue with me about, like washing dishes.

Jamie graduated from a 2-year college. She shared the details:

Yes, I had graduated from FCC we ... aahm I graduated from there, last year [2017] September with aahm, MA- medical assistant and I wanted that but I

couldn't [pause] take the job offer because of the living situation, my sister needed a baby sitter for my niece, so I couldn't take it.

Jamie informed about her current job and her short-term plans for the future:

I have to get a better job ... am working at Windsor [name changed] [both laughing hard] ... No, I want to [work as MA], I want to start like, I am so like, in like, I am on another level this year ... bridge out on my own. I am 24 years old and I have always been sheltered. So, I am ready to like go out on my own, get my own place, get me a car, start my own life, so I am ready to that this year, so that's why I am trying to like do that now. But I could took the job, it's just like my sister was being, I had two offers that I could took. See the thing is she works 6 to 3 and I switch my schedule for Windsor to 4 to 12, so I used to get up when she used to work over night, when the baby was a new born, she would go to work from 5-7 in the morning and I would watch the baby overnight, which is a new born ... so when she comes home I would go to school, that was when I was going to school. Go to school go to work and do the same thing all over again. That is tiring, especially with a new born? That is so draining. So, I used to do that, a couple of months, [pause] until she switched over to aahm, 6 to 3. So, her child would go to work, no she, her child would go to day care throughout the week.

Weekend I watch her, cause she work. Thinking about myself, to be honest, because I feel like some people would take advantage of you and when you don't say nothing they, they just go to take advantage of you and just like run over you, so now, it's like I am thinking about myself now about putting myself first, now I

am just like [pause], I am not how where I used to be, as far as, I was always thinking about other people's feelings, I was always thinking about, Oh what if this person don't have this and that what if I could be s this person couldn't help me. So, I learned a lot last year, going through everything that I went through, but this year, I was just like, it just about me, like I can't, sometimes you have to be selfish to get what you want, where you want to be at. So, this year I have to be selfish, within myself to get where I wann be at as far as, to be working in the field that I want to be working at medical assistant that school for nursery [pause], and just myself first. And not nobody else feelings ... Like I wanna go back to school, probably this year ... Probably this year, but it's like [pause] it so [pause], I am trying to get a car first, and them I'm trying to get my way back to school.

Jamie shared her experience with intimacy:

Well it' [pause], it's hard to like, to even like, if you waan like you now, have sex or like whatever? You can but it's like you have to let your partner know before you can do that and it like, as I see it it's why like, not why, but it's so like scary to tell that person, because you don't know how they gonna react, and you know, what if you like that person and you tell that person so Oh! I am HIV positive, and they just look at you like [pause] ... Like [pause] you just you basically scaring them off, and you don't want that, so you just stay to yourself, you just don't have sex. But I feel that's like that's like that being selfish, that's selfish that's selfish in a way because it like you, you want to do that type of stuff [have sex] but you have to tell your partner before you do it, and it like me you don't want to tell

them ... because you're scare of the reaction if your gonna tell them, or if they gonna tell somebody else, you just scared.

Jamie was then asked by the researcher if she was involved in an intimate relationship, she responded, "No ... No, it's like [pause], I don't wanna put that on nobody." This she attributes to the fact that she would have to disclose her HIV status to a partner, and she cannot always be certain of how such an individual would respond to the information of her HIV status. Jamie was afraid of being rejected and of her information being disclosed to others who does not need to know. She stated that her life was normal, except, "I don't wanna take medicine every day! [laughing]."

Jamie disclosed her desire to have children I the future:

Yeh, I am very aware of it [having HIV negative children], but it's still like, I don't like to [pause] like to take caution, I like to be cautious of what I do with people, far as people, relationships, family, anything; and it like if I didn't have it [HIV] I wouldn't have to worry about, that's one less thing I would have to worry about ... I want kids, but it has to be with somebody that understands my condition, like, it can't be nobody that's just gonna like [pause], take this and like, OH! You know what I am saying? It has to be somebody that's understanding, that knows a lot about it, that's knowledgeable about it ... you just can't be just out hear and just think it's just like so contagious, it's stuff that's waay worse than HIV.

Jamie informed the researcher that she did not participate, volunteer, or work with any advocacy group. She shared what a typical day in her life was like:

Aah getting up, take my medication [pause], relaxing [pause] until work because it has a side effects as in dizziness, feeling sick, so ill lay down and try to take a nap, wake up go to work, eat something, come home take a shower, eat, take my medicine again and then all over again ...

Jamie also spoke about her medication:

I take two times a day, five pills, two times a day, so ... Sometimes when you take, well! when I take my medication [pause], sometimes I don't feel good for certain period of time, for like 30 minutes, 20 minutes on the medicine, aahm the side effects and aahm you want to do things like other people do and sometimes you can't do that like other people, like sports or whatever it is, or sometimes you have to limit your [pause] self of doing things ... aahm, no my aahm physician she basically give me my aahm prescriptions and I basically take it to the aah the pharmacy and they give me my medication ... Yeh, this, this what you need to make your immune system go up and make your T cells go up, that's that.

Jamie added the following to the conversation:

Aahm [pause long], not really, I mean, I am just living day by day taking it one step at a time. That's all I can do. I can't do nothing else, it's not my fault that I have this?

Jamie explained where she saw herself in 5 years:

In five years? I would probably have a family [chuckle] with a nice house and good successful job. I would probably be a nurse [pause], and taking vacation ... aah I don't know, sometimes I let it hold me back sometimes.

Blessed

Blessed was born with cystic fibrosis in addition to HIV, another chronic illness. She successfully completed high school and planned to pursue further studies in preparation to become a professional photographer. During the first 8 years of her life, Blessed lived with her grandmother, after which she went to live with her mother.

Blessed explained about her mother, "Aahm, no, I guess she wasn't ready to raise kids just yet?" She continued living at home with her mother, stepfather, and other siblings. Her biological father has been in and out of her life and as far as she knows, he was HIV negative. Blessed described her life growing up with HIV:

It was [pause] it was really hard growing up, because I thought I was like something disgusted [pause] and I wanna think that [if people] know what I had they wouldn't like me or associate themselves with me. So, it was pretty hard growing up, because I told people that I thought I could trust, then they went around and tell the whole school, so that was pretty hard.

Blessed shared what a typical day in her life was like:

Now it's very peaceful. I am glad my other half knows about it, and it's much easier because I know what I have is serious, but people still enjoy my company and aren't afraid to, like hug me or touch me [pause] in a friendly manner. Not like that, but just to, just to enjoy my company, that's all I want.

Blessed also told the researcher what she thought her life would be like if she did not have HIV, "My life would still be the same either way [pause] because I already go through a lot with my disability? So, having HIV isn't really a big deal."

Blessed shared that she was sexually active, and that her first sexual encounter was the result of rape by a friend, while she was in high school. She was involved in an intimate relationship with her HIV negative partner, and they shared a daughter together, who was also HIV negative. Blessed reported that her boyfriend was aware of her HIV status; that they usually practice safe sex; and that her partner goes for regular doctor's checkups. Blessed was of the mindset that even though she had HIV, she could accomplish just about anything that she sets her mind to, once she was safe, which made her no different from her peers who were HIV negative. For the future, she would like to stay healthy, get married, have more children and have a home of her own. Blessed did not participate or volunteer in any group or organization.

Margarita

Margarita was only informed of her HIV status after her mother died of complications from HIV/AIDS. She said, "When I found out I was in 9th grade ... After my mom passed away my aunts took me to the doctor, and he told me." Prior to being informed of HIV status, Margarita reported that she was always curious as to why she had to take medication every day, when her siblings and cousins did not have to. The response she received, according to Margarita was, "Well, my mom told me I had asthma, and that's why I was taking all the pills." However, Margarita was not convinced that she had asthma, or even if she did have asthma, that it was not complicated enough for her to be taking medications every day. Margarita communicated, "I was like, this asthma is nothing, I can kill this asthma, it's nothing. So, prior to knowing I felt unstoppable."

Margarita was also very aware that her extended family [aunts and uncles] treated her differently. After her mother passed, her extended family [aunt] became her primary caregivers. Margarita reported the following about her family:

My aunts and uncles were never really aunts and uncles ... they never told me but they looked down on me ... my aunts still didn't want to take care of me ... they didn't want me around their children ... My aunt told me I was a bad influence and that I wasn't going to do nothing but hurt her children.

Margarita graduated from high school and planned to enroll in college to become a teacher. She was not involved in an intimate relationship because she was coming off a very recent emotional break-up. However, she mentioned two prior relationships, where the individuals were HIV negative. In one of those relationships, they were trying to get pregnant but was unsuccessful. She still desired having children but had decided to take a break from relationships for a while. Margarita also suffered from depression, requiring multiple hospitalization. She divulged, "After finding out I fell into a deep depression and that stopped me from dancing and stop me from doing a lot of things that I actually wanted to do [pause]." Margarita lived with her older brother, who worked multiple jobs to take care of her.

When asked by the researcher how she thought her life was different from her peers who were HIV negative, **Margarita** responded:

Honestly, I am very antisocial now, because of that ... I am very terrified to go around other people. Like, [pause] when you first walk in, there was a bunch of people sitting down? I am afraid to do that because, [pause] you know there is.

Margarita also responded to the question of what she thought her life would be like if she did not have HIV:

I think I would not be so depressed ... a lot of times, my depression come from the way people treat me because of it ... I think, I would have a lot of more friends, I wouldn't be so antisocial, I wouldn't be so depressed.

Margarita said the following concerning her future:

Aaah, I have a lot of goals, but reality is, just like knocking me down [chuckle hard] ... My goal is to find a job, which I have, two interviews coming up, so hopefully I get them. But to find a job? ... I want a big family.

She did not participate or volunteer in any group or organization. Figure 17 is a pencil drawing which **Margarita** presented as her reflection of the interview.

Pencil Drawing



Figure 17. Pencil drawing: Reflection of living with HIV (Wright, 2018, adopted from Margarita, 2018).

Ashley

Ashley has been with her adoptive parents since she was 5 or 6 years of age. They have remained supportive and continued looking out for her well-being. **Ashley** stated, "They [parents] take care of me, they gave me life, like you know, outside of what I knew." She spoke proudly about her father:

My dad as I got older, he started learning more about it ... it was funny because he got so excited about it, he was teaching me about it like I didn't know ... He took the initiative to learn, ... yeah, to understand, and you know, I think that's very cool.

Ashley also spoke proudly about her mother:

She still tries, are you going to the doctor? Are you taking your meds? ... She will know, about when I am lying, because like, when I would start getting aah, like these, like weird rashes on my skin or something, and she would look, "are you taking your meds? No, you're not taking your meds" ... We have a good relationship.

Ashley found out about her HIV status at around age 7 years, after she enquired about having to take medications every day. She reported that her adoptive mother took her to see her primary care physician (PCP), who informed her of her HIV status and explained to her what HIV was. Both of her biological parents were deceased. Ashley reported that her biological mother died of complications from HIV/AIDS; however, she does not know the HIV status of her biological father. She grew up with her foster parents who were good parents to her and who have remained supportive of her while she now lives elsewhere with a partner.

Ashley was in college from which she was scheduled to graduate in May 2018, with a bachelor's degree in sociology and a minor in psychology. She was looking forward to a career as she stated, "I was looking to two career fields, whether it was social work, like child welfare, or aahm drug, drug rehab, like drug counselling?" She was employed as an administrative assistant, which is not what she would like to do in the future. Ashley was involved in an intimate relationship with an individual who was HIV negative. She would like to get married and have children in the future. Ashley considered her life to be just as normal as her HIV negative peers. When asked by the

researcher how she perceived her life being different from her peers who were HIV negative, **Ashley** responded:

I notice that I have to go to the doctor a lot more, I mean, I notice that like [pause], if I have a cold, I am probably going to be like, you know, like sick for a week or so compared to anybody else ... I notice if I go to a pharmacy and I pick up my meds [pause], like people start acting different toward, like the technicians, I, like, once they see what meds I am on, they start acting differently ... So, I feel a little bit different in that sense. Because, I mean [pause], by looking at me you can't tell [pause] that I have it ... You'd think that I am this normal person, but once you actually talk to me, sit down with me and I tell you, yeh I have it, I was born with it, then people kinda start like doing their thing, their stigma thing and I was like, they would either do they are either, "Oh, I am so sorry", you know, and I am there like "I am not dying" ... I feel a little bit different when the topic comes up ... If I disclose it, other than that I can accomplish basically, anything that anybody else can.

Ashley did not participate or volunteer in any group or organization. When asked by the researcher what she thought that her life would be like if she did not have HIV, she responded:

I never thought about it that way. A mean ... I don't? Maybe, my life would probably be different if I didn't have to go to the doctors all the time ... I was sick when I was young, so maybe like, instead of being in a hospital or something, like when I was 4 or 5, I probably could have been like playing, or, you know, doing something educational or something you know? ... I probably could have made me

more [pause] and know what you call it, smarter or something, maybe more advanced in you know certain situations ... I don't know think maybe a different outcome. I think it probably would have been the same.

Figure 18 is **Ashley's** presentation at the member check meeting, as her recollection of the interview.

HIV positive people are the same as people who were born negative. We share interests, go to school, work or anything else a HIV negative person would do.

HIV positive people just have to take meds every day to keep going with life. We may see doctors more often but at least we know what's going on in our bodies versus HIV negative people who go once a year.

These are just two examples of how we might vary or how I look or compare myself to others.

But in the end, we are not so different.
I can do anything a HIV negative person can do and probably better, because I have a strive for doing better.

(Ashley [Pseudonym], 2018)

Figure 18. Ashley's reflection of living with HIV (Wright, 2018, adopted from Ashley 2018).

Ahmazin

Ahmazin was born with HIV, but she was not actually diagnosed until after she became ill at about 15 years of age. She gave the following account:

When I was diagnosed I was a teenager ... Well, I was, it was my 9th grade year, aahm, in high school ... they had also did a HIV/AIDS test ... that's when at that moment, my tests came back positive ... However! my parents didn't notify me at

the hospital. My parents probably told me a month after I got out of the hospital, when I had my first appointment at the UM.

Prior to her diagnosis, **Ahmazin** reflected:

I think mom, I think my mom said something to the effect that aahm [pause], cause I used to get sick a little bit more often than my, my siblings aahm, I had shingles 3 times aahm and aahm, I remem I remember my mother was telling me aahm that the doctors didn't know why I was getting shingles, because she knows, normally, older people get them not really younger people get shingles ... if I recall correctly I believe my mother was telling me something to the effect that the test was proposed to her, aahm, that she should get me tested? But she declined.

Ahmazin explained what it was like living with the disease:

[Clears throat] growing up, it was difficult because when I was diagnosed I was a teenager so it was very diff a difficult thing for me to receive, aahm, because at that time, I [pause] was also dealing with self-esteem issue, and low confidence so, that just kinda added to it, and it put me into a depression. That I dealt with for [pause] probably about 3 years? 3 ½ years [pause] ... Aahm, at first, it was very challenging, because on top of me having low self-esteem issues and everything aahm, there was also issues that started to take place between my mom and my dad ... So, there is a lot of things that took place which aahm, which affected me, mentally greatly, which added to my depression [pause] aahm there was a time where like I had suicidal thoughts, I want to kill myself, I never attempted anything, but I did have those thoughts ...

Ahmazin continued to describe her state of mind, after she was diagnosed:

But aahm, there is a lot of times aahm, I was frustrated and upset, I felt like aahm, I really felt like I was being punished. I grew up in church ... So, aahm, I come from a faith-based family, aahm, around that time I lost my faith and everything. Like, I feel like I really thought that I was being punished, I was like, here I am, a young girl, I wasn't out there having sex, I am still a virgin, I wasn't doing drugs, I wasn't, you know, I was an honor roll student. I had honors classes, advanced classes and everything. So, I'm like, here I am, I am a good person, I am a good student you know, I am not a bad person, I am not doing anything that I should not be doing. And it's like, "why me of all people?" That I have to go through this, and it's one thing to go through it, but it's like I just got into high school, you know? Like sometimes for some people, like your teenage years are the best, like I just got into high school, you know, you wanna aahm.

You are getting a little bit older, you are that much closer to adulthood, you're that much closer to finally going away to college and being out on your own. And when you are a child, everybody wants to be on their own, so it's like, "Why! is this happening now?" So, I thought about that a lot and that also like added to everything that I was going through. Because it's just like "I don't deserve this, I don't!" Aahm however, as far as how it changed my life, aahm, after I got out of my depression, aahm, in which me personally, I did that myself because I never felt comfortable talking to anybody. When I would go to UM, and you know and they would have me do like checkups with the psychologist and stuff? I was never interested in talking to no psychologist, no, I don't. I would actually sit there, I would not just say anything I deal with it, I dealt

with it myself, I brought myself out of it because aahm, I didn't really talk to my family either. So aahm, slowly overtime, aahm any, any, negative thought, I just really try to rebuke it, just put it behind me and just keep going forward. Because at the end of the day I can't change it, unfortunately, aahm, so [pause] yes, so overtime I started to transition to a more positive mind frame, aahm I started taking my meds consistently, because I also went through this rebellion stage. I started off on 7 pills. I am actually down to one now. Aahm, I didn't want to take my pills.

According to **Ahmazin**, both of her parents were HIV positive, and their statuses were always known among family members, including her four older siblings:

My mom, aahm she knew but she didn't found out until after I was born. So, this was like in the late 90's when she found out aahm ... So, I didn't find out about my parent's status until I found out about mine ... Because, my older siblings knew, but I was unaware [pause] of everything. Which also added to my depression as well ... On my mom's side I have, it's four of us, so it's 2 boys 2 girls. On my dad's side I have one sister ... No, me and my siblings on my mother side, we don't share the same father and on my dad's side we don't share the same mother ... It was brought to my attention that she did [HIV positive], but we're [pause] 18 years apart, so I never met her, because she passed away right after I was born.

Regarding her present relationship with her parents, **Ahmazin** said:

So, we're more in a better positive place than what we were in before ... Me and my dad's relationship has gotten way better than it has been over the last few years

way better ... we communicate aah [pause] more freely and openly without there any issue or any negative energy or negative vibes there ... we are not the closest thing in the world, but. It's a working progress, we are getting there ... my mom, me and my mom is pretty cool aahm, you know, I live with her so, its, we have a pretty good relationship, but we are not the closest thing in the world, because I really don't tell my mom everything not as far as my relationship and stuff goes. I keep that to myself.

Ahmazin shared residence with her grandmother, her mother, and her other siblings. She was involved in an intimate relationship that she described as follows:

Uhu, me and my current boyfriend, we have been together since June of last year [2017]. Aahm, I told, I disclosed my status to him, probably 3 weeks of us dating. And 3 weeks to some people is not, it would seem you know too early. But when we started dating, we actually started to spend a lot of time together about every day, or every other day. So aahm, I just went ahead and got it out there, because the feelings between the both of us starting to develop very, very quickly. Aahm he was very receptive and open to me and my situation, aahm. He said he is not going anywhere, and ever since then, he has been supportive aahm so far everything has been going greatly. We are sexually active aahm and if there may be any question or concern in regards to aahm, our intimacy, aahm, we talk about it, we talk about everything. He knows, he knows aahm, he has been invited, invited to my doctor's appointment. He hasn't actually been able to make any of

them. But he has been invited to my doctor's appointment. He knows my status, he knows, ahh that I am undetectable. So, he knows everything.

Additionally, **Ahmazin** was educating herself on pre-exposure prophylaxis (PrEP), its uses and efficacy in preventing the transmission of HIV, to educate her boyfriend on this option. Presently, **Ahmazin** said that PrEP is effective against HIV Type I [HIV] and not HIV Type II [AIDS]. She recently gained employed at a HIV/AIDS service organization, where she first heard about PrEP. **Ahmazin** plans to attend an upcoming information session to better inform herself.

Ahmazin was scheduled to graduate from college in June 2018 with a master's degree in business administration, and her goal was to become an entrepreneur. She said:

I want to have my own business ... I want to have my own organization [cough] I am sorry, I want to have my own non-profit organization ... I want to provide a platform to encourage them to open up, so they can get the help and the support that they need ... my boyfriend is working on aahm two business right now.

Ahmazin already had two projects in the works, as well as a foundation established to assist others with any chronic illness to find their way by maintaining good health, both physiologically and psychologically. The researcher asked how she perceived her life being different from her HIV negative peers, **Ahmazin** responded:

It's interesting, because I really didn't thought about that ... I just have to be more careful, because when you're HIV positive, although you're undetectable and you're healthy, at the same time, you know, you have a virus so, you have to make sure that you don't get those germs, you know, that you don't get sick... the virus attacks your immune system, you are more prone to get sick before, you know,

anyone else, you are more prone to catch a flu, or whatever, compared to someone who is negative ... So that's one aahm, one struggle that [clear throat] I have to deal with compared to a person that may be negative, because it's like you have to be more careful, and the choices that you make especially when it comes to dating someone? ... as far as like, just being out there, you have to be, you have to make sure that you keep your immune system healthy, so, who, if anyone surrounded by you and they have any germs or flu, fever whatever, you have to make sure you go the extra mile, make sure you don't, you know, get anything that they may be dealing with ... the only other thing that comes up is sex, but yes and no for that, because, I still have sex like a regular person and I still do sex like a regular person. The only other thing is that I could say that it's different, is that you have to be cautious when [clear through] you doing oral sex, because if a person aahm is giving you oral sex and you're the person that's with the virus, the virus can be contracted through semen and vaginal aah fluids ... if you are undetectable, it makes the chances very unlikely that that person can contract anything. But that doesn't mean that there's no possibility that that person can contract anything ... So, when you having oral sex, you have to be very careful of that ... As a female I always have sex with a condom, but if you are going to be having sex without a condom, as a female it's harder, it is more difficult for a person, for a female to pass it on to a male than for a male to pass it on to a female ... you can't just, compared to a person that's negative, you can't just, you know, do it freely as you want when you're a person who is positive you have to take into account ...

In the future **Ahmazin** would like to get married, have children, travel, gain financial stability and help others. She was already actively involved in a Faith Based Civic organization that supports people living with HIV/AIDS, she volunteers, and she sometimes speak publicly about her HIV experience.



"For I know the thoughts that I think towards you, sayeth the Lord, thoughts of peace and not of evil, to give you an expected end."

Jeremiah 29:11

Holy Bible (Authorized King James Version), n.d.

Figure 19. Tattoo image: Reflection of living with HIV (Wright, 2018, partially adopted from Ahmazin, 2018).

Figure 19 is the picture of a tattoo of the scripture verse 'Jeremiah 29:11' that was imprinted on **Ahmazin's** upper right shoulder. She gave permission to use the picture and add the words from the scripture passage.

Loren

Loren shared when and how she was informed of her HIV status:

9 years old ... aahm, one of the nurses from the clinic that I went to, she came to my house and she told me about it. She sat me down and she explained what it was and, you know, pretty much that I had it Aahm, apparently, I think it's something by law, because my sister knew, my older sister, because she knew, and I was getting of age.

Loren lived with her biological mother all her life. She spoke about her parents:

Aahm, my real father passed away years ago, aahm, my mom ...Yeh, aahm and my mom is good, she is holding up. My mom has always been there... She always make sure I always have food on the table, take care of me, clothes. Make sure I was brought up right, how to take care for myself as a woman, young adult, a girl. She took me to Church aahm, heh! [pause].

Loren did not want to speak about her father who died several years before of complications from HIV/AIDS. She shared the following about her siblings:

Three sisters, one brother. One, one of my sisters passed away, so right now I have 3 siblings ... Aahm, out of my siblings? Yes ... I mean, my sister that passed away, she had it but? ... She was older than me My brother eeh, he is always himself, he is good, knuckle head but ... No, he doesn't [have HIV]. He is blessed ... He is older.

Loren explained what it was like growing up and having HIV:

Aahm, for me I feel like it, it's kind of normal? Aahm as long as, well for me as long as others don't know about it, because I feel like certain people [pause] will treat you differently, if they knew that you had it, whereas when you don't know, people treat you like, you know, like you are, your' a regular person, a regular

human being, doing regular stuff going to school, going to work, you know. I don't really see that much of a difference. Yeh! I really don't Well for me, actually, you know what, let me correct myself because if it's [pause], If it's visible, like you're healthy is visible, like it's poor health? Then people might ask question, might be concerned, might know something is wrong. But if you're taking care of yourself, you're taking your medication like you're suppose to, or you're just resistance aahm, your body is able to fight off the virus, aahm, and it doesn't physically show aahm, then [silence] people will just see you, like you walk out the door and people would treat you regularly, and then there is actually some people who carry themselves, even though they, they know they have it [pause] and they express it to the world and they don't really care of how people treat them, so they don't really are affected by people's opinion, whereas some others based on have their, you know, I guess because of concern of how people would treat them, they keep it privately. So, I mean, for me it doesn't affect me, because I keep it private, and I can kinda a little concerned of how people would treat me so that's why I do keep it private, but I feel like it's based on each person's perspective, you know, just for me, it seems like the average thing, like it's not.

Loren shared what a typical day in her life was like:

Aahm I wake up, brush my teeth, take a shower, aah I either go to work, or go to school or go hang out with one of my sisters. Aahm I take my meds when I ah, it's time to, because you are supposed to take it at a certain time, and aahm. sometimes I skip doses, which is like aah, I really need to work on that, you

know, because it's not good. But aahm [pause] living with it, it seems like an average day, I mean, because I was born with it, like, going to the clinic, you know. Getting blood drawn, you know, I have appointments set up to go to for it, it's something that I am used to, so I don't really see it as, you know, out of, something abnormal. It's normal for me.

Loren also shared her medication schedule:

At the moment, because it changed, now it's Tivicay, Prezista, Norvir and Descovey Four medications ... one time a day.

Loren discussed her thoughts on if her life would have been different in any way, if she did not have HIV:

[Pause] well, that's a good question, I never really thought of that, didn't think about it, actually yes! Yes! Then I wouldn't have to take no medication [chuckle]. I would be so happy like I won't have to think about aahm if I missed a dose, ah I got to take my medication or be concerned that my health, you know, be affected. I don't have to have that fear when I get into a serious relationship to tell a dude, because you know, I am not, so it's like I don't have to fear people judge me ... or, how he would react, so that a good thing, that's I would miss some of the doctors and nurses that was really nice to me because then, you know, their work is done, so that kind of stuff.

Loren explained her thoughts on her life being different from her HIV negative peers:

I feel like, aah, its different because, you have to take medication, you know aahm, aah, I am guessing the average peer doesn't have to do that, you know, they don't have to. I remember, I mean, like years ago I used to take like 10 pills a

day. That was a lot, but because I was born with it, it's like Oh! Oh! These are medication that I have to take, and I was dealing with it since I was little, so, that's not something that most people would be used to or, it's different from what the average peer would do. Aahm having to constantly go to the doctor's appointment to get blood drawn, aahm making sure that I am healthy, and also aahm, peers my age tends to be sexually active and aahm [pause], this disease aahm, it's not curable yet, so if, I can't just be, you know, out there being sexually active just like you know, because people can catch it, the average peer doesn't have to think about it, or they are not as concerned, whereas for me I feel like it's different because I have to make sure that, aahm, I am safe if I am sexually active. If I do decide to be sexually active, I definitely want to tell my partner beforehand, before we even get involved in being sexually active, I want to make sure, that this person is someone I can trust, that this person wouldn't judge me, and I would definitely want them to know about it before hand to make a choice whether they still want to continue being in a relationship with me, if they want to be sexually active. So that's something that aware of and concerned about whenever I consider being sexually active with someone.

Loren was not involved in an intimate relationship, but she had been involved in the past, with individuals who were HIV negative. She hopes to become involved again in the future. She shared her opinion of having sex, as an individual who was HIV positive:

You always have to be protective, you always have to bring protection, aahm, condoms, ah, take your medications, because the lower it is in your system, the virus, aah, the less of a chance of your partner getting it, so that's definitely

important as well, because condoms is not always 100%, you know, proof to protect HIV, aahm, to protect your partner from receiving HIV.

Loren discussed her opinion on having children:

I think it beautiful, you know, to have a child, you know, someone that loves you, you know, aah, someone you can raise. Someone that, someone that has your DNA, ah mini version of me, which is cool and you just love them. Take care of them, you know, watch them grow. I think it's just, I think it's a beautiful thing ... technology aahm and health has advanced in that field, whereas you can protect yourself, aahm, make sure your baby is not born with it, you know, if you plan parenthood, correctly. You can make sure you go to the clinic, and you talk to your doctors and tell them your plans, and how to make sure child doesn't get it, because it is possible in this day and age.

Loren was enrolled in college and resolved to complete her associate degree by the end of 2018. She shared her experience, plans and career goal:

Ok! So, I have changed my career a lot, so [hard chuckle] right now, right now I have decided aahm to make sure I get my AA by the end of this year, and then [pause] ... Yes, Associates of Arts ... Aahm General, just a general AA degree, and aahm, hopefully before then I can figure out exactly what I want to go for and what best fits me for a bachelor's degree, and then after that I want to [pause], maybe get my master's degree.

Loren described her passion and the motivations for her career:

God, I am not even sure, that, I have been juggling a lot of career choices, but I know I am an introvert, so I want a job that doesn't require me to socialize too

much. Aahm, I definitely want to help people, which I kind of weird, how, if you're quiet, how are you going to be able to help? Because you have to socialize. I want to do something that is helpful towards other but [pause] it behind the scenes so I am not directly interacting with them.

Loren shared her vision of what the future would include:

Whatever I paint it to be So [pause], I want to be financially stable, aahm, I want to have a bachelor's degree, aahm, I want to have 2 kids, I want to be married, you know, aahm, long term healthy relationship, aahm. I want my mom to see, you know, her grand kids, you know, be happy. I want my brother to be like, aah his nephews or nieces aahm and my other sisters, my two other sisters as well ah want them to have a good life you know! Yeh, a house, cliché white picket fence.

Loren did not volunteer, but she was involved with a women's church group that provides support to other women:

I go to church, I go to school. I am involved in, I just recently start going to aah, a women's religious group called ..., ah BOB and ... it women of my age, you know, they talk about religious views and also like what we go through and things, tip, you know, as women to use and stuff, you know, hygiene wise, relationship advise, it's pretty nice.

Loren explained Figure 20 as her reflection of the interview:

I chose it because your research allows those who are positive to speak about their experiences which allows the public to get a better understanding of us because

it's directly from a first person's perspective, this research allows our voices to be heard in a positive way.

MY VOICE

MY VOICE MOVES
IN DIFFERENT TONGUES
MY VOICE SINGS REDEMPTION SONGS
MY VOICE SUPPRESSES SEGREGATION
AND ARISES INTEGRATION

MY VOICE SPEAKS FOR MINORITIES
WITH NO VOICE OF THEIR OWN
SPEAKS FOR THE CHILD LIVING IN THE STREET
WITH NO HOPE OF TOMORROW

MY VOICE SPEAKS FOR THE WOMEN ROBBED OUT OF THEIR BEAUTY GIRLS ROBBED OUT OF THEIR VIRGINITY

MY VOICE SPEAKS FOR THE VICTIM OF RAPE

LIKE THUNDER MY VOICE STRIKES
RAIN IS COMING TO WASH AWAY
MY SORROWS
WHEN THE RAIN STOPS
MY ADRENALINE SEEMS TO
START FROM SCRATCH

LIKE THUNDER MY VOICE LIGHTENS
THE SOUND SO GREAT
IT BREAKS THE NEGATIVITIES
BREAKS THE CLOUDS
AND CLEARS THE SKY

MY VOICE DANCES IN DIFFERENT
RHYTHMS
MY VOICE IS MY PRIDE
MOVES IN
DIFFERENT TONGUES

MY VOICE CLIMBS HIGH MOUNTAINS OF EXCITEMENT MY VOICE SPEAKS OF JUSTICE

POET: NTHATENG MACHAEA, 2017

Figure 20. Loren's reflection of living with HIV (Wright, 2018, adopted from Machaea, 2017).

Keisha

Keisha became aware of her HIV status as she stated, "I think I was eleven [pause]. She reported her experience prior to being informed of her HIV status:

No, I knew I took a lot of medicine, but I didn't know why ... No, and I was, I was like a rebel child. I didn't want to take the medicine. So, I would just spit it up and stuff like that, but I never asked ... No, and that's the weird thing. I didn't even get sick even though I didn't take all [pause] my meds how I was supposed to take them.

Keisha lives with her aunt, who was her primary caregiver, and who continued to provide support. In response to the researcher's question about her primary caregivers **Keisha** responded:

Aahm, mostly my aunt. My mother also, but my mother had a visa, so she would be here for a couple and then she would have to go back. But mostly my aunt ... Well, my mom is passed, but my relationship with my aunt, she is like, she is like a second mom to me ... So, it's the same as it would be as it would be with my mom ... She knows my diagnosis. When I was younger, she would take me to the clinics herself, all the medical staff knew who she was, so she was a big part of my like, she is a big part of my life.

Keisha was enrolled in a bachelor's program at a local university. When asked by the researcher about her career goal, she said, "I plan to go to medical school, and become a doctor." She was engaged to be married within a year. **Keisha** and her fiancé were sexually active, and he was fully aware of her HIV status. They planned on having children in the future, as she shared that they would like to have two children. When

asked by the researcher how she perceived her life to be different from her peers who were HIV negative **Keisha** responded, "I don't really see a difference, [silence] ... I think that's one thing that makes me, or living with HIV different from a normal person, because there are some information that's reserved." When asked by the researcher if she thought that her life would be different if she did not have HIV, **Keisha** responded:

Yes, and the fact that I wouldn't need to remember to always take pills, but ... Yes, I think relationships would be different, and the fact that, it would be less pressure when you meet someone to figure out when to disclose and aahm, the time frame and if the person is even worth telling ... If the relationship is even a relationship, that is gonna to be meaningful.

Keisha was then asked to paint a picture of what she thought her life would look like in 5 to 8 years, she responded, "Well, hopefully I will be a doctor by then [laugh] aahm maybe I'll have a kid, have some type of money, real money coming in." While **Keisha** attended church, she did not participate or volunteer in any church, community, civic, nor sport organizations.

POEM

I WAS MADE TO BE WILD
WICKED AND FREE
TO CARVE OUT MY OWN
CRAZY DESTINY
TO FIND A PLACE
IN THIS WORLD
WHERE I CAN BE
THE MOST AUTHENTIC
VERSION OF ME

Christy Ann Martine

Figure 21. Poem: Keisha's reflection of living with HIV (Wright, 2018, adopted from Martine, n.d.).

Figure 21 is a representation of **Keisha's** reflection of the interview conversation, which she explained:

Aahm because, the poem is just talking about how your being, how you were made to be free, made to be yourself; how you already had your own destiny.

Already you had your own path of life, so I feel like even though I have HIV, my life was already planned out for me. So, whatever I was already gonna I feel like I would have been doing it without HIV.

Melissa

Melissa was not aware of HIV status in her early years, as she explained:

Well. Growing up, is very, you know, it's difficult. I'd say that when you living with having the virus and your sisters don't have it, you have to grow up with that struggle alone, just figure out what you are gonna [have] to do. Because, as I growed up, I didn't have really, didn't go through nothing tragically you know but losing my mom. But I didn't feel that the worse, because I have spoken with people that went through the worse. But I can say that it gets lonely sometimes living with the virus and just [pause, sigh]. It's, I don't know, I just feel like, sometimes I wonder "why me? Why did it happen to me?" But I don't really think like that anymore. It's just like [pause] deep breath.

Living with the virus, since I was born with it, I could say that I didn't really have a tuff life growing up with the virus, because like, once I found out that I had it, I didn't really, I didn't really start feeling like depressed about the virus, [but] once I started like, dating, you know. When I got older, my teenager like in high school, because like, growing up I didn't, I just play, and I just, because I didn't know until I was 13 so, when I was in elementary. I had a good, you know, run, like having and just being a child. Then when I found out, in aahm, in aahm, in middle school, I was like nervous and stuff. I was nervous about that. I didn't have sex until I was about sixteen, because I was sensitive to, you know, I can give it to someone and I was just like, I don't want no one to go through the same thing that I go through. I made sure I was, I didn't do anything, once they tell and stuff, and I like protected my partner and made sure I did the right thing and stuff, and [pause], that's about it to be honest.

Melissa shared her response to her HIV diagnosis:

I was crushed, I was like sad, I was crying because like, you know, growing up people, I didn't know that kids could I didn't know kids were born with it, that was my because I didn't know but I was like, I was the one that was born with it. I always thought that you got it from sex, and you know, you can get it from sex but they didn't explain, no one didn't explained that you know, kids could be born with it, it's just like oh yeh, if you had sex you can get it, unprotected sex you can get HIV and stuff, and it can turn into AIDS, and stuff.

I was wondering how did I get this virus? And then, I know I got the virus from my mom passed away, but when my mom did passed away and I would ask my sister what happen to her for her to die because, she was fine and stuff, but I guess when you have the virus and also other stuff on top of that and you are not doing good of, you know, keeping yourself up, it sometimes could you know, deteriorate your body and shut down your organs can shut down bad infection, knowing that you are HIV positive and you are not taking care of your body and stuff, basically it can kill you and die. So basically, me knowing that it was like wow! I am living like, I am living with this virus and I didn't even know I had it and stuff, but I was just loss at that moment, because I didn't have sex, I didn't do this and stuff, I was born with it. I cried, but after I left the doctor's office I forgot about the whole thing and just went on about my life.

Melissa recalled events that were happening in her life before she was informed of her HIV diagnosis:

Aahm, I couldn't do certain things and stuff, if I you know, if I get sick and stuff, it could have an impact on my body. Like, I have to be careful at the work stuff

when it's like, I had to be like covered, because I had cancer when I was younger. So, by me having cancer and everything, it was all, I felt it was all connected if I didn't take my medicine, it could cause the cancer to come back and stuff. So, it's like, living with it, it kinda help me with my other problems that I had before when I was younger, so it's like, I have to take my medicine, or for me not to even have like have, my white blood cells to get low, and everything, because if I didn't take it then, the virus, probably, I probably have cancer again, to be honest. And, when I was 13 I kinda like feel say, at certain points I kinda like feel like not take my medicine because I was like, I can't do this and stuff because it hard, especially when you to take, like I had to take this medicine call Calexia, it was so gross and I.

I think I took it til I was like 13, yeh, it had to be 13, till they switched me to the pills. And the things I had to do to survive that, it was horrible. I had to eat like peanut butter, put it in my cheeks, and squirt because it was only in liquid, you have to squirt it in my mouth [chuckle]. It was gross, and I had to take it like bout 5 different medicines to maintain, but now I only took 2 so it's like, it got better and [pause] It just, you know, I just wish that I could be, I was more open when I was younger, and I could be more. I feel like if I was open when I was younger, it would be easy for me, to like just not feel uncomfortable when people say things like "Oh you probably have it, this and that," like not knowing that I do, but if I was more, I wish that I was more open about it when I was younger, more educated about it and stuff I had, aahm, aahm, lymphoma, virgus cancer, I think, I don't know not sure of the name ... At age 3 ... All I am saying, basically,

once I got remisc, how you say the word? ... Remission, by me taking my medicine, it actually, like I felt like I, because my viral load was up. And I wasn't you know, I wasn't keeping well, so I didn't feel like I was, I feel like the HIV kinda keep my cancer away or something, because most people at age would probable had, the cancer would probably had came back ... That's what I believe in, because like by me taking my medicine and everything my cancer didn't come back because I know kids is, that was positive had cancer too and they pass away. I had a couple friends that was HIV positive and had died from cancer too, but they wasn't maintaining they medicine, and stuff and they end up passing away from it.

Melissa shared what a typical day in her life was like:

Well, the typically life is, you know, normal ... I do everything like a normal person would do. You know, wake up in the morning, work, aahm, take care of my son and then once, by the time you know, take my medicine, or I might have to go to my doctor's appointment, and you know? ... Other than that, I just, you know, I will still talk to my friends. I also have a friend that was positive, who was born with it. So, we talk every day. So, I'll talk to her about stuff. We share a peace of mind about being positive, by you know, we just like, you know.

Melissa compared her life to that of her HIV negative peers:

Aahm, sigh, I can't really say that it's a difference. It just feel the same, I don't see nothing different about it. I, my sister don't have it, but we, we on the same journey of you know, want a better stuff for our life. For we both have a child. The same thing that she did I push out a baby, I was able to do the same thing.

Only thing that you know, I just have to be more careful, with certain stuff and how I do stuff, like with relationship and having kids. That's the only thing that's different ... I have to plan my pregnancy because I am positive, I just can't just I am pregnant and that's it, because you know, you don't want so medicine to affect them or anything. Like verses my sister, she can just have a baby or she could, her relationship is more different because their argument is not about positive and stuff, like my baby father, I am trying to like, get him more to open up to me, like if something bothering him he just need to like open up because of how he feel. Because, in my last relationship, that person did not open up to me and I didn't know that he felt this way about my situation. So, it's like, I struggle with that, you know, would a, what a normal person would go through without having, positive argue about stupid stuff, my argument is about you know, about me being positive and stuff. Like, it's not my fault, so it's like, I don't know.

Melissa's mother died when she was 10 years of age, at which time her older sister became her primary caregiver. She gave an account of her relationship with her sisters:

My two older sisters did took care of me and everything ... My sister, Monica, she took care of me and stuff ... They are my only sisters and they are fine, my rock ... It's good, we hang out, do everything together. For them to be my older sister, they like my best friends and stuff. Like they, my older sister is 36 and I am 24, but it's like, it feels like we in the same age and we not. But, we, we very close. I can go to her and tell her everything and be open about and stuff, now that I am older, but before I used to thing scared because my sister didn't play. She had like the mom figure, so it's like I couldn't, I know that was my sister and stuff, but I still

respected her like a mother figure, because she took care of me and stuff. And, but ... Yes, she is still supportive.

Melissa has completed high school and one semester of community college. She does not believe that she is good at academics. **Melissa** believes that she is better at using her hands. She has not fully decided on what career path she would like to take, but she has some ideas of what she would like to pursue. She explained:

I wanna do, you know, nurse technician. I kinda wanna be an entrepreneur. You know, cause like I have been doing, this little job that I have been doing, its life an independent contractor, but by me doing it, it just made me realize that aahm, I am very good with, I want to help people, so I said I could put hope I could come up with like a business plan and so I have. I want to go back to school dm, but I want to go back for business. I feel like I wanna, I want to be able to, I want to help people that struggle with the same thing that I go through, you know, by being positive, motivation speaker, and help others get through their problems, or I could be like a counselor, that would be something that I would be interested in aah [pause] to run? ... aahm, I would like to have a aahm, an online store ... with I am not like, I like the whole thing you know, about natural. I like the whole thing about skin. Like natural stuff. I would like to do something like that or make up.

According to **Melissa**, her first sexual encounter occurred around age 16, at which time she used protection and she did not disclose her HIV status. However, around age 19 when relationships were more committed, she disclosed her status to her partners. **Melissa** expressed her opinion on having sex as an individual with HIV:

Aah, sigh, aah, sometimes I am like, I don't know, I don't really think about that experience, but I know that, it's like you have to be careful with certain stuff, but I can't be that careful [sigh]. Well, it's as if that person come to agreement, like wanting to be intimate with you and he know your situation, it's all up to both of us, if we just going to be constantly thinking about that, because if we constantly think about, like me being positive. We won't be able to enjoy being intimate.

Melissa shared how being HIV positive affected her intimate relationship:

It will be a hard time, this and that to a point where he had to be do something with me even though he knows about it. At the beginning we use protection and then after a while, you know, we start getting comfortable with each other and then stop using it. So, he, he was the one stop using it and I ask him if he was sure? Because And he was like ok and everything. Once we start being intimate he start getting tested every once in a while, and stuff and that became and then he spoke to one of the person at the clinic about because like I told him about the pill, and he like get a sample of the pills and stuff, so it's like, its ok. We just got to work on our communication and that's the only thing with our relationship, we lack communication. It affect it I could say 20% of it. And everything ... aah, it because it's like your partner like he like who you are but it's like they be so afraid that they might get it and stuff so they just, they have their moments when they be get wordy and stuff ... aahm sometimes he get, it not like it like he just, he never went through an experience before, like this so it like its different ... Like being with someone who is positive. He don't know what the right things to say and how to like, to do things in a way not being rude, so it's like we just

trying to be like more communication about it and stuff about the whole virus thing. I am just educating him about it because he knows that he can't get it, because I am taking medicine, you know. So, he is taking the little pill that they have, but it's just like, I don't know people just have cold feet sometimes.

Melissa was involved in an intimate relationship with the father of her son. Her partner and her son were HIV negative. She shared more details about their relationship:

When we was dating like 2 months in I told him. Told him when we were at the park. We went to go walk in the park it like, it's like I just blurted it out and tell him, and he was like "OK'. You know, most people would be like, he did say, you know what? When you tell someone they don't really feel, get away from me type of thing, that's a big secret, that you could tell someone. He was like, thank me for opening up to him because most people would never told was like told them when it was too late or something happen.

Melissa had a negative experience in a situation where the individual spoke publicly of her diagnosis, after she ended their relationship. When asked about her thoughts on what her life would be like if she did not have HIV, Melissa said, "I would say it the same, aahm better relationships you know? ... No. No, I don't feel like it will be different. I feel like it would just be the same as a normal person." She shared her vision of the future:

It will get better. I feel like bout 10 years from now I won't, you know, I won't say there will be a cure, but it, medicine will, the medicine is better already, but it will just be a whole lot different 10 years from now. It will probably be beyond, people probably won't be worry about HIV. They will probably be worried about

something else that's coming to take over the human body, but otherwise than that, I feel like it will be; probably be, I will probably be like in my career, and hopefully married and everything. If I feel like whatever about this virus, you probably won't matter to me ... Yes, probably like two more kids.

Melissa volunteered at her doctor's office, but she was not involved in any organization.

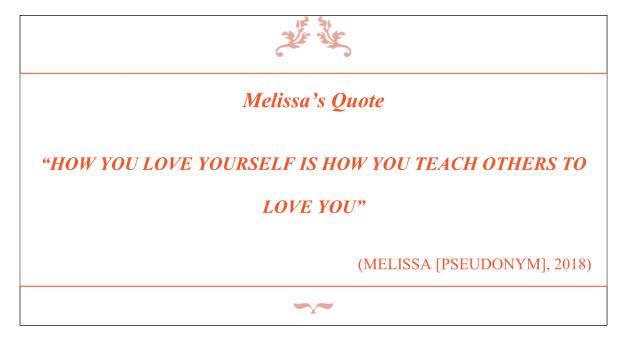


Figure 22. Melissa's reflection of living with HIV (Wright, 2018, adopted from Melissa, 2018).

Figure 22 represents **Melissa's** quote, which she presented as her reflection of the interview. She explained the meaning:

Self-love is a basic feeling, which each of us need to have. Loving yourself is important, because the only person who can love you unconditionally, accept you with all your flaws and misgivings and forgive you no matter what, is you.

Edward

Edward always knew that he had a medical condition while growing up;

however, when asked by the researcher when he was told of his HIV diagnosis, **Edward** said:

I think this is pretty much the same across the board, but when we at least for prenatal babies, they aahm, we all went to camp for kids with chronic illnesses, and aahm, various camps that we have attended, they teach us how to live with HIV and how to deal with HIV ... I would say about 12 or 13 ... in camp, in the camp they teach us and they tell us, this is HIV.

The researcher asked about his family dynamics, and **Edward** responded:

My family, I am really close with my mother. My mother is HIV positive, aahm, I am not so close with my dad, he aahm. He wasn't around the family too much, and I have one brother, and he is 26, he has his own family.

Edward disclosed, "My mom ... from birth till now" as his primary caregiver, who provided guidance and emotional support through the years. He informed the researcher that his mother instilled in him that he could not tell anyone about his HIV status. She rationalized it by saying that the information would get out and people would look at him differently. Edward's mother also instilled in him the importance of always taking his medication on time. Consequently, he has always been diligent at taking his medication on time, even when he would be at sleepovers. Edward believed that he was enjoying good health because his viral load was never detectable, as a result of him keeping his medication schedule.

Edward participated in wrestling and football in school when he was younger, but he gave it up because he was having problems with his knees, and he did not want to injure himself any further. While he was enrolled in a 2-year college program, he wanted

to go into the Army; however, he was unable to follow through on that goal because of his HIV status. **Edward** eventually transferred to a 4-year university program, where he was introduced to research, in a research mentorship program. His area of focus was in mechanical engineering in nano composite. **Edward** reported that in summer 2018 he would be attending a summer research fellowship. He planned to continue his education until he achieved a Doctor of Philosophy (PhD) in Engineering. His career goal is to become a researcher, a professor in his field, and to operate his own business. **Edward** did not believe that his life would have been any different if he did not have HIV, except for the secrecy, taking medication daily, and having to disclose his status to potential intimate partners. When asked by the researcher, how his HIV status affected his sexual relationships, **Edward** responded:

Aahm, it's definitely more aahm tentative, due to the stigma attached to aah HIV and positive people, and so we, at first you need to educate the person if they are not already educated about it, and you need to teach them that you are healthy and you've been here this long and you are going to be here for a much longer time due to this medicine. So, it's just things like that. They have to get over the stigma, so I have had good experiences and I have had horrible experiences.

Edward acknowledged that he was involved in an intimate relationship, and that he disclosed his HIV status to his partner a week after they met. The researcher asked Edward why he felt comfortable enough that early in the relationship to disclose his HIV status, and he said:

Yes, it's extremely difficult, it's extremely difficult and it's taken much time to get over the fact that or get used to disclosing. It's taken years to get to that point,

aahm, especially due to how I was raised by my mother, saying that this is a secret, and you shouldn't tell anybody, and so aahm. The reason I felt comfortable was because I ... I don't want to get in trouble, because you get into you know things move fast and you get into. You start doing things and that not good. You can get in a lot of trouble and [pause], I just, I don't know, I feel it's my responsibility to tell people.

When asked about his partner's response to his disclosure, **Edward** responded, "She was open to aahm, convincing that's not the word I want to use, but I am at a loss for words." **Edward** also informed the researcher that in the past, he had been involved in other intimate relationships where he was disappointed in his partner's reaction to his disclosure of his HIV status. **Edward** choked up when he talked about those experiences:

Aahm, I think, I think you did not want to ask because I kind of explained it a little personally? Aah but, I would like to add that, some of the experiences that I have had, disclosing to partners, it's like I said, some of them were good, some of them were bad aahm, the bad ones, when they are bad, they're really bad, and so aahm, so, so I disclose to this girl, and you know, they, they take it the same way for the most part "Oh my God I am so sorry" or "Oh My God thank you for telling me," and then aahm, I have gotten some that I haven't heard from them in years. I aah they deleted me off snap chat, off all social media, and ... When you see that for the first time that I saw that, I felt, I felt really bad, I felt like useless, you know? ... that was the first time I felt I was different, and so, it's really tough.

It takes a lot, took a while to get over that too. Other than, that I am in a happier place now.

The researcher then asked **Edward** if anyone had ever disclosed his information and he did not want them to, and he said, "Yes, they did, and aahm, but usually they just tell their closest friends and then aah, I know there is legal option for that, but, why go through the trouble?" When asked by the researcher what he thought his life would be like in 10 years, **Edward** responded:

Aahm, I would want my life to be aahm, starting to gain tenure at a university as a professor, and aahm, running my own research lab, and guiding students like myself that are interested in techno research idea and aah, family, young family 2 kids, house. That was a little far fetch but.

Edward did not think that his life was any different from his HIV negative peers, as he expressed:

Aah, for the most part, when looking at it from a whole perspective of the whole population, I am no different from somebody who is aah, completely healthy, and, we are not that different, but we do have little restrictions. Like I can't be as promiscuous as somebody who is completely healthy. Aahm, I, I have to understand that I have a responsibility to inform the people that I am in a relationship with and aahm, I guess in that aspect, we are different. But, other than that, my life is completely normal.

Edward did not volunteer, but he participated in clubs and peer groups on his college campus.

When you walk through a storm, hold your head up high And don't be afraid of the dark At the end of the storm, there's a golden sky And the sweet, silver song of a lark Walk on through the wind Walk on through the rain Though your dreams be tossed and blown Walk on, walk on With hope in your hearts And you'll never walk alone You'll never walk alone Walk on, walk on With hope in your hearts And you'll never walk alone

(Lyrics/Song writers: Oscar Hammerstein II, Richard Rodgers Singer: Gerry & The Pacemakers)

Figure 23. Edward's reflection of living with HIV (Wright, 2018, adopted from Rodgers n.d.).

You'll never walk alone

Figure 23 is **Edward's** presentation as his reflection of the interview. He explained what the song meant to him:

Aah, towards the end of our meeting last time, you asked me what my perception of my life with HIV was, and I told you that, it was kind of, if life was like

running a marathon and there is obstacles in that marathon, people with HIV have more obstacles than the regular person. So, the song is linked to the last conversation we had by saying that, "You'll never walk alone, keep your head up high and there is light at the end of the tunnel."

Kayden

Kayden reported the following regarding his HIV status:

Honestly, I don't recall not knowing ... I have friend that like, say you know, they didn't find out "Until I was 16, 13," you know, older and stuff like that ... But I honestly don't remember "Not knowing" that I was HIV positive. I always knew as a kid.

The researcher asked **Kayden** what it was like for him, growing up and having HIV, and he said:

Aah, growing up having HIV aah, I wouldn't say it's like the easiest thing [pause]. It's, more so complicated, as far as aahm, you know, trying to figure out if you should disclose to certain people, who you want to find out, aahm, if anybody is going to find out, you know? People are very judgmental, so it's like, this is not something that is, a mean, I felt like it got easier as you become older, and making that decision, and the world has kinda changed in a way? But as far as like, just going through life, it's [pause] I wouldn't want to put that on anybody.

Kayden was further asked to explain what he meant by "It got easier as you become older" and he clarified:

I guess because of experiences, like you know? You choose your battles wisely, aahm, and you know, a mean it's not a good thing but, as common as it [HIV] has

became in today's society it's like you know, you come across more people that are in the same situation as you. Like I find it a little easier for me because, when I come across people in the same situation I feel like I can give them advise, I can give them the guide that they need that they probably didn't have, where I know that I didn't have while growing up. That person to talk, or that person with that knowledge. It's kinda harder when, you know, you hear from a doctor or a nurse, you don't have nobody that on the same level as you, that are really experiencing or have been experiencing the same condition ... you know, when they become positive, you know, [they] would feel a certain way, or take it negatively, or you know, and I am glad I can be like that person, you know, that turns that perspective around for them, as far as, I have been living with it all, my entire life, I have made it this far aahm, you know, these are the do's and don't ... its mostly like a one-on-one, like, like a friend of mine tell me about somebody they come across, this a mean, I can refer them and ... It like more of a friendly thing. Like it's not as something I do as work, it's just something you know, I feel like I can offer to the next person.

When asked about the battles that he had encountered, as he had mentioned before,

Kayden explained:

Aahm, ok, well the biggest battles is always disclosure, I feel like it, there is no way around it. Aahm, it's just the, knowing like is this person going to take it the way you want them to take it? Or if they going to go the whole opposite direction, should you tell them? Shouldn't you tell them? When should you tell them? Aahm, as far as friends, romantic relationship, as far as if you think the

person needs to know, aah, even like, for me at work, for me, when I get sick or burnt out. I go to the doctors a lot. It's like, should you tell your manager the situation so that they can have a better understand why you are always bringing a doctor's note. Why you know, you're always calling out of work? If that's the case aahm, you know, and, are you going to have that confidentiality with your manager or with the person that you are disclosing to because you never know that they can turn around and tell the next person, and tell the next person, Oh, I didn't tell nobody, but they really did, that's one of the biggest you know thing, you know. I feel like normal people didn't like to tell their friends "Oh you know I am diabetic," or "Am have cancer," or even if they did disclose, it's not like an issue that would conflict between two people.

Kayden's parents both died from complications of HIV/AIDS, when he was about 5 years old. At the time of his parents' death, the adjoining burial spot was purchased for his burial, because they thought that he was going to die soon after his parents died.

Kayden's maternal cousin who he considered his mother has been the primary care giver to him and his two older siblings, since his parents died. She continued providing emotional and other support to them as a parent does, although it has not been without conflict. When asked by the researcher about his caregiver, Kayden said:

My mom's cousin took us in ... It was [pause] it was really good, I mean, I don't really have no complaints ...Only thing I could remember is aahm, growing up is, aah, I felt like she used to use it like a sob [cry] story in a way? ... I see it at times, where she will break down in front of people, and say, you know, "Oh he is sick, he is this" aahm, not as far as like trying to bash me or anything like that but [pause], I

mean ... I don't know how she was taking it, you know, but I just see it as her, you know, every time I see her cry ... This used to be a line that I use to always hate when growing up. She will be like, "Oh I have 4 kids, but I only push that one" or something like that ... sometimes I feel like why does it matter or why do you have to say you push that one, because she has a daughter which I call my sister [clear throat], why would she have to say that? Why would you have to, what does it matter to the person you're telling that you have 4 kids to because they ask you how many kids you have? ... I used to like that was one of those lines that I hate to hear, aahm ... I think she was a good, I mean, to this day I still call her my mother, I know her as my mother ... I consider her as my mother, I wouldn't, you know not consider her.

Kayden reported on the status of their relationship, "Pretty good, I mean we are really close, aahm, I felt like we have gotten closer as I got older, I guess? ... I found that I got closer when growing up." **Kayden's** siblings and other family members were all HIV negative. Consequently, there were times while growing up, that he had to address his reality all by himself, as he explained:

Correct! [pause] and you know, growing up being positive ... I felt alone so, I felt like nobody would understand. I was the only person that had it within my family, so it just like, I felt alone, and I also felt like, you know, I wouldn't say abandon, but left to like cope and deal with things on my own, as far as being HIV positive.

Kayden described a typical day in his life in the context of his HIV status:

It's you know, making sure that [pause] you have your meds, that's like, I don't know, some people take their meds first thing in the morning, some people take it late at night. I take mines late at night, aahm. Having HIV like with my meds, my stomach, every morning it's like irritated, because, you know, I take it at night before I go to bed. When I wake up it like annoyed and agitated, to me aahm ... sometimes I do try to take it with meals, aahm.

The researcher also asked **Kayden** if he was taking his medication as prescribed and he responded:

To the best of my ability, as far as like, sometimes I work crazy hour, so sometimes I get home, or I don't come home at night. I would be between 2 jobs and sometimes I forget to package, because I usually keep it in a little canister on my key chain but if like the night before I took it, because keep it on my key chain I forget to replace what's in my keychain then that night I would probably miss it.

Kayden explained what he thought his life was like when compared with his HIV negative peers, as to whether he saw a difference:

Aahm, not necessarily, I mean, we all go to work, we all go to school, we all, like, at the same level, aahm, you know. I feel like everybody has their struggles and battles in everyday life, but I don't see a big differential between the 2 as far as, you know, life goes, I mean. Everybody 25 are pretty much dealing with the same thing, working, trying to live on their own or going to school or just graduating. Trying to find a career job ... No, I honestly feel like, for me, aahm, that I have been achieving the benchmarks as normal kids. I went to elementary

school, I went to middle school, I graduate from high school, I went to college, I got a job, aah, I did everything else that a normal child without HIV would have, you know? ... Yeh, it doesn't set you apart.

The researcher also asked **Kayden** what he thought his life would be like if he did not have HIV, and he said:

I know at time I get like real frustrated. Aahm, guess it like, I always feel like I am sick, in a sense, like, sometimes it could be just a slightest headache, or the slightest stomach pain and I feel like, Oh, my if I didn't have HIV, you know, I probably wouldn't feel like this every day. Or I won't feel this way, I won't be as you know, aah, sick so, aahm, I just feel [silence]. Sorry I just lost my train of thought ... I didn't feel like it would be any different. I wouldn't have that feeling in the back of my mind connecting HIV yeh, be like oh I have a common cold, but its lasting a longer, a lot longer than some else I know. I got the cold from, you know, and it's like, if I didn't have HIV, would I be still sick or would the cold last this long?

Kayden's first sexual encounter was around the age of 17 years. He has been involved in multiple intimate relationships since then, mostly with other men who were HIV negative. Presently, he is involved in a committed relationship with his partner who is HIV positive. His partner was not born with the disease; he acquired the virus behaviorally at an early age before they became partners. **Kayden** explained his perspective on having children:

Aahm, I am still on the fence about that, because before I used to be like, "I am not having my own kids, I will just let everybody around me have kids and I do

for them," aahm. Now I am kinda, aah, "maybe I could have a kid." But, I don't know, I just always felt like I don't wanna do to my kids, like how I felt like my parents did to me, kind of. Sometimes I feel like they kinda left me to deal with this by myself, aahm, I mean, I know it's not their fault, you know, they can't help themselves from dying or anything like that.

Kayden has a bachelor's degree in criminal justice with a minor in psychology and he is planning to enroll in a master's degree program August 2018, to major in either public administration or criminal justice. He is presently employed fulltime at a bank as a customer service representative and at a national store in retail. **Kayden** had interviewed for a Transportation Safety Administration (TSA) position that was more consistent with his academic preparation, and he was very hopeful that he would get this job. His career goal was to become a TSA Custom and Border Patrol Officer.

Kayden continues living at home with his cousin and other family members. He was asked about his vision for his future, and he expressed:

I notice that when I do think of a future, somebody brought it to my attention not too long ago, that I always say "If I make it that far" or "if I be there" instead of saying that I am going to be there or I am going to see that or, you know? So, it's like, [pause] I mean, now with technology and everything. But I just, growing up it's like that was the factor, that was the thing, you know, if you are going to make it that far? if you're gonna live that long? But now a day, you can live that long, you can see that far, you can see the future. But I came so accustom to being if I make it that far, or if I be there, that you know, I still kinda put that perspective, of not having that longevity life.

Kayden volunteers at an annual camp for children with HIV and other chronic diseases, which he also participated in as an adolescent. He also participates in a program for children with PAHIV at his Doctor's office, and he often cease the opportunity to provide support and guidance to individuals who have been newly diagnosed with HIV.

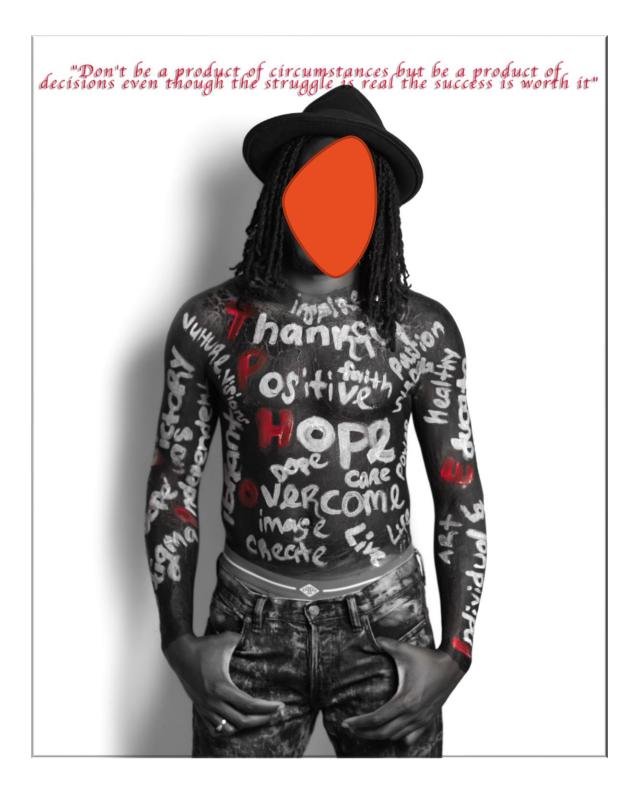


Figure 24. Body Mapping Art: Reflection of living with HIV (Wright, 2018, adopted from Kayden, 2018).

Figure 24 is a body art map picture of **Kayden**, which he created for his member check submission. It represents his reflection of the interview. He was advised by the researcher that this picture would be published and probably reach a larger audience, to which he agreed.

Rashad

Rashad acknowledged when he found out that he was HIV positive, "Ah, I would have to say that I was probably, 10, 11; 11 may be?" He explained further about how he found out:

We were at camp [pause], we were at camp and aah, and they were talking about how, because I didn't know but some kids knew. They were talking about you know, while we were at camp, and I was just like no, I might be here for a different reason because that not me. And then DP actually pull me into one of the medicine room and actually, tell me, and then, when we got back to aah Florida, because the camp was in Texas. When we got back to Florida, we had, you know, a big sit down, and she told me about it with the phlebotomist and another amazing doctor, DLF was in there, and she just kinda sat me down and ran through it. And told me that I didn't have anything to worry about because I have been taking my meds and I am undetectable, so ... yeh! It was very sad, very sad ... Because I didn't understand it ... Because of all the stigma that was going on. I didn't understand it, I thought I am gonna die soon, but it's not like that ... Not any more.

Rashad spoke glowingly of his mother who was his primary caregiver while he was growing up, and who continues to motivate him, providing him with his greatest source

of strength, "My mom, she is alright, she is doing fine. She is working, aah, Monday through Saturday." About their relationship, he said:

It's great. I love my mom ... She is there if I need her, she is there when I don't need her. She is, you know, she is alright at the end of the day but, I mean, our relationship is great ... Yeh, I have, I have a strong, when you grow up aahm, I feel like if, when you grow up with a single mom she is raising 3 kids, and she is trying her best, she is even struggling but you would never see the struggles that she had to go through, you don't know half of the stories of the struggles she had to go through, but she made sure that she provided, Christmas, every holiday, birthdays, we went out of town, we went out of state. We went out of the country, we were doing the amusement parks, theme parks. She is a single mom with 3 kids. So that kind of give me the drive and the motivation to, you know, get up So, she never let me, even with knowing my status, and even with knowing everything, she never give me a give-up mentality. She gives me hope ... even when I felt like, I want to give up, she was there to, you know, kick me in my butt and tell me "Push on, you got to go."

Rashad told the researcher that he had another chronic disease when he was younger, for which he had to undergo multiple surgeries and regular follow-up appointments with a physician. He confided that his mother and grandmother were the only members of his family who were aware of his HIV status, and that having that other condition allowed them to maintain that secret. Rashad was asked by the researcher what it was like growing up and having HIV, to which he responded:

Oh it's, it's in one word "Cautious", you have to be cautious about everything, not only, you know, very, your health but you also have to be cautious because you can't take ah, different types of aspirin, because it won't be beneficial or mix with your medicine. You can't drink alcohol while on your medicine. You can't, you know, do certain type of things, some people can't even put on, like lotion, different types of lotion like because of how the medicine will react to their skin, so it makes you cautious.

Rashad was the first participant to go into such details about the side effects of the medications, so the researcher enquired more from him:

Yes, the complications that can arise from either the virus or the medicine. So, it just, it just, I just look at it, as it just make me more cautious. I mean, my days of dwelling in it, were over a long time ago from when I was young, so I don't look at it as, you know, curse or anything, lesson because some of the stuff that I would do, I don't because of the virus so.

The researcher asked **Rashad** to explain what he meant by saying that there were certain things that he did not do because he has the virus, which he considered a blessing. He answered:

Yes ... it just, it's just certain things you have to be cautious with, like certain foods, that you don't eat or certain pills, like if you're regular or if you're normal, I should say, that you would take those pills but like as far as like different types of aspirin, like different types of vitamins and some of that stuff has recall on it, and some of that stuff is actually, it turns out bad for you, so it just makes you cautious, and it makes you more aware, like I just said aahm, when you are out in

the nighttime and you do take pills before you go to bed, it makes you second guess, you know, that drink of alcohol alcohol that you are about to take or you would have token before you, I mean if you weren't infected. So, it just makes you more cautious, of situations like that.

The researcher then asked **Rashad** to clarify what he meant by saying that he would "dwell on it," which he explained:

Yes! When I was younger I used to dwell on it. I used to aahm, kind of have resentment for my mom. Which most people who grew up with the virus that I know about actually did. And grew up with it from birth, it's basically resentment, basically why me? I am the middle child and I am the only one that was infected. So, it just basically, put me in the state of "Why did this happen to me?" and like it wasn't in my power, it wasn't in my hand, I had no choice, so, I used to dwell on it when I was younger, but now I basically accept it.

Rashad was asked how he saw his life as someone with HIV compared to his peers who were HIV negative to which he responded:

Not different. I am actually doing better than most of my peers that, I believe, don't have it. It's like I said my days of dwelling has been over so, I look at myself as a regular person, and my doctor from since I was born till now, DP, she actually told me that, you know, she gave me words of wisdom that actually stuck with [me]. Just because you have the virus doesn't makes you. So, I stuck with that that it, I have it but it doesn't control me, as long as I take my medicine and do everything that I have to do, I will be fine.

Rashad explained what a typical day in his life looked like:

For me, is getting up, aahm, aah about 8:30, taking a shower, daily routines take my meds, and then I go to work, which I work at AMS school, as a student life coach. So, I go to work ... depend on traffic, it's about 45 minutes. Aah, got to work, I'm in work, aah at AMS school from 10 O'clock to sometimes 7 o'clock, depends on when the parents pick them up, because I also run the after-school program as well ... aah, actually after 7 O'clock I come home, and I construct things, what is called case notes. Case notes are basically observational conversation that you have with the student that you have to document. Come home, do my case notes, aah, sometimes I stop get something to eat. After I do my case notes. After I do my case notes come home, relax, try to relax, watch TV. Aah, right before I go to bed I will have either, whatever drink that I am drinking for some and I take my night meds and basically go to sleep. I do that Monday to Friday.

Rashad reported taking his medication, "Every day ... twice a day, once when I get up, once when I go to bed." The researcher then enquired about his career goals, and where he was on that trajectory, to which he responded:

My career goal is to actually graduate college, aahm, occupational therapy assistant and work with kids with disabilities ... I am actually, aah, I am actually on, like going through the process to go back to school. I had to be postponed because I am expecting a child in September [2018] ... What I have accomplished so far is actually associate, on my way to get my associates I should say, ah and then there was stand still because it was a shock, so it was just more of, alright,

how do I pull myself away from school but not entirely? And work so I can be able to save up money so I can make sure my child can have ...

The researcher then asked **Rashad** his opinion on having children, in response to the information he shared about expecting a child, which he clarified:

Aah, I didn't want any, to be honest with you, I didn't, aah not now, but ... Yeh, I didn't want any now, so ... I need, I just felt like as if I had my whole life ahead of me. And I like, I picture me having kids when I was set in my career and financially stable. But I mean things happen, that doesn't deter me away from making sure that my child has the best life that it possibly have, best "Negative" life that it could possibly have.

Rashad reported on the likelihood of his baby being born and having HIV:

Aah, its very slim to none. That's what the doctor said. The mother is also positive, but she has one child already that's negative so ... She knows what she is doing. She takes care of herself and the baby should come out. She is undetectable, I am undetectable, so the baby shouldn't have a problem.

He explained his sexual history in response to the researcher's enquiries, "No, oh aahm, I have, I have been ... I have been sexually active since I was about 15, 14? He further explained that all his sexual partners have been HIV positive, consequently, he has never had to disclose his HIV status. He said, "I had, I hadn't had to face that yet." **Rashad** continued to explain why he had never had to disclose his HIV status to an intimate partner:

Yeh, alright, I will explain. Aahm, when we were younger, about 7 years old we went to a camp called Camp Hope, and it was aah for kids with AIDS and HIV

that were either transmitted with the virus or prenatally infected, aahm or I should say, got the virus or perinatally infected, and we grew up basically together and established a bond and aah, I have been having sex with just those females. Not saying that I was pick, pointing them out, it's just something that, its kind a just happen, know you, you have HIV and I have HIV, that cancels out the disclosure part. I guess we were running away from the disclosing part. And that what kinda ... yeh, that's what kind a drove us to, like be in a relationship, or even try to be a thing, so as far as disclosure, I never have to encounter that yet.

Rashad divulged his opinion on marriage:

Marriage is nice, I like people that get married, but I can't get ... [Laughing] aah men, that was something else I was running from too. But I mean, I feel it's good. I would get married when the time comes, when I know it's right. I am not saying that it will come in the next 10 or 15 years, but, I think I will probably, like, cause when people say yeh, I get married it like they are forcing themselves to get married. I just like for it to just happen naturally. If I feel like this is the woman that I want to spend the rest of my life, like you know, I can't stop thinking about her, aah, you know I want to spend every waking day with this woman, and you know, and it hurts me when I am not around her and I feel like she would be the best for me and I would be the best for her, and we can both better each other, then yeh I will consider marriage.

The researcher followed up by asking **Rashad** to explain how the child he was expecting figures in his life, and he said:

Yeh, this child, I mean, I am a great person, like, I practically raised my niece and my nephew, so I mean, I love kids, and kids attract to me for some reason. I don't know why but they do. I volunteer at the camp that I have been going to since I have been 7. I still go back every year, as I say it's in Texas, so I go back every year and volunteer and help those kids, out so I mean a kid will probably slow me down, a lot [both laughing].

Rashad imagined what his life would have been like if he did not have HIV:

If I did not, Oh! My goodness, aah, I would probably have like 12 babies ... I would probably, oh, I don't know, I would probably wouldn't have any drive, but I don't know ... it's just [laugh] it's a just, I don't know because, I got a sister, she is not infected, but she is like she is stuck in this, she is stuck in this thing where it's like, it's like, I don't even know how to explain it. It's like she is stuck in the hood mentality, and she doesn't want better for herself. She says she does, but her actions doesn't show it ... But then, I have my brother who is in college, he is a junior in college, my younger brother. He is not infected, and he is a junior in college aah, he is going to school to be a Broward Sheriff Officer (BSO), he also plays college basketball ... It's just like, I don't know where I will end up, but I know I wouldn't let myself be defeated by anything, so it's like you've got the good and you got the bad, and they both not infected. So, if I wasn't infected, it just like, I don't know ... Yeh, it doesn't change anything, like I am always going to be me at the end of the day ... I am always going to be hopeful, because that just how my mom raised us ... I don't know what happen to my sister, but you know, that's how my mom raised us.

Rashad's discussed his vision of the future:

Aah, I don't know, the sky is the limit at this point. My options are open. I don't, I don't limit myself or, my future is what I will make of it. And there it just like, at this point I am not sure about it, I just know I won't I won't be unsuccessful, and I won't be another statistic in this world, especially when 45 [U.S President] you have to make, try to make better for yourself regardless. Because you're, when I say you're, that's speaking of only me and the people who are infected. You are gonna have this virus whether you dwell in it, and give up on life or you strive for greatness, so why not strive for greatness?

Rashad volunteers at an annual camp for children with chronic diseases, especially HIV/AIDS, which he participated in as an adolescent. Towards the end of the interview **Rashad** added:

Aah, I would just add that, you know, some days it's hard, harder than others sometimes you just don't feel like taking your medicine, just too tire to take it and it's just like, it's just it's just very hard so, aah, the sensitive like side to it, is and, I can see why people give up, I can see why they don't have any drive, I can see why they're stuck in a dwelling point, because you're forced to face reality every single day you take medicine.

Rashad further clarified the above statement:

I will say at the fact that you're taking the medicine. Some people have side effects, but I know I don't. Well I do, I get tired, I am tired, all day but other than that, it was like stomach ache, throw ups and everything else, but as I got used to my medicine the only, the only side effect that stuck was drowsiness. But even

with that, it's just like, every time you take your medicine, it just like, your forced with that realization that I have HIV, it's not going anywhere. It's what you do in those thoughts, in those moments that actually determines your future, and it determines what you want to make of yourself. Because, you can, nobody can tell me that, living with the virus, when they take their medicine they don't think about it because it's, its, I ask, 100% of the people I talk to, who positive, 100% agree with me. When you take your medicine you think about the virus, but it's what you do in that moment, what you think about in that moment actually determine your future and how you live your life. You can take your pills and dwell on it, "I got HIV I don't know what I am going to do with it," or you can take your pills, "I got HIV and take this medicine for the better," so I can be alive forty fifty years from now, God's willing.



DON'T LET IT DEFINE YOU!

The words that we hear all the time to cover up the fact that we weren't taught how to live and grow in society.

DON'T LET IT DEFINE YOU!

The shame that we hide behind characters because of bad stigma and ignorance, the thoughts always linger of "what if they found out?"

DON'T LET IT DEFINE YOU!

So that we can be free in this world, take our meds, and muscle up the pain and move forward, all while asking "WHY MEI?"

DON'T LET IT DEFINE YOU!

A STRONG mentality and a willpower to live fuels your success in life, a support system like family and Doctors offices also push for you to rise up, but its your life and you only progress if you help yourself.

DON'T LET IT DEFINE YOU!

So I won't, I will always strive for greatness and be the best person I could be despite the obstacles I had to overcome.

DON'T LET IT DEFINE YOU!

I will always have HIV, but I don't let that Define me!

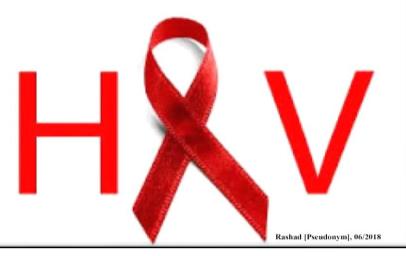


Figure 25. Poster: Reflection of living with HIV (Wright, 2018, adopted from Rashad, 2018).

Figure 25 poster was created and presented by **Rashad** as his reflection of the interview.

Brittany

Brittany shared how she found out about her HIV diagnosis:

When I was 11 ... through my sister ... well, I asked her what is HIV? She searched it up for me and then she told me ... Because my doctor asked me what do I have, and I didn't know what I have ... No, no, I am sorry he told me ... but I really didn't know what it was ... and my parents didn't tell me yet. They wasn't ready to tell me yet. That's what they told me ... but then, it just all happened, when I asked my sister.

Brittany also shared that both of her parents subsequently died within a short time of each other of complications from HIV/AIDS. She said, "Aahm, I think I was sixteen, yes, 16 turning 17." Prior to being informed of her HIV diagnosis, **Brittany** recalled:

Yes, I was on medication and, I was like going to the doctor every 3 months, and aahm, but then [pause]. Before I found out [pause], I wasn't really worried about, well, to be, I didn't even know, so I was just living my life, yeah ...

Brittany's medication regimen is one pill once a day. She shared her thoughts on what her life was like growing up and being HIV positive, "Aah I mean it's [pause], well, it's normal to me now, but I still like, I still think about it [pause], aahm [pause], I just feel normal [pause], yeh I just feel normal." **Brittany** further explained what normal meant to her, "Well, before, when I first found out I was really scared, but then now I realize it and all that stuff, and I am comfortable with it." **Brittany** described what her life with HIV and a typical day in her life was like:

Aahm, I don't know, like, I mean, I am just, I go to school, I do this, I do that, the only think that I have to remember is drinking my pills, every single day ... like, waking up every morning, go to school; hang out with friends, being able to go out and aahm, yeh!

When asked what she thought her life would have been like if she did not have HIV, **Brittany** responded:

Aah, my life would be still the same, with HIV or without ... It's gonna be the same ... Like, aah [pause] I mean it's gonna be like a normal life to me ... being able to, ok, being able to do stuff [sex], not like everything, because I don't would probably like aah ... aah, my life would be still the same with HIV or without.

Brittany revealed her caregivers while growing up: "My parents and my sister."

Brittany lived with her older sister, and she described their relationship:

Since, I think it's 2 years ago ... I, we get along and [pause] ... Yes, she takes care of me. She make sure I be straight, like how aahm, some other sister, they don't really check up on you, they don't really tell you "Oh drink your medicine" Oh, this and that like and help you like she is helping me like build up aahm, my career. Like she is helping me go to class for wigs, makeup and aah, she is a very big supporter.

Brittany reflected on how her life was different from her HIV negative peers:

Aahm [pause] I never really thought about that [long pause] I don't know what to say about that one ... kinda, yeh ... Aahm, yeh and no, because, well sometimes I see like everybody, well, I see everybody getting pregnant, but that's not my

interest though ... And then for them to not worry about what this person have or what that person have ...

Brittany described her future vision, "It's gonna be the same ... Like, aah [pause] I mean it's gonna be like a normal life to me." She painted a picture of what "normal life" will look like for her in 10 to 15 years:

Like, healthy, aahm, reaching for my goals ... cosmetology, owning my own beauty salon ... yes, and [pause] and just, aahm ... Being healthy, being undetectable, [pause] aah ... aahm, being able to, ok, being able to do stuff [sex], not like everything, because I don't would probably like aah ... like owning my own beauty salon, being aahm, having a husband and kid, aah, yeh, [smiling radiantly].

Brittany informed the researcher that she has never been involved in an intimate relationship before:

I see myself getting involved in the future, aah, but ... Because I don't want the a person that no to judge me when I tell them. So, I just like think they are gonna say. Are they going tell somebody, do [they] call me bad words and all that stuff. She elaborated on her personal choice to not be involved in an intimate relationship:

That too, both of them. That and [pause] I just don't want, just don't want people to come at me sideways, saying rude things about me, even though they don't know, like my personal stuff. They just judge what the other person is telling them and aah, Yeh.

Brittany discussed having sex in the context of having HIV:

If a person wants to have sex? My opinion? I would like, tell a person first, before having sex, and I would want to wait until I am ready. I don't wanna just go fast, and everybody having sex, well, no. I want to take my time get to know the person and tell them, when we are ready [pause].

Brittany asked, "I think I do. When, is there, ok. If I wanna have kids in the future, is there a pill for a guy to take?" The researcher told her that there is a pill, Pre-Exposure prophylaxis (PrEP), that individuals involved in high-risk relationships could take if the individual is not already HIV positive, and that she should have a discussion with her doctor about it, when she is ready. **Brittany** also shared her opinion on having children, "I hope to have children in the future. Yeh, when I am ready to have children ... aahm, I wanna have [pause] 4."

Brittany graduated from high school and is attending a career college:

Aah, ML Educational Center ... they have a college. I am studying for cosmetology ... After cosmetology I am going to, I am going to actually be an assistant for one of my friend's beauty salon, like helping her and all that stuff, so she could teach me more of what I need to learn about hair.

Ultimately, she would like to have her own cosmetology business in the future. **Brittany** explained her career choice:

Well when I at first no, well before cosmetology, I really wanted to be like dancer, and then that didn't work out for me, so, I didn't ... because I can't do all these, flips. I was, well I was in cheer leading before for like, only like 2 years, and I didn't like it. I did not like it! I like dancing, but those type of dances are not for me ... its, aah, and I wanted, I wanted to be [pause], a nurse, but –t, I am

scared of needles, I don't like needles ... I am never going to be used to it [Both smiling] ... yeh, so I can help other people ... Because, I guess, if someone is going through the same thing that I was going through I could und, I could understand it. Like completely, like with my own ...

Brittany did not participate in any group activities:

Aahm, no ... I don, I don't know, I just be going to school, that's all ... aahm, last time, when it was my doctor, it was just recently, aahm, they asked me if I want to sit with a group of girls that have the same thing I have, watch a movie about a situation where the girl and the guy, like, she told him like 3 months before the she was HIV positive, and then they wanted to know what our opinion about the movie ... I already went.

Brittany explained her involvement in church activities, "I used to, but now I don't, because I don't have any time to like go, but no, I go to church every Sunday ... But are you talking about like dance? ... So, Like dancing, right? ... I used to.

I need to be loved more and more

(Don't) come into my room,

Don't stand at the door ...

Sit and talk or read me a book.

Don't judge me by the way I look.

Remember HIV was not bought at the mall

Even though it's affecting us all.

And in spite of HIV give them your love

You will be rewarded by God above.

(Brittany [Pseudonym], 2018)

Figure 26. Brittany's reflection of living with HIV (Wright, 2018, partially adopted from Brittany, 2018).

Brittany composed and submitted the content of Figure 26 as her reflection of the interview.

Travis

Travis was adopted by a couple when he was a toddler; however, there has been some breakdown in that family structure. Nevertheless, he maintained a relationship with both parents. **Travis** discussed his family situation:

No, basically, I was raised by my parents ... I am still, there's been some event, unfortunately for my family, aahm, between my parents. However, that being said,

I, [excuse me] I am still in touch with my mom, I am still really close to her, my dad, not so much ... Unfortunately, there just been things that have happened that just kind of hurt the relationship, not just between me and him but between him and the rest of the family. I still love him, I still keep in contact with him, but. And I also don't live with him, I live with my mom. So, I don't see my dad as much as my mom versus you know, back when I was little, and I saw them both.

Travis shared when he was informed of his HIV status:

I couldn't tell you exactly when I was told ... I know there was sometime around elementary school, so. It was probably, like maybe, maybe 4th 5th grade, was when I really knew that I had it, aahm. But again, it's honestly hard to say when I was first told about it aah ... That was when I kinda start learning about it.

Travis graduated from high school and started college; however, he was not enrolled for any significant amount of time because soon after he realized, that the college situation was not for him. Ultimately, he did not think that he would go back to college because he did not believe that he needed a college degree to be successful in his future endeavors. He enjoyed playing music and planned to pursue a career in music, including writing and composition.

Travis reported that he was not involved in an intimate relationship and that he has never experienced its consequences. He hoped to meet someone with whom he could have an awesome relationship in the future. Travis also reported that he was not sexually active—he had never had sex, and he did not plan on having children in the future.

Travis explained his thoughts on his life being different from his HIV negative peers:

It was, I just felt different, aahm, whether I felt like I wasn't going to be allowed to have a family, because like, I was going to give this disease to them ... Aahm, again like I said before, I kind of felt like an outcast, and I just felt like it was, it was a secret I wanted to be kept and like I said, I didn't know much about it at all when I was little ... So, I would say before, it was, it was just weird. It just feel, I didn't feel normal, I didn't feel like a [pause] a normal kid in a normal family. So, it just, it felt really weird and strange ... I see myself as pretty normal ... the only way, the only difference I would see aah a difference is in my sexual like ... Obviously aah, it's something that eventually has to be brought up and I have had mixed feeling about it even to this day ... And it something that I am at peace with. It's not like I am ashamed of it, but at the same time, it's something that ... But honestly, I don't feel any different from anyone else, I really don't, and even going back to like the sexual life, it not like, it's a curse.

When asked by the researcher what he thought his life would have been like if he did not have HIV, **Travis** shared:

Honestly, I think it would be the same. I think it would be exactly the same ... I think one little difference though would be, I think I would be a little more, at peace with a relationship, just because, I wouldn't have to bring up that whole conversation about it.

Travis aspires to become a musician. He shared what he is doing now to what he would like to be doing in the future. **Travis** stated, "But, besides that, you know, I have a band. I, my career I would say its music." His view of the future also included a nice home, a compatible partner, and a successful music career. **Travis** did not see children in his

future; however, he was open to discussion about it in the future, with his partner. **Travis** brought his drum and sticks to the follow-up meeting to demonstrate his reflection of the interview. He gave the researcher permission to take pictures of them to convey his message to a wider audience.



Figure 27. Travis's reflection of living with HIV (Wright, 2018).

Travis explained the significance of Figure 27:

So, this is my practice pad and my sticks. Aah, like I said in the interview, I play drums and pursue music, and I brought these as a reminder of the interview because, I am pursuing my passion in music, regardless of my virus, you know, it doesn't hold me back, you know. I still love music and I am still pursuing it.

And I believe that you can pursue anything you want regardless of the virus, you know, it doesn't have to be a setback. It's just a normal part of your life, it's just

a normal part of my life, and aahm, I am still drumming away and aah, not letting anything hold me back.

Lovely

Lovely was born prematurely at 23 weeks gestation. In addition to being born with HIV, she also had other birth anomalies, including cognitive, developmental and physical challenges. **Lovely** was adopted when she was an infant. She continued living at home with her adoptive mother, but there were plans in place for her to move into a group home in the near future. Lovely communicated that she wanted to become a nurse, but that it was difficult for her to pass all those classes, so she would like to have a farm, where she could take care of horses. She loved animals and horseback riding. **Lovely** also loved the Lord and would like to travel to other countries, where she could tell people who did not know Him that He cared. She was looking forward to a missionary trip to Uganda later this summer [2018] to do just that. She volunteered at the church that she attended frequently. Lovely was preparing herself for a job, to earn money to buy a house, a car [she would like a Hummer], a farm, and to travel to other countries. When asked by the researcher what she would like to be **Lovely** stated, "I want to work on the farm ... I know, I know how to work, I know how to work with horses. And I know how to feed them by hand ... It's hard." When asked by the researcher what she thought her life would have been like if she did not have HIV, **Lovely** simply stated, "I don't know ... aahm, [long pause], I don't know." **Lovely** shared her opinion on marriage and children:

I don't wanna, I don't wanna [stutter] get married, I just want to have my own life ... No, I don't want no children.... It's a lot, it's a lot to take care of a child ... you have to feed them, and you have to take care of them.

Explication Phase: Themes and Sub-Themes

During this phase of the data analysis process, the researcher gathered the individual depictions for all 15 participants and entered the process of immersion with intervals of rest until the universal themes and sub-themes of the experience were thoroughly internalized and understood. The researcher then constructed a composite depiction that represents the universal themes and sub-themes of the essence of the experience of an emerging adult with PAHIV. According to Moustakas (1990)

The composite depiction (a group depiction reflecting the experience of individual participants) includes exemplary narratives, descriptive accounts, conversations, illustrations, and verbatim excerpts that accentuate the flow, spirit, and life inherent in the experience. It should be vivid, accurate, alive, and clear and encompass the core qualities and themes inherent in the experience. The composite depiction includes all of the core meanings of the phenomenon as experienced by the individual participants and by the group as a whole (p. 52).

In this study, the core meanings or the essences of the emerging adult with perinatally acquired HIV (PAHIV) are the themes and the sub-themes that were derived from the individual depiction of the participants and elucidated by the researcher in the composite depiction. In developing these themes and sub-themes, the researcher utilized the concepts of immersion, focusing, and indwelling to explicate a more comprehensive depiction of the themes of the essence of the emerging adults' experience of living with HIV since birth, in more detail for each participant (Moustakas, 1990). This process was further facilitated by using NVIVO 11 data management system, Excel spreadsheets, and Word documents including tables to organize the information in creating the major

themes and sub-themes. The major themes that emerged include: *Panorama of Living With HIV; Consciousness*, and sub-themes *Kinship, Concealing and Paradox; Realities of Living With HIV;* and *Affirming Milestones* were derived from the individual depictions.

Theme – Panorama of Living With HIV

Panorama is defined as a "unlimited view in all directions ... a continuous series of scenes or events; constantly changing scene ..." (Neufeldt & Guralnik, 1986, p. 976). Beck (2010) used Panorama to describe the scope of Florence Nightingale's legacy. This legacy encompassed Nightingale's recognition in nursing history and her influences, which continues to echo beyond her neighborhood and the battlefield where she served; in villages and cities around the world; in the halls of leadership; and in behind the scenes discussions that have shaped the history of healthcare (Beck, 2010). According to Beck (2010), the highlighted stories were drawn from the much larger Panorama of Nightingale's 50-year career and she refers to the larger Nightingale Panorama as nursing.

In this study, *Panorama of Living With HIV* describes the participants' overall view (common thoughts) of living with HIV from birth (what it was, what is it; what it will be); their experiences with HIV and its effects on their entire lives – living with HIV. This includes the participants' perception of life; what a typical day in their lives entails; what they consider a normal life to be; how they perceive their lives with HIV to be different from their HIV-negative peers; and their perception of what life without HIV would be like.

Theme – Consciousness

Consciousness is described as a noun meaning "the state of being conscious; awareness of one's own feelings, what is happening around one, etc...." (Neufeldt and Guralnik, 1986, p. 296). Consciousness was demonstrated in Madiba and Mokgatle's (2016) qualitative exploratory study that "explored how adolescents with PAHIV experience living as HIV positive adolescents and examined their perceptions and experiences about disclosure and onward self-disclosure to friends, sexual partners, and others" (p. 2). The researchers found that all participants in their study were formally advised of their HIV status either at home, in the clinic, or at the hospital and that formal disclosure occurred at a variety of ages, ranging from 5 to 16 years. Most participants have known about their diagnosis for more than 5 years at the time of the study. In this study, Consciousness represents the participants becoming aware of their HIV status and disclosure of their HIV status to them. It describes when they were informed of their HIV diagnosis, how they were informed; their knowledge of HIV at the time they were informed of their diagnosis; their concerns before being informed; their response to their HIV diagnosis; and the impact that their knowledge of the disease had on them.

Sub-Theme of Consciousness – Kinship

Kinship is described as a noun meaning "family relationship ... close connection" (Neufeldt & Guralnik, 1986, p. 744). According to Parsons (1943), Kinship system in the American family is better understood when considered in the context of the "social structure and the strain and psychological patterns to which it is subjected" (p. 22). He characterized the American family as being similar to their European counterpart, as an open, multilinear, conjugal system; where the basic conjugal family unit of the Kinship

system consists of parents and children. In multiple interlocking kinship systems with a common member, the relatives emerge as *Kinsman*, belonging to both conjugal families (the family of orientation, which is the family into which one is born and the family of procreation, which is founded on marriage) (Malinowski, 1930).

Malinowski (1930) further asserted that *Kinship* is a cultural rather than a biological fact, where culturally defined *Kinship* is somewhat individual. Individual parenthood therefore forms the initial situation of *Kinship*, where the parents educate and materially equip the child, watch over their adolescence, control their marriage, become the grandparents of their children, and rely on them in their old age. According to Malinowski (1930), the bonds of *Kinship* start in the initial situation and persist throughout life, and the "individual's own family remains a stable unit throughput his lifetime" (p. 26). The bonds of *Kindship* were supported in the findings by Silva-Suarez Bastida, Rabionet, Beck-Sague, Febo, & Zorrilla (2016); Stangl, Mackworth-Young, Sievwright, Singh, Clay, ... Konayuma (2015); Lefkowitz (2005); and Li, Jaspan, O'Brien, Rabie, Cotton, & Nattrass (2010).

Silva-Suarez et al. (2016) qualitative study, which explored "the life experiences of Puerto Rican PAHIV-1 youth within a family context" (p. 2), found that participants spoke of the most significant people in their lives being their family who meant everything to them; and that family consisted of bonding among the most significant people in an individual's life, where love, trust and support are encountered. Among emerging adults in general, quality of family relationships was also found to be of importance. Stangl et al. (2015) conducted a formative research among adolescent girls

(15-19 years) living with HIV in Zambia to generate evidence-based ideas for services and programmatic interventions that support health transitions to adulthood.

Stangl et al. (2015) found that many participants received significant and valued support from their family, friends, and trusted community members. Lefkowitz (2005) conducted a quantitative study among 220 university students (18-25 years). The purpose of the study was to categorize emerging adults' perceptions of changes in their relationships with their parents, religious views, and sexuality since they started college; to examine the extent to which they portrayed these changes as positive or negative; and to understand how these perceived changes were associated with number of years since beginning college. Lefkowitz (2005) found that emerging adults acknowledged that their parents have always treated them with concern and respect as they would an adult, prior to going to college. Overtime they experienced changes in the quality of those relationships, which was marked by the feeling of being closer to their parents, and having more open communication, more appreciation and respect for parents, and more mature friendship-like relationships.

Li et al. (2010) in their qualitative study that explored the experiences and needs of a group of adolescents (7-15 years), living with HIV in Cape Town, South Africa, also found positive aspects of life as an emerged theme, where participants found that strong family relationships enabled them to remain positive about their illness and that caregivers helped them to take their medication, stay healthy, and accept their situation.

In this study, *Kinship* refers to the familial type relationship that participants enjoy. These relationships came in various forms for this population. Participants enjoyed parental type care, love, support, and guidance from biological parents, adoptive

parents, foster parent, family member, and/or siblings. This sub-theme addressed parents, caregiver relationship, and siblings as *Kinship*.

Sub-Theme of Consciousness – Concealing

Concealing is the present participle of conceal, meaning "to put out of sight - hide; to keep from another's knowledge - keep secret" (Neufeldt & Guralnik, 1986, p. 287). Concealing was defined by Pachankisa, Hatzenbuehlerb, Hicksonc, Weatherburnc, Bergd, Marcuse, and Schmidtc, (2015), in the context of sexual orientation, as men having few or no other individuals who knows about their sexual orientation, which also described the state of being closeted or not being "out." Concealing was also demonstrated in studies conducted by Namukwaya, Paparini, Seeley, and Bernays (2017) and Stangl et al. (2015).

In their quantitative study among men who have sex with men in Europe, Pachankisa et al. (2015) assessed concealment by asking the question: "Thinking about all the people who know you (including family, friends and work or study colleagues), what proportion know that you are attracted to men?" (Pachankisa et al., 2015, p. 4). Participants had the following answer choices: (a) all or almost all; (b) more than half; (c) less than half; (d) few; and (e) none. Panchankisa et al. (2015) classified participants reporting 4 = few or 5 = none as high concealment. The researchers found that participants who were classified as high concealment were "significantly younger, more likely to be single, be employed, have less education, live in a smaller settlement, be not diagnosed HIV-positive, and live in a high-stigma country than those who reported low concealment" (p. 6).

Namukwaya et al. (2017) longitudinal qualitative study was conducted between 2011 and 2016 in Uganda to contribute to and compare study findings with available literature in Uganda. The study was intended "to contribute to a better understanding of the local dynamics pertaining to the Ugandan context and to illuminate caregivers as well as young people's perspective on disclosure" (Namukwaya et al., 2017). Namukwaya et al. (2017) found that caregivers often "delayed disclosure until young people were considered competent in managing information" (p. 5), and in some cases, they kept the HIV status of the child from other household members.

Participants in this study have acknowledged the importance of taking their medication on schedule. To maintain the secret of their HIV diagnosis, they have also expressed having concealed their medication or the process of taking their medication to prevent others from discovering this activity and invariably their diagnosis. Stangl et al. (2015) found that while most participants reported good adherence to treatment, the fear of others knowing their status sometimes led to challenges with taking ART. In this study, *Concealing* refers to keeping the HIV diagnosis a secret from others (family, friends, and associates). It describes the secrecy and stigma associated with the disease.

Sub-Theme of Consciousness – Paradox

Paradox is described as a noun meaning "a seemingly absurd or self-contradictory statement or preposition which when investigated or explained may prove to be well-founded or true" (Stevenson, 2007, p. 2095). Paradox was described by Gabbett (2016), in the contest of sports science and sports medicine. According to Gabbett (2016), the goal of sport science and sports medicine practitioners is to keep athletes free of injury. However, their approaches/views are somewhat Paradoxical, in

that the aim of sports science (strength and conditioning) is "to develop resilience through exposing players to physically intense training" (Gabbett, 2016), which can result in injury; whereas sports medicine practitioners (doctors and physiotherapists) are responsible for "managing players away from injury" (Gabbett, 2016, p. 273). Gabbett (2016) used training monitoring to determine the relationship between training load and injury risks. In this study, *Paradox* is the thankfulness burdensomeness [appreciation-disfavor] relationship that participants experience with the medication (antiretroviral therapy - ART). It describes the conflictions of their emotions or experiences with ART, which has given them this great opportunity at life by extending and improving their lives, yet it has been very difficult for them to maintain the almost rigid schedule, which is important to its efficacy and to endure the sometimes-debilitating side effects.

Theme – Realities of Living with HIV

Reality is described as a noun, meaning the "the quality or fact of being real; a person or thing that is real – fact; the quality of being true to life" (Neufeldt & Guralnik, 1986, p. 1118). Brashers, Neidig, Cardillo, Dobbs, Russell, and Haas (1999) described the *Realities of Living With HIV* in the context of "the uncertainty experiences of HIV-infected individuals who had faced death, but now report increased optimism about survival because of advances in treatment and care" (p. 202). Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas (1999) conducted a phenomenological study to describe data relevant to the phenomenon of revival and uncertainty in HIV-infected Individuals among adults diagnosed with HIV or AIDS. The researchers found that the major source of uncertainty among participants was revival, having experienced denial, anger, and the acceptance of their premature death, when they were diagnosed. Antiretroviral therapy

(ART) has now given them hope for recovery from the disease because it has improved the health of individuals with AIDS.

The authors reported that their participants' improved health status created, "new uncertainties, that can become unexpected and significant life stressors ... as the prospects of recovering from AIDS brings with it a multitude of new complex issues that can be difficult for persons to address in their lives" (Brashers et al., 1999, p. 205). The new prospects of living now required individuals with AIDS to renegotiate many of the *Realities of Living With HIV* that they had come to expect. This renegotiation is a source of uncertainty and stress in itself, which were associated with the four themes that emerged from the study: (a) feelings of hope and future orientation, (b) social roles and identities, (c) interpersonal relations, and (d) the quality of their lives. Brashers et al. (1999) concluded that the stressors are "the result of having accepted death and then having that reality change as new treatments provided a basis for optimism about survival" (p. 214).

In this study, *Realities of Living With HIV* is the participants' presence in the normal activities of life that their HIV-negative peers at the same developmental stage would be involved in and the consequences of such involvement. These activities include pursuing post-secondary education at different levels; working; living in varied residential arrangements; sharing their lives with others in intimate relationships; disclosing their HIV to their partners; braving the uncertain consequences of disclosing their HIV status to intimate partners; and having sex as individuals who are HIV positive; and volunteering to help others whom their experiences can benefit.

Theme – Affirming Milestones

Affirm is considered a verb, meaning "to say positively – declare firmly – assert to be true; to make valid – confirm – uphold …" (Neufeldt & Guralnik, 1986, p. 22).

Milestone is characterized as a noun meaning, "a significant or important event in history, or in the career of a person, etc." (Neufeldt & Guralnik, 1986, p. 860). Affirming

Milestones were demonstrated in studies conducted by Confavreux and Vukusic (2006) and Stangl, et al. (2015). Confavreux and Vukusic (2006) used the Kurtzke Disability

Status Scale [DSS] (1961, 1983) to determine disability milestones in multiple sclerosis.

The DSS rated irreversible disability as follows:

A score of 4: limited walking ability but without aid or rest for > 500 meters;

A score of 6: the ability to walk with unilateral support no greater than 100 meters without rest;

A score of 7: the ability to walk no greater than 10 meters without rest while leaning against a wall or holding onto furniture for support (Confavreux, and Vukusic, 2006).

Irreversible disability was assigned when a given score persisted for at least 6 months, excluding transient worsening of disability related to relapses; all scores of disabilities subsequently assessed were either equal to or higher than the assigned DSS. The date of assignment of irreversible disability status were assessed when appropriate. End-points were ages at the time of assignment of an irreversible score of DSS 4, DSS 6 and DSS 7. Age was considered a survival data, consisting of the time interval from birth to assignment of the disability scores.

Confavreux and Vukusic (2006) found the median age at the time of irreversible disability for each score to be approximately DSS 4 = 44 years; DSS 6 = 55 years; and DSS 7 = 63 years. They concluded that "age at assignment of disability landmarks is not substantially influenced by the type of the initial course of multiple sclerosis, be it exacerbating-remitting or progressive" (Confavreux & Vukusic, 2006, p. 603). Stangl et al. (2015) also found that, at the individual level, participants "overwhelmingly asserted that living with HIV was not going to hold them back from achieving their dreams" (Stangl et al., 2015). They aspired to receive "a good education, having a career, having a family with children and living a comfortable life with nice possession" (Stangl, et al., 2015). In this study, *Affirming Milestones* are the goals for a successful future that participants are looking forward to. These goals include furthering their education; career; having children; helping people (altruism); and what their future looks like. These themes and sub-themes will inform the composite depiction as elucidated by the researcher.

Composite Depiction of Sample Participants

A composite depiction "represents the universal or common qualities and themes that embrace the experience of the co-researchers" (Moustakas, 2001, p. 271); it is a group depiction that reflects the experiences of the individual participants (Moustakas, 1990; Moustakas, 2001). The composite depiction for this study include exemplary narratives, descriptive accounts, conversations, illustrations, and verbatim excerpts from the participants, which accentuate the flow, spirit, and life inherent in their experiences, and includes all the themes and sub-themes of the phenomenon as experienced by the individual participants and by the group as a whole (Moustakas, 1990; Moustakas, 2001).

The participants' *Panoramic View of Living With HIV* all their life is that their lives are normal because living with the disease is all that they know; they are engaged in normal activities of daily living; and their lives are not any different from their HIV negative peers. They consider themselves as having the same hopes and dreams and being just as successful as their peers by graduating high school, going to college, and earning a degree, having a job, having children, and preparing and looking towards a future. Participants also believe that their lives would not have been any different if they did not have HIV. This section includes the participants' perception of life; what a typical day in their lives entail; what they consider a normal life to be; how they perceive their lives with HIV to be different from their HIV-negative peers; and their perception of what life without HIV would be like.

Ahmazin described her perception of life:

Growing up, it was difficult ... One thing I appreciate about this experience, is aahm, it its grounded me and allowed me to make choices more carefully ... The only thing that I can say is aahm, that with the HIV, being HIV positive aahm [pause] [silence] is that HIV lives with me, I don't live with HIV, [pause] and I use that as my stepping stone to go above and beyond in all aspects of life.

Ahmazin shared what a typical day in her life was like, "basically aahm, work aahm school, and on the days that I don't have school or not doing anything school related work and then most likely hanging out with my boyfriend."

Ashley explained her perception of life with HIV:

I mean it's no different growing up, like being a normal kid ... I mean, living with the disease, like, yeah, ... people being born with it, we become so use to it, like it's just a part of us. It's like you already know ...

Ashley described a typical day in her life:

I get up, I get ready, I go to work, aahm go to school, come back aahm I know towards before I go to bed I have to take my medicine, because its once a day, so I take it, aahm, I eat dinner with it, take it, aahm then that's basically it.

Ashley shared her thoughts of what her life would be like if she did not have HIV:

I never thought about it that way. A mean, I don't? Maybe, my life would probably be different if I didn't have to go to the doctors all the time ... instead of being in a hospital or something ... I probably could have been like playing, or, you know, doing something educational ... I probably could have made me more [pause] ... smarter or something, maybe more advanced in you know ... I think it probably would have been the same.

Ashley communicated her perception of her life in relationship to her HIV negative peers:

You still go ahead and play, you know, your games, go to school, all that, except that you just have to take medicine every day, to stay alive ... I don't see myself any different from anybody else.

Blessed explained her perception of life with HIV:

It was [pause], it was really hard growing up, because I thought I was like something disgusted [pause] ... I am glad my other half knows about it, and it's much easier because I know, what I have is serious but peoples still enjoy my

company and aren't afraid to, like hug me or touch me [pause], in a friendly manner. Not, like that, but just to just to enjoy my company, that's all I want.

Blessed questioned her luck and voiced her optimism:

I honestly, I hated it, I hated life, because I felt like, how, why, I was the only one who was taking medicine. Why do I have to go through this? ... Honestly, having a health issue shouldn't stop you from doing what you should do, that's honestly, that's just another excuse for you to make yourself depressed and everything, you shouldn't hold back or anything.

Blessed divulged how a typical day in her life was, "now it's very peaceful." She also described her life with HIV:

My life would still be the same either way [pause] because I already go through a lot with my disability ... Yes, high school, high school graduate, I accomplish having a beautiful healthy daughter, and I accomplished just being here and taking my medicine every day. So, I accomplish a lot by having by having HIV.

Blessed expressed her opinion of what her life would be if she did not have HIV, "I think even if I have HIV I am still able to do everything, if I set my mind to it, just not think about what I have, just do it as long as you are safe."

Brittany described her life with HIV, "I mean it's [pause], well, it's normal to me now ... I still think about it [pause], aahm [pause] ... yeh I just feel normal." She explained what a typical day in her life, was like:

I go to school, I do this, I do that, the only think that I have to remember is drinking my pills, every single day ... waking up every morning ... hang out with friends, being able to go out and aahm, yeh!

Brittany spoke about what she believed her life would be like if she did not have HIV:

Aah, my life would be still the same, with HIV or without ... like, aah [pause] I mean it's gonna be like a normal life to me, being able to, ok, being able to do stuff [sex], not like everything ...

Bryan shared his perception of life for those who were born with HIV:

We are here for something we may not know what is for, we are meant to teach somebody something ... it not our fault, ok, we're just born with it unfortunately ... growing up with it you're a normal person.

Edward compared his life with HIV to running a marathon:

If life is you trying to run a marathon to the finish and finish is success, you, somebody with HIV is going to have more obstacles than somebody who is healthy ... and these obstacles are things that everybody encounter, but you just have to deal with them and you have to overcome them. And I am ok with overcoming obstacles.

Edward explained what a typical day in his life was like:

Usually when I wake up I am on my phone and I go to the bathroom. I have breakfast and then, I get my cup of water and I take my medicine and then from there on out it's out of my mind. I completely forget it, because it's second nature to me.

Edward expressed his opinion on his life being any different if he did not have HIV:

Aahm, I do think it would be different, aahm, because of the certain restrictions ...

Aahm, back in high school I was really, I really wanted to join the army and join

the armed forces and so, I think if I did not have HIV I would have pursued that career instead of the career that I am in now.

Jamie shared her perception of life with HIV:

Aaw, it has its pros and its cons, like, you feel like, sometimes you feel like you don't wanna like be bothered because of the condition that you're in. You feel different sometimes ... like couples they can live with each other without like secret and you have this secret that you wanna tell your partner, if you have a partner, and it's like you don't wanna [pause] tell them because you are scared of their reaction ... at the end of the day you can' let it get to you, you can't let it beat you because you're bigger than what it is, it's just a disease it's not ... the end the world, it's something that you can really [pause] learn from and just embrace it and just deal with it, and live a normal life ... people live with it people have kids with it a whole family with it and it's like people live normal life with it, and some people just like, they misjudge you, just like, not educated about it more, so I just feel like people should be more educated about it before they judge [pause].

Jamie described a typical day in her life:

Aah getting up, take my medication [pause], relaxing [pause] until work because it has a side effects as in dizziness, feeling sick, so ill lay down and try to take a nap, wake up go work, eat something, come home take a shower, eat, take my medicine again and then all over again.

Jamie also discussed her opinion of what her life without HIV would be like:

I see my life would be more happier but I wouldn't be more depressed, wouldn't be like sad [pause] sometimes I have my moments when I don't like wanna be messed with or I feel like I am different you ... Just living life, trying to get myself, [pause] working in the field that I want to work in, which is medical, aahm, going back to school to be a nurse, aahm, helping people, as in homeless people, anybody, helping anybody aahm, playing sports doing [pause] like working a better job [pause], and just living, being happy.

Kayden described his life with HIV:

Aah, growing up having HIV aah, I wouldn't say it's like the easiest thing [pause] ... I felt like it got easier as you become older, and making that decision, and the world has kinda changed in a way ... growing up being positive ... I felt alone so, I felt like nobody would understand ... I was the only person that had it within my family, so it just like, I felt alone, and I also felt like, you know, I wouldn't say abandon, but left to like cope and deal with things on my own, as far as being HIV positive. But as far as like, just going through life, it's [pause] I wouldn't want to put that on anybody.

Kayden believes that his life is normal. He said, "I honestly feel like, for me, aahm, that I have been achieving the benchmarks as normal kids." His experiences have brought him to a realization. He divulged the following:

I guess because of experiences, like you know? You choose your battles wisely, aahm, and you know, a mean it's not a good thing but, as common as it has became in today's society it's like you know, you come across more people that are in the same situation as you. Like I find it a little easier for me because, when I come

across people in the same situation I feel like I can give them advise. Ok, well the biggest battles is always disclosure, I feel like it, there is no way around it. But now a day, you can live that long, you can see that far, you can see the future. I came so accustom to being if I make it that far, or if I be there, that you know, I still kinda put that perspective, of not having that longevity life.

A typical day for **Kayden**, "it's you know, making sure that [pause] you have your meds." **Kayden** also described his vision of what a life without HIV would be like for him:

I know at time I get like real frustrated ... I didn't feel like it would be any different. I wouldn't have that feeling in the back of my mind connecting ... HIV yeh, be like oh I have a common cold, but it's lasting a longer, a lot longer than some else I know ... I got the cold from, you know, and it's like, if I didn't have HIV, would I be still be sick or would the cold last this long?

Keisha shared her view on her life with HIV:

W-e-l-l, in my younger days I had this thought about what it would be like. Like, Oh I can't get married, I can't have kids, [pause] but [pause] that's all I really thought about. It's when I became, towards my teen years and towards my young adult years, like now is when it really was a challenge. Like relationships, making sure I am on top of my health, being an adult. My mom can't go with me no more, so I have to make sure I know what all the terms mean, medically, and I am taking my meds.

According to **Keisha**, a typical day in her life entails:

When I wake up I have to remember, before class, to take my pills, so I always keep like a bottle of water in my room, so I can rush out because I am always in a rush, aahm, then I go to class. I come home, I study, I watch TV, and then I go to sleep and then do it all over.

Keisha shared her opinion of how her life would be different if she did not have HIV:

Yes, I think relationships would be different, and the fact that, it would be less pressure when you meet someone to figure out when to disclose and aahm, the time frame and if the person is even worth telling. If the relationship is even a relationship, that is gonna to be meaningful ... But other than that, normal living was regular as a child ... other than the health part of it, I would say day-to-day life was pretty regular.

Loren shared what it has been like living with HIV:

Well for me as long as others don't know about it, because I feel like certain people [pause] will treat you differently, if they knew that you had it, whereas when you don't know, people treat you like, you know, like you are, your' a regular person, a regular human being, doing regular stuff going to school, going to work, you know.

Regarding her HIV negative peers, **Loren** said:

I feel like, aah, its different because, you have to take medication, you know aahm, aah, I am guessing the average peer doesn't have to do that, you know ... These are medication that I have to take, and I was dealing with it since I was little, so, that's not something that most people would be used to or, it's different from what the average peer would do.

If **Loren** did not have HIV, she thinks that:

Then I wouldn't have to take no medication [chuckle]. I would be so happy like I won't have to think about aahm if I missed a dose, ah I got to take my medication or be concerned that my health, you know, be affected ... don't have to have that fear when I get into a serious relationship to tell a dude, because you know I don't have to fear people judge Me ... I would miss some of the doctors and nurses that was really nice to me because then, you know, their work is done, so that kind of stuff.

She described a typical day in her life as follows:

I wake up; brush my teeth; take a shower, aah I either go to work, or go to school or go hang out with one of my sisters. Aahm I take my meds when I ah, it's time to, because you are supposed to take it at a certain time.

Loren believed that her life was normal:

I feel like it, it's kind of normal ... I don't really see that much of a difference.

Yeh! I really don't ... living with it, it seems like an average day, I mean, because I was born with it, like ... going to the clinic, you know, blood drawn, you know, I have appointments set up to go to for it, it's something that I am used to, so I don't really see it as, you know, out of, something abnormal. Its normal for me.

Lovely described her life with HIV, "It's [pause] different ... [pause] it's fine... [pause] I have a nice family, [pause] and [pause]." **Lovely** shared a typical day in her life:

I wake up in the mornings [pause] and I [paused-stutter] get dressed and make my own [pause] coffee in the mornings, and I make my own coffee in the mornings I wait ... I wait for I wait at the lobby so my van can come [stutter] and pick me up,

and then I pack my lunch, Monday through Friday. Then we watch movies on Fridays. We watch movie there.

When asked what her life would be like if she did not have HIV, **Lovely** simply stated, "I don't know ... aahm, [long pause], I don't know." **Lovely** considered her life, "[pause] It's fine." She emphatically stated, "I will be here," when asked what she will be doing at age 26 years.

Margarita expressed what she considered her life with HIV to be like:

You gotta love yourself more than you love other people ... I look at myself as me, because, this is something I couldn't help life just gave it to me, so I just look at it as a good thing now ... if was different I probably would be in longer relationships, honestly ... people should be strong because its ['pause], its hard living with it, but you know you gotta love yourself ... Once you love yourself everything will fall a lot in place ... nobody is going to love me like me.

Margarita described a typical day in her life as follows:

My days are typically [pause] happy, because I have learned to not look at myself as a "positive" person ... I wake up and I just make sure, I give myself ... positive affirmations ... even if my breath stinks, or even if my hair is looking funny, I try to give myself a positive affirmation ... a typical day would be, me trying my best to love me, because it's hard to love me when I am HIV positive.

When asked what she thought her life would be like if she did not have HIV, **Margarita** responded:

I think I would not be so depressed ... I think, I would have a lot of more friends, I wouldn't be so antisocial ... I would say it the same, aahm better relationships you

know? ... No. No, I don't feel like it will be different. I feel like it would just be the same as a normal person.

Melissa described what growing up with HIV was like:

Is very, you know, it's difficult. I'd say that when you living with having the virus and your sisters don't have it, you have to grow up with that struggle alone ... it gets lonely sometimes living with the virus and ... sometimes I wonder "why me? Why did it happen to me?" But I don't really think like that anymore ... living with this thing, it's not the end of the road ... It be lonely sometimes because people don't understand you, they don't know how you feel ... I am not depressed but I get like emotional sometimes. It's like, I have to constantly pull myself together, wake up in the mornings and stuff. I have to say I don't want to give up, like, I never say that I be done, but there are moments when it's like, "eeh! enough" ... the people that love you don't want you to go.

Melissa shared what a typical day in her life was like:

Well, the typically life is, you know, normal. I do everything like a normal person would do. You know, wake up in the morning, work, aahm, take care of my son ... take my medicine, or I might have to go to my doctor's appointment, and you know?

Melissa expressed her thoughts on her life being any different if she did not have HIV by saying: "No. No, I don't feel like it will be different. I feel like it would just be the same as a normal person ... I would say it the same, aahm better relationships you know?"

Rashad shared his perspective of the effect of HIV on his life:

Oh it's, it's in one word "cautious", you have to be cautious about everything I mean, my days of dwelling in it, were over a long time ago from when I was young, so I don't look at it as, you know, curse or anything I used to aahm, kind of have resentment for my mom ... it's basically resentment, basically why me? It wasn't in my power, it wasn't in my hand, I had no choice, so I used to dwell on it when I was younger, but now I basically accept it. So, I stuck with that it, I have it but it doesn't control me, as long as I take my medicine and do everything that I have to do, I will be fine ... You are gonna have this virus whether you dwell in it, and give up on life or you strive for greatness, so why not strive for greatness? ... Yeh, it doesn't change anything, like I am always going to be me at the end of the day, I am always going to be hopeful ... aah, some days it's hard, harder than others sometimes you just don't feel like taking your medicine, just too tire to take it and it's just like, it's just it's just very hard so, aah, the sensitive like side to it, is and, I can see why people give up, I can see why they don't have any drive, I can see why they they're stuck in a dwelling point, because you're forced to face reality every single day you take medicine.

Rashad described a typical day in his life:

For me, is getting up, aahm, aah about 8:30, taking a shower, daily routines, take my meds, and then I go to work, which I work ... after 7 O'clock I come home ... do my case notes, aah, sometimes I stop get something to eat ... come home, relax, try to relax, watch TV. Aah, right before I go to bed I will have either, whatever drink that I am drinking for some and I take my night meds and basically go to sleep. I do that Monday to Friday.

Rashad's imaged what his life without HIV would be like:

If I did not, Oh! my goodness, aah, I would probably have like twelve babies right now ... I would probably, oh, I don't know, I would probably wouldn't have any drive ... it's just [laugh] it's a just ... I don't know where I will end up, but I know I wouldn't let myself be defeated by anything ... So, if I wasn't infected, it just like, I don't know ... Yeh, it doesn't change anything, like I am always going to be me at the end of the day ... I am always going to be hopeful, because that just how my mom raised us.

Travis gave his account of living with HIV:

Aahm, it been king of a journey for me, I would say it was kind of irrelevant for me, until possibly elementary school ... I start felling outcast about it, because all I knew at that point in time was that it was something bad ... Like I start learning more about it. But it was more like, something I was ashamed of ... I became more accepting of it, and it got to the point where it's, I barely even notice, I don't even think of it, it's part of me ... Aahm, I take my meds regularly, I am healthy, and as long as you are, you know, talk to your doctor about it and taking your meds regularly, and staying fit, you know, you're, you can live just as long as anyone else and feel just as healthy and be as healthy as anyone else.

So, I would say before, it was, it was just weird. It just feel, I didn't feel normal, I didn't feel like a [pause] a normal kid in a normal family. So, it just, it felt really weird and strange. Like you know, I set goals and I pursue them, it doesn't really matter ... I work out, aahm, you know. I talk to my doctor about things that might come up, but besides that it looks pretty average, I would say, [laugh] ... It's just

knowing, that this disease isn't like, you didn't do anything wrong, aahm, it doesn't make you a bad person having it, aahm, you just have this aahm, and you bring it up. But, that's not to say like I wouldn't have a successful relationship ... I will say this, having HIV is, long story short, not a big deal, aahm, like I have said, it's just a matter of staying healthy being honest, you know, in intimate relationship and just living life normally, and you can have a long successful happy life. I know you can because that's what I am doing now.

Travis described a typical day in his life:

Just like any other day, I wake up, I have breakfast, I go to work So, pretty much, if I am not working, I am doing music, I am working on music. I play drums ... So, I am working on that or other things too you know. I am trying to learn Spanish, for a trip to Spain later, so.

When asked, what he thinks his life would be like if he did not have HIV, **Travis** responded:

Honestly, I think it would be the same. I think it would be exactly the same. I think one little difference though would be, I think I would be a little more, at peace with a relationship, just because, I wouldn't have to bring up that whole conversation about it.

Travis considered his life to be normal:

This is, it's something that's just a part of me and that's all there really is, needs to be said about that. Like I don't think to myself, oh, now I have HIV, no it not like that anymore. HIV is a part of my life. I see myself as pretty normal the only way,

the only difference I would see aah a difference is in my sexual like ... I have had mixed feeling about it even to this day.

The presence of HIV in the lives of the sample population of emerging adults who were born with HIV came into their *Consciousness*, at varying times, typically between childhood and early adolescence. This *Consciousness* embodies when participants became aware of the HIV status; their knowledge of HIV at the time; their concerns or red flags before knowing their HIV status; their response to the diagnosis; and the impact of the disease on their lives. Participants described their *Consciousness* of their HIV status as follows: **Ahmazin** and her family became aware of her HIV status much later in her life than for all the other participants. She explained that she was only diagnosed at 15 years of age:

When I was diagnosed I was a teenager ... it was my 9th grade year, aahm, in high school ... that's when they notified my parents ... my parents didn't notify me at the hospital ... My parents probably told me a month after I got out of the hospital, when I had my first appointment at the Immunology Clinic (IC).

Ahmazin described the concerns that she and her family had prior to being diagnosed:

I used to get sick a little bit more often than my, my siblings aahm, I had shingles three times aahm ... I remember my mother was telling me aahm that the doctors didn't know why I was getting shingles... normally, older people get them not really younger people get shingles.

Ahmazin also shared her response to the HIV diagnosis:

At first, it was very challenging, because on top of me having low self-esteem issues and everything aahm, there was also issues that started to take place

between my mom and my dad.... I had suicidal thoughts, I want to kill myself, I never attempted anything, but I did have those thoughts ... Around that time, I lost my faith and everything ... I really thought that I was being punished ... I am not doing anything that I should not be doing. And it's like, Why me of all people? That I have to go through this?

Ahmazin reflected on the impact of the disease on her life:

Overtime I started to transition to a more positive mind frame. It's actually, aah, push me and encourage me to do more things ... it's better to be safe than sorry, but who would have known that maybe if I probably would have found out at a earlier time, maybe I would handle it differently, compared to how I handled it as a teenager. It could have possibly been worse, it possibly could have been better, who knows?

Ashley had knowledge of her HIV status from an early age as she explained, "When I found out I was positive, I was probably around 6 or 7." She further described her concerns prior to being informed of her HIV status, "[I] asked my mom all the time, why do I have to take medicines? Like, you know why every day? ..."

Ashley shared an account of her response to the HIV diagnosis:

I mean [drawn out], I was just in shock. Because I was like, I didn't know what it was, so I was like, what is it? What is HIV? ... he told me you know ... So, I guess I am living with this now. So yes. I mean, at first, I was mad at my mom because he told me how you get it, so I was mad at her ... why would you give to me, this that and the other thing? But, it's out of their control, like at that time it was out of their control. So, I was like you know, ok.

Blessed spoke about growing up and being HIV positive:

It was [pause], it was really hard growing up, because I thought I was like something disgusted [pause]. I would think that if people know what I had they wouldn't like me or associate themselves with me ... I didn't know much back then but now I know a lot now ... I still felt like I hated life, because I was the only one diagnosed with the disease.

Bryan was informed of his HIV status when he was 14 years of age. He gave an account of how he was informed that he was HIV positive:

I keep asking him [dad] why I was taking the medication and he didn't tell me, so I refused to take them ... So, he [dad] felt like "I have to tell him so he can start take the medication" ...

Prior to being informed of his HIV status **Bryan** said, "[I] Always wonder like, why do I take this liquid medication at night? ... when my mother passes I had a lot of anger build up in me ... I am not letting it hinder me."

Brittany explained how she become aware of her HIV status:

When I was 11 ... aahm, through my sister ... well, I asked her what is HIV? ...

Because my doctor asked me what do I have, and I didn't know what I have ...

didn't know what it was ... and my parents didn't tell me yet. They wasn't ready
to tell me yet... but then, it just all happened when I asked my sister.

Prior to being informed about her status, **Brittany** recalled, "I was on medication and, I was like going to the doctor every 3 Months ... I didn't even know, so I was just living my life." **Brittny** described her reaction to the HIV diagnosis, "Well, before, like when I first

found out I was really scared, but then now I realize it and all that stuff and I am comfortable with it."

Edward explained when he first became aware of his HIV status:

I would say about 12 or 13 ... in camp ... aahm, we all went to camp for kids with chronic illnesses, and aahm, ... they teach us how to live with HIV and how to deal with HIV.

Edward also expressed, "I am lucky enough to have control of my viral load, all my life." **Jamie** explained how she gained knowledge of her HIV status, "I was twelve years old when I found out I had it ... I finally asked my cousin, why did I take medicine? And she told me..." **Jamie** shared her reaction to the HIV diagnosis:

It hurted me, yeh! Like I was very shocked, but I took that and I embraced it and I just dealt with it because I know, it's like, I can't let it beat me ... Basically, the disease itself do not bother me, it bothers me but it don't, I don't let it affect me. Like! I don't let it get to me.

According to **Kayden**, he had always known his HIV status. He said, "But I honestly don't remember "not knowing" that I was HIV positive. I always knew as a kid." **Kayden** discussed the impact of the disease on his life:

Growing up being positive ... I felt alone so, I felt like nobody would understand. I was the only person that had it within my family, so it just like, I felt alone, and I also felt like, you know, I wouldn't say abandon, but left to like cope and deal with things on my own, as far as being HIV positive ... Aahm, guess it like, I always feel like I am sick, in a sense, like, sometimes it could be just a slightest headache, or the slightest stomach pain and I feel like, oh, maybe if I didn't have

HIV, you know, I probably wouldn't feel like this every day ... Or I won't feel this way, I won't be as you know, aah, sick so, aahm, I just feel [silence].

Keisha remembered coming into knowledge of her HIV status, "I think I was 11 [pause], when she told me ... aahm, my mother told me." Prior to being given that information, Keisha said, "I knew I took a lot of medicine, but I didn't know why."

Loren described learning that she was HIV positive:

Nine years old ... one of the nurses from the clinic that I went to, she came to my house and she told me ... I think it's something by law, because my sister knew, my older sister, because she knew, and I was getting of age.

Loren shared the impact of the disease on her:

It doesn't affect me, because I keep it private ... if it's visible ... like its poor health? Then people might ask question ... it doesn't physically show aahm, then [silence] people will just see you.

Margarita informed about coming into knowledge about her HIV status:

When I found out I was in 9th grade ... I didn't find out until I was about 14 that I was living with it all my life ... After my mom passed away my aunts took me to the doctor and he told me.

Prior to being informed of her status **Margarita** said, "My mom told me I had asthma, and that's why I was taking all the pills ... as a child I always wondered, why my family treated me different." **Margarita** described her response to the HIV diagnosis:

After finding out I fell into a deep depression and that stopped me from dancing and stop me from doing a lot of things that I actually wanted to do [pause].

... when I first found out I was, I didn't have much knowledge of it, so I just felt like, oh my gosh I am going to die, oh my gosh this, oh my gosh, you know? But I learned a lot of knowledge from it.

Margarita explained how the disease has impacted her life, "Well! It's kind a hard ... I am going from different school, to school, to foster care. It was just a bunch of things on me." The researcher asked Margarita if it would have made a difference if she had known about her HIV diagnosis before her mother passed or when she was younger and Margarita responded, "If I knew before my mom passed away, and before I found out I probably would be [pause] aaah I think it would because I would have my mom there to help me cope with it."

Melissa divulged about becoming aware of her HIV status:

I found out through my social worker, and my doctor had told me ... I didn't know until I was 13 so, when I was in elementary ... when I found out, in aahm ... I was like nervous and stuff ... I was crushed, I was like sad, I was crying because like, you know, growing up people, I didn't know that kids could ... kids were born with it ... I always thought that you got it from sex ... I was wondering how did I get this virus? I am living with this virus and I didn't even know I had it ... I was just loss at that moment ... Once I found out that I had it, I didn't really, I didn't really start feeling like depressed about the virus.

Rashad spoke of finding out that he was HIV positive:

Aahm, when we were younger, we went to a camp, and it was aah for kids with AIDS and HIV ... I would have to say that I was probably, 10, 11; 11 may be? ... I didn't know but some kids knew ... and I was just like no, I might be here for a

different reason because that not me. And then DP actually pull me into one of the medicine room and actually tell me ... and then, when we got back to aah Florida ... we had, you know, a big sit down, and she told me about it ... she just kinda sat me down and ran through it. And told me that I didn't have anything to worry about because I have been taking my meds and I am undetectable, so, yeh. It was very sad, very sad.

Rashad explained the impact of the HIV diagnosis on his life:

I don't look at it as, you know, curse or anything, lesson because some of the stuff that I would do, I don't because of the virus so ... Yes! When I was younger I used to dwell on it. I used to aahm, kind of have resentment for my mom ... basically why me? I am the middle child and I am the only one that was infected ... and like it wasn't in my power, it wasn't in my hand, I had no choice ... but now I basically accept it.

Travis shared about coming into knowledge of his HIV status:

It was probably, like maybe, maybe 4th, 5th grade, was when I really knew that I had it, aahm. But again, it's honestly hard to say when I was first told about it aah ... That was when I kinda start learning about it. Aahm, I had heard my parents tell me that I had it, aahm ... I really didn't know much about it, it just was something bad. I just felt like I had this bad thing and it was kinda like something I didn't really understand ... Like I start learning more about it. But it was more like, something I was ashamed of ... It wasn't until high school ... that I realized that this thing HIV, wasn't a big deal, at least, not anymore.

The *Kinship* or the parental like support that was afforded to participants came in the forms of biological parents, adoptive parents, foster parents, family members, and siblings. For this sub-theme, parents, caregiver relationships and siblings are revealed.

Ahmazin described her relationships with her biological parents as caregivers while growing up:

We're more in a better positive place than what we were in before ... Me and my dad's relationship is gotten way better than it has been over the last few years ... we are not the closest thing in the world, but ... it's a working progress. My mom, me and my mom is pretty cool ... we have a pretty good relationship, but we are not the closest thing in the world ... I really don't tell my mom everything. My mom, aahm she knew [about her HIV status] but she didn't found out until after I was born ... I didn't find out about my parent's status until I found out about mine. My older siblings knew, but I was unaware [pause] of everything ... I guess she didn't want to believe that I had possibly contracted the virus I do understand, aahm, that doesn't make it right ... My parents are now divorced ... there was a time she got really small, because she would not take her meds. But that was before.

Ahmazin spoke about her siblings:

On my mom's side I have, its four of us, so it's 2 boys 2 girls. On my dad's side I have one sister. It was brought to my attention that she did [have HIV], but we're [pause] 18 years apart, so I never met her, because she passed away right after I was born.

Ashley explained her relationship with her adoptive parents as caregivers growing up:

They took care of, me you know, they give me like a life, like you know, outside of what I knew, it's been normal ... He took the initiative to learn yeah, to understand, you know, I think that's very cool. Ok, so around fourish, my dad [biological] died, my mom [biological] was the, my birth mom, she was the, basically the sole custody, like you know? primary care giver, they found her unfit, because like she was on drugs and stuff like that. So, they took me, ... and I am aahm with my, adoptive parents now ... I was there like, from 6 around 5 or 6, aahm, they basically took me in.

Blessed spoke about her relationships with her parents while growing up:

No, I guess she [her mother] wasn't ready to raise kids just yet ... they treat me
the same ... And then that's when my real dad came in the picture. We kind a talk
[pause] on and off. I just, I just learn how to just ignore stuff, and just move on
with my life ... Well! He didn't know I was HIV positive until I told him ... No,
I told him, that's when he started getting on me about taking my medicine.

Brittany described her relationship with her sister as primary caregiver since her parents died:

Yes, she takes care of me ... She make sure I be straight ... some other sister, they don't really check up on you, ... she is a very big supporter. My parents didn't tell me yet. They wasn't ready to tell me yet. That's what they told me ... aaaah, they are good, well they passed away. Aahm, I think I was sixteen, yes, 16 turning 17 [when her parents died].

Bryan's maternal aunt and godmother has been his primary caregiver for most of his life. He described their relationship:

I would consider her a parent ... I was never like you're not my mom ... even her husband, like me and him may never have gotten along ... but at the end of the day I saw him as a second dad ... she educates me if I ever have a question, if I ever have a concern she will sit down and talk to me about it ... she is like a parent or a mother to me.

Bryan also spoke about his biological mother, "I never really knew how she would a handle it." **Edward's** mother has been his primary caregiver all his life:

My family, I am really close with my mother. My mother is HIV positive, I am not so close with my dad, he aahm. He wasn't around the family too much. I have one brother, and he is 26, he has his own family.

Jamie was asked about her family dynamics while growing up, and she responded:

My mom died when I was six, and my parent, my dad, my dad, he is somewhere, [pause] New York, somewhere. I was staying at my mom's house, when my mom passed, we stayed with my grandma, when my grandma passed we stayed with my aunt and my aunt used to always [emphasis and pause], I think I was 7 or 8 years old, she used to always make, have me drink out of a different cup, she use to always have me drink out of like, eat out of different spoon, like dishes completely ... When I would stay with my aunt, I was going through so much stuff, so. I was, she would be having me miss doctor's appointment. I was not eating right, not going to school, I was in high school. Walking in cold, like I was sick, so, I mean I am better [pause], that's all that matters.

Jamie also spoke about her siblings, "I have two brothers and my sister ... they don't treat me no different they all treat me like I don't have nothing ... they don't see me different, that's it." Kayden's biological parents died when he was about 5 years of age. He explained about his primary caregiver:

Aahm, before my mother and father passed away, well after my mother and father passed away my ... my mom's cousin took us in ... yes, it's me and my brothers, there is 3 of us ... No, just me [HIV positive] ... She has a daughter which I call my sister [clears throat].

Kayden elaborated on his relationship with his primary caregiver:

Pretty good, I mean we are really close, aahm, I felt like we have gotten closer as I got older, I guess? aahm, yeh, I found that I got a lot closer when growing up. Aahm, [pause] ... I knew who my original mother is, and I know who she is and stuff like that. I consider her as my mother, I wouldn't, you know not consider her.

Keisha's aunt has been her primary caregiver while growing up. She explained:

Aahm, mostly my aunt. My mother also, but my mother had a visa, so, she would be here for a couple and then she would have to go back. But mostly my aunt ... Well, my mom is passed, but my relationship with my aunt, she is like, she is like a second mom to me ... So, it's the same would be as it would be with my mom. She knows my diagnosis. When I was younger, she would take me to the clinics herself, all the medical staff knew who she was, so, she was a big part of my like, she is a big part of my life.

Keisha's siblings came in the form of her aunt's children. She explained, "Yes, she does [have children] ... aahm, I am older than all of them., so [both laugh] ... I was here first, so, they got it together ... No, I never had to feel different." **Loren** spoke about her parents as primary caregivers while growing up:

Yeh, aahm and my mom is good, she is holding up ... She is definitely supportive, helpful too ... stable? Question my father, but, my mom has always been there for me, aahm ... Lived in a house, my whole life. She always make sure I always have food on the table, take care of me, clothes ... Make sure I was brought up right, how to take care for myself as a woman, young adult, a girl. She took me to church aahm, yeh! [pause] ... my real father passed away years ago my mom is good, she is holding up.

Loren also discussed her relationship with her siblings:

Three sisters, one brother ... One, one of my sisters passed away, so right now, I have 3 siblings ... I mean, my sister that passed away, she had it but? ... My brother eeh, he is always himself, he is good, knuckle head but ... No, he doesn't [have HIV virus]. He is blessed ... He is older.

Lovely was adopted when she was an infant; however, when asked about who took care of her, she responded:

I was little, I was aah living in aaah, I was living in the a [pause] Connor's nursery ... yeh, I was like this [cup hands like drinking from a tap] ... when I was little, I could fit in my hand, when I was little ... Yes, I came out early ... aahm, I could hold in my hand like this [cups both hands like drinking from a tap] ... and I have birth mom, and she was really, really sick. She had HIV and she

couldn't [pause] take care of me no more. I only saw her once at the morgue, and then she left. She passed away my mom wasn't married. My birth Mom wasn't married.

When prompted further about who took care of her, **Lovely** said, "My mom." When asked about her siblings, **Lovely** responded:

I had, and then I had a brother and an older sister [biological] ... I don't know what their names are. When I saw, when I saw them, I never knew who they were [silence].

Margarita spoke about her caregivers while growing up:

After my mom passed away my aunts took me ... I am going from different school, to school, to foster care. It was just a bunch of things on me ... And my aunts still didn't want to take care of me because [pause]. Well! He [her dad] is trying to help me now, because I just got out of a Rehab he is trying to help me because I had a mental break down, again ... he is trying to help me so I don't fall back into depression ... Well my dad was incarcerated - since I was four. But I found a lot of bad things about him ... My dad, me and my dad had not been talking, when he first came out of prison, because I always looked at him as the reason for all my pain, and that's not nice that's not good. He infected my mom, didn't tell my mom until after she was, she found out she was HIV positive ... When I came out infected, my mom is like, "what do you mean?" Then he is like, "I am sorry" and [pause] it just a lot ... Since I was 17, he has been out, and trying to build a connection with me, so [pause]. We've been working on that. I grew up not having a father, so I kinda miss not having a dad. So, I want a dad.

Regarding her siblings, **Margarita** said, "My mom had seven ... the only person I really have is my brother, he is working double jobs, just to take care of me ... he is older."

Melissa referenced her mother, "She passed in 2004 ... I was 10 ... I feel like my Mom should have been here, I always, I get emotional, but she could have been here." When asked about her primary caregivers while growing up, Melissa answered, "My sister, Carron [name changed], she took care of me and stuff. My two older sisters did took care of me and everything. They are my only sisters and they are fine, my rock." Melissa expounded on her relationship with her sisters:

It's good, we hang out, do everything together. For them to be my older sister, they like my best friends and stuff. Like they, my older sister is 36 and I am 24, but it's like, it feels like we in the same age and we not. But, we, we very close. I can go to her and tell her everything and be open about and stuff, now that I am older, but before I used to think scared because my sister didn't play. She had like the mom figure, so it's like I couldn't, I know that was my sister and stuff, but I still respected her like a mother figure, because she took care of me and stuff ... Yes, she is still supportive."

Rashad's primary caregiver while growing up was his mother of whom he spoke admirably:

My mom, she is alright, she is doing fine ... She is a single Mom with 3 kids ... give me the drive and the motivation to, you know, get up. So, she never let me, even with knowing my status, and even with knowing everything, she never give me a give-up mentality. She give me hope even when I felt like, I want to give

up, she was there to, you know, kick me in my but and tell me push on, you got to go.

Rashad explored his relationship with his mother:

It's great. I love my mom. She is there if I need her, she is there when I don't need her. She is, you know, she is alright at the end of the day but, I mean, our relationship is great.

Rashad has two siblings, of which he is the middle child and the only one who has the virus.

When asked about his primary caregivers while growing up, **Travis** said:

My mom, my parents ... No, basically, I was raised by my parents. My adoptive parents ... there's been some event, unfortunately for my family, aahm, between my parents. However, that being said, I, [excuse me] I am still in touch with my mom, I am still really close to her, my dad, not so much ... my adoptive mom, I live with my adoptive mom ... I don't know my biological parents.

The *Concealing* of their diagnosis from other family members, friends, and associates is a common occurrence among the sample population. *Concealing*, the subtheme of *Consciousness*, addresses the issues of secrets, secrecy, and stigma. **Ahmazin** spoke about keeping secrets from her mother, "I really don't tell my mom everything not as far as my relationship and stuff goes. I keep that to myself." **Ashley** shared how her family was able to maintain the secret of her HIV status from other family members:

She kinda kept it from my family ... Mom would always, she would always make up a lie ... now my parents left it up to me to basically tell people ... they even raise me to be that way.

Bryan gave several accounts of how he and his family were able to maintain the silence/secrecy about he and his mother's HIV diagnosis:

- 1) Regarding his mother's diagnosis, he said, "My family told me that they was an incident with my mom had a aahm ... it was a hospital accident, because she was a nurse."
- 2) To his friends, "If you told somebody in the beginning, nobody wanna talk to you, no body wonna affiliate with you, but as I experience through my high school life, if I don't tell them up front, that when they will cut me off."
- 3) His girlfriend's family, "My aunt knows that she knows, so we haven't come to the time we think it's safe to talk to her family about it ... we haven't told her family yet."
- 4) His girlfriend, "I had that conversation with her from the first day I told her."
- 5) In general, "My aunt was always like... Oh aahm, don't spread it around, don't let people know. It's just like what's the point in me hiding it?"

Edward explained how he has been able to keep his HIV status a secret:

It's very say like sneaky... you hang out with your friends and you grow up just like a regular guy, but you know, on the side, it's like "Don't forget to take your medicine" ... I would always have my little napkin with my pills in it, and I would sneak off to the bathroom.

Keisha shared why she keeps her HIV status a secret:

That was interesting when you said the stigma part ... because it not what it was many years ago ... it's very different, ... it a whole new look on HIV; sometimes

you may feel like ... this person is suppose to be so close ... maybe they should know 100% of you ... I guess everybody has information that's reserved to them.

Loren disclosed the following about keeping her HIV diagnosis a secret:

I keep it private, and I can kinda a little concerned of how people would treat me so that's why I do keep it private, but I feel like it's based on each person's perspective, you know, just for me, it seems like the average thing ...

Margarita gave an account of her experience with stigma and exposure of her health information to individuals who had no right to know her HIV status:

They told everyone. Friends, people I didn't know. I had, when I found out? like a month later I had some lady, I didn't know her, I didn't know her name. She came up to me at a party and she is like, "oh, its ok that you are living with this, you are gonna get through this." I am like aah! What! Who told you this? "Your aunt told me, but I am not gonna tell anybody." I was like, "why is she telling my information?" so!

Travis shared his opinion of stigma, and how he keeps his diagnosis a secret:

It just, the stigma that most people had, that I had of it, it's just not based in reality ... at church camp, I would be kind of afraid of like bringing my meds ... I didn't want people to ask ... I just felt like it was, it was a secret I wanted to be kept.

The medications that participants take are somewhat of a *Paradox* to them because it has allowed them to live for as long as they have; and be able to enjoy better health and stay out of the hospital. It allows them the opportunity to look toward a future, for which they are very thankful. However, the daily drill of taking medications

and having to experience their side effects are burdensome, which elicits contradictory emotions, yet participants remained committed to taking these lifesaving medications.

Paradox as a sub-theme of Consciousness, addresses medications and medications schedules for these participants.

Ahmazin explained her changing attitudes towards her medications:

I started taking my meds consistently, because I also went through this rebellion stage ... I didn't want to take my pills ... and take them with me ... because I didn't want anyone to see me taking my meds, I would intentionally leave them home, and not take them. Overtime I just really aah try my best.

Ahmazin further communicated her medication schedule, "I started off on seven pills. I am actually down to one now." Ashley shared her medication schedule "It's a handful of pills, because at that time we were taking, like seven, eight, 12 pills, verses now when you take like two once a day. Bryan expressed his opinion on the medications, "If I don't take my medication that when it starts to get out of hand ... back then, medicine wasn't really around to keep us alive ... we're fermented technically say marinated in the disease."

Edward explained his medication schedule and how he has been able to maintain it without being found out:

I would always have my little napkin with my pills in it, and I would sneak off to the bathroom with some water or something and go take my pills ... I was reduced down to just 2 pills a day, or 2 pills once a day; it's second nature to me.

Jamie summarized her view of the medications:

Sometimes when you take, well! ... [pause], sometimes I don't feel good for certain period of time, for like 30 minutes, 20 minutes on the medicine, aahm the side effects ... I just feel like something is wrong with me, just because I take medication and like [pause] ... I wouldn't have to take medication, [pause] every day for the rest of my life ... I take two times a day, five pills, two times a day, so...

Kayden shared his struggles to maintain his medication schedule:

Having HIV like with my meds, my stomach, every morning it's like irritated ... sometimes I work crazy hour, so sometimes I get home or I don't come home at night ... I would be between 2 jobs and sometimes ... I forget to replace what's in my keychain then that night I would probably miss it.

Melissa spoke about her experience with the HIV medications:

Years ago, I used to take like 10 pills a day ... I have to take my medicine ... if I didn't take it then, the virus, probably, I probably have cancer again; at certain points I kinda like feel like not take my medicine ... Calexia, it was so gross, I had to eat like peanut butter put it in my cheeks, and squirt because it was only in liquid, you have to squirt it in my mouth [Chuckle].

Rashad divulged his experience and opinion of the HIV medications:

You also have to be cautious, because you can't take ah, different types of aspirin; you can't drink alcohol while on your medicine ... some people can't even put on, like lotion, different types of lotion. I get tired, I am tired, all day; stomach ache, throw ups; I got used to my medicine; the only side effect that stuck was

drowsiness. I got HIV and take this medicine for the better, so I can be alive forty fifty years from now, God's willing.

Travis lamented on his medication, "I would be kind of afraid of like bringing my meds ... I take my meds when I am suppose to."

Participants are experiencing the theme of Realities of Living With HIV by actively participating in the normal activities that individuals at their developments stage are involved in. Participants were graduating from high school and going to college to further their education, in preparation for more lucrative jobs and setting a foundation for their future. They were earning degrees; working to maintain their daily existence; being involved in intimate and sexual relationships; living in different residential situations (parents, siblings, individually, and with partners); and helping others whom their experience could benefit by volunteering. **Ahmazin** shared her academic achievements:

I go to PSU, I am pursuing my master's in business administration, concentrating on entrepreneurship. I will actually be graduating on, in June, June 8th [2018]. I also have a bachelors from PSU. I have a bachelor's in finance and I have an Associates in Business administration from MD.

Ahmazin spoke about her intimate relationship:

Spend a lot of time together ... I disclosed my status to him, probably 3 weeks of us dating ... 3 weeks to some people is not, it would seem you know too early. I just went ahead and got it out there, because the feelings between the both of us starting to develop very, very quickly. He knows my status, he knows, ahh that I am undetectable. So, he knows everything.

Ahmazin also spoke about the difficulties she experienced with disclosing her HIV status to intimate partners:

That's like a crossroads that I never want to face. It's like you have to [clears throat] me personally, I always go through the battle of when to tell them, like when is the right time to tell when you are dating someone, especially if it is someone that you just met, you know? A part of you want to go ahead and get it out of the way and let the person know. If they may have a problem with it or may be uncomfortable, then you now, you guys wouldn't be wasting each other's time, you guys could just be friends, go your own separate ways. Another part of you aahm [clears throat] you have to think about is, is this person trustworthy too, because if this person you are just meeting? As dating, you are telling him [pause] or her, very private information most people, you know, you could be living with the virus and be healthy and be fine, but some people are still aahm uncomfortable with other people knowing their status or their business, possibly getting out there, so you have to think about that too ... you don't know what that person is like, does that person loves to gossip, is if that person is like the type of person that gets mad and just tell all your business to the world.

Ahmazin explained her boyfriend's reaction to her disclosure of her HIV status, "He was very receptive and open to me and my situation ... He said he is not going anywhere, and ever since then, he has been supportive so far everything has been going greatly." She continues living with her family as she reported, "My mom at my grandparents," in reference to where she was living. **Ahmazin** shared about her community involvement,

"I am involved in my community, aahm, I have been involved with the family foundation for [pause], this will be 7 years, doing outreach, HIV/AIDS prevention and outreach."

Ashley stated, "I am graduating in May [2018], so I will be getting my bachelors. Well I am getting my bachelor's degree in Sociology with a minor in Psych." She spoke about the complications that are sometimes involved in disclosing her HIV status:

Because they have like such a stigma in their head, or they don't know much about it ... Like if I am undetectable and you use protection then you're not gonna get it, like is a less likely chance that your' gonna get it ... In general, it makes it harder, cause you do have to disclose. You have to explain the whole situation.

Ashley explained the reactions she received after disclosing her HIV status:

I disclosed to a few people, where it was just like they didn't want anything to do with me after that, so like they are gonna catch it, like the first thing and you're there like "no" ... 'yeh! I know, I'm just not gonna', then they like cut you.

Ashley shared her opinion of having sex in the context of being HIV positive, "As long as you're careful."

Blessed described her accomplishments, "I accomplished aah, graduating school." She said the following about intimacy, "He start getting tested," and about disclosing her HV status to her partner she confided, "I told him, before we started dating I told him right away. We met at a [pause] at a complex." Blessed explained her boyfriend's reaction to disclosing her HIV status:

He always goes for his monthly checkup, and he is not HIV, so he knows he is safe ... He is, he was much ok with it. He was very ok with the fact that I had it, just as long as I stay safe.

Blessed continues to live at home with her mother and other family members.

Brittany spoke about her education:

I am studying for cosmetology after cosmetology I am going to, I am going to actually be an assistant for one of my friend's beauty salon, like helping her and all that stuff, so she could teach me more of what I need to learn about hair.

She expressed her fear of a potential partner's reaction to her disclosure: "So, I just be scared about like what they are gonna say. Are they going tell somebody, if they do, everybody is gonna call me bad words and all that stuff."

Brittany also shared her opinion on having sex considering that she is HIV positive:

I would like tell a person first, before having sex, and I would want to wait until I am ready. I don't wanna just go fast, and everybody having sex, well, no. I want to take my time get to know the person and tell them, when we are ready [pause].

Bryan explained about his education:

I received a scholarship to go to STT ... unfortunately after my first year I had to transfer due to the fact I moved up to DLL ... doing that part time so that I can work and maintain a job and maintain financial stability while I am in school ... So, I decided to make the sacrifice for me to get my associates degree later ... The disease takes up 30 seconds of my time if I am studying, because all I've got, all I've got to do is take my medication.

Bryan discussed disclosing his HIV status to his girlfriend:

She is known since [pause] my first day talking to her ... At first, I told her Hey! I know that you may feel some way towards it, because I am your first boyfriend

and everything, you may not know too much about the disease and everything like that, but after we got pass that, it doesn't affect it at all.

He reported the following about her reaction to his disclosure, "She sees nothing different towards me, she doesn't look at me different ... Me and her have done our own research as well." **Bryan** lives at home with his father.

Edward spoke about his education:

Right now I am a mechanical engineering student at ZEU [name changed] and aahm, ... I had just transferred from DBC [name changed] ... once I transferred, I applied for this program at the school. It's a research-oriented program ... of undergraduate researchers ... I have been involved in that program, and through that program I have gotten involved in research ... so right now that's what I want to do.

Edward shared the following narrative about disclosing his HIV status:

Yes, I did disclose about a week after we met. Yes, I did yes, it's extremely difficult ... I disclose about a week after we met. It's taken years to get to that point ... The reason I felt comfortable was because I, I one, I don't want to get in trouble, because you get into you know things move fast and you get into ... Some of the experiences that I have had, disclosing to partners, it's like I said, some of them were good, some of them were bad aahm, the bad ones, when they are bad, they're really bad.

Edward elaborated further on the issues of disclosing his HIV status:

We, at first you need to educate the person if they are not already educated about it, and you need to teach them that you are healthy, and you've been here this long

and you are going to be here for a much longer time due to this medicine. I am already over that [chuckle] But aahm, now, the hardest part is finding the right person that is willing to get educated on such a sensitive matter, that's the biggest difference.

Edward explained his partner's reaction to his disclosure of his HIV status, "She was open to aahm, convincing that's not the word I want to use, but I am at a loss for words." He also shared his experiences with other potential partners' response to his disclosure:

They didn't want anything to do with me after that ... "yeh! I know, I'm just not gonna", then they like cut you off. They have to get over the stigma, so I have had good experiences and I have had horrible experiences ... aahm I haven't heard from them in years ... Aahm, at first it was a little shocked, aahm, I always get the response "Oh my Gosh, I feel so bad for you" aahm. "OH my God, you don't deserve it" ... I disclose to this girl, and you know, they, they take it the same way for the most part "Oh my God I am so sorry" or 'Oh My God thank you for telling me," and then aahm, I have gotten some that I haven't heard from them in years ... They deleted me off snap chat, off all social media, and ah, at that, when you see that for the first time that I saw that. I felt, I felt really bad, I felt like useless, you know.

Jamie shared about her education:

I had graduated from FCC [name changed] ... I graduated from there, last year September [2017] with aahm, MA- medical assistant and I wanted to do that, but I couldn't [pause] take the job offer because of the living situation.

She spoke about intimacy, "It's hard if you want to have sex." **Jamie** also spoke about having to disclose her HIV status:

Some people can live with each other if I am dealing with this person, I don't have to tell this person such and such and such, what is going on with me that I have HIV. I have to let my partner know this ... you have to let your partner know before you if you like that person and you tell that person so Oh! I am HIV positive, and they just look at you like.

She expressed her fear of being rejected, "You're scare of the reaction if your gonna tell them, or if they gonna tell somebody else, you just scared."

Jamie shared living accommodation. She reported, "Me and my sister we stay together." When asked about her involvement in intimate relationships, **Jamie** responded, "No, it's like [pause], I don't wanna put that on nobody." She expressed her concerns about having to disclose her HIV status to a partner:

Well it' [pause], it's hard to like, to even like, if you waan like you now, have sex or like whatever? You can but it's like you have to let your partner know before you can do that and it like, as I see it it's why like, not why, but it's so like scary to tell that person, because you don't know how they gonna react, and you know, what if you like that person and you tell that person so Oh! I am HIV positive, and they just look at you like [pause] ... Like [pause] you just you basically scaring them off, and you don't want that, so you just stay to yourself, you just don't have sex. But I feel that's like that's like that being selfish, that's selfish that's selfish in a way because it like you, you want to do that type of stuff [have sex] but you have to tell your partner before you do it, and it like me you don't want to tell them ...

because you're scare of the reaction if your gonna tell them, or if they gonna tell somebody else, you just scared.

Kayden explained about his education, "Well, I just graduate in December [2017] with my bachelor's in criminal justice with a minor in psychology." He spoke about his intimate relationship and disclosing his HIV status to his partner:

Yeh I disclosed to him. Well, we knew each other for about 2 months prior to my disclosure to ... we were talking and stuff like that, aahm, I asked him test questions and stuff like that, and then I just finally came out and disclose, and then that's when vice versa he disclosed back his status ... aahm, it is easier, to disclose to somebody that's positive, verses that somebody who is not. But I personally like to disclose to people that's not, just so I ... I didn't disclose at first ... aahm [pause], but it wasn't [pause], sexual to that point. It got after that point, that it got more intimate, aahm, but [silence] ... It's like, you got that factor that should I disclose, do I continue in the moment what the hell with it?

Kayden further revealed issues he encountered with disclosure:

Its, more so complicated, as far as aahm, you know, trying to figure out if you should disclose to certain people, who you want to find out, aahm, if anybody is going to find out, you know? Ok, well the biggest battles is always disclosure, I feel like it, there is no way around it. It's just the, knowing like is this person going to take it the way you want them to take it? Or if they going to go the whole opposite direction, should you tell them? shouldn't you tell them? When should you tell them? ... as far as friends, romantic relationship, as far as if you think the person needs to know, even like, for me at work, for me, when I get sick

or burnt out, I go to the doctors even like, I go to the doctors a lot. It's like, should you tell your manager the situation so that they can have a better understanding why you are always bringing a doctor's note. Why you know, you're always calling out of work? If that's the case aahm, you know, and, are you going to have that confidentiality with your manager or with the person that you are disclosing to because you never know that they can turn around and tell the next person, and tell the next person, Oh, I didn't tell nobody, but they really did, that's one of the biggest you know thing, you know ... if I can trust this person, or if I feel comfortable enough to tell this person or, I really like this person ... I don't want them to kinda leave, so you just kinda hold back and then it's just kinda, the bond or whatever kind phases out because you're holding back so much.

Kayden expressed his frustration with intimate relationships:

But with this relationship now, [silent] I was just at a point where, because it's like, you don't tell, you hold off on telling, and you know, you get to know the person, and you're thinking; they are gonna get to know me and see me before I tell them, and then you tell them, and they still run. Or you tell them from the jump and they run ... You know it's just like...

Kayden shared his opinion on having sex, in the context of being HIV positive:

My opinion? I think it's pretty normal, either way it goes ... I mean, not saying it doesn't happen, but you know, you just always have to use protection, you always have to like [pause], I say it difficult when in that heat in the moment action, that,

because it like, ok you always make sure you carry your condom with you or that if you want to go this far...

Kayden continues to live at home. He explained, "I live with her [adoptive Mom]." He also explained his volunteer activities:

It's mostly like a one-on-one, like, like a friend of mine tell me about somebody they come across ... I can refer them and, it like more of a friendly thing ... Like it's not as something I do as work, it's just something you know, I feel like I can offer to the next person ... I mean, like my doctor's office create this, a peer group for us ... I am a part of that, with kid that I grew up with in the same situation as me, as being born, or contract it at a young age ... I also volunteer at a summer camp once a year, a week ...

Keisha shared her academic pursuit, "Right now, I am in undergrad, and I plan to go to medical school, and become a doctor." She discussed disclosing her HIV status to her fiancé:

I think I disclosed, six months into it, into the relationship ... Like my doctor, she was open, she has aahm, she was open to him coming in or asking questions ... but in the beginning, it was difficult because it's ...

Keisha also spoke about her partner's response to her disclosure. She informed the researcher, "Once I let him know about the new medical advances and if I take my medicine and we use condoms, and all the protection then he'll be fine. After that it was normal." **Keisha** shared her opinion on having sex in the context of being HIV positive, "It's a normal [laughs] thing, I don't know." She continues to live at home with her aunt while she attends college. **Keisha** does not volunteer; however, she expressed a desire to

become involved, "If there was a way for me to get involved, I would get involved in, the destignatizing it, because it not what it was many years ago."

Loren communicated the following about her education, "I have changed my career a lot ... I have decided aahm to make sure I get my AA by the end of this year." She spoke about intimacy, "I can't just be out there being sexually active." **Loren** also spoke about disclosing her HIV status to a partner:

I want to make sure, that this person is someone I can trust, that this person wouldn't judge me, and I would definitely want them to know about it before hand to make a choice whether they still want to continue being in a relationship with me, if they want to be sexually active.

Loren shared her opinion on having sex, in the context of being HIV positive:

This disease aahm, it's not curable yet, so if, I can't just be, you know, out there being sexually active just like you know, because people can catch it ... You always have to be protective, you always have to bring protection, aahm, condoms, ah, take your medications, because the lower it is in your system, the virus, aah, the less of a chance of your partner getting it, so that's definitely important as well, because condoms is not always 100%, you know, proof to protect HIV, aahm, to protect your partner from receiving HIV, so. The average peer doesn't have to think about it, or they are not as concerned, whereas for me I feel like it's different because I have to make sure that, aahm, ... I am safe if I am sexually active ... If I do decide to be sexually active, I definitely want to tell my partner beforehand, before we even get involved in being sexually active ... So that's something that aware of and concerned about whenever I consider being

sexually active with someone ... You always have to be protective, you always have to bring protection, aahm, condoms, ah, take your medications, because the lower it is in your system, the virus, aah, the less of a chance of your partner getting it, so that's definitely important as well, because condoms is not always 100%, you know, proof to protect HIV, aahm, to protect your partner from receiving HIV.

Loren continues to live at home with her mother.

Lovely reported the following about disclosing her HIV status:

It's aah [pause, stutter] personal. I don't want anybody else ... to know that I have HIV, except for me ... I don't wann tell the whole world about it. Because, [pause] I am a little bit [stutter] embarrassed ... I am a little bit ashamed to tell anybody that I have HIV.

She lives with her adoptive mother; however, they are in the process of making arrangements for her to move into a group home. **Lovely** expressed her desire to serve others:

I wann go, I wanna save my money so I can go on a mission trip ... aah [long pause] to U... to aah, to U... to Uganda and ... It's the trip I want to go on, and this is my first trip ... no, it's a church, the church that I grew up in, and they go and aah M SW, and aah MW, MW go every year. They aah, they put me, they put me on the list ... and I have, they have a clinic over there. They have a clinic and they have a- a- a school over there, and a church an orphanage too ... and see, and see the older kids and tell them how old I am and where I am from ... it's not, it's not gonna be the same like here in Florida, because over there it different over

there in Uganda, and I was watching the video on my phone, and it's like ... it's like so careful over there, that kids over there that ride motorcycle, and they walk, they walk, to school and they get aah, and aah, they get aah, school supplies.

[pause] yeh! ... aah [pause] I want, I want to be a mis a missionary when I grow up and go abroad and tell a lot of people about Jesus Christ, and how, and how he [pause, stutter] died on the cross and rose again.

Margarita explained the following about her education, "I was depressed, but I went through with school ... when you are in school, you learn about things ... I stopped at some college." **Margarita** spoke about disclosing her HIV status to an intimate partner:

It's like [pause] my past relationship, the one I was just recently in, I told him within two weeks of us being together in his head, he told me, that he felt bad for me that's the only reason why he wanted to give me a baby, and be with me he felt bad for me my relationship before him, he used to always scream in my head that "nobody is gonna love you, nobody is gonna love you, you are HIV positive who wants a woman that's sick"?

Margarita also shared her partner's response to disclosing her HIV status:

I told him about it and he felt bad for me, so he didn't wanna leave me. That's what made him cheat, because he didn't want to leave me but he didn't want to be with me either. I had some really, bad break-ups because of it, so, it hard but it's you know? it took him a day before he can actually, he actually call back and said you know what! I really want to be with you, through thick and thin ... after I told him that, he didn't want to touch me, he didn't want to be around me. I actually knew it, but he always said "that's not a problem. I aahm not looking at you like

that" ... after two years of us being together and him cheating, I found out that the reason he didn't want to be with me was because I was HIV positive. After he found out, he was like, we can work this out, then he ends up cheating and left me ... it's very hard trying to open up to someone and trying to be with someone. I catch feelings very fast ...

When asked about her opinion on having sex, in the context of having HIV, **Margarita** said, "Sex is just hard when it's time to tell someone."

Melissa shared her experience with intimate relationships:

Your partner may like who you are but it's like they be so afraid that they might get it and stuff so they just, they have their moments ... He don't know what the right things to say and how to like, to do things in a way not being rude ... at the beginning we use protection and then after a while, you know, we start getting comfortable ... he was the one stop using it.

She also spoke about disclosing her HIV status to her partner, "When we was dating like 2 months in, I told him."

Melissa explained her boyfriend's reaction to her disclosing her HIV status, "He was like 'Ok' ... he was very receptive and open to me and my situation."

She shared her opinion on having sex in the context of being HIV positive:

You have to be careful with certain stuff, but I can't be that careful [sigh]. Well, it's as if that person come to agreement, I like wanting to be intimate with you and he know your situation, it's all up to both of us ... if we constantly think about, like me being positive, we won't be able to enjoy being intimate ... It will be a hard time, this and that to a point where he had to be do something with me even

though he knows about it ... I like protected my partner and made sure I did the right thing and stuff, and [pause], that's about it to be honest ... So, he is taking the little pill that they have ... I hear about PrEP, so we tried to get the PrEP, we tried to wear condoms.

Melissa reported that she volunteers, "Sometimes, I also volunteer at CD, the aahm, where I used to go to the doctor ... We just helped out with stuff ... just help people [with] the turkey, turkey drive ..."

Rashad explained the following narrative about his education:

I am actually, aah, I am actually on, like going through the process to go back to school. I had to be postponed because I am expecting a child in September [2018] ... I pull myself away from school but not entirely? ... so I can be able to save up money, so I can make sure my child can have ...

Rashad talked about not having to disclose his HIV status to an intimate partner and how he was able to avoid doing so:

I hadn't had to face that yet. Aahm, when we were younger ... we went to camp ... we grew up basically together and established a bond and aah, I have been having sex with just those females ... Not saying that I was pick, pointing them out, it's just something that, it kind a just happen, know you have HIV and I have HIV, that cancels out the disclosure part. I guess we were running away from the disclosing part ... so as far as disclosure, I never have to encounter that yet.

Rashad volunteers as he explained, "I volunteer at the camp that I have been going to since I have been 7 ... I still go back every year, so I go back every year and volunteer and help those kids out."

Travis spoke about his education:

I went to a bible college ... aahm, I did that for a couple months. I just realized it wasn't for me, so, I went right into the working world. I am still not really sure if I want to go to school. In fact, I don't think I will, to be honest ... the best way I could answer that is yes and no. I have talked to people about it. I have thought of it myself and I have got everything from yes to no, and it's honestly, gotten to the point where if, I honestly want to, I will, but until then I am not ... in fact I am sure it would.

Travis expressed his opinion on intimacy, "It's something we shouldn't be ashamed of aahm, it's something that you can still have." He also shared information about having to disclose his HIV status to a partner, and his expectations when he discloses his HIV status to a partner:

So, I believe you know, once you bring that to the table, and you know, letting your partner know ... you can kind of go from there, and you know, the responses might be mixed ... Yes, I, it was high school love. Aahm, I did have a girlfriend in high school, aahm, aahm, its basically just, it up to you, you know, its determined by how comfortable you are with it. I mean, it's not like you are required to disclose it, in my opinion. But at the same time, I believe it's necessary to disclose, depending on the situation ... Aahm, like going back to, you know, sexual relations, you know, I think it's something that should absolutely be brought up. But without shame or guilt, that's the key ... Whenever I disclose my status to someone, I felt comfortable. If I did not feel comfortable doing it, I did not do it, and I would say that to anyone else. You know, it's up to you, as far as

disclosure and what you feel comfortable with ... So, it something that you really have to come to terms with. If you, as far as the context of having a partner being or positive in a relationship. And that goes to the other person as well. If it was, you know vice versa. Aahm, but honestly, it should be on the table in regards to relationship anyways ... in my mind I believe it is 110% possible to have a successful relationship even while being POS [HIV positive]. You just need to be honest and open and go from there.

Travis also shared his opinion on having sex, in the context of being HIV positive:

I could still have an awesome relationship and that this virus doesn't have to hold me back ... I believe it something again, I have said this, and I really want this to hit home with people, it's something we shouldn't be ashamed of aahm, it's something that you can still have ... I think what is really cool is just the concept of just knowing that I could still have an awesome relationship and that this virus doesn't have to hold me back, and it doesn't have to hold anyone back. Aahm on that same token, it does needs to be taken seriously, aah, it's something that shouldn't be hidden ... So, it something that you really have to come to terms with.

Affirming Milestones are the attainable goals and plans for a successful future, that participants are making. These include higher education, stable career, having children, hope for the future, and helping people. Ahmazin reported her career choice as, "To have my own business ... I want to have my own non-profit organization." She also explained that she would like to have children, "When I am ready to have children

...aahm, I wanna have [pause] four." **Ahmazin** described her vision of what her life will be in the next 5-10 years:

I want to be financially stable; long term healthy relationship ... I want to be married ... I want to do a lot of travelling ... my husband, aahm, and our family if we do have kids by that time, in which 10 years we should definitely have... I want to have my own businesses ... being a partnership with what I will be doing in the future, as far as having my non-profit organization.

Ahmazin shared her strong desires and plans to help people:

Encourages people of all ages, and of all races ... I want to provide a platform and make them, aahm, comfortable and encourage them to speak about any issue that they dealt with ... I think that by me sharing my story will encourage other people to share theirs.

Ashley would like to have children, she said, "Yeah, to take care of them, or tell them like, 'ok this is what your Mom ..." She also shared her vision of what her life will be in 5 to 10 years from now:

At the end of the day, I feel like the virus might catch up to me or something ... sometimes I do feel like in my, you know, if my time comes. But there are other times when ... I see myself like having like kids, a house, a husband [chuckle], a career uum ... basically, it's just anything that anybody else would dream of, you know, money! too.

Ashley explained that she would like to help others who have been affected by the issues that she has encountered in her life:

Substance abuse! counselling, substance abuse like working with those because, I mean, both of those kinda hit home for me, so, that's why I want to do it ... I was in the system, like you know, taken from my mom, put into an adoptive home, and all that, so I kinda wanna help kids on that sense, like make them feel like you do have someone that, like helping you out ... with the drug? with the substance abuse counsellor? Like, seeing my mom like, on drugs, like? You know, at a young age? You kinda like, you're like what was going on through her mind, you know, that she didn't want you as a kid, like keep you? Or do anything to get you back or whatever? ... Yeh! Change it for somebody, and see like, it kinda start with them, like the actions that they take, so it's like, it helps guide those choices to be right choices.

Blessed shared her plans to go to college, "Yeah! I am planning to go to college to be a photographer [pause]." She already has one child which she explained, "It was an accident, I don't really call baby an accident ... I hope to have children in the future. In 5 to 10 years, "I will be living in a better home, I will be more better, than going through all this I am going through, with pain and sickness." Brittany explained her preparation for her career, "Cosmetology, owning my own beauty salon." She also expressed her desire to have children, "I want kids, but it has to be with somebody that understands my condition; yes, I want to have children." Brittany divulged her vision for the next 5 to 10 years:

It's gonna be like a normal life to me ... Like, healthy, aahm [pause], reaching for my goals ... cosmetology, owning my own beauty salon ... Being healthy, being

undetectable, [pause] aah ... like owning my own beauty salon, being aahm, having a husband and kid, aah, yeh.

Edward shared his career goal, "Professor, Scientist." He is pursuing his college degree. He elaborated on his education plans, "Once I graduate I want to, to aahm, to pursue a PhD in mechanical engineering to do research in nano composites." **Edward** shared his vision of what his life will be like in 5 to 10 years. He pontificated:

I would want my life to be aahm, starting to gain tenure at a university as a professor, and aahm, running my own research lab, and guiding students like myself that are interested in techno research idea and aah, family, young family 2 kids, house.

Jamie has plans to go back to college to become a nurse. She shared her vision of the future:

I vision it to be a normal [pause] life! ... Just living life, trying to get myself, [pause] working in the field that I want to work in, which is medical, aahm, going back to school to be a nurse, aahm, helping people, as in homeless people, anybody, helping anybody aahm, playing sports doing [pause] like working a better job [pause], and just living, being happy.

Jamie explained her view on having children:

Yeh, I am very aware of it, but it's still like, I don't like to [pause] like to take caution, I like to be cautious of what I do with people, far as people, relationships, family, anything; and it like if I didn't have it I wouldn't have to worry about, that's one less thing I would have to worry about ... I want kids, but it has to be with somebody that understands my condition, like, it can't be nobody that's just

gonna like [pause], take this and like, Oh! You know what I am saying? It has to be somebody that's understanding, that knows a lot about it, that's knowledgeable about it ... you just can't be just out hear and just think it's just like so contagious, it's stuff that's waay worse than HIV.

Jamie also shared her hopes for the next 5 to 10 years, "Have a family [chuckle] with a nice nice house and good successfully job ... taking vacation."

Keisha has concrete plans for her career which she shared:

Right now, I am in undergrad, and I plan to go to medical school, and become a doctor ... if it doesn't go smoothly, then after undergrad, I plan to get a masters, and then go to medical school.

Keisha also expressed her plans to have children:

Kayden stated his opinion on having children:

Aah, about the whole thing about having children, I think it's possible, as long as, you know, I take my meds ... yes, I want to have children ... 2 ... For me to pass it on to them? ... That's no concern but that, but with all the medical advances, you know?

Keisha explored her vision of her life in 5 to 8 years, "Well, hopefully I will be a doctor by then [laughs] aahm maybe I'll have a kid, have some type of money, real money coming in." Kayden explained his career goals, "TSA agent, and Customs and Border Patrol." Regarding furthering his education, he said "I do plan on going back in August [2018], hopefully to pursue my Masters ... Either public administration or criminal justice."

I am still on the fence about that, because before I used to be like, "I am not having my own kids, I will just let everybody around me have kids and I do for

them, aahm ... Now I am kinda, aah, maybe I could have a kid. But, I don't know, I just always felt like I don't wanna do to my kids, like how I felt like my parents did to me.

Kayden shared his vision of his life in 5 to 10 years. He stated, "I came so accustom to being 'If I make it that far, or if I be there', that you know, I still kinda put that perspective, of not having that longevity life." **Kayden** also mentioned that he hopes to continue helping others:

When I come across people in the same situation I feel like I can give them advise ... I can give them the guide that they need that they probably didn't have, where I know that I didn't have while growing up ... I am glad I can be like that person, you know, that turns that perspective around for them... I have been living with it all, my entire life, I have made it this far aahm, you know, these are the do's and don'ts ...

Loren explained her education plan, "Trying to get my way back to school ... I want to go for and what best fits me for a bachelor's degree, and then after that I want to [pause], maybe get my master's degree." Although she is preparing herself by working on a degree, Loren is uncertain of her career path as she shared, "[A career that] doesn't require me to socialize too much." Loren also expressed her opinion on having children as follows:

I think it beautiful, you know, to have a child, you know, someone that loves you, you know, aah, someone you can raise. Someone that, someone that has your DNA, aa mini version of me, which is cool and you just love them. Take care of them, you know, watch them grow. I think it's just, I think it's a beautiful thing.

Loren also explained her desire to help people, "Definitely want to help people ... I want to do something that is helpful towards other but [pause] it behind the scenes so I am not directly interacting with them."

Lovely expressed wanting to become a number of things, "I want to be a nurse ... I want to work on the farm ... I know, I know how to work, I know how to work with horses. And I know how to feed them by hand." Regarding having children, she stated, "No, I don't want no children." Lovely also shared what she would like her life to be in 5 to 10 years:

I wanna. I wann go, I wanna save my money so I can go on a mission trip ... Save it, I am not ... I an [not] [Stutter]) going to spend it all at once ... save it for like vacations and stuff ... My own house my own farm ... my own, my own [stutter stutter] car and I want to have, I want to have myself a hummer.

Margarita has plans to go to college, however, she shared, "Well! I am waiting on my brother because its, I have to get my mom's death certificate, and that's what holding me from going back to school ... To be a teacher [pause]." She also shed that she would like to have children, "I have been having a lot of complication to actually having children ... I want a big family ... I want to have at least 3, at most I want 7 like my mom..."

Melissa disclosed a couple career ideas that she had in mind, "Nurse technician ... entrepreneur ... I could be like a counselor, that would be something that I would be interested in." She expressed her awareness that she would need to further her education, "I want to go back to school, but I want to go back for business." Melissa also discussed her hopes for the next 5-10 years:

The medicine is better already, but it will just be a whole lot different 10 years from now ... I will probably be like in my career, and hopefully married ... I just feel like I am going to achieve growing old with this virus.

Melissa expressed that she would like to be of service to others:

I want to help people ... I want to be able to, I want to help people that struggle with the same thing that I go through ... by being positive, motivation speaker, and help others get through their problems, or I could be like a counselor, that would be something that I would be interested in.

Rashad shared about his education plans, "I want to have a bachelor's degree ...

My career goal is to actually graduate college, aahm, occupational therapy assistant and work with kids with disabilities." He expressed his opinion on marriage, "Marriage is nice ... I would get married when the time comes, when I know it's right ... So, I believe that partner, when that person comes." Rashad is expecting a child later this year (2018).

Rashad disclosed his hopes for the next 5 to 10 years:

I don't know, the sky is the limit at this point ... My options are open. I don't, I don't limit myself or, my future is what I will make of it ... at this point I am not sure about it, I just know I won't, I won't be unsuccessful, and I won't be another statistic in this world, especially with 45 [U.S. President] you have to make, try to make better for yourself regardless ... you are gonna have this virus whether you dwell in it, and give up on life or you strive for greatness, so why not strive for greatness?

Travis expressed his aspirations to become a musician, "I love music, it's something I am passionate about ... I am producing, I am writing, I am collaborating. Aah

just really immersed in that world, and, and making a living off of it." **Travis** indicated that he has no plan of going back to college:

I have thought of it myself and I have got everything from yes to no, and it's honestly, gotten to the point where if, I honestly want to, I will, but until then I am not ... I am not saying that getting a degree wouldn't help ... but it's not necessarily things I feel like are required for me to pursue the dream and goals that I have ... Especially since I have heard of real-life story of people in similar line of work and who haven't gone to school whatsoever, as far as post education.

Travis expressed his opinion on having children, "Not for me! [laughs] short answer." He also presented his vision for the next 5 to 10 years:

I see myself in a ... condo ... you know house ... in a really good home with a studio ... with a partner of loving awesome healthy relationship ... Extremely healthy, both mentally, physically and the whole nine yards; and just happy ... Content with where I am, not just with where I am in life, but with myself. The obviously, still taking care of myself and my virus, but at the same time doing more things like this, you know, just educating people ... Whether it's educating people about music or educating people, about HIV, and realizing that you can talk about it like this.

Exemplary Portraits

During the process of creating the exemplary portraits, the researcher returned to the raw data from the individual interview transcripts; NVIVO 11 nodes; EXCEL spreadsheets of the demographic data that compared participants' experiences among the themes and sub-themes; and the individual depictions, to select three participants who

exemplified the group as a whole (Moustakas, 2001). The researcher used the data, member check submissions, and individual depictions for the three selected participants and developed a comprehensive portrait for each. According to Moustakas (1990, 2001), these "individual portraits should be presented in such a way that both the phenomenon investigated and the individual person emerged as real" (p. 271). The themes — *Panorama of Living With HIV; Consciousness* and sub-themes *Kinship, Concealing and Paradox; Realities of Living With HIV; and Affirming Milestones* emerged from the individual depictions. Three participants (**Melissa, Keisha**, and **Kayden**) were selected by the researcher for the exemplary portraits. They were selected as individuals who exemplified the emerging adults' experience of living with HIV since birth as a whole.

Melissa's Portrait

Melissa shared what her life has been like while growing up and having the virus:

Well, growing up, is very, you know, it's difficult ... when you living with having the virus and your sisters don't have it, you have to grow up with that struggle alone ... I can say that it gets lonely sometimes living with the virus and just [pause, sigh] ... because people don't understand you, they don't know how you feel ... I don't know, I just feel like, sometimes I wonder "Why me? Why did it happen to me?" but I don't really think like that anymore.

Melissa considered herself more fortunate than others because her worst experience was that of losing her mother, while her peers have suffered much greater loss. She explained, "As I growed up, I didn't have really, didn't go through nothing tragically you know, but losing my mom. I didn't feel that the worse, because I have spoken with people that went through the worse."

Melissa remained encouraged as indicated:

In life going through, living with this thing, it's not the end of the road. Just keep on track, taking your med and not worry too much about it, and you will get through life easy ... You can't let the virus take over you. Because if you let it take over you, you would just, you would just like be, you have to fight. I feel like as long as you fighting, you want to live and want better for yourself because people say you got to live for yourself, but the people that love you don't want you to go. They want you to be here with them and be oh, I want to achieve that goal of being here.

Melissa explained that she often experience melancholy:

I am not depressed but I get like emotional sometimes ... it's like, I have to constantly pull myself together, wake up in the mornings and stuff ... I have to say I don't want to give up, like, I never say that I be done, but there are moments when it's like, eeh! Enough.

Melissa strongly believed that her life with HIV is normal, as she described a typical day in her life:

I do everything like a normal person would do. You know, wake up in the morning, work, aahm, take care of my son and then once, by the time you know, take my medicine, or I might have to go to my doctor's appointment, and you know?

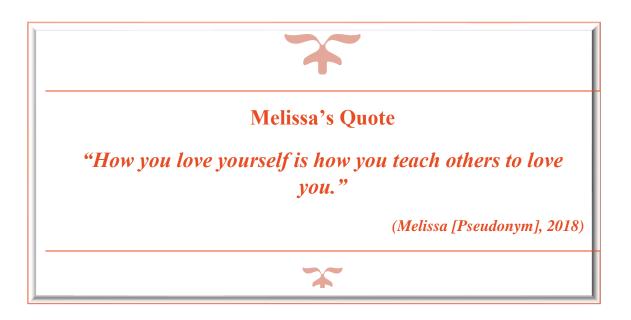


Figure 28. Melissa's quote: Reflection of living with HIV (Wright, 2018, adopted from Melissa, 2018).

Figure 28 illustrates **Melissa's** reflection of the interview, presented in a quote. She explained the meaning of the quote:

Self-love is a basic feeling, which each of us need to have. Loving yourself is important, because the only person who can love you unconditionally, accept you with all your flaws and misgivings and forgive you no matter what, is you!

Keisha's Portrait

Keisha is a 22-year-old African American female. She is poised, confident, petite and soulful, while gracefully exhibiting her Afrocentricity. **Keisha** has all the dreams and aspirations of a typical American young adult who have successfully completed high school and went straight into a four-year college program. She acquired HIV perinatally of which she said, "My mother told me ... I think I was 11 [pause]." Her recollection of the time prior to being informed was explained:

I knew I took a lot of medicine, but I didn't know why ... No, and I was, I was like a rebel child. I didn't want to take the medicine. So, I would just spit it up and stuff like that, but I never asked ... No, and that's the weird thing. I didn't even get sick even though I didn't take all [pause] my meds how I was supposed to take them.

Keisha's perception on having the virus and the effects that it had on her, she recounted:

W-e-l-l, in my younger days I had this thought about what it would be like. Like,

Oh I can't get married, I can't have kids, [pause] but [pause] that's all I really

thought about. It's when I became, towards my teen years and towards my young

adult years, like now is when it really was a challenge. Like relationships,

making sure I am on top of my health, being an adult.... other than the health part

of it, I would say day-to-day life was pretty regular.

Keisha described a typical day in her life:

Is when I wake up I have to remember, before class, to take my pills, so, I always keep like a bottle of water in my room, so I can rush out because I am always in a rush, aahm, then I go to class. I come home, I study, I watch TV, and then I go to sleep and then do it all over.

Keisha considered what her life without HIV would be:

The fact that I wouldn't need to remember to always take pills, but ... I think relationships would be different, and the fact that, it would be less pressure when you meet someone to figure out when to disclose and aahm, the time frame and if the person is even worth telling ... If the relationship is even a relationship, that is gonna to be meaningful.

In considering her life and the life of her HIV negative peers, **Keisha** shared, "Don't really see a difference, [silence] ... I think that's one thing that makes me, or living with HIV different from a normal person, because there are some information that's reserves." **Keisha** explained about her caregivers while growing up:

Aahm, mostly my aunt. My mother also, but my mother had a visa, so, she would be here for a couple and then she would have to go back. Well, my mom is passed, but my relationship with my aunt, she is like, she is like a second mom to me ... So, it's the same would be, as it would be with my mom ... She knows my Diagnosis. When I was younger, she would take me to the clinics herself, all the medical staff knew who she was, so she was a big part of my like, she is a big part of my life.

Keisha continues to live with her aunt, who continues to provide care, support, and guidance. She attends a prominent university on the border of Miami Dade and Broward County. Regarding her education, she stated:

Right now, I am in undergrad, and I plan to go to medical school, and become a doctor... But, hopefully it goes smoothly like that, but as you know things don't go smoothly, but if it doesn't go smoothly, then after undergrad, I plan to get a masters, and then go to medical school.

Keisha is engaged to be married within the next year, to her partner who is HIV negative. On reflection of their relationship, she shared:

I think I disclosed, 6 months into it, into the relationship ... Aahm, in the beginning, it affected it [pause], being [pause] as having the person understand. Like my doctor, she was open, she has aahm, she was open to him coming in or

asking questions, but in the beginning, it was difficult because it's like, you want this person to understand that, there is preventions - so, they'll be safe, they won't contract it. But once I was able to let him know about the new medical advances and if I take my medicine and we use condoms, and all the protection then he'll be fine. After that it was normal.

Keisha would like to have two children, which she explained, "About the whole thing about having children, I think it's possible, as long as, you know, I take my meds ...

That's no concern but that; but with all the medical advances, you know?" **Keisha** attends church but she does not participate or volunteer in any group or organization; however, she would like to affect change:

That was interesting when you said the stigma part, because I think that's one of the things also that [pause] if there was a way for me to get involved, I would get involved in, the destigmatizing it, because it not what it was many years ago ... and I feel like it's very different, still yes, people contract it if they are not being safe or caring about their health. I feel like it a whole new look on HIV.

After reading the interview transcript at member check, **Keisha** added:

Ok, so what I would like to add is, sometimes, well living with HIV ... sometimes around certain family members or around friends, if they are close enough to you? when they are close enough to you, you sometimes feel like they may not fully know you 100% because, even though they are close to you, you still feel that they don't need to know that you have HIV or you still feel like you may not even trust them enough to know it. So that's the only thing I would add on.

Keisha further clarified:

Yeah, and sometimes you may feel like, oh well, this person is suppose to be so close, you know, maybe they should know 100% of you, but I think that's one thing that makes me, or living with HIV different from a normal person (HIV negative), because there are some information that's reserves. I guess everybody has information that's reserved to them.

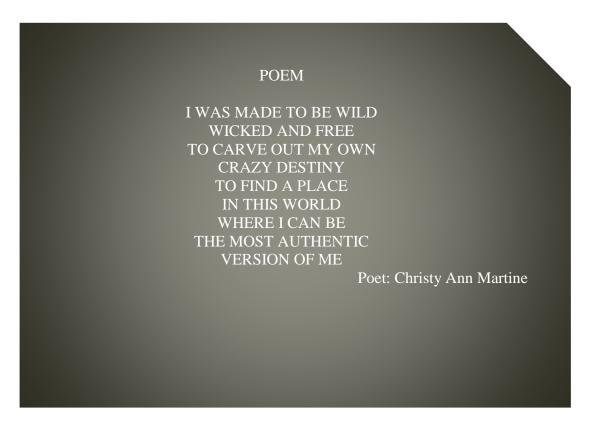


Figure 29. Keisha's reflection of living with HIV (Wright, 2018, adopted from Martine).

Figure 29 illustrates **Keisha's** reflection of the interview, presented in a poem by Christy Ann Martine. She explained the meaning of the poem from that perspective:

Aahm because, the poem is just talking about how you're being, how you were made to be free, made to be yourself, how you already had your own destiny.

Already you had your own path of life, so I feel like even though I have HIV, my

life was already planned out for me. So, whatever I was already gonna I feel like I would have been doing it without HIV.

Kayden's Portrait

Kayden is 25 years young and has lived much longer than anyone thought he would. His parents died when he was 5 years of age, at which time a burial spot was bought for him because he was expected to live much longer. His maternal cousin took Kayden and his siblings (two brothers) in, and she had a daughter who completed his new family. He felt alone in his woes, having to bear the burden of having HIV alone. Kayden shared, "I felt like nobody would understand, I was the only person that had it within my family." When asked when he was told, Kayden disclosed, "I honestly don't recall not knowing ... I always knew as a kid that I was positive." Antivirals are his lifeline. They keep him strong and healthy; and they keep AIDS away. However, taking the medications are not an easy task, because of the effects it has on him:

I take mines late at night ... with my meds, my stomach, every morning it's like irritated, ... when I wake up it like annoyed and agitated, to me aahm ... sometimes I do try to take it with meals.

Sometimes he misses taking a dose, although he is aware that he should not. He explained:

Sometimes I work crazy hour, so sometimes I get home late, or I don't come home at night ... I would be between 2 jobs and sometimes I forget to package, because I usually keep it in a little canister on my key chain but if like the night before I took it, because I keep it on my key chain I forget to replace what's in my keychain then that night I would probably miss it.

What has this thing [HIV] done to him? He conveyed:

I always feel like I am sick, in a sense, like, sometimes it could be just a slightest headache, or the slightest stomach pain and I feel like, Oh, maybe if I didn't have HIV, you know, I probably wouldn't feel like this every day.

HIV is no deterrent to **Kayden's** success, he boasted, "I went to elementary school, I went to middle school, I graduate from high school, I went to college, I got a job." He is planning to return to college in the Fall [2018] to pursue a master's degree. **Kayden** works more than one job to stay afloat, not daring to let his bosses knows of his afflictions and his woes. What would it benefit telling them, he considered? Can they maintain his privacy? Never mind, that's not the job he wants, he awaits a response from his future boss, to fulfill his dreams of the job he truly aspires to have.

Kayden is young, strong, dark, and masculine. He has found himself a similar man to share his love, affection, thoughts, and time. That has not always been the case; having to disclose and then see them chase. He accounted:

Previous relationship, aahm, I want to say I had, like this would probably be my first serious, long-term relationship ... because it's, [silent] it's that trust barrier that kinda prohibits me from getting into relationships ... the biggest battles is always disclosure.

Then having to experience the sudden closure, which he shared:

You hold off on telling, and you know, you get to know the person, and you're thinking; they are gonna get to know me and see me before I tell them, and then you tell them and they still run. Or you tell the from the jump and they run.

So, what about sex in the presence of HIV? **Kayden** explored:

I think it's pretty normal, either way it goes ... I mean, not saying it doesn't happen, but you know, you just always have to use protection, you always have to like [pause], I say it difficult when it that heat in the moment action ... It's like, you got that factor that should I disclose, do I continue in the moment what the hell with it?

As for his peers who do not share [HIV], **Kayden** lamented:

I don't see a big differential between the two ... I mean, everybody 25 are pretty much dealing with the same thing, working, trying to live on their own or going to school or just graduating. Trying to find a career job.

Not knowing when he will die, **Kayden** was always thinking of when his time comes, of which he said, "I came so accustom to being if I make it that far, or if I be there, that you know, I still kinda put that perspective, of not having that longevity life." So, what would life be without [HIV]? **Kayden** expressed his perspectives:

I didn't feel like it would be any different. I wouldn't have that feeling in the back of my mind connecting ... HIV yeh, be like oh I have a common cold, but it's lasting longer, a lot longer than someone else I know ... I got the cold from, you know, and it's like, if I didn't have HIV, would I be still be sick or would the cold last this long?

Kayden believed that the world has changed, especially when it comes to HIV:

You know, this is how it is, you know you don't have to don't touch somebody because ... I am going to be that change in their lives to open their eyes like ... Ok I can date somebody that positive, you know [pause], and don't feel scared to date somebody that's positive...

On a typical day, **Kayden** informed the researcher, "It's you know, making sure that [pause] you have your meds." He does his best to help others he explained, "I do my best to give back ... Like it's not as something I do as work, it's just something you know, I feel like I can offer to the next person ... I also volunteer at a summer camp once a year."

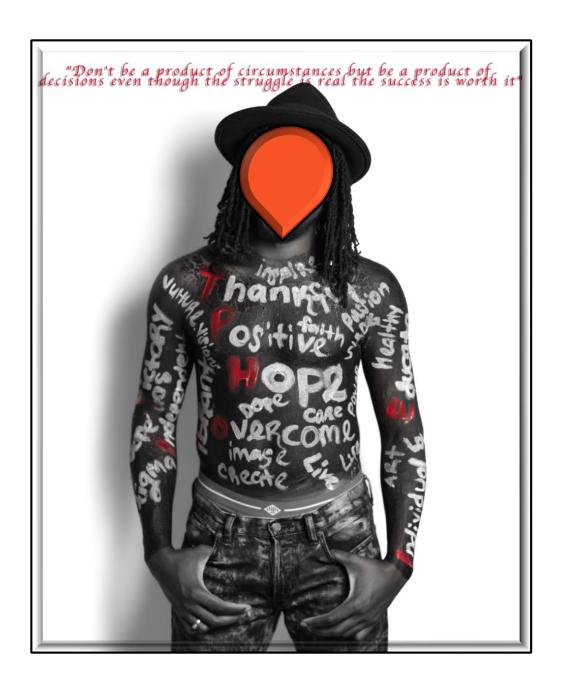


Figure 30. Body mapping art: Reflection of living with HIV (Wright, 2018, adopted from Kayden, 2018).

Figure 30 illustrates a picture of body mapping art map of **Kayden**, which he created for his member check submission, as his reflection of the interview.

Creative Synthesis

The creative synthesis is the final step in the heuristic data analysis process, where the researcher, through the processes of immersion, illumination, and explication, develops an aesthetic rendition of the themes (*Panorama of Living With HIV*; *Consciousness* and sub-themes *Kinship, Concealing* and *Paradox; Realities of Living With HIV*; and *Affirming Milestones*), and the essential meanings of the emerging adults' lived experience of PAHIV (Moustakas, 1990). In the aesthetic rendition, the researcher taps into their imaginative and contemplative source of knowledge and insight by synthesizing the experiences and presenting the discovery of essences and value that can be expressed through a narrative, story, poem, work of art, metaphor, analogy, or tale (Moustakas, 1990; 2001).

Aesthetic Renditions

The emerging adults with perinatally acquired HIV *Panoramic View of Living*With HIV all their life was that their lives are normal, because living with the disease was all that they knew. A typical day in their lives included the normal activities of daily living, and from their perspective, their lives were not any different from their HIV negative peers. They considered themselves as having the same hopes and dreams and being just as successful as their HIV negative peers. They also believed that their lives would not have been any different if they did not have HIV.

The presence of HIV in the participants' lives came into their *Consciousness* at varying times, typically between childhood and early adolescence. The parental support

or *Kinship* they experienced came from different sources. Their biological parents, adoptive parents, relatives, stepparents, family members and siblings provided the *Kinship* or parental support they experienced. However, *Concealing* their diagnosis from other family members, friends and associates occurred frequently among participants. They have recollections of taking medications (antiretroviral therapy [ART]) daily; of being hospitalized and/or making frequent doctor's visits; and of being treated indifferently, prior to their HIV status coming into their *Consciousness*. Their life-saving medications (ART) were somewhat of a *Paradox*, in that it has extended and improved their lives, however, the daily drill of taking medication and experiencing the side effects were burdensome. The medications elicited contradictory emotions, yet participants remain committed to taking them for their life saving properties.

Participants are experiencing the *Realities of Living With HIV* by actively participating in the normal activities that other individuals at their developments stage were involved in. They are graduating from high school, furthering their education in preparation for more lucrative jobs, and setting a foundation for their future; working to maintain their daily existence; living in different residential situations [parents; siblings; individually and with partners]; helping others whom their experience can benefit by volunteering; and being involved in intimate and sexual relationships. *Affirming Milestones* include their realistic goals for a successful future. These goals include higher education; stable career; having children; helping people; and hope for the future. The painting titled, Life's Aspirations 2 (Papas, 2013) was also presented as an aesthetic rendition of the emerging adults' essences of the experience of perinatally acquired HIV.



Figure 31. Life's aspirations 2 (Wright, 2018, adopted from Papas, 2013).

The painter Papas (2013), explained the relevance of Figure 31:

The expectations of busy urbanites and their life's aspirations, the upright climb of the social ladder or staircase to the lit door, sometimes someone waiting to

receive them or trying to reach the top of the ladder through what would be a difficult journey to ultimate success in one's life. Happy people, sad and lonely all have dreams and goals to realize in their life. The abstraction of the buildup city is relevant to the abstract energy incurred by mass living environment.

Connection of the Themes and Sub-Themes to The Human Becoming Theory

The concepts of Parse's Human Becoming Theory (1992)—Meaning,
Rhythmicity, and Cotranscendence—aligns with the themes of *Panorama of Living With HIV*; *Consciousness* and sub-themes *Kinship, Concealing*, and *Paradox; Realities of Life With HIV*; and *Affirming Milestones*, which emerged from this study. The sample of 15 emerging adults shared their experiences freely with the researcher, often divulging very private and personal information. This is important to mention because of the stigma associated with HIV, and consequently, participants' desire to guard their privacy. The information they provided by freely sharing their experiences, allowed for a better understanding of their essences of the experience of living with HIV since birth. The human becoming theory (1992) focuses on human beings and their experiences in the world in the cocreation of health (Parse 1981, 1997, 1992). The theory has three underlying principles, with each having three related concepts/paradoxes: (a) Meaning - imaging, valuing, languaging; (b) Rhythmicity – revealing-concealing, enabling-limiting, connecting-separating; and (c) Cotranscendence – powering, originating, transforming.

Chapter Summary

This chapter presented the findings of this study on the emerging adults' lived experience of perinatally acquired HIV. The heuristic research method (Moustakas, 1990) was used to guide the exploration of the participants' essences of the experience of

living with the disease from birth. Demographic data were organized and presented, as well an individual depiction for each participant. From the individual depictions the themes [Panorama of Living With HIV; Consciousness and Sub-Themes Kinship, Concealing, and Paradox; Realities of Living With HIV; and Affirming Milestones] emerged, and were further elucidated in a composite depiction. Three exemplary portraits (Melissa, Keisha, and Kayden); a creative synthesis; and an aesthetic rendition were also presented. The themes were further connected to the human becoming theory. Chapter Five, which follows, explores and interprets the findings, significance of this study, significance to nursing, implications for nursing education, nursing practice, nursing research, health and public policy, the strengths and limitations of the study, and recommendations for future research.

CHAPTER FIVE

DISCUSSION AND CONCLUSION OF THE INQUIRY

The purpose of this qualitative heuristic study was to explore the emerging adults' lived experience of perinatally acquired Human Immunodeficiency Virus (PAHIV). This chapter presents the exploration and interpretation of the meaning of the study, which includes the themes *Panorama of Living With HIV; Consciousness* and sub-themes *Kinship, Concealing, and Paradox; Realities of Living With HIV;* and *Affirming Milestones*. The themes and sub-themes are linked to Parse's (1992) human becoming theory. A synthesis of the essence of the experience and their connection to current literature are provided, and participants' psychosocial development are explored. The significance of the study, the significance of the study to nursing, the implications for nursing education, nursing practice, nursing research, health and public policy are also presented. The strengths and limitations of the study are discussed and recommendations for future research presented.

Exploration of the Meaning of the Study

Since the HIV/AIDS epidemic of the 1980s, individuals who acquired HIV from their mothers have not been adequately studied because they were not expected to survive infancy (Hazra, Sidberry, & Mofenson, 2010; Levine, Aaron, & Foster, 2006; Phillips, Rosenberg, Dobroszycki, Katz, Samsara, Goat, ... Abadi, 2011). However, they have defied the odds and have survived into the developmental stage of emerging adulthood, where most individuals have not yet entered in the social or institutional roles of marriage, parenthood, and long-term employment (Arnett, 2006). Consequently, not much is known about the physiological, psychological, or sociological challenges that the

emerging adult with perinatally acquired HIV may encounter, nor their essences of the experience of living with HIV since birth. Therefore, this study explored the emerging adults' lived experience of perinatally acquired HIV to elucidate their essences of the experience of living with HIV since birth and to determine if they have met the benchmarks of the developmental stage of emerging adulthood.

The heuristic research method (Moustakas, 1990) was selected to guide the data analysis of the exploration of the essences of emerging adults' lived experience of perinatally acquired HIV (PAHIV) because it is an organized and systematic form for the investigation for human experiences (Moustakas, 1990). The researcher was able to capture the participants' voices of their experience through semi-structured interviews, and their artistic presentations of their recollections of the interview. From these voices emerged the themes of *Panorama of Living With HIV; Consciousness* and sub-themes *Kinship, Concealing, and Paradox; Realities of Living With HIV; and Affirming Milestones.* According to Douglas and Moustakas (1985), the objective of *Heuristic* research is to "discover the nature of the problem or phenomenon itself and to explicate it as it exists in human experience" (p. 42), as opposed to traditional inquiry, which presupposes the actuality of cause and effect. Douglas & Moustakas (1985) wrote:

Heuristics is concerned with meaning, not measurements; with essence, not appearance; with quality, not quantity; with experience, not behavior. Formal hypotheses play no part, though the researcher may have initial beliefs or convictions regarding the theme or question based on intuition and/or prior knowledge and experience (p. 42).

According to Moustakas (1990), the heuristic design embraces beliefs, values, theory concepts, processes, and methods that are essential to the understanding and conducting of heuristic research. Moustakas (1990) further communicated that rigor in heuristic research is a question of meaning, for both the researcher and the participants, in the ultimate depiction of the experience.

The trustworthiness of this study was demonstrated through rigor in the methodological process and relevance of the findings (Findley, 2006); the processes that have been established to determine the scientific integrity of qualitative studies. The criteria of trustworthiness or rigor as proposed by Lincoln and Guba (1986) includes credibility, dependability, confirmability and transferability. Lincoln and Guba (1986) also suggested appropriate techniques for each criterion that would increase the probability that the criteria are met or test the extent to which they have been explicated. Lincoln and Guba (1986) suggested using prolonged engagement, persistent observation, triangulation (cross-checking) of data, peer debriefing, negative case analysis, or member checks as techniques to ensure the credibility of a study. According to Krefting (1990), "central to the credibility of qualitative research is the ability of informants to recognize their experiences in the research findings" (p. 219). The member check process of this study satisfied the credibility criteria in qualitative research rigor in part, where n = 13(87%) of the 15 participants attending their member check meeting. Study participants were asked to review the individual depiction from the transcribed tape-recorded interviews to confirm the accuracy of the depiction and to determine if the data were reflective of the information they wanted to share.

Melissa was one of the 13 participants who kept their appointment for the member check meeting. At the initial interview, Melissa was emotional and unfocussed, and she mumbled at times. Her emotional state at that time prompted the researcher to offer to discontinue the interview; however, she objected. At the member check meeting, Melissa had quite the opposite demeanor. She was more lucid, unemotional, poised, and clear in thoughts. Melissa was evidently not pleased with the person/voice that came through in the depiction from the transcribed recorded interview. She pondered and sighed over the content of the depiction for over 30 minutes and decided to do over the interview.

Credibility was also maintained by obtaining Barry University's Institutional Review Board (IRB) approval before initiating the study, by obtaining an informed consent from each participant, and by advising each participants of their right to withdraw from the study at any point without any consequences. Credibility was further maintained by the researcher's frequent consultation with dissertation chair for clarifications and directions in the research process. Dependability and confirmability were evident in the detailed description of the research process and methods of arriving at the themes and sub-themes and the paper trail provided of the study. These included the use of NVIVO data management system, word documents, and Excel spreadsheets to clarify thoughts and processes that the researcher employed to maintain the integrity of the study. The researcher presented an experiential context in the literature review exposing prior assumptions and preconceptions of the phenomena. The researcher also maintained a reflexive journal throughout the research process. Consistent with the heuristic research process (Moustakas, 1990), the participants' voices were maintained

throughout the data analysis process in the: individual depictions, composite depiction, exemplary portraits, creative synthesis – aesthetic renditions, and the presentation of themes: *Panorama of Living With HIV; Consciousness* and sub-themes of *Kinship*, *Concealing and Paradox; Realities of Living With HIV;* and *Affirming Milestones*. Transferability was demonstrated in the thick, rich descriptions of the context in which this study was carried out and the challenges encountered in the access and recruitment of participants.

Interpretive Analysis of the Findings

Demographic Characteristics

In this study sample, all participants were between the age of 18 and 25 years old. Most participants were in the age group 24-25 years where n = 7 (46.66%). There were more females n = 10 (66.67%) than males n = 5 (33.33%). Females aged 24 to 25 years n = 5 (33.33%) accounted for the largest age/gender group overall. The older age among this population sample was reflective of the challenges encountered in the access and recruitment of participants phase of the study. These older emerging adults represented individuals who were able to make independent decision to participate in this study. Study participants had either already transferred from pediatric care and/or were more autonomous in making health care decisions.

Black African or American participants n = 13 (87%) accounted for the largest ethnic group; Hispanic n = 2 (13.33%) accounted for the second largest ethnic group; and Whites/Non-Hispanics n = 0 (0%) were not represented in the sample. Most participants 66.67% (n = 10) were employed; and 33.33% (n = 5) were unemployed. Of those who were employed 60% (n = 6) were employed part time, and 40% (n = 4) were employed

full-time. Most participants 80% (n=12) were still living at home with their parents/family. All participants n=15 resided in South Florida, in either Broward, Miami-Dade, or Palm Beach county. Most participants n=10 (66.67%) resided in Broward County, which accounted for the largest group; n=3 (20%) participants resided in Miami-Dade County, accounting for the second largest group; and n=2 (13.33%) participants resided in Palm Beach County, accounting for the fewest number of participants.

Themes and Sub-Themes

Theme: Panorama of Living With HIV

Panorama is defined as a "unlimited view in all directions ... a continuous series of scenes or events; constantly changing scene ..." (Neufeldt & Guralnik, 1986, p. 976). Beck (2010) used Panorama to describe the scope of Florence Nightingale's legacy by highlighting Nightingale's influence on nursing and healthcare. This legacy that Beck (2010) described encompassed Nightingale's recognition in nursing history; her influences, which still echoes beyond her neighborhood and the battlefield where she served; in villages and cities around the world; in the halls of leadership; and in behind the scenes discussions that have shaped the history of healthcare. The stories Beck (2010) highlighted were "drawn from the much larger Panorama of her [Nightingale's] 50-year career" (p. 291). Beck (2010) also referred to the larger Nightingale Panorama as nursing.

In this study, *Panorama of Living With HIV* described the participants' overall view (common thoughts) of living with HIV from birth (what it was, what it is; what it will be); their experiences with HIV and its effects on their entire lives – living with HIV. This

includes the participants' perceptions of life; what a typical day in their lives entailed; what they consider a normal life to be; how they perceive their lives with HIV to be different from their HIV-negative peers; and their perception of what life without HIV would be like. Participants expressed their perception of life growing up, especially during the earlier years, to have been difficult, lonely, secretive, and a struggle to get through the day. However, they have acknowledged that their lives have changed and that they now find themselves more grounded and making better choices. They now consider their lives as being normal and not any different from a normal child. Madiba and Mokgatle (2016) found similar results in their qualitative exploratory study among 37 adolescents (12-18 years) in South Africa. The study explored how adolescents with perinatally acquired HIV (PAH) experience living as HIV positive adolescents and examined their perceptions and experiences about disclosure and onward self-disclosure to friends, sexual partners, and others. Madiba and Mokgatle (2016) found that participants had learned to get on with their lives by conveying a sense that they had learned to live with their diagnosis and that their lives were normal and similar to other emerging adults. Participants in this study shared their perceptions of life. **Ahmazin** discussed her perception of her life with HIV:

One thing I appreciate about this experience, is aahm, it it's grounded me and allowed me to make choices more carefully. The only thing that I can say is aahm, that with the HIV, being HIV positive aahn [pause] [silence] is that HIV lives with me, I don't live with HIV, [pause] and I use that as my stepping stone to go above and beyond in all aspects of life.

Ashley shared her perception of growing up with HIV: "I mean it's no different growing up, like being a normal kid." **Blessed** explained how difficult it was for her growing up with HIV:

It was [pause], it was really hard growing up, because I thought I was like something disgusted [pause].... I hated life, because I felt like, how, why, I was the only one who was taking medicine.... Honestly, having a health issue shouldn't stop you from doing what you should do ... that's just another excuse for you to make yourself depressed and everything.

Brittany disclosed her perception of growing up with HIV: "I mean it's [pause], well, it's normal to me now. I still think about it [pause], aahm [pause], I just feel normal [pause], yeh I just feel normal." **Edward** explained his perception of growing up with the disease as having to keep a secret:

Growing up having HIV ... is like having a secret that you cannot tell anybody, and that's at least what my mom raised me to believe ... it's like "don't forget to take your medicine. If you do, bad things are going to happen, so don't."

Jamie shared the effects that the disease had on her:

I feel like [pause] I just can't do like [pause] stuff that normal people do ... I just feel like something is wrong with me ... I feel like I would be more free because sometimes I feel trap [pause].... I just feel like I would be more like relaxed, more suitable, more [pause] ... I am just living day by day taking it one step at a time.

Kayden explained what his life was like growing up with the disease:

I wouldn't say it's like the easiest thing [pause].... I felt like it got easier as you become older ... You choose your battles wisely ... I came so accustom to being

if I make it that far, or if I be there, that you know, I still kinda put that perspective, of not having that longevity life ... growing up being positive ... I felt alone so, I felt like nobody would understand.... I wouldn't say abandon but left to like cope and deal with things on my own, as far as being HIV positive.

Keisha expressed her thoughts on growing up with HIV:

In my younger days I had this thought about what it would be like. Like, Oh I can't get married, I can't have kids ... It's when I became, towards my teen years and towards my young adult years, like now is when it really was a challenge. Like relationships, making sure I am on top of my health, being an adult ... I have to make sure I know what all the terms mean, medically, and I am taking my meds.

Loren shared her perspective of living with HIV, "I feel like certain people [pause] will treat you differently ... whereas when you [they] don't know, people treat you like ... your' a regular person. Lovely communicated, "It's [pause] different ... [pause] It's fine [pause] I have a nice family, [pause] and [pause]." Margarita reflected on what was important:

I look at myself as me, because, this is something I couldn't help ... life just gave it to me, so I just look at it as a good thing now. If it was different I probably would be in longer relationships, honestly ... people should be strong because its [pause], its hard living with it ... Once you love yourself everything will fall a lot in place.

Melissa explained her perception of life growing up with HIV:

As I growed up, I ... didn't go through nothing tragically you know, but losing my mom.... sometimes I wonder 'why me? Why did it happen to me?'... but I don't really think like that anymore. It be lonely sometimes ... I am not depressed but I get like emotional sometimes it's like, I have to constantly pull myself together ... I have to say I don't want to give up ... there are moments when it's like, eeh! Enough! I feel like as long as you fighting, you want to live and want better for yourself ... the people that love you don't want you to go. They want you to be here with them and ... I want to achieve that goal of being here.

Rashad reflected on living with the virus:

I mean, my days of dwelling in it, were over a long time ago from when I was young, so I don't look at it as, you know, curse or anything.... I used to aahm, kind of have resentment for my mom.... It wasn't in my power, it wasn't in my hand, I had no choice, so I used to dwell on it when I was younger, but now I basically accept it. Just because you have the virus doesn't makes you.... I have it but it doesn't control me, as long as I take my medicine and do everything that I have to do, I will be fine.... I am always going to be hopeful aah.

Travis expressed his perception of life growing up with HIV:

Aahm, it been kind of a journey for me, I would say it was kind of irrelevant for me, until possibly elementary school.... I start feeling outcast about it ... something I was ashamed of, I became more accepting of it, and it got to the point where it's, I barely even notice, I don't even think of it, it's part of me.... having

HIV is, long story short, not a big deal ... and you can have a long successful happy life.

Participants saw themselves as living a life that is similar to or no different from a regular person or another who does not have the challenges of living with HIV for as long as they have. Madiba and Mokgatle (2016) also found in their study that participants desired for a healthy and normal life. According to the researchers, participants conveyed a sense of positivity in their lives and most understood the importance of taking care of their health. In this study, participants displayed the same sense of positivity. They described their lives growing up as being normal because it was the life that they knew and that HIV did not affect anything that they were doing in a negative way. They were comfortable, successful, and living regular lives similar to others who were HIV negative. Participants contended that HIV had no control over them; it is just a part of their life. They shared their perspectives of their normal lives as follows: Ahmazin said, "I can live a normal life, just like a person that is negative ... the thing is, with HIV doesn't affect anything that I am doing in a negative way." Ashley explained why her life was normal:

I mean it's no different growing up, like being a normal kid ... they kind of shielded me, and the fact that, you know, you're still a child ... So, to me it wasn't any different ... people being born with it, we become so use to it, like it's just a part of us.

Blessed made it clear that her life would not be any different:

My life would still be the same either way [pause] because I already go through a lot with my disability. Yes, high school, high school graduate, I accomplish

having a beautiful healthy daughter, and I accomplished just being here and taking my medicine every day. So, I accomplish a lot by having by having HIV.

Brittany explained that her life would still be the same:

Well, before, like when I first found out I was really scared, but then now I realize it and all that stuff, and I am comfortable with it ... aah, my life would be still the same, with HIV or without ... I mean It's gonna be like a normal life to me. Like, healthy, aahm [pause], reaching for my goals ... cosmetology, owning my own beauty salon.

Bryan shared his thoughts on why his life was normal:

Until your parent or your guardian actually tells you what's going on you don't really know you actually have this thing, you just think that you are a normal kid ... growing up with it you're a normal person.

According to **Edward**, "But, other than that, my life is completely normal ..." **Jamie** expressed her thoughts on living a normal life:

At the end of the day you can' let it get to you, you can't let it beat you ...

it's just a disease ... it's something that you can really [pause] learn from and just
embrace it and just deal with it and live a normal life ... people live with it,
people have kids with it, a whole family with it, and it's like people live normal
life with it.

Kayden imparted, "I honestly feel like, for me, aahm, that I have been achieving the benchmarks as normal kids." **Keisha** stated, "Normal living was regular as a child ... But other than that, other than the health part of it, I would say day-to-day life was pretty regular." **Loren** revealed her thoughts on living a normal life:

I don't really see that much of a difference. Yeh! I really don't ... I feel like it, it's kind of normal living with it ... because I was born with it ... I don't really see it as, you know, out of [pause], something abnormal.

Lovely mentioned, "... [pause] It's fine ..." **Melissa** explained, "Aah, [heavy sigh] ... sometimes I forget that I have the virus, I just like ... I do everything like a normal person would do." **Rashad** shared how he saw himself:

I look at myself as a regular person. So, I stuck with that it, I have it but it doesn't control me, as long as I take my medicine and do everything that I have to do, I will be fine.

Travis discussed his experience of a normal life:

I realized that this thing HIV, wasn't a big deal, at least, not anymore. I became more accepting of it, and it got to the point where it's, I barely even notice, I don't even think of it, it's part of me ... and that's all there really is, needs to be said about that ... HIV is a part of my life ... I see myself as pretty normal.

Williams, Ferrer, Lee, Bright, Williams, and Rakhmanina (2017) qualitative study, which described the lived experience of PAHIV-infected young adults, reported an emerged theme of limited social capital where participants described their typical day as being without purpose, idle, and missing something. Their description of a typical day is different from participants in this study who reported that a typical day in their lives involved the normal activities of daily living (personal hygiene, eating); attending regular activities (school, work, doctor's visit); spending time with relatives or intimate partner; relaxation; self-love/care and taking care of their children. Participants also emphasized

having to take their medication on a daily basis, sometimes twice per day. They shared what a typical day in their lives was like. **Ahmazin** explained a typical day in her life:

Well, aahm because I have two jobs and I go to school, it's basically work and school ... and on the days that I don't have school or not doing anything school related work and then most likely hanging out with my boyfriend.

Ashley shared what a typical day in her life looks like:

I get up, I get ready, I go to work, aahm go to school, come back aahm I know towards before I go to bed I have to take my medicine ... I eat dinner with it, take it, aahm then that's basically it.

Blessed said, "Now it's very peaceful." **Brittany** explained what a typical day in her life looks like:

I go to school, I do this, I do that, the only think that I have to remember is drinking my pills every single day ... waking up every morning, go to school; hang out with friends, being able to go out and aahm, yeh!

Jamie shared what a typical day in her life looks like:

Getting up, take my medication [pause], relaxing [pause] until work because it has a side effect as in dizziness, feeling sick, so ill lay down and try to take a nap, wake up go work, eat something, come home take a shower, eat, take my medicine again and then all over again.

Kayden mentioned, "It's you know, making sure that [pause] you have your meds." **Keisha** explained a typical day in her life, "When I wake up I have to remember, before class, to take my pills ... then I go to class. I come home study, I watch TV, and then I go to sleep and then do it all over." **Lovely** shared a typical day in her life:

I wake up in the mornings [pause] and I [paused-stutter] get dressed and make my own [pause] coffee in the mornings ... I wait ... I wait for I wait at the lobby so my van can come [stutter] and pick me up, and then I pack my lunch, Monday ... We watch movie there.

Margarita explained what a typical day in her life is like:

I have learned to not look at myself as a "Positive" person ... I try each morning when I wake up give myself a positive affirmation, even if my breath stinks, or even if my hair is looking funny ... a typical day would be, me trying my best to love me, because it's hard to love me when I am HIV positive.

Melissa echoed, "You know, wake up in the morning, work, aahm, take care of my son and then ... take my medicine, or I might have to go to my doctor's appointment, and you know?" **Rashad** shared what a typical day in his life was like:

For me, is getting up, aahm, aah about 8:30, taking a shower, daily routines, take my meds, and then I go to work ... depend on traffic, it's about 45 minutes. ... from 10 o'clock to sometimes 7 o'clock depends on when the parents pick them up ... after 7 o'clock I come home, and I construct things, what is called case notes ... sometimes I stop get something to eat ... After I do my case notes come home I relax, try to relax, watch TV.

Travis discussed a typical day in his life:

I wake up, I have breakfast, I go to work. ... If I am not working, I am doing music. I talk to my doctor about things that might come up, but besides that it looks pretty average, I would say [laugh].

Participants consider that their life without HIV would be normal except they would not have to take medication, go to the doctor as frequently or be hospitalized, and they would have more friends and be in longer-termed intimate relationships.

Participants shared their thoughts on what their lives would be like if they did not have HIV. Ahmazin explained, "HIV doesn't affect anything that I am doing in a negative way. It's actually, aah, push me and encourage me to do more things." Ashley shared her thoughts:

Maybe, my life would probably be different if I didn't have to go to the doctors all the time ... I was sick when I was young, so maybe like, instead of being in a hospital or something, like when I was 4 or 5, I probably could have been like playing, or, you know, doing something educational or something you know? ... I probably could have made me more [pause] ... smarter or something, maybe more advanced.

Blessed stated, "I think even if I have HIV I am still able to do everything, if I set my mind to it, just not think about what I have, just do it as long as you are safe." **Brittany** explained, "My life would be still the same, with HIV or without ... It's gonna be the same ... Like, aah [pause] I mean It's gonna be like a normal life." **Kayden** expressed his thoughts:

I know at time I get like real frustrated ... I didn't feel like it would be any different. I wouldn't have that feeling in the back of my mind connecting ... HIV ... I got the cold from, you know, and it's like, if I didn't have HIV, would I be still be sick or would the cold last this long.

Keisha stated, "Yes, and the fact that I wouldn't need to remember to always take pills ..." **Loren** explained:

Yes, I think relationships would be different, and the fact that, it would be less pressure when you meet someone to figure out when to disclose and aahm, the time frame and if the person is even worth telling ... If the relationship is even a relationship, that is gonna to be meaningful.

Lovely said, "I don't know ... aam, [long pause], I don't know." Margarita stated, "I think I would not be so depressed ... I think, I would have a lot of more friends, I wouldn't be so antisocial, I wouldn't be so depressed." Melissa explained her thoughts on what her life without HIV would be like, "I would say it the same, aahm better relationships you know? ... No. No, I don't feel like it will be different. I feel like it would just be the same as a normal person." Travis shared his perception of what his life without HIV would be like:

Honestly, I think it would be the same.... I think one little difference though would be, I think I would be a little more, at peace with a relationship, just because, I wouldn't have to bring up that whole conversation about it.

Participants does not consider their lives as being different from their HIV negative peers, except that they have to be more cautious and practice safe sex; they have more doctor's visit; and they have to keep their disease a secret, while also having to disclose their HIV status to their intimate partners. Otherwise, they consider their lives to be the same. This finding is consistent with the findings in Mutumba, Bauermeister, Musiime, Byaruhanga, Francis, Snow, and Tsai, (2015) phenomenological study among 38 PAHIV adolescents (13-19 years). The purpose of the study was to:

Contribute to the literature by focusing on adolescents living with HIV (ALH) in a resource-limiting setting (Uganda) and highlighting both the stressors and coping strategies employed by ALH in order to identify and inform the development of evidence-based programs, as well as recommendations for future practice and research. (Mutumba et al., 2015, p. 87)

The themes that emerged from Mutumba et al. (2015) study were psychosocial challenges; disclosure; adherence; coping strategies; treatment confidence; avoidance and distraction; secrecy; social support; and spirituality and religiosity. The coping strategies reported by participants in Mutumba et al. (2015) included comparing themselves to their HIV negative peers, "particularly in relation to dealing with the hassles of taking medications every day, high pill burden, and even accepting their HIV status" (Mutumba, et al., 2015). Participants in this study shared their belief that their lives are not different from their HIV negative peers. **Ahmazin** said about her life not being different from her HIV negative peers:

I just have to be more careful; you are more prone to get sick ... the only other thing that comes up is sex ... I still have sex like a regular person and I still do sex like a regular person.... you can't just, you know, do it freely as you want when you're a person who is positive you have to take into account...

Ashley explained her perception of her life not being different from her HIV negative peers:

I have to go to the doctor a lot more; if I have a cold, I am probably going to be like, you know, like sick for a week or so compared to anybody else ... if I go to a pharmacy and I pick up my meds [pause], like people start acting different toward ... other than that I can accomplish basically, anything that anybody else can.

Brittany informed the researcher about her opinion of her life not being different from her HIV negative peers, "Sometimes I see like everybody, well, I see everybody getting pregnant ... but that's not my interest. And then for them to not having to worry about what this person have or what that person have." Keisha described her life not being different from her HIV negative peers, "I don't really see a difference, [silence] ... I think that's one thing that makes me, or living with HIV different from a normal person, because there are some information that's reserved." Melissa expressed her opinion of her life being no different from her HIV negative peers:

I can't really say that it's a difference. It just feel the same, I don't see nothing different about it ... my sister don't have it, but we, we on the same journey of you know, want a better stuff for our life ... For we both have a child, the same thing that she did, push out a baby, I was able to do the same thing ... Only thing that you know...

Loren confided about not being different from her HIV negative peers, "Peers my age tends to be sexually active and aahm [pause] ... I have to make sure that, aahm, I am safe if I am sexually active. I just have to be more careful, with certain stuff." **Rashad** shared his perception of his life when compared with his HIV negative peers:

I am actually doing better than most of my peers that, I believe, don't have it ... I look at myself as a regular person ... if you're regular or if you're normal, I should say, that you would take those pills.

Travis informed the researcher about his perception of his life not being different from his HIV negative peers:

I see myself as pretty normal ... the only difference I would see aah a difference is in my sexual like ... But honestly, I don't feel any different from anyone else, I really don't, and even going back to like the sexual life, it not like, it's a curse.

Participants' essence of living with HIV since birth as described in *Panorama of Living With HIV*, is their perception of life growing up being difficult in the early years and becoming normal and similar to their HIV uninfected peers as they got older.

Normalcy was demonstrated in their typical day involving regular activities, except for having to take their medications daily and on schedule; and frequent doctor's visits and hospitalizations. Participants acknowledged that their lives are different from their HIV negative peers in some regard. They have to be more cautious by practicing safe sex; keep their HIV status a secret; and disclose their HIV status to intimate partners. Their essence of living with HIV since birth as portrayed in *Panorama of Living With HIV* was also compared with findings in research studies conducted by Madiba and Mokgatle (2016), Williams et al. (2017), and Mutumba et al. (2015).

Theme: Consciousness

Consciousness is described as a noun meaning, "the state of being conscious; awareness of one's own feelings, what is happening around one, etc..." (Neufeldt & Guralnik, 1986, p. 296). Consciousness was demonstrated in Madiba and Mokgatle (2016) qualitative exploratory study that "explored how adolescents with PAH experience living as HIV positive adolescents and examined their perceptions and experiences about disclosure and onward self-disclosure to friends, sexual partners, and others" (Madiba & Mokgatle, 2016). The researchers found that all participants in their study were formally told of their HIV status either at home, in the clinic, or at the

hospital. Formal disclosure occurred at varying of ages, ranging from 5 to 16 years.

Most participants knew about their diagnosis in excess of 5 years at the time of the study.

In this study, *Consciousness* is the participants becoming aware of their HIV status – disclosure of their HIV status to them. It describes when they were informed of their HIV diagnosis; their knowledge of HIV at the time they were informed of their diagnosis; their concerns before being informed; their response to their HIV diagnosis; and the impact that their knowledge of the disease had on them. Similar to the findings in Madiba and Mokgatle (2016), study participants became *Conscious* of their HIV status at varying ages, and all were informed by the age of 15 years. The HIV knowledge data informing this study were self-reported by participants. Unlike the other study participants, **Ahmazin** reported being diagnosed with the disease when she was 15 years of age. While she was the only participant in this study who was diagnosed when she was a teenager, the late diagnosis of HIV, which was transmitted from mother to child, is not an uncommon occurrence.

According to the WHO (2013), this group of "slow progressors" is recognized as an increasing proportion of adolescence who were born with the disease, remain undiagnosed, and their initiation on anti-retroviral therapy (ART) was delayed. The WHO (2013) further indicated that this late diagnosis and initiation of care often resulted in chronic medical and developmental problems (WHO, 2013). Study participant Ahmazin also reported becoming sick, which prompted a visit to the hospital where she was diagnosed with HIV that she acquired from her mother sometime between conception and shortly after birth. She shared her experience of becoming *Conscious* of having the disease at that late stage of development, "It was my 9th grade year, aahm, in

high school ... I had bloody diarrhea, so, as I go to the bathroom. I felt perfectly fine, it was just, you know, the bathroom situation [chuckle]."

Other participants shared the age or point in time that they became *Conscious* of their HIV status: **Ashley** mentioned, "When I found out I was positive, I was probably around 6 or 7." **Brittany** stated, "When I was eleven." **Bryan** explained, "I found I had it when I was in the fifth grade ... I keep asking him why I was taking the medication and he didn't tell me, so I refused." **Edward** reported, "I would say about 12 or 13 ... in camp, in the camp ... I was 12 years old." **Jamie** divulged, "I think I was 7 or 8 years old." **Kayden** stated, "I honestly don't recall not knowing that I was HIV positive. I always knew as a kid." **Keisha** shared, "aahm, my mother told me ... I think I was eleven [pause], when she told me." **Loren** explained when and how she became *Conscious* of her HIV status:

Nine years old ... aahm, one of the nurses from the clinic that I went to, she came to my house and she told me about it. She sat me down and she explained what it was and, you know, pretty much that I had it.

Margarita explained how she became *Conscious* of her HIV status, "When I found out I was in 9th grade ... After my mom passed away." Melissa commented about becoming *Conscious* of her HIV status, "I didn't know until I was 13 so, when I was in elementary." Rashad conveyed about becoming *Conscious* of his HIV status, "I was probably, 10, 11 ... 11 may be." Travis informed the researcher about his *Consciousness* of his HIV status, "Maybe 4th 5th grade."

Participants' knowledge deficit was evident around the time that they became *Conscious* of their HIV status. Their knowledge deficit was related to what HIV was and the impact

it would have on their lives. Participants were not aware of the different ways an individual may acquire the virus. They were of the opinion that an individual had to have had sex to acquire the virus, not knowing that children could be born with the disease as well. An opposite result was found in Stangl, Bond, Mackworth-Young, Sievwright, Singh, Clay, ... Konayuma (2015) formative research among adolescent girls (15-19 years) living with HIV in Zambia. The purpose of the study was to generate evidence-based ideas for services and programmatic interventions that supports health transitions to adulthood. Stangl et al. (2015) found that all participants had at least basic knowledge about HIV, although there were specific gaps in their knowledge.

Participants in this study shared the extent of their knowledge about HIV and the fears and concerns that they had when their HIV status came into their *Consciousness*. **Ashley** communicated, "At the time I didn't know what it was ... I mean [drawn out], I was just in shock.... I was like, what is it? What is HIV?" **Brittany** conveyed, "My doctor asked me what do I have, and I didn't know what I have ... but I really didn't know what it [HIV] was ... when I found out I was really scared." **Margarita** expressed, "When I first found out ... I didn't have much knowledge of it, so I just felt like, Oh my gosh I am going to die ... after finding out I fell into a deep depression ..." **Melissa** explained:

I didn't know that kids could ... I was just loss at that moment, because I didn't have sex, I didn't do this and stuff, I was born with it. I cried, but after I left the doctor's office I forgot about the whole thing and just went on about my life.

Rashad conveyed, "I didn't understand it ... Because of all the stigma that was going on.

I didn't understand it, I thought I am gonna die soon..." Travis affirmed, "I didn't know

much about it at all when I was little ... it was just weird.... I didn't feel like a [pause] a normal kid in a normal family."

Participants shared that when their HIV status came into their *Consciousness*, their caregivers did not have much knowledge about HIV and caring for an HIV infected child in need. They were unprepared for their role; however, they went the extra mile to learn about the disease by attending courses and conducting internet searches. Caregivers did their best with the resources that they had to be supportive. Similar results were found in Stangl et al. (2015), where their participants received practical, financial, and treatment support from their family members, who were also found to lack detailed knowledge about HIV. Participants shared their experiences, including **Ashley** who explained her adoptive parents' experience:

My mom didn't know anything about it at the time, neither my dad, so they both had to go through like you know like different courses ... my dad as I got older, he started learning more about it ... he was teaching me about it, like I didn't know ... He took the initiative to learn.

Brittany disclosed, "I asked her [sister] what is HIV? She searched it up for me and then she told me." **Travis** stated, "My parents, they, they did their best to explain it to me aahm, but they could only explain so much."

Participants in this study described concerns they had about their caregivers' ambiguity or lack of straight forwardness related to their diagnosis before their HIV status came into their *Consciousness*. They reported that caregivers delayed disclosing their HIV status by withholding information, avoiding answering related questions, and being deceptive. Similar results were found by Namukwaya, Paparini, Seeley, Bernays

(2017), where some young people felt aggrieved by their caregiver's ambiguity, which raised their initial suspicions and led to questions. However, Madiba and Mokgatle's (2016) findings were contrasting to the results from both studies. Participants in Madiba and Mokgatle's (2016) study were satisfied with how their parents or caregivers handled their disclosure; they were relieved and happy to hear of their illness, and few reported neutral reactions and not feeling anything after they learned of their HIV status. Study participants shared their experiences: **Ahmazin** lamented, "My parents didn't notify me at the hospital. My parents probably told me a month after I got out of the hospital." **Brittany** stated, "My parents didn't tell me yet. They wasn't ready to tell me yet. That's what they told me." **Bryan** expressed his opinion about his caregiver's ambiguity:

They [parents] don't want you to freak out so they might tell you a lie ... I didn't feel comfortable going to my mom about it because of course she is the one who told me that it was a hospital accident.

Jamie informed the researcher about the treatment she received from her caregiver:

She [aunt] used to always make, have me drink out of a different cup, she use to always have me drink out of like, eat out of different spoon ... as I got older I asked my cousin, that's when everything came together, like Oh! ... this is why she used to do that and it's just like [pause], why you used to treat me that way, you know?

Margarita affirmed, "He infected my mom, didn't tell my mom until after she was, she found out she was HIV positive. I feel like he could have told her."

Participants reported having concerns or events occurring in their lives, prior to their HIV diagnosis coming into their *Consciousness*, which made them questioned or pondered the significance of those occurrences. They reported recollections of having to

take medications daily; having other illnesses such as shingles; frequent doctor's visit; the loss of biological parents; of others treating them with indifference; and of deceit and omission of information. They also reported that their lives were normal, before associating these activities with HIV. Similar findings were elucidated in Williams et al. (2017), qualitative study among 17 youths (18-24 years), which described the lived experience of PAHIV young adults. The themes that emerged from their study were: (a) lived space, (b) lived time, (c) lived body, and (d) lived human relation, which supported their findings of a life not expected.

The theme lived time as described by Williams et al. (2017) is related to the time before their participants learned about their diagnosis, they were deceived and information regarding their HIV diagnosis was withheld from them. Madiba and Mokgatle (2016) found in their study that disclosure to participants in most cases, were proceeded by episodes of serious illnesses. Study participants shared their reflections of events occurring prior to their HIV status coming into their *Consciousness*, that were of concern to them: **Ahmazin** shared, "[Mother] didn't know why I was getting shingles ... older people get them ... the test was proposed to her, aah, that she should get me tested? But she declined." **Brittany** explained occurrences in her life prior to becoming *Conscious* of her HIV status:

Yes, I was on medication and, I was like going to the doctor every 3 months, and aahm, but then [pause]. Before I found out [pause], I wasn't really worried about, well, to be, I didn't even know, so I was just living my life, yeah.

Bryan mentioned, "You always wonder like, why do I take this liquid medication at night, why do I have to take a pill or three pills at morning or night? Until you actually find

out..." **Keisha** said, "I knew I took a lot of medicine, but I didn't know why ... I didn't want to take the medicine ... and that's the weird thing. I didn't even get sick even though I didn't. **Margarita** divulged, "As a child I always wondered, why my family treated me different ... my mom told me I had asthma, and that's why I was taking all the pills ..." **Melissa** communicated, "As I growed up, I didn't have really, didn't go through nothing tragically you know, but losing my mom. But I didn't feel that the worse ..."

Participants described their initial response, when they became *Conscious* of their HIV diagnosis, as being shocking, challenging, frustrating, crushing, and adding to preexisting issues in their lives. Their *Consciousness* of their HIV status left them feeling depressed and with suicidal thoughts without attempt; sad; crying; refraining from having sex until a later age; and the feeling that they were going to die. Participants eventually, embraced the news, forgetting about the diagnosis and went on with their lives, with the perspective that things happen to people in life. Participants in Madiba and Mokgatle's study (2016) also had both positive and negative reaction to their HIV diagnosis. Some reported being shocked and hurt and having cried after learning that they were HIV positive, while others reported anger, pain, confusion, disbelief, and the feeling as if they were going to die. Study participants shared their experiences of becoming *Conscious* of their HIV status. Ahmazin reflected on her dismay when she became *Conscious* of her HIV status:

At first, it was very challenging ... added to my depression [pause] ... suicidal thoughts – I want to kill myself, I never attempted anything, but I did have those thoughts ... I was frustrated and upset ... I really felt like I was being punished.

Ashley described her frustration:

I mean [drawn out], I was just in shock. I was mad at my mom, because he [doctor] told me how you get it... I am like, why would you give to me... at that time it was out of their control. So, I was like you know, ok, so.

Jamie declared about her response, "I was very shocked, but I took that, and I embraced it and I just dealt with it." **Margarita** communicated her reaction:

When I first found out I was, I didn't have much knowledge of it ... I just felt like, Oh my gosh I am going to die ... that was when life hit me, because when I was 14 I lost my mom, and then I found out the major, I found out ...

Melissa narrated her reaction when she became *Conscious* of her HIV status:

I was crushed, I was like sad, I was crying ... I cried, but after I left the doctor's office I forgot about the whole thing and just went on about my life.... I was like nervous and stuff. ... I didn't have sex until I was about sixteen, because I was sensitive to, you know?

Rashad expressed his response, "Yeh! it was very sad, very sad ... Because I didn't understand it ... because of all the stigma that was going on ... I didn't understand it, I thought I am gonna die soon."

Participants shared how the *Consciousness* of their disease impacted their lives, expressing having both positive and negative experiences. Participants described that it was very difficult for them to receive the diagnosis; being scared; filled with anger; always feeling sick; feeling like an outcast; being in unstable situations related to school and living arrangements; and not feeling like a normal child in a normal family. However, they also described having adopted a more positive attitude since they had no control over acquiring the disease or changing their diagnosis. Participants reported

keeping their diagnosis private; transitioning to a more positive frame of mind and not allowing the disease to bother or hinder them; being encouraged to do more positive thing; and having a sense of being lucky to have had control of their viral load.

Their experiences were similar to findings in Proulx-Boucher, Fernet, Blais, Lapointe, Samson, Levy, Otis, ... & Trottier (2017) qualitative study among 18 youths (17-18 years old) in Canada, which explore how family, secrecy, and silence contribute to the adoption of stigma management strategies.

In Proulx-Boucher et al.'s (2017) emerged theme, "turning point toward weakening or dissolution of family ties," participants reported that their relationships with their immediate family dissolved or weakened as a result of either a significant event or a sense of injustice. Participants who experienced a sense of injustice also expressed feelings of helplessness towards their living conditions and or their HIV infection. Study participants explained the impact that coming into *Consciousness* of their disease had on them. **Ahmazin** expressed, "Over time, I started to transition to a more positive mind frame; it's actually, aah, push me and encourage me to do more things..." **Brittany** disclosed, "When I first found out I was really scared, but then now I realize it and all that stuff, and I am comfortable with it." **Bryan** explained, "When my mother passes I had a lot of anger build up in me ... I am not letting it hinder me." **Edward** stated, "I am lucky enough to have control of my viral load, all my life" **Jamie** reflected, "The disease itself do not bother me, it bothers me but it don't ... I don't let it affect me."

Kayden confided, "I always feel like I am sick, in a sense ... a slightest headache, or the slightest stomach pain and I feel like, Oh, maybe if I didn't have HIV ... I probably wouldn't feel like this" **Loren** declared, "It doesn't affect me, because I keep it private

... [if] it doesn't physically show aahm, then [silence] people will just see you, like you walk out the door and people would treat you regularly." **Margarita** divulged, "Well! It's kind a hard ... I am going from different school, to school, to foster care. It was just a bunch of things on me." **Melissa** explained, "I didn't really have a tuff life growing up with the virus ... Once I started like, dating ... living with it, it kinda help me with my other problems that I had before when I was younger." **Travis** discussed:

I start feeling outcast about it, because all I knew at that point in time was that it was something bad; before, it was, it was just weird; I didn't feel normal ... like a [pause] a normal kid in a normal family.

Participants' essence of living with HIV since birth as described in *Consciousness* is their becoming aware of their HIV status, which describes how and when they were informed of their HIV diagnosis; their knowledge of HIV at the time; their concerns before being informed; their response to their HIV diagnosis; and the impact that their knowledge of having the disease had on them. Participants' HIV status came into their *Conscious* at varying ages, by the age of 15 years. Their essence of living with HIV since birth as described in *Consciousness* were compared to the findings in research studies conducted by Madiba and Mokgatle (2016); Stangl et al. (2015); Namukwaya et al. (2017); Williams et al. (2017); and Proulx-Boucher et al. (2017).

Kinship – Sub-Theme of Consciousness

Kinship is described as a noun meaning "family relationship ... close connection" (Neufeldt & Guralnik, 1986, p. 744). According to Parson (1943), *Kinship* system in the American family is better understood when considered in the context of the "social structure and the strain and psychological patterns to which it is subjected" (p. 22). The

American family, which is not much different from their European counterpart, is characterized as "an open, multilinear, conjugal system" (Parson, 1943, p. 24), where the conjugal family unit consists of parents and children as the basic unit of the *Kinship* system. In multiple interlocking *Kinship* systems with a common member, the relatives emerge as kinsman, belonging to both conjugal families (the family of orientation, which is the family into which one is born and the family of procreation, which is founded on marriage) (Malinowski, 1930).

Malinowski (1930) described *Kinship* as a cultural rather than a biological fact, where culturally defined Kinship is somewhat individual. Individual parenthood therefore forms the initial situation of *Kinship*, where the parents educate and materially equip the child, watch over their adolescence, control their marriage, become the grandparents of their children, and rely on them in their old age. Consequently, the bonds of *Kinship* start in the initial situation and persist throughout life, and the "individual's own family remains a stable unit throughout his lifetime" (Malinowski, 1930, p. 26). Kinship was demonstrated in Silva-Suarez, Bastida, Rabionet, Beck-Sague, Febo, & Zorrilla (2016) qualitative study among 20 PAHIV-1 men and women (18-30 years), which explored "the life experiences of Puerto Rican PAHIV-1 youth within a family context" (p. 2). The researchers found that participants spoke of the most significant people in their lives being their family who meant everything to them. Silva-Suarez et al. (2016) also discovered that family consisted of a bonding among the most significant people in an individual's life, where love, trust, and support were encountered. Among emerging adults in general, quality of family relationships was also found to be of importance.

Stangl et al. (2015) found that many participants received significant and valued support from their family, friends, and trusted community members. Similar results were found by Lefkowitz (2005) in their quantitative study among 220 university students (18-25 years). The purpose of their study was to categorize emerging adults' perceptions of changes in their relationships with their parents, religious views, and sexuality since they started college; to examine the extent to which they portrayed these changes as positive or negative; and to understand how these perceived changes were associated with number of years since beginning college. Lefkowitz (2005) found that emerging adults acknowledged that their parents have always treated them with concern and respect as they would treat an adult prior to going to college. However, they were experiencing changes in the quality of those relationships, which was marked by the feeling of being closer to their parents; having more open communication, appreciation and respect for parents; and having more mature, friendship like relationships.

Li, Jaspan, O'Brien, Rabie, Cotton, & Nattrass (2010) in their qualitative study that explored the experiences and needs of a group of adolescents (7-15 years) living with HIV in Cape Town, South Africa, also found positive aspects of life as an emerged theme, where participants found that strong family relationships enabled them to remain positive about their illness and caregivers helped them to take their medication, stay healthy, and accept their situation. In the context of this study, *Kinship* – Sub-Theme of *Consciousness* refers to the familial type relationship that participants enjoy. These *Kinship* relationships came in various forms, as participants enjoy parental type care, love, support, and guidance from biological parents (divorced, single mothers, widows), adoptive parents (married, separated), relatives (aunts, uncles, cousins, godparent, step

relatives) and siblings (sisters, brothers). The *Kinship* between participants and their caregivers have been plagued with unfortunate break-ups between parents; participants still being regarded as a child and not being allowed to become as independent as they possibly could be; and not having the closest kind of relationship. Participants also shared being treated indifferently by relatives. These findings were also demonstrated in Silva-Suarez et al. (2016) study, which found "The 'dark side' of family" (p. 5) as a sub-theme in their study, where some participants recalled experiencing rejection from specific family members.

Participants in this study have also reported relatives having them use separate utensils, missing school and doctor's appointments; making a spectacle of their illness; berating them; and not wanting them to associate with their biological children. They have also reported having loving caregivers who have led by example and continues to play a significant role in their lives by encouraging and motivating them; becoming closer to their caregivers as they got older and remaining in contact; and their relationships continues to being great. The study participants described their primary caregivers and their *Kinship*. **Ahmazin** shared the status of her *Kinship* with her parents:

Me and my dad's relationship is gotten way better than it has been over the last few years ... My mom, me and my mom is pretty cool aahm, you know, I live with her so, it's, we have a pretty good relationship, but we are not the closest thing in the world.

Ashley expressed her *Kinship* with her adoptive parents:

I am aahm with my, adoptive parents now ... Which I was there like, from 6 around 5 or 6, aahm, they basically took me in. They took care of, me you know, they give me like a life, like you know, outside of what I knew, so, a mean, it's been normal.

Blessed reported of her *Kinship* with her mother, "I have lived with my mom.... I didn't really much live with my mom when I was younger till I was 8 or 9? ... Aahm, no, I guess she wasn't ready to raise kids just yet?" **Brittany** explained her *Kinship* with her sister:

We get along and [pause] ... She is a good big sister? ... she takes care of me. She make sure I be straight ... she is helping me like build up aahm, my career. Like she is helping me go to class for wigs, makeup and aah, she is a very big supporter.

Bryan expounded on his *Kinship* with his Godmother:

I always consider her my mom especially, consider that she is already my godmother, and the fact that she is my mother's biological sister and I never saw anything different of her.... Even her husband ... I saw him as a second dad as well ... Me and her are just fine like me and her get along fine, she educates me if I ever have a question, if I ever have a concern she will sit down and talk to me about it.

Jamie lamented on her *Kinship* relationship with her sister:

Me and my sister we're close ... we're pretty close but we buck heads a lot, because we both two strong [pause] headed people.... I am growing up and she can't see that [pause], so it's like that's why we always bumping heads.... My aunt used to always [emphasis and pause], I think I was 7 or 8 years old, she used to always make, have me drink out of a different cup, she use to always have me drink out of

like, eat out of different spoon, like dishes completely.... She would be having me miss doctor's appointment. I was not eating right, not going to school, I was in high school. Walking in cold, like I was sick.

Kayden expounded on his *Kinship* with his mother's cousin as primary caregiver: My mom's cousin took us in ... I don't really have no complaints ... at times, where she will break down in front of people, and say, you know, "Oh he is sick, he is this" aahm, not as far as like trying to bash me or anything like that but [pause] ... I know her as my mother ... we are really close, aahm, I felt like we have gotten closer as I got older, I guess?

Keisha discussed her *Kinship* relationship with her aunt as primary caregiver, "My relationship with my aunt, she is like, she is like a second mom to me ... So, it's the same would be as it would be with my mom ... she is a big part of my life." **Loren** explained her *Kinship* with her mother, "My mom has always been there... Make sure I was brought up right ... She took me to Church aahm, heh! [pause]." **Lovely** described her *Kinship* with her adoptive mother:

I have a nice family, [pause] and [pause] ... my mom [adoptive mom takes care of her] ... and I have birth mom, and she was really, really sick. She had HIV and she couldn't [pause] take care of me no more ...

Margarita divulged her *Kinship* relationship with her aunts and uncles as primary caregivers:

My aunts and uncles were never really aunts and uncles ... they never told me but they looked down on me ... my aunts still didn't want to take care of me ... they didn't want me around their children ... My aunt told me I was a bad influence and that I wasn't going to do nothing but hurt her children...

Melissa indicated her *Kinship* with her sisters as primary caregivers as follows:

My two older sisters did took care of me and everything ... My sister, Monica [name changed] ... They are my only sisters and they are fine, my rock ... She had like the mom figure, so it's like I couldn't, I know that was my sister and stuff, but I still respected her like a mother figure, because she took care of me and stuff.

Rashad informed the researcher about his *Kinship* with his mother:

I love my mom ... She is there if I need her, she is there when I don't need her ...

Our relationship is great ... She give me hope ... Even when I felt like, I want to
give up, she was there to, you know, kick me in my butt and tell me "push on, you
got to go.

Travis discussed his *Kinship* with his adoptive parents:

I was raised by my parents [adoptive] ... there's been some event, unfortunately for my family, aahm, between my parents. However, that being said, I, [excuse me] I am still in touch with my mom, I am still really close to her, my dad, not so much ... I still love him, I still keep in contact with him, but.... So, I don't see my dad as much as my mom versus you know, back when I was little, and I saw them both.

Participants in this study n = 10 (66.67%), have experienced the loss of either one or both biological parents; n = 4 (26.67%) have not experienced a parental loss and n = 1 (6.66%) study participant **Travis**, did not report on his biological parents. He was adopted as an infant, and he refused to discuss his biological parents. The absence or death of a parent or both parents can be traumatic and often leave the individual in

unfavorable situations, without the care and the support that they need. This was demonstrated in Silva-Suarez et al.'s (2016) study, which found that most families had experienced very difficult times, including losing family members or dealing with a potentially fatal illness, which participants in their study have also had to cope with. Study participants who had lost one or both parents discussed their loss or the absence of their biological parent. **Ashley** shared the loss of both her biological parents:

So around 4-ish, my dad died. Like aah, he died and then my mom was the, my birth mom, she was the, basically the sole custody, like you know? Primary care giver, but aah they found her unfit, because like she was on drugs and stuff like that. So, they took me, they took me out ...: She died [biological mother].

Brittany declared the loss of both her parents, "Aaah, they are good, well they passed away." Bryan said about losing his mother, "The only time it [diagnosis] comes across my mind is around the time my mom passed and her birthday because they are around the same days." Jamie explained about losing her mother, "My mom died when I was six, and my parent, my dad, my dad, he is somewhere." Kayden divulged about the loss of his parents, "Aamh, before my mother and father passed away..." Keisha informed about the loss of her mother, "Well, my mom is passed." Loren declared the loss of her father, "Aahm, my real father passed away years ago..." Lovely shared about the loss of her biological mother, "I only saw her [biological mother] once at the morgue, and then she left [pause]. She passed away." Margarita discussed about losing her mother, "When I was 14, I lost my mom ..." Melissa explained the loss of her mother, "[Growing up] I didn't have really, didn't go through nothing tragically you know, but losing my mom."

Participants in this study reported their *Kinship* with their biological or adoptive siblings, some of whom have taken on the responsibility of primary caregivers in the absence of another responsible adult. In birth order, participants fall either in between or at the end and often they were the only sibling in the household who had the virus, although they sometimes share biological parent and have a sibling who was born after them. Participants also experienced the loss of an older sibling to the disease. Study participants have also reported siblings being the only other family member besides the parents who were aware of their HIV diagnosis and about their sibling keeping their confidences and being protective of their secret. They reported sister taking on the responsibility of primary caregiver, even when they have other life responsibilities of their own, and of brother finding them a way out of difficult situations.

Not many studies were found that explored sibling relationships among PLWHIV in general and emerging adults with PAHIV in particular. However, Grant, Vance, Keltner, White, James Raper (2013) mixed method study among 150 PLWHIV (19+ years), identified reasons why PLWHIV included various individuals in their chosen families (or families of choice). The themes that emerged from the study indicated that PLWHIV include individuals in their chosen family because of love and acceptance, support, blood and family ties, and commonality. According to Grant et al. (2013), for PLWHIV, an unconditional positive regard and emotional closeness is very important in a family relationship. They desire to be loved and accepted even though they are HIV positive. In the context of the family, they regarded emotional, informational, and tangible support as being important and blood and familial ties were valued and regarded as important reasons to include individuals in the family as well, even in the presence of

discord. *Kinship* by blood or marriage, regardless of emotional valence and acceptance, was regarded as important reasons for PLWHIV to include individuals in their families. Furthermore, having things in common, was found to be an important reason for PLWHIV to include others in their family.

Study participants spoke about their *Kinship* with their siblings (biological, adoptive and step). **Ahmazin** informed the researcher about her *Kinship* with her biological siblings:

On my mom's side I have, its four of us, so it's 2 boys 2 girls. On my dad's side I have one sister.... It was brought to my attention that she [sister on dad's side] did [have HIV], but we're [pause] 18 years apart, so I never met her, because she passed away right after I was born.

Ashley clarified about her *Kinship* with her adoptive sibling:

She told [drawn out] was my brother, she told my older brother ... so he is the only one that knows, besides my parents... when these kids would ask he would kinda like look, he don't say nothing. But he, tell them don't mention it, like don't mention nothing about the medicine or whatever...

Blessed indicated about her *Kinship* with her biological and step siblings, "I lived with mom, my stepfather, my sister and my two brothers, my stepbrother and my brother." **Brittany** expressed about her *Kinship* with her sister, "Aahm, through my sister." **Edward** divulged about his *Kinship* with his brother, "I have one brother, and he is 26, he has his own family." **Jamie** shared her *Kinship* with her siblings, "I have 2 brothers and my sister." **Kayden** explained his *Kinship* with his siblings and his Cousin's daughter, "My mom's cousin took us in.... Yes, it me and my brothers, there is 3 of us.... she has a daughter

which I call my sister." **Keisha** evaluated her *Kinship* with her aunt's children, "Ahm, I am older than all of them., so ... I was here first, so, they got it together" [both chuckled]. **Loren** indicated her *Kinship* with her siblings, "Three sisters, one brother. One, one of my sisters passed away, so right now I have 3 siblings ... my sister that passed away, she had it but! She was older than me." **Lovely** shared her *Kinship* with her biological siblings, "I had a brother and an older sister and, and my mom wasn't married.... I don't know what their names are. When I saw, when I saw them, I never knew who they were [silence]." **Margarita** stated about her *Kinship* with her siblings, "Seven, my mom had seven [children] ... I am my mom's only daughter so..." **Rashad** informed the researcher about his *Kinship* with his siblings, "Mom she is raising three kids ... I am the middle child and I am the only one that was infected."

Participants' essence of living with HIV since birth as described in *Kinship* is the familial type relationship they enjoy, which came in different forms (parents, adoptive parents; relatives; and siblings). These relationships feature both good and bad experiences; however, participants have reported receiving love, encouragement and motivation in these relationships. Most participants have experienced the loss of one or both biological parents and some have reported the loss of a sibling. They reported positively on their relationship with their siblings, some of whom have taken on the responsibility of primary caregivers, and often times being the only other family member besides the parents who were aware of their HIV diagnosis. Participants' essence of living with HIV since birth as described in *Kinship* were compared to research studies by Stangl, et al. (2015); Lefkowitz (2005); Li et al. (2010); Silva-Suarez et al. (2016); and Grant et al. (2013).

Concealing – Sub-Theme of Consciousness

Concealing is the present participle of conceal meaning "to put out of sight - hide; to keep from another's knowledge - keep secret" (Neufeldt & Guralnik, 1986, p. 287). Concealment was defined by Pachankisa, Hatzenbuehlerb, Hicksonc, Weatherburnc, Bergd, Marcuse, and Schmidtc (2015) in a quantitative study among 157,211 men from 38 European countries, who have sex with men. The authors defined *Concealment* in the context of sexual orientation where men have few or no other individual who knows about their sexual orientation. This also describes the state of being closeted or not being "out." Concealment was assessed by asking the question: "Thinking about all the people who know you (including family, friends and work or study colleagues), what proportion know that you are attracted to men?" (Pachankisa et al., 2015, p. 4). Participants had the following answer choices: (a) all or almost all; (b) more than half; (c) less than half; (d) few; and (e) none. Panchankisa et al. (2015) classified participants reporting 4 = few or 5 = none as high *Concealment*. The authors found that participants who were classified as high *Concealment* were "significantly younger, more likely to be single, be employed, have less education, live in a smaller settlement, be not diagnosed HIV-positive, and live in a high-stigma country than those who reported low *Concealment*" (p. 6).

In this study, *Concealing* refers to keeping the diagnosis a secret from others (family, friends, associates). It describes the secrecy and stigma associated with the disease. Study participants acknowledged the importance of taking their medication on schedule. To maintain the secret of their diagnosis, they also expressed having to *Conceal* their medication, or the process of taking their medication, to prevent others from discovering this activity and invariably their diagnosis. Study participants reported

being sneaky or afraid to take their medication in public. They hid their medication or intentionally left them at home, and not take them to stayovers. Study participants reported caregivers who raised them to be secretive; advising them to not spread their diagnosis around and let others know of their illness. Participants have noted that when they *Conceal* their diagnosis from their friends, their friends tend to cut them off when they become aware of the secret. They also indicated that they have been advised to deliberately *Conceal* their diagnosis from their intimate partner's family and other close family members or friends, because those people might not fully understand and should not be trusted with the information. Now that participants are older and more independent, the decision to disclose their HIV status to whoever they want.

Concealing was also demonstrated in Namukwaya et al. (2017) longitudinal qualitative study among PAHIV young people and their caregivers, which found that caregivers often "delayed disclosure until young people were considered competent in managing information" (p. 5). In some cases, caregivers kept the HIV status of the child from other household members. Stangl et al. (2015) also found in their study that most participants reported good adherence to treatment, but the fear of others knowing their status sometimes led to challenges with taking ART. Participants in this study shared their experiences. Ahmazin declared about Concealing her HIV status, "I didn't want anyone to see me taking my meds, I would intentionally leave them home, and not take them." Ashley explained about her family Concealing her HIV status:

She kinda kept it from my family, so basically, up to this day my family doesn't now, like most of my family ... my mom would always, she would always make up a lie. Should would always like because of her asthma, or she has a lung

disorder, they won't say. But then she told (drawn out) was my brother ... now my parents left it up to me to basically tell people ... Yeh! and they even raise me to be that way to basically tell people; they even raise me to be that way.

Bryan's family *Concealed* both his and his mother's HIV status from him and other family members, as he explained:

My family told me that there was an incident with my mom ... it was a hospital accident, because she was a nurse ... After I told my dad, he didn't really say anything. He just started crying because he didn't think that I was gonna figure it out, or even if I am right or wrong. The only person I ever spoke to about that was my father ... I didn't feel comfortable going to my mom about it.

My aunt was always like... Oh aam, don't spread it around, don't let people know. It's just like what's the point in me hiding it?... She was scared that if I would told somebody, nobody would want to affiliate with me or anything like that.

Bryan gave an account of the consequences of *Concealing* his HIV status from his friends, "But as I experience through my high school life, if I don't tell them up front, that when they will cut me off." He also explained about *Concealing* his HIV status from his girlfriend's parents:

My aunt knows that she [girlfriend] knows, so we haven't come to the time we think it's safe to talk to her family about it ... I had that conversation with her from the first day I told her ... we haven't told her family yet.

Edward reflected on *Concealing* his HIV status, "It's very say like sneaky... you hang out with your friends and you grow up just like a regular guy, but you know, on the side, it's

like "don't forget to take your medicine...." **Keisha** shared about *Concealing* her HIV diagnosis:

That was interesting when you said the stigma part ... it not what it was many years ago ... it's very different, ... it a whole new look on HIV ... Sometimes when you have ... certain family members or around friends, if they are close enough to you? when they are close enough to you, you sometimes feel like they may not fully know you 100% because, even though they are close to you, you still feel that they don't need to know that you have HIV, or you still feel like you may not even trust them enough to know it ... I guess everybody has information that's reserved to them.

Travis reported about *Concealing* his HIV status because of the stigma associated with the disease:

It just, the stigma that most people had, that I had of it, it's just not based in reality ... at church camp, I would be kind of afraid of like bringing my meds ... I didn't want people to ask; I just felt like it was, it was a secret I wanted to be kept.

Participants' essence of living with HIV since birth as described in *Concealing* is the secrecy and stigma associated with the disease that they experienced. Study participants reported that their caregivers raised them to be secretive by keeping their HIV status from intimate partner's family, other close family members, and friends. These actions have led to isolation and mistrust. As participants become older and more independent, they now have the choice to disclose their HIV status to whoever they want. Participants' essence of living with HIV since birth as described in *Concealing* were

compared to findings in other research studies conducted by Namukwaya et al. (2017) and Stangl et al. (2015).

Paradox – Sub-Theme of Consciousness

Paradox is described as a noun meaning "a seemingly absurd or self-contradictory statement or preposition which when investigated or explained may prove to be well-founded or true" (Stevenson, 2007, p. 2095). Paradox was demonstrated in the context of sports science and sports medicine, in Gabbett (2015) experimental study, which describes the training-injury prevention Paradox model phenomenon where athletes accustomed to high training loads have fewer injuries than athletes training at lower workloads. According to Gabbett (2015), the goal of sport science and sports medicine practitioners is to keep athletes free of injury. Their approaches or views are somewhat Paradoxical, in that the aim of sports science (strength and conditioning) is "to develop resilience through exposing players to physically intense training" (Gabbett, 2015, p. 272), whereas in sports medicine practitioners (doctors and physiotherapists) are responsible for "managing players away from injury" (Gabbett, 2015, p. 273). Gabbett (2015) used training monitoring to determine the relationship between training load and injury risks.

In this study, *Paradox* is the thankfulness, burdensomeness [appreciation-disfavor] relationship that participants experience with the medication (anti-retroviral therapy [ART]). It describes the conflictions of their emotions or experiences with ART, which has given them a great opportunity at life by extending and improving their lives, yet it has been very difficult for them to maintain the almost rigid schedule, which is important to ART's efficacy. Study participants also have to endure the debilitating side

effects of ART. They are maintaining undetectable viral loads (self-reported), requiring less frequent hospitalizations, and longer lives. The medication schedules are sometimes difficult to maintain and the side effects intolerable, which are discouraging to individuals. Consequently, the *Paradox* exists, where participants are experiencing the dual effect (negative and positive) of the medication regimen simultaneously.

The improvements in the form and quantity of medication taken, and the positive results of having the medication is addressed in this section, where participants reported taking as few as one pill a day or at most two pills once or twice each day. This marks a significant improvement from before when they were required to take as many as seven to 12 pills multiple times each day and having to take a liquid medication, which was distasteful. Participants also reported starting to taking their medications more consistently, which has become second nature to them now. They have devised ways to help them to be consistent in getting it done, for instance, by always keeping a bottle of water at the bedside; keeping a keychain pill cadaster; or heading straight to the bathroom after waking up in the mornings. Participants reported on the medication and the schedule that they maintain: **Ahmazin** informed the researcher about taking her medication, "I started off on seven pills. I am actually down to one now ... I started taking my meds consistently, because I also went through this rebellion stage ... I didn't want to take my pills." **Ashley** divulged the improvements in the medications she takes, "It's a handful of pills, because at that time we were taking, like seven, eight, or 12 pills, verses now when you take like two once a day" **Bryan** expressed about the medications he takes:

I take one pill a day, at night, instead of me having to take two at morning or three at night or having to take a disgusting liquid all the time ... you are taking your medication that you doesn't get sick.

Edward shared about his medication, "I was reduced down to just two pills a day, or two pills once a day; it's second nature to me" Jamie divulged about her medication, "I take two times a day, five pills, two times a day ..." Kayden mentioned about taking his medication, "I take mines late at night, aahm." Keisha confided about taking her medications, "I have to remember, before class, to take my pills, so I always keep like a bottle of water in my room." Loren declared about her medication schedule, "Twice a day, once when I get up, once when I go to bed." Melissa expressed about the improvements in her medications, "It was gross, and I had to take it like bout five different medicines to maintain, but now I only took two so it's like, it got better."

Rashad shared about his medication, "Twice a day, once when I get up, once when I go to bed." Travis said about his medication, "I take them once a day."

In this study, participants also reported not wanting to take their medication consistently when they were younger or when they were going through a difficult or rebellious stage. As they became older, they came to the realization that taking their HIV medications worked similarly to taking medications for any other illness. They recognized that their medications prevented them from becoming sick; having frequent hospitalizations; and looking different from others or looking sick. It allowed them to function as normal human beings and it has kept them alive. Participants also realized that by taking the medication, they have to exercise caution because the medications have side effects and contraindications. They reported sides effects such as of nausea,

dizziness, stomach agitation, feeling sick and having to rest, feeling tired, vomiting, and drowsiness. The contraindications noted are the potential effects that the medication may have on a fetus, therefore participants have to plan their pregnancies.

While most participants have acknowledged the *Paradox* associated with their medications, they are all aware of the importance of maintaining their medication schedule. Some have reported missing doses and that each time they take the medication, it forces them to face their reality of having HIV. They have expressed appreciation for the medications and schedules that have improved tremendously over the years; however, the daily requirements are burdensome and inconvenient; and the side effects are often difficult to experience at times. These findings are partly supported by the findings in Newman, Persson, Miller, and Brown (2016) qualitative study, which was conducted among young people (13-21 years), who were growing up with HIV in Australia. The study sought to understand what responsibilisation meant for a cohort of young people and their HIV care providers in building their professional confidence in successfully supporting children with HIV transitioning to adult life. According to Newman et al. (2016) "the concept of responsibilisation seeks to explain the processes through which individual citizens of advanced liberal states are encouraged to become 'self-governing', in contrast to relying on the state for lifelong health and welfare" (p. 132). The themes that emerged from that study were: (a) Responsibilisation as imperative; (b) Responsibilisation as practice; and (c) Responsibilisation as contest. The authors found that responsibilisation as imperative required that participants take their medicine as directed and recognize the risk of not accepting clinicians' messages of treatment adherence; while clinicians believed participants were not able "to appreciate mortality,

or to understand the importance of taking personal responsibility for preventing early death" (Newman, et al., 2016).

Stangl et al. (2015) in their study, also found that participants understood the importance of adhering to treatment, experienced side effects such as feeling dizzy, weak, having blurred vision; and were unable to concentrate in school. Williams et al. (2017) elucidated the theme lived body (the absence of physical strength and tiredness - side effects of medications) as a reason for participants in their study to not participate in some physical activities. Medication side effects as a barrier to adherence was also found by Fields, Bogart, Thurston, Hu, Skeer, Safren, and Mimiaga (2017) in their grounded theory study among behaviorally and perinatally HIV-infected youths (14 -24 years). The purpose of their study was to expand on existing research on adherence barriers among behaviorally infected and perinatally infected youths by exploring the psychosocial context of those barriers.

Fields et al. (2017) found that 67% of behaviorally infected and 83% of perinatally infected participants were taking ART at the time of the study and 50% behaviorally infected and 40% perinatally infected reported adherence less than 85%.

Both groups in the study described common barriers to medication adherence including medication side effects and unstructured lifestyle, where their experience of side effects led to medication avoidance, and remembering medication was difficult in the context of unstructured lifestyle. Fields et al. (2017) also found that medication served as a reminder of HIV status for both groups, although the role HIV plays in their lives were different. For the perinatally infected youths, medications served as a reminded that they were different from their friends and family, while for the behaviorally infected youths, it

served as a reminder of their new diagnosis, a reality to which they often had not adopted to. According to Fields et al. (2017), the barriers specific to perinatally infected youths, were reflective of the youths' lifelong experience with ART, and their complicated medication regiments made adherence more difficult in social settings where they would otherwise wish to keep their status undisclosed. Fields et al. (2017) also found that despite having easier regimens than in early childhood, the PAHIV participants discussed fatigue as a barrier to adherence.

Participants in this study have a *Paradoxical* relationship with their medications, which is evident in them taking their medication although they experience side effects that limits their activities in some cases and presents challenges in their effort to maintain such schedules. They also expressed that responsibly taking their medication has maintained their health to the extent that others cannot tell that they are HIV-positive by merely looking at them. This finding was supported by the results in Stangl et al.'s (2015) study, where all participants understood the importance of adhering to treatment and many reported that taking the drugs made them look healthy and feel more confident. Study participants shared their *Paradoxical* experiences with medication regimen.

Ahmazin shared her medication *Paradox*:

I started taking my meds consistently, because I also went through this rebellion stage ... I didn't want to take my pills ... when I transition more into, slowly, into a more positive mind frame, I started to be more consistent with my meds and actually take them and take them with me ... when I was staying the night over to someone else's house or a friend's house.

Ashley explained her *Paradoxical* relationship with her medications:

When you're younger you don't want to take meds ... you think that you're invincible ... "you're not gonna die;" when you get older ... you start realizing ... I really need this to like, to live ... I need to take this like every day so, I could be a normal functioning human being ... at first, I wasn't really like taking it; I noticed that I was started getting like cold, flu ... it kinda like change, you know me, a little bit for the better... I notice if I go to a pharmacy and I pick up my meds [pause] ... once they see what meds I am on, they start acting differently. So, I feel a little bit different in that sense. Because, I mean [pause], by looking at me you can't tell [pause] that I have it. You know? You'd think that I am this normal person.

Bryan reflected on his relationship with his medication, "If I don't take my medication that's when it starts to get out of hand ... you are taking your medication that you doesn't get sick." **Jamie** divulged her *Paradox* with medication:

When I take my medication [pause], sometimes I don't feel good for certain period of time, for like 30 minutes, 20 minutes on the medicine take my medication [pause], relaxing [pause] until work because it has a side effects as in dizziness, feeling sick, so ill lay down and try to take a nap.

Kayden confessed his Paradox with medications:

I forget to replace what's in my keychain then that night I would probably miss it ... I take my meds when I ah, it's time to. Having HIV like with my meds, my stomach, every morning it's like irritated.

Keisha confided about her Paradoxical relationship with medications:

I was like a rebel child. I didn't want to take medicine. So, I would just spit it up and stuff like that ... that's the weird thing, I didn't even get sick even though I didn't take all [pause] my meds how I was suppose to take them.

Loren shared her *Paradox* with medications:

If it's visible ... like it's poor health? But if you're taking care of yourself, you're taking your medication like you're suppose to ... it doesn't physically show aahm, then [silence] people will just see you, like you walk out the door and people would treat you regularly...sometimes I skip doses ... I really need to work on that.

Melissa explained her *Paradoxical* experience with medications, "She [her Physician] just call me yesterday and said that, aahm, you know, the medicine that I am taking will have a birth effect on the baby, so she was like 'don't get pregnant."

Rashad shared his *Paradoxic* experience with medications:

You have to be cautious about everything ... because you can't take ah, different types of aspirin, because it won't be beneficial or mix with your medicine. You can't drink alcohol while on your medicine, some people can't even put on, like lotion, different types of lotion like because of how the medicine will react to their skin ... you're forced to face reality every single day you take medicine....

Aah, ... some days it's hard ... I am tired all day but other than that, it was like stomach ache throw ups and everything else, but as I got used to my medicine the only, the only side effect that stuck was drowsiness.

Participants' essence of living with HIV since birth as described in *Paradox* is the thankfulness and burdensomeness (appreciation-disfavor) relationship that they experience with the medications (anti-retroviral therapy [ART]). Study participants

described conflicting emotions between the benefits of the medications extending and improving their lives and the difficulties they experience in maintaining the almost rigid schedule and the debilitating side effects. Participants' essence of living with HIV since birth as described in *Paradox* were compared to the findings in research studies carried out by Newman et al. (2016), Stangl et al. (2015), Williams et al. (2017), and Fields et al. (2017).

Theme: Realities of Living With Human Immunodeficiency Virus (HIV)

Reality is described as a noun, meaning the "the quality or fact of being real; a person or thing that is real – fact; the quality of being true to life" (Neufeldt & Guralnik, 1986, p. 1118). In their qualitative study, Brashers, Neidig, Cardillo, Dobbs, Russell, & Haas (1999) described the realities of living with HIV in the context of "the uncertainty experiences of HIV-infected individuals who had faced death, but now report increased optimism about survival because of advances in treatment and care" (p. 202). The authors found that the major source of uncertainty among participants was revival, having experienced denial, anger, and the acceptance of their premature death, when they were diagnosed. Now with ART, many can hope for recovery from the disease, because ART has improved the heath of individuals with AIDS.

According to Brashers, et al. (1999), this improved health status created "new uncertainties that can become unexpected and significant life stressors ... as the prospects of recovering from AIDS brings with it a multitude of new complex issues that can be difficult for persons to address in their lives" (p. 205). The new prospects of living now requires individuals with AIDS to renegotiate many of the realities of living with the disease that they had come to expect. This renegotiation is a source of uncertainty and

stress in itself, which was associated with the four themes that emerged from the study:

(a) feelings of hope and future orientation, (b) social roles and identities, (c) interpersonal relations, and (d) the quality of their lives. Brashers et al. (1999) concluded that the stressors are "the result of having accepted death and then having that reality change as new treatments provide a basis for optimism about survival" (p. 214).

In this study, *Realities of Living With HIV* represents the participants' presence in the normal activities of life that their HIV-negative peers at the same developmental stage would be involved in, and the consequences of such involvement. These activities include pursuing post-secondary education at different levels; working; living in varied residential arrangements; volunteering to help others whom their experiences can benefit; sharing their lives with others in intimate relationships; disclosing their HIV status to their partners; braving the uncertain consequences of disclosing their HIV status to intimate partners; and having sex as individuals who are HIV positive. Participants' *Realities of Living With HIV* related to education indicates that all participants have achieved the minimum of a high school diploma (HSD); varying levels of post-secondary education attempts and accomplishments; and present engagement in the educational process, in preparation for a career and or financial stability.

Participants were either planning to get into a program of study; pledged to complete a program already started; thinking of entering a program; seriously going through a program; or graduating from a program of study as illustrated in the demographic data. The demographic data indicates that, of the 15 participants, 6.67% (n = 1) have already earned an associate degree; 13.33% (n = 2) have already earned a bachelor's degree; 6.67% (n = 1) have already earned a master's degree; 26.67% (n = 4)

are presently enrolled in either an associate or a technical degree (A/TD) Program; and 13.33% (n = 2) are presently enrolled in bachelor's degree programs. The other 33% (n = 5) have either not yet attempted or have decided not to pursue education beyond the high school level. Of those who have not yet attempted post high school education, 60% (n = 3) have plans to do so in the future. **Blessed** responded, "Yeh! I am planning to go to college to be a photographer [pause] so that ... Yes, a professional." **Margarita** said, "Well! I am waiting on my brother because it's, I have to get my mom's death certificate, and that's what holding me from going back to school." **Melissa** declared, "I want to go back to school dm, but I want to go back for business."

Among the 40% (n = 2) who does not have a plan to pursue post-secondary education, 20% (n = 1) does not have the cognitive ability to successfully pursue higher education and 20% (n = 1) does not believe that he was made out for college. This was demonstrated in the cases of **Lovely** and **Travis**. **Lovely** who is cognitively and developmentally challenged and has been attending Goodwill since she graduated from high school in 2011. Goodwill have been preparing her for job interviews. **Lovely** explained:

I want to be a nurse ... So, I can work, so I can take a lot of classes, yeh ... It's hard ... yeh ... because you have to fil, you have to everything, you have to like aah, [pass] classes and ...

Travis declared his position on earning a college degree:

I did go to college for a little bit.... I did that for a couple months. I just realized it wasn't for me, so, I went right into the working world.... I have thought of it [going to college for music] myself and I have got everything from yes to no ... I am not

saying that getting a degree wouldn't help, in fact I am sure it would ... I have heard of real-life story of people in similar line of work and who haven't gone to school whatsoever, as far as post education.

These results are consistent with the findings from Godsay, Kawashima-Ginsberg, Kiesa, and Levine (2012), which found that 42% of all Americans (18-29 years) had no formal education beyond high school. However, their findings of only 62% of those with no formal education beyond high school, having attained a high school diploma is inconsistent with the results of this study, which found that 100% of all participants have attained an HSD.

Other participants' Realities of Living With HIV related to education indicated that they have also attained technical, associate, and bachelor degrees and are about to graduate with master degree, while others are in pursuit of similar degrees with the ultimate goal of achieving a doctoral degree. The demographic data indicates that of the n = 10 (67%) participants who have attempted post-secondary education, n = 1 (6.67%) have already earned an associate degree; 13.33% (n = 2) have already earned a bachelor degree; 6.67% (n = 1) have already earned a master degree; 26.67% (n = 4) are presently enrolled in either an associate or a technical degree (A/TD) program and are very focused, having a high degree of probability of completing these programs successfully; and 13.33% (n = 2) are presently enrolled in bachelor degree programs. Study participants explained their Realities of Living With HIV related to their educational pursuits. Ahmazin informed, "I also have a bachelors from PSU ... I have a bachelor's in finance and I have an associates in business administration from MD." Ashley disclosed, "I am graduating in May [2018], so I will be getting my bachelors. Well I am getting my

bachelor's degree in Sociology with a minor in Psych." **Brittany** shared, "Parkway Educational Center ... they have a college. I am studying for cosmetology." **Bryan** explained:

STT [name changed] ... unfortunately after my first year I had to transfer due to the fact I moved up to DLL [name changed] ... I switched over to DLL ... I decided to make the sacrifice for me to get my associated degree later.

Edward informed, "I am a mechanical engineering student at ZEU and aahm, ...
undergraduate researchers ... material science." Jamie said, "I had graduated from FCC
... last year September [2018] with aahm, MA- medical assistant ..." Kayden stated,
"Well, I just graduate in December [2017] with my bachelor's in criminal justice with a
minor in psychology." Keisha explained, "Right now, I am in undergrad, and I plan to
go to medical school, and become a doctor." Rashad articulated, "I am actually on, like
going through the process to go back to school.... What I have accomplished so far is
actually associate, on my way to get my associates ..."

Participants' Realities of Living With HIV related to employment indicate that they are employed in different roles. The demographic data indicates that 66.67% (n = 10) participants were employed and 33.33% (n = 5) were unemployed. Of those employed, 60% (n = 6) were employed part time, and 40% (n = 4) were employed full time. Participants' Realities of Living With HIV related to employment also indicates that they are working in different areas, such as community outreach where their experience and willingness to talk about their experience with HIV have opened the doors to more lucrative opportunities; administrative assistants; guest services; retail sales; banking; warehousing and security; school counselor and life coach; and telemarketing. These

results are inconsistent with the findings in Williams et al.'s (2017) qualitative study, which researched 17 PAHIV young adults (18-24 years). The purpose of their study was to describe the lived experience of PAHIV young adults.

Williams et al. (2017) found that most of their participants have not begun the transition to adult life and reported that they were not educationally prepared for employment. Participants' Realities of Living With HIV indicates that while achieving a high school diploma does not entirely prepare them for traditional work roles, or economic success, it affords them access to entry-level positions in the workforce. Additionally, those who are in pursuit of higher education will be prepared for professional roles, which are beyond the normal expectations for this population. Participants shared their *Realities of Living With HIV* related to their current job roles: **Ahmazin** reported, "I am trying to be more open about my status as well. I think that played a very big part in getting the new job that I have now." Ashley declared, "Administrative Assistant, so I'm, technically a secretary to my boss ... I mean that's basically it." **Bryan** disclosed, "I have been working for a year and a half," on the beach dealing with hotel guests and beach equipment." **Jamie** presently works a full-time schedule at Windsor in retail sales. **Kayden** responded, "I work at MS and Windsor." **Melissa** declared, "I have been doing, this little job that I have been doing, it's like an independent contractor." Rashad confirmed, "I work at Apollo School, as a student life coach ... I also run the after-school program as well ..." **Travis** shared, "I actually just got a job, as we are doing this, aahm, it's an online marketing job ... Right now, I do music therapy, I also do social work ..."

Participants' Realities of Living With HIV indicates that they are living in different residential arrangements, either with their parents (biological, adoptive, or foster); relatives; or sharing accommodation with a sibling or a partner. This was substantiated by the demographic data, which indicates that 80% (n = 12) of all participants still lives at home with their parents/family; 6.67% (n = 1) is living with an intimate partner; 6.67% (n = 1) shares living space with a sibling; and 6.67% (n = 1) lives independently. Consistent with these results, Gaudet (2007) in a policy development discussion paper for Canada, which explored emerging adulthood (18-25 years) as a new stage in the life course, reported that youths are leaving the family home later than before, and that men were more likely to be single and extend their stay. According to Fry (2016) from the Pew Research Center, in 2014, there were more adults (18-34 years) (32.1%) living with their parents than were living with a spouse or partner (31.6 %) for the first time in 130 years. This shift was attributed to a dramatic drop in the number of adults choosing to settle down romantically before age 35. Young adults as head of households either as single parents, sharing with a roommate, or living alone represented 14%, and 22% were living in the home of another family member or a non-family member or group quarters.

Study participants described their *Realities of Living With HIV* related to their living arrangements. **Ahmazin** stated, "My mom at my grandparents." **Ashley** is living with a partner. **Blessed** declared, "I live with my mom ... growing up I live with, actually growing up, I went from house to house ... I didn't really much live with my mom when I was younger till I was eight or nine." **Brittany** lives at home with her sister. **Bryan** affirmed, "My father." **Edward** clarified, "My mom." **Jamie** mentioned, "Me and my sister we stay together ." **Loren** revealed, "My mom has always been there for

me, aahm ... Lived in a house, my whole life." **Lovely** lives at home with her adoptive mother, however, she has made arrangement to move into a group home in the near future. **Kayden** expressed, "I live with her [mothers' cousin]." **Keisha** continues to live at home with her aunt. **Margarita** lives at home with her older brother. She said, "Like the only person I really have is my brother, he is working double jobs, just to take care of me." **Melissa** continues to live with her sisters. **Rashad** lives alone. **Travis** informed, "I live with my adoptive mom."

Participants described their Realities of Living With HIV through volunteering to help others who may benefit from their life's experiences and to help remove the stigma associated with the disease. The demographic data revealed that n = 7 (46.66%) of participants volunteer in either a church or civic/peer program or both, and n = 8(53.33%) does not volunteer. However, n = 2 (25%) of those who were not volunteering shared their interest in volunteerism with the researcher. According to Lopez (2004), volunteering among youths is generally higher than among adults (26+ year). For the year prior to 2002, the national volunteer rate among adults (16+ years) was estimated at approximately 27.6%. During Spring 2002, youths (15-25 years) reported volunteering at the rate of 40.2% over the previous 12 months. Surveys suggested that there was a growing volunteer rate among young people and that young people were volunteering at a rate higher than their older counterpart. According to Gaudet (2007), youths today are less involved in political parties and official organizations, and their involvements are more individualized and focused on supporting awareness. Consequently, they are less likely to defend groups and more likely to defend causes. Their positions are based on ethics and personal responsibility (Gaudet, 2007).

Study participants' Realities of Living With HIV related to volunteering is the service they provide to children who are going through experiences which are similar to the experiences that they had while growing up. Participants are hopeful that their experiences may empower them to make a difference in the lives of these children. They volunteer to help individuals who were recently diagnosed, to help them cope and connect with available resources. They participate in community outreach and prevention programs; religious groups; mission trips; and peer groups. Study participants shared their Realities of Living With HIV related to their involvement and interest in volunteering. Ahmazin shared, "I am involved in my community, aahm, I have been involved with the family foundation for [pause], this will be 7 years.... Doing outreach, HIV/AIDS prevention and outreach ..." **Edward** volunteers on campus in different groups and organizations, and he is an officer in the A&E Club. Kayden declared, "Mostly like a one-on-one—I can refer them ... I also volunteer at a summer camp once a year, a week ... that's the only two things I volunteer in." **Keisha** shared, "If there was a way for me to get involved, I would get involved in, the destigmatizing it." **Loren** indicated, "I am involved in, I just recently start going to aah, a women's religious group." Lovely emphasized, "I want to be a mis, a missionary when I grow up and go abroad and tell a lot of people about Jesus Christ." Melissa shared, "Sometimes, I also volunteer at CD, the aahm, where I used to go to the doctor, DA. ... We did aahm, just small stuff, just helping out ... if they need help with stuff." **Rashad** explained:

I volunteer at the camp that I have been going to since I have been 7. I still go back every year, as I say it's in Texas, so I go back every year and volunteer and help those kids out....

Participants' Realities of Living With HIV also included their involvement in intimate relationships although they are HIV positive. The demographic data indicates that n = 11 (73%) of the 15 participants were involved or have been involved in an intimate relationship during their lifetime; and that n = 9 (60%) of the sample population are presently involved in an intimate relationship. Of the n = 11 who have ever been involved in an intimate relationship, n = 10 (67%), have been involved in intimate relationships with individuals who were HIV negative. Only n = 1 (7%) participant who has been involved in an intimate relationship, has only been involved with a HIV positive partners who acquired the virus perinatally. All participants in this study who have been sexually involved reported that they were aware of their HIV status before they became sexually active. There were no report of a participant transmitting the virus to a partner to date. This information was deducted from the demographic data, which also indicated that all participants were informed of their HIV status by age 15 years and that the youngest age of first sexual experience was between 14 to 15 years. Study participant **Rashad** had his first sexual encounter at the age of 14 years, which was after he became Conscious of his HIV status and the risks of transmitting the virus to an intimate partner.

Study participants reported their *Realities of Living With HIV* related to being sexually active and involved in intimate relationships. They reported using protection for their own benefit to guard their fragile immune system as well as to protect their partners from acquiring the virus. Participants regard maintaining a relationship as being very difficult because they have problems opening up and trusting their partners to keep their secret, and to not judge and avoid them because they have the disease. Participants' *Realities of Living With HIV* are also related to being sexually active and involved in

intimate relationships. Intimate partners were often afraid of acquiring the virus and did not always communicate their fears in a cohesive manner, resulting in coming across as being rude or disrespectful. Some partners become comfortable in the relationship and decided not to use protection, while others have explored and actually use pre-exposure prophylaxis (PrEP) to prevent themselves from acquiring the virus.

Participants described their *Realities of Living With HIV* related to disclosing their HIV status to their partners as being difficult and a crossroads that they would prefer not to encounter. They acknowledged that it was best to get the disclosure out of the way early and that they had disclosed their HIV status from as early as the first day of meeting their partner to as late as the point of becoming intimate. Participants referenced their *Realities of Living With HIV* as their personal responsibility to inform their partners; not wanting to get into trouble with the law; and giving their partner a choice to continue in the relationship, which were also reasons given for their disclosure. Participants voiced their *Realities of Living With HIV* as having to explain to their partners the new medical advances and ways of preventing the transmission of the virus; the uncertainty of their partner's response; and the trustworthiness of the partners to keep their confidence. Participants reported having both good and bad experiences, and that they have difficulty finding the right person whom they can trust who would not judge them, and who were willing to be educated. The disclosure data were self-reported by participant.

In their study, Stangl et al. (2015) found that all participants had at least basic knowledge about HIV, but that there were specific gaps in their knowledge. These gaps were related to the effectiveness of ART in reducing the risk of transmission of HIV to sexual partners and neutral information on sexual health virus to a sexual partner. These

results were inconsistent with the findings of this study where participants also had basic HIV knowledge, but they were aware of measures to prevent their partners from acquiring the virus, which included maintaining an undetectable viral load. Study participants shared their *Realities of Living With HIV* in their experiences with intimate relationships. **Ahmazin** explained:

Me and my current boyfriend, we have been together since June of last year (2017). We are sexually active ashm and if there may be any question or concern in regards to ashm, our intimacy, ashm, we talk about it ...

Blessed disclosed, "I am glad my other half knows about it...peoples still enjoy my company ... he start getting tested." Bryan reported, "I have been in a committed relationship for a year and nine months starting today. It's been good ever since...."

Edward indicated, "It's definitely more tentative due to the stigma attached to aah HIV and positive people." Keisha responded, "Aahm, in the beginning, it affected it [pause], being [pause] as having the person understands." Kayden shared, "He, he wasn't born with it. He contracted it before we met ... Previous relationship, aahm, I want to say I had, like this would probably be my first serious, long-term relationship." Margarita conveyed:

It's hard, relationships are very hard [pause] to be in ... my relationship before him, he used to always scream in my head that 'nobody is gonna love you, nobody is gonna love you, you are HIV positive who wants a woman who that's sick.

Melissa divulged, "Your partner may like who you are but it's like they be so afraid that they might get it and stuff so they just, they have their moments ..."

In their qualitative cross-sectional study among PAHIV youths (17-25 years), Greenhalgh, Evangeli, Frize, Foster, & Fidler (2016) examined how young adults with PAHIV in the UK negotiate disclosure challenges in their intimate relationships. Four themes emerged from the study:

 Decisions about starting, continuing or resuming relationships shaped by disclosure: participants admitted that anticipating rejection affected relationship decisions; participants reported avoided having sex within intimate relationships for fear of revealing their status.

In this study, **Jamie** shared having taken this stance, "Like [pause] you just you basically scaring them off, and you don't want that, so you just stay to yourself, you just don't have sex."

2. Disclosing early to avoid the pain of future rejection: disclose before emotional attachments were formed.

Study participants Ahmazin, Margarita and Melissa reported having similar experiences – Ahmazin verbalized, "I disclosed my status to him, probably 3 weeks of us dating ... because the feelings between the both of us starting to develop very, very quickly" Margarita shared, "I told him within two weeks of us being together."

Melissa shared having a similar experience as well, "When we dating like 2 months in I told him ... I just blurted it out and tell him, and he was like "Ok'.... [He] thank me for opening up to him because most people would never told ... [until] it was too late, or something happen."

- 3. Using condoms to avoid disclosure: a method of avoiding or postponing disclosure and rejection and to divert attention from their own health to that of their partner.
- 4. Testing likely partner reactions to disclosure: test their partner's knowledge of and attitude towards HIV before disclosure, to determine their partner's likely response and form a judgment concerning the possible risk of rejection in a "safe" way.

Study participant **Kayden** employed this approach to disclose his HIV status to his current partner. He said, "We were talking and stuff like that, aahm, I asked him test questions ... and then I just finally came out and disclose, and then that's when vice versa he disclosed back his status.

Participants in this study also expressed their *Realities of Living With HIV* in their apprehension and fear of having to disclose their HIV status to individuals; therefore, they tread cautiously. Similar findings were reported by Williams et al. (2017), Galano, Turato, Succi, de Souza Marquez, Negra, Henrique da Silva, ... Machado (2016); and Weintraub, Mellins, Warne, Dolezal, Elkington, Bucek, ... Abrams (2016). In Williams et al. (2017) qualitative study among 17 PAHIV young adults (18-24 years), which described the lived experience of PAHIV young adults, the researchers elucidated unanticipated adult issues as an emerged theme, where young adults had limited experience navigating romance and adult relationships and discussing their HIV status with their partners.

Galano et al. (2016) qualitative study among researchers from Brazil, Canada, and France, assessed the experiences of perinatally HIV-infected teenagers when disclosing

their diagnosis to friends and partners. Three themes and six sub-themes emerged from that study: (a) theme: living with the secret – sub-themes: the secret across generations and the right to privacy; (b) theme: the secret in romantic relationships – sub-themes: the responsibility to reveal the secret and dilemmas; and when and how to tell a sexual partner about HIV; (c) theme secrets: to keep it or not – sub-themes motivation to tell, and benefits and costs of the secret. Weintraub et al. (2016) conducted a longitudinal quantitative study in New York City among youths (9-16 years) perinatally exposed to HIV and their caregivers. The researchers used Social Action Theory (SAT) as a theoretical framework to guide the analysis and interpretation of the data. Weintraub et al. (2016) concluded that:

Similar to same age peers, PAHIV- positive youths are having sex with and without condoms and both within and outside of committed relationships ... many of these sexually active adolescence and young adults are not disclosing their status to any of their partners especially when those partners are casual (p. 136-137).

In this study, participants spoke about their *Realities of Living With HIV* related to condom use. **Blessed** mentioned, "it broke," she now has a daughter as a result, and **Melissa** reported:

At the beginning we use protection and then ... we start getting comfortable with each other and then stop using it. So, he, he was the one stop using it and I ask him if he was sure? And he was like ok and everything.

Study participants also shared their *Realities of Living With HIV* related to disclosing their HIV status to their intimate partner. **Ahmazin** explained, "A part of you want to go ahead and get it out of the way and let the person know ... The feelings between the both

of us starting to develop very, very quickly." **Ashley** shared, "You do have to disclose. You have to explain the whole situation. Because they have like such a stigma in their head, or they don't know much about it ..." **Blessed** expressed, "I told him, before we started dating I told him right away." **Bryan** discussed, "She is known since [pause] my first day talking to her ..." **Edward** reported, "I disclose about a week after we met....

The reason I felt comfortable was because ... I don't want to get in trouble..." **Kayden** also explained, "I didn't disclose at first ... but it wasn't [pause], sexual to that point. It got after that point, that it got more intimate, aahm, but [silence]." **Keisha** reported, "I think I disclosed, six months into it, into the relationship ... but in the beginning, it was difficult ..."

Participants reported their *Realities of Living With HIV* pertaining to their partners reaction to their disclosure as being very receptive and open to their situation and that their partners reassured them that they would not go anywhere, as long as they remain safe. After crossing the disclosure hurdle, participants reported that their HIV status did not affect their intimate relationships, which they considered to be normal. Participants also reported partners taking time to consider their options before agreeing to participate in an intimate relationship; of partners being indiscreet which they blame of the participant's HIV status; and of disclosing to potential partners who did not want anything to do with them afterwards. Participants shared their *Realities of Living With HIV* in their partner's reactions to their disclosure. **Ahmazin** shared, "Aahm he was very receptive and open to me and my situation, aahm. He said he is not going anywhere, and ever since then, he has been supportive." **Blessed** divulged, "He is, he was much ok with it. He was very ok with the fact that I had it, just as long as I stay safe." **Bryan**

explained, "But after we got pass that, it doesn't affect it at all." **Edward** shared, "She was open to aahm, convincing that's not the word I want to use, but I am at a loss for words ..." **Keisha** confided, "Once I was able to let him know about the new medical advances and if I take my medicine and we use condoms, and all the protection then he'll be fine. After that it was normal." **Margarita** mentioned:

It took him a day before he can actually, he actually call back and said you know what! I really want to be with you, through thick and thin ... after two years of us being together and him cheating, I found out that the reason he didn't want to be with me was because I was HIV positive.

Melissa stated, "He was like "Ok" ... he was very receptive and open to me and my situation."

Participants' *Realities of Living With HIV* are that they are sexually active individuals who are HIV positive, and they consider having sex to be a normal event, which they made sure that they were ready for and that they were being careful. They considered protection for themselves and their partners by always having and using condoms; partners taking PrEP and going for monthly checkups, and participants taking their medication to keep their viral loads undetectable. Participants' *Realities of Living With HIV* are that they cannot always act in the heat of the moment. As the demographic information indicates, the majority of participants are either in or have been involved in an HIV sero-discordant relationship. Sero-discordance when taken apart: sero means blood and discordant means differing, is presently used to "describe a relationship between two people with different viral statuses" (Persson, Newman, Hamilton, Bryant, Wallace, & Valentine, 2017). When the virus is HIV, sero-discordance refers to a

relationship between an HIV-positive and an HIV-negative individual, which is also referred to as HIV sero-discordance. Participants' *Realities of Living With HIV* are that they are involved in intimate relationships with HIV negative partners. However, being involved in an HIV sero-discordant relationship does not automatically mean that the HIV negative partner will invariably acquire the virus.

This was demonstrated in Morton, Celum, Njoroge, Nakyanzi, Wakhungu,
Tindimwebwa, Ongachi, ... & Heffron, for the Partners Demonstration Project Team
(2017) counseling framework, which addresses couples in serodiscordant relationships
where one partner could remain HIV-negative while maintaining a sexual relationship
with an HIV-positive partner. The framework promotes ART use by the HIV-positive
partner as a long-term strategy to both treat and prevent HIV. The clinical benefits ART
adherence and treatment non-interruption by the HIV-positive person is shown as a
commitment to the relationship and the HIV-negative partner by maintaining the viral
load at undetectable levels. Undetectable viral load can be achieved within 3-6 months of
daily use and decreases the risk of transmission of the virus. Antiretroviral therapy was
also deemed safe to use during peri-conception, pregnancy, and breastfeeding to optimize
pre-pregnancy health; decrease viral load; establish a routine with ART use; and prevent
HIV transmission to babies.

Morton et al. (2017) framework further promotes the use of PrEP by the HIV negative partner for HIV prevention in both men and women. Unlike ART, PrEP is not a lifelong intervention; it is only used during periods of high HIV risk such as the time right before the HIV-positive partner achieves viral load suppression; when couples are attempting pregnancy; and in the presence of other HIV transmission risks (partner's

unknown HIV or ART status). Pre exposure prophylaxis (PrEP) is also considered safe to use by HIV negative women during pregnancy. According to Morton et al. (2017), by combining ART and PrEP in the prevention of HIV transmission among HIV discordant couples, when the HIV positive partner achieves viral load suppression, the HIV negative partner may discontinue PrEP, given that there are no other risk factors involved in the relationship, including a third partner of uncertain HIV status.

The issue of sero-discordant relationships was also addressed by Newman, Persson and Ellard's (2018) qualitative study, which investigated the experiences of gay men and heterosexual couples of mixed HIV status in Australia. Two primary themes emerged from that study: disclosing discordance to extended family members and pursuing sero-discordant parenthood. Under the theme disclosing discordance to extended family members, Newman et al. (2018) found that most couples were very careful about who they told about their serodiscordant relationship and that many had decided to deliberately keep this information from some or all of their extended family members. Study participants shared their Realities of Living With HIV related to having sex and being involved in HIV sero-discordant relationships. Ashley relayed, "As long as you're careful." Blessed added, "When I was ready I made sure that I was ready for it ... He always goes for his monthly checkup, and he is not HIV, so he knows he is safe." **Kayden** shared, "You just always have to use protection, you always have to like [pause], I say it difficult when it that heat in the moment action ... you always make sure you carry your condom with you." **Keisha** communicated, "It's a normal [laughs] thing, I don't know." **Loren** explained, "You always have to bring protection, ahm, condoms, ah, take your medications, ... because condoms is not always 100%, you know, proof ...

to protect your partner from receiving HIV." **Margarita** expressed, "I hear about PrEP, so we tried to get the PrEP, we tried to wear condoms." **Melissa** shared, "So he is taking the little pill that they have, but it's just like, I don't know people just have cold feet sometimes"

Participants' essence of living with HIV since birth as described in *Realities of Living With HIV* represents the participant's presence in the normal activities of life: post-secondary education, work, residence, volunteer, and intimate relationships that their HIV-negative peers are involved in and the consequences of such involvement. Their essence of living with HIV since birth as described in *Realities of Living With HIV* were compared to research studies conducted by Galano et al. (2016), Gaudet (2007), Greenhalgh et al. (2016), Godsay et al. (2012), Lopez (2004), Morton et al. (2017), Newman et al. (2018), Stangl et al. (2015), Williams et al. (2017) and Weintraub et al. (2016).

Theme: Affirming Milestones

Affirm is considered a verb, meaning "to say positively – declare firmly – assert to be true; to make valid – confirm – uphold …" (Neufeldt & Guralnik, 1986, p. 22). Milestone is characterized as a noun meaning "a significant or important event in history, or in the career of a person, etc." (Neufeldt & Guralnik, 1986, p. 860). Milestones were demonstrated in Confavreux and Vukusic's (2006) quantitative study, which used the Kurtzke Disability Status Scale [DSS] (1961, 1983) to determine disability milestones in multiple sclerosis. The DSS rated irreversible disability as follows:

A score of 4: limited walking ability but without aid or rest for > 500 meters;

A score of 6: the ability to walk with unilateral support no greater than 100 meters without rest;

A score of 7: the ability to walk no greater than 10 meters without rest while leaning against a wall or holding onto furniture for support (Confavreux & Vukusic, 2006).

Irreversible disability was assigned when a given score persisted for at least 6 months, excluding transient worsening of disability related to relapses; all scores of disabilities subsequently assessed were either equal to or higher than that score. The date of assignment of irreversible disability status were assessed when appropriate. Endpoints were ages at the time of assignment of an irreversible score of DSS 4, DSS 6, and DSS 7. Age was considered a survival data, consisting of the time interval from birth to assignment of the disability scores. Confavreux and Vukusic (2006) found the median age at the time of irreversible disability for each score to be approximately DSS 4 = 44 years; DSS 6 = 55 years; and DSS 7 = 63 years. They concluded that "age at assignment of disability landmarks is not substantially influenced by the type of the initial course of multiple sclerosis, be it exacerbating-remitting or progressive" (Confavreux & Vukusic, 2006, p. 603).

In this study, *Affirming Milestones* are the goals for attaining a successful future that participants are looking forward to. These goals include furthering their education and career, having children, helping people (altruism), and imagining what their future looks like. Stangl et al. (2015) reported similar aspirations demonstrated among adolescent girls (15-19 years) living with HIV in Zambia. The researchers found that, at the individual level, participants "overwhelmingly asserted that living with HIV was not going to hold them back from achieving their dreams" (p. 2). They aspired to acquiring "a good education, having a career, having a family with children and living a

comfortable life with nice possession" (Stangl et al., 2015, p. 2. Participants in this study have attempted post-secondary education and have *Affirming Milestones* to pursue higher education in the future. They shared their educational aspirations. **Edward** shared, "I want to, to aahm, to pursue a PhD [Doctor of Philosophy] in mechanical engineering ..." **Jamie** declared, "Going back to school to be a nurse...." **Kayden** explained, "I do plan on going back in August [2018], hopefully to pursue my Masters ... Either public administration or criminal justice ..." and **Keisha** articulated, "I plan to go to medical school and become a doctor. ... but if it doesn't go smoothly, then after undergrad, I plan to get a masters, and then go to medical school."

Participants have Affirming Milestones for future career which will provide them with personal satisfaction as well as economic gain. They Affirm to become doctors, nurses, occupational therapy assistants, cosmetologists, business women, social workers or psychologists, Transportation and Safety Agents (TSA), musicians, missionaries, tenured professors, and teachers. Career aspirations among 35 adolescents and young adults (AYA) with PAHIV was also explored by Fair, Rupp, Mitchell and Gatto (2017) in their phenomenological study. The purpose of their study was to examine the career aspirations of adolescents and young adults (AYAs) through the unique and largely unstudied lens of PAHIV. Two themes emerged from that study: participants' career aspirations were linked to their relationships with families and medical providers and the participants' HIV status. Family member's motivation and emotional support were factors that influenced their efforts. Medical providers were encouraging, instrumental in gaining access to resources, and motivating. Fair et al. (2017), found that participants' HIV status was an influence on career choice in some instances, while it had no influence

in others. In this study, participants shared their *Affirming Milestones* related to their career. **Ahmazin** discussed, "I want to have my own organization [cough] I am sorry. I want to have my own non-profit organization ... me and my boyfriend is working on aahm 2 businesses right now." **Ashley** shared, "I was looking to two career fields ... social work, like child welfare, or aahm drug, drug rehab, like drug counselling. ... both of those kinda hit home ..." **Brittany** emphasized, "Cosmetology, owning my own beauty salon." **Edward** declared, "Professor, Scientist." **Jamie** considered, "Nurse." **Kayden** wished, "I am currently in the process of TSA, and Customs and Border Patrol." **Keisha** responded, "Become a doctor." **Loren** explained, "A job that doesn't require me to socialize too much." **Lovely** declared, "Work on the farm." **Melissa** discussed:

I wanna do, you know, nurse technician. I kinda wanna be an entrepreneur ... I would like to have a aahm, online store. I like the whole thing you know, about natural. I like the whole thing about skin.... I would like to do something like that or make up.

Rashad shared, "Occupational therapy assistant and work with kids with disabilities." **Travis** expressed, "A career in music, where I am not just in a band, but I am producing, I am writing, I am collaborating"

In this study, participants expressed *Affirming Milestones* to have children, the number of children they would like to have, and the knowledge that they can have healthy HIV-uninfected children. Twelve (80%) of the 15 study participants from the sample either already have a child, have a child on the way, and/or desires to have children in the future. As this population ages, the need for procreation or their desire for reproduction increase, which is not an unusual occurrence. According to Malinowski

(1930), parenthood "is the starting point of most other sociological relationships" (p. 25). Silva-Suarez, et al. (2016) also had an emerged theme "transition to adulthood: becoming a parent," where participants agreed that they would like to become parents and for those participants who were already parents, they agreed that being a parent was "the most wonderful thing they have experienced" (p. 8). Participants in Fair et al. (2016) study who already have children also reported that their children and the other parent were HIV negative, and that they were concerned about their children experiencing HIV-associated stigma and discrimination because the children have an HIV-infected parent.

Similar results were also found by Evangeli, Greenhalgh, Frize, Foster and Fidler (2014) in their qualitative cross-sectional study which was conducted among 65 individuals (16-25 years) to examine their parenting experiences, and the hopes and concerns in young people with PAHIV. Four themes emerged from that study: impact of children on intimate relationships; impact of culture, family and social norms on parenting intensions and expectations; disclosure of HIV status to children; and impact of HIV on procreational intentions. Evangeli et al. (2014) found that participants either had a child or desired to have children and that participants were concerned about the risk of transmitting HIV to their babies during pregnancy. In this study, participants who were already parents reported that their children and their partners were HIV negative. They also shared that they were aware that they could not transmit HIV to their children, when their viral load was undetectable. Study participants discussed their Affirming Milestones regarding having children. Ahmazin declared, "Me and my boyfriend have actually talked about having children.... we won't be planning for that until after we get married." Ashley shared, "I want children, but I want them to be like, negative, because I

wouldn't them to go through this situation ..." Blessed wished, "I hope to have children in the future." Brittany dreamed, "I hope to have children in the future. Yeh, when I am ready to have children ... aahm, I wanna have [pause] 4." Edward shared, "I would love to have children ... young family 2 kids." Jamie hoped, "I want kids, but it has to be with somebody that understands my condition ..." Kayden explained, "I don't know, I just always felt like I don't wanna do to my kids, like how I felt like my parents did to me." Keisha clarified, "Aah, about the whole thing about having children, I think it's possible, as long as, you know, I take my meds ... yes, I want to have children." Loren elaborated, "I want to have 2 kids ... someone that loves you, you know, aah, someone you can raise.... someone that has your DNA, aa mini version of me" Margarita expressed, "I have been having a lot of complication to actually having children ... I want to have at least 3, at most I want 7 like my Mom." Melissa declared: "Yeah, anything possible.... Having TD is like, you know, medicine is good. There's nothing to worry about."

Participants expressed their *Affirming Milestones* related to providing support to others who are experiencing some of the same issues that they have experienced being HIV positive. They have plans to help others navigate the emotional and social minefields, to provide a platform to address some of the social issue they may encounter, and to help destignatize the disease, among other plans. According to Kirby, Marcelo, and Kawashima-Ginsberg (2009), volunteering has become common among young Americans since the 1970s, and college educated young people were more involved than their peers without a college education. Youths without college experience who attended religious services were twice as likely to volunteer than their peers who did not attend

services regularly. They were found to be more likely to spend their time mentoring, teaching, or tutoring other youths.

Marta and Pozzi (2008) conducted a quantitative study among 158 volunteers (82 females and 76 males), to understand long-term volunteer behavior in young people. They concluded that "volunteer identity can be a prominent role, not only for the defined social tasks and characteristics the volunteer assumes, but also for the symbolic, effective, and value investment that the same individual and the broader society have upon them" (p. 44). In this study, participants were motivated by their experience with HIV, which gave them a heightened sense of awareness about the emotional and psychological impact of living with the disease. They shared their Affirming Milestones related to helping people. **Ahmazin** shared, "I want to provide a platform to encourage them to open up ... I think that by me sharing my story, it will encourage other people to share theirs." **Ashley** considered, "Yeh! Change it for somebody, and see like, it kinda start with them, like the actions that they take, so it's like, it helps guide those choices to be right choices." **Brittany** mentioned, "So I can help other people. ... if someone is going through the same thing as I was going through." **Kayden** explained, "I feel like I can give them advice ... when they become positive ... I am glad I can be like that person, you know, that turns that perspective around for them..." Loren declared, "I definitely want to help people ... I want to do something that is helpful towards other but [pause] it behind the scenes so I am not directly interacting with them." **Melissa** stated, "I want to help people that struggle with the same thing that I go through." **Travis** divulged, "Just educating people ... Whether it's educating people about music or educating people, about HIV."

Participants have *Affirming Milestones* regarding their future (being healthy; having a career, home and family; vacationing); and more specifically, the next 5-10 years. Li et al. (2016) found similar results in their qualitative study among 26 patients (7-15 years old). The study explored the experiences and needs of a group of adolescents living with HIV in Cape Town, South Africa. In the emerged theme, "views on life in the future," the majority of participants (two-thirds) indicated that they were happy about the future; optimistic about the opportunities that the future holds, and hopeful in their dreams of leading a normal life. Participants also expressed mixed emotions about their future, where positive emotions were driven by their expectations of the future and negative emotions were driven by the uncertainty of how they would achieve their goals. Study participants explained their Affirming Milestones associated with what their future looks like and, what they expect their lives will be like in the next 5-10 years. **Ahmazin** shared Affirming Milestones of what her future looks like, "My husband, aahm, and our family if we do have kids by that time, in which 10 years we should definitely have ... I want to do a lot of travelling ... I want to have my own businesses ... having my nonprofit organization." Ashley procrastinated about Affirming Milestones of what her future looks like:

Sometimes ... I feel like the virus might catch up to me ... if my time comes. But there are other times when ... I see myself like having like kids, a house, a husband [chuckle], a career uum ... just anything that anybody else would dream of, you know, money! Too.

Blessed declared *Affirming Milestones* of what her future looks like, "I will be living in a better home, I will be more better, than going through all this I am going through, with

pain and sickness." **Brittany** shared *Affirming Milestones* of what her future looks like, "It's gonna be like a normal life ... Like, healthy, aahm [pause], reaching for my goals ... cosmetology, owning my own beauty salon ... being undetectable, [pause] aah ... being ahm, having a husband and kid..." **Bryan** clarified *Affirming Milestones* of what his future looks like, "Normal life! I would like to get married, I would like to have children, have my own house. Have my own stable job ..." **Jamie** outlined *Affirming Milestones* of what her future looks like:

I vision it to be a normal [pause] life! ... working in the field that I want to work in ... going back to school to be a nurse ... helping people ... have a family [chuckle] with a nice nice house and good successfully job ... taking vacation.

Kayden reported *Affirming Milestones* of what his future looks like, "I came so accustom to being if I make it that far, or if I be there, that you know, I still kinda put that perspective, of not having that longevity life." **Keisha** narrated *Affirming Milestones* of what her future looks like, "I will be a doctor by then [laugh] aahm maybe I'll have a kid, have some type of money, real money coming in." **Loren** outlined *Affirming Milestones* of what her future looks like, "Whatever I paint it to be ... I want to be financially stable ... long term healthy relationship ... I want to be married." **Lovely** declared emphatically, her *Affirming Milestones* of what her future looks like, by age 26 years "I will be here." She also said the following about what her future looks like:

I wanna save my money so I can go on a mission trip ... save it for like vacations and stuff ... My own house my own farm ... my own, my own [stutter stutter] car and I want to have, I want to have myself a Hummer.

Melissa explained *Affirming Milestones* of what her future looks like:

People probably won't be worry about HIV ... I will probably be like in my career, and hopefully married and everything ... I just feel like I am going to achieve growing old with this virus ... have grand kids and stuff.

Rashad divulged *Affirming Milestones* of what his future looks like for the next 10-15 years:

My future is what I will make of it ... I won't be unsuccessful, and I won't be another statistic in this world ... I would get married when the time comes ... I am not saying that it will come in the next 10 or 15 years ... I just like for it to just happen naturally.

Travis shared *Affirming Milestone* for the next 5-10 years, "I see myself in a condo ... with a partner of loving awesome healthy relationship ... Extremely healthy, both mentally, physically ... educating people."

Participants' essence of living with HIV since birth as described in *Affirming Milestone* concerns their goals to achieve and maintain a healthy and economically stable future. Study participants have plans to further their education as they aspire to become professionals; have healthy, HIV uninfected children; help others who are having a difficult transition (altruism) and destignatize the disease; and have a positive outlook on what their lives will be like in 5-10 years. Their essence of living with HIV since birth as described in *Affirming Milestones* were also compared with findings from research studies conducted by Evangeli et al. (2013), Fair et al. (2017), Kirby et al. (2009), Li et al. (2016), Malinowski (1930), Marta and Pozzi (2008), Silver-Suarez et al. (2016), and Stangl et al. (2015),

Emerging Adulthood Benchmarks

Participants demonstrated characteristics or features of one or a combination of the three phases of the psychosocial tasks of emerging adulthood. Phase 1 is transitioning into emerging adulthood where participants share the responsibility of making decisions about their lives with their parents. According to Tanner and Arnett (2009), "power is shared, mutual and the responsibility for care and support gain in reciprocity" (p. 40). Phase 2 is emerging adulthood where commitment to roles and relationships are temporary and Phase 3 is adulthood where there is a commitment to enduring roles and responsibilities in career, marriage and partnership, and parenthood. Tanner and Arnett (2009) also theorized that there is a worldview of evidences on emerging adulthood, which are also evident among this sample population as follows:

- 1. Increased rate of post-secondary education: the results of the study indicates that 66.67% of the sample population has gone on to pursue post-secondary education at varying levels, and 20% have expressed plans to pursue post-secondary education in the future.
- 2. Increased age at first marriage: approximately 87% of all participants are over the age of 20 years and none (0%) are married; one (6.67%) is engaged to be married; and 12 (80%) have expressed the desire to get married in the future. This signifies that this group is delaying marriage until they are older.
- 3. Increased age at first child birth: only three (20%) participants either already have a child or has one on the way, while an additional nine (60%) have plans to have children in the future. With most participants being over the age of 20 years, this trend mirrors the global phenomenon of increased age at first child birth.

- 4. Increased roles and opportunity for women: this study did not evaluate for gender-based opportunities.
- 5. Increased acceptance of premarital sex: Nine (60%) of all participants had their first sexual encounter between age 16-18 years or younger; nine (60%) are sexually active; and none (0%) are married. These results are consistent with the worldview and places participants at high risk for sexually transmitted diseases and unintended pregnancies.

Participants enjoy variability in residential status and school attendance. Twelve (80%) participants continue to live at home with relatives, while others live with intimate partners, share living space or lives independently. Of the 10 (66.67%) who have pursued post-secondary education, five (33.33%) have pursued or earned an associate or technical degree, four (26.67%) a Bachelor Degree, and one (6.67%) a Master Degree. Participants' characteristics of the psychological tasks of emerging adulthood, worldview evidence, and variability in residential status and school attendance are demonstrated as follows.

Ahmazin (Phases 1 and 3)

Ahmazin shares power and reciprocity with her mother and her grandmother who continues to provide living accommodation. She has commitment to enduring responsibilities to her future career as an entrepreneur having earned a graduate degree in business administration and maintaining employment in roles that are preparing her for her future career. Ahmazin has committed to an enduring role in partnership as demonstrated in her relationship with her boyfriend with whom she shares a strong emotional bond, although they are not married. They continue to discuss and make plans

for their future together, such as starting their own business together, getting married, having children, and traveling.

Ashley (Phase 3)

Ashley has committed to enduring role and responsibilities in her career and partnership. Her commitment to her career is demonstrated in her earning a bachelor's degree in sociology and a minor in psychology. Ashley's current employment demonstrates her commitment to her career, although her job is not within the same discipline. Her job provides administrative experience which will be useful in the future. Ashley's current employment status also demonstrates commitment to her partnership in her intimate relationship because her income contributes to their living accommodation and supports their lifestyle.

Blessed (Phase 1, 2, and 3)

Blessed shares power and reciprocity with her mother and stepfather who continue to provide living accommodation. She has temporarily committed (less than concrete plans) to pursue post-secondary education in preparation to become a photographer. **Blessed** has committed to enduring roles in partnership and parenthood in her relationship with her intimate partner and their child.

Brittany (Phase 1)

Brittany shares power and reciprocity with her sister who continues to serve as her primary caregiver and with whom she continues to reside, while she is pursuing post-secondary education in preparation for a career in cosmetology.

Bryan (Phase 1, 2, and 3)

Bryan shares power and reciprocity with his father with whom he still resides, and his godmother who continues to provide support and direction which he depends on. He has temporary commitment to a future career, which he has not identified, although he continues to pursue post-secondary education. **Bryan** works to provide a source of income. He has commitment to an enduring role in partnership in his relationship with his girlfriend.

Edward (Phase 1, 2, 3)

Edward shares power and reciprocity with his mother whom he continues to reside with. His commitment to roles and responsibilities in relationships are temporary. **Edward** acknowledged being involved with an intimate partner, but he does not describe that involvement as a relationship, where they are planning for a future together. He demonstrates commitment to an enduring role and responsibilities to his future career as a mechanical engineer, as demonstrated in his pursuit of a bachelor's degree; his plans for graduate study; and his present job as a student researcher.

Jamie (2)

Jamie has temporary commitment to roles and responsibilities in her career. She has an associate degree in medical technology; however, her career desire is to become a nurse. **Jaime's** work roles are unrelated to her career goals.

Kayden (1, 2, 3)

Kayden shares power and reciprocity with his mother's cousin while he continues to live at home. He has temporary commitment to roles and responsibilities in partnership because he has only just now found himself in a committed relationship. He

is committed to enduring roles and responsibility to his future career as a transportation and safety agent. **Kayden** has already earned a bachelor's degree and has plans to pursue a graduate degree towards become qualified for his career. His current work roles, although unrelated, provide experience that he will be able to utilize in the future.

Keisha (1, 3)

Keisha shares power and reciprocity with her aunt as she continues living at home. She has commitment to enduring roles and responsibility to her future career as a medical doctor and in partnership in her relationship with her fiancé. **Keisha** is pursuing a bachelor's degree and has plans to pursue graduate studies towards her career goal. She and her fiancé are planning their wedding for some time in the near future.

Loren (1, 2, 3)

Loren shares power and reciprocity with her mother while she continues to live at home. She demonstrates temporary commitments to roles in a future career, and partnerships. She is a college student with periods of absences, and she works occasionally.

Lovely (1)

Lovely shares power and reciprocity in deciding where to live. She continues to require care and supervision from an adult at all times.

Margarita (1, 2)

Margarita shares power and reciprocity with her brother with whom she resides. He provides her with a place of safety and emotional support. **Margarita** demonstrates temporary commitment to education, career, and partnerships. She has made multiple

attempts at post-secondary education, but has not focused on a particular career choice; and she has been in and out of intimate relations.

Melissa (1, 2, and 3)

Melissa shares power and reciprocity with her sisters with whom she continues to reside. She has temporary commitment to roles and responsibility in career and partnership as evidenced by her haphazard enrollment in educational programs, unstable work commitment, and unreliable intimate relationships. Melissa is committed to enduring roles and responsibility of parenthood, as demonstrated in her having a child and taking the necessary precautions to ensure that her future offspring(s) will be given a fair chance of being born without birth defects and HIV-uninfected.

Rashad (3)

Rashad is committed to enduring roles and responsibility to his future career in occupational therapy and parenthood. These are demonstrated in his intermittent but resolved college attendance; his present job working with special needs children, which is related to his career vison; and having a child on the way, about which he is excited and making preparation.

Travis (1, 2, and 3)

Travis shares power and reciprocity with his mother with whom he continues to reside. He demonstrates temporary commitment to his future career. Travis has multiple job in unrelated areas although he practices his art of drumming frequently.

Collectively, these study participants have attained enough features of emerging adulthood to be considered as having achieved the benchmarks of the developmental stage.

Connection of The Human Becoming Theory to the Themes and Sub-Themes

The 15 emerging adults who participated in this study shared their experiences of living with HIV since birth by describing how they became aware of their diagnosis and how living with the disease has affected their lives; what they have accomplished; and their goals for the future. Their willingness to participate in this study and sharing those experiences afforded an understanding of their essences of the experience of living with HIV since birth. The principles and concepts of the Human Becoming Theory are linked to the themes and sub-themes that emerged from this study.

The Human Becoming Theory

The human becoming theory is categorized as a grand theory because the "concepts and propositions are written at a relatively abstract level" (Fawcett, 2005, p. 473). The theory has its philosophical foundation in Dilthey's (1998, 1983) original works; Martha Rogers' Science of Unitary Human Being (1992), particularly "the concept of energy fields, openness, pattern, and pandimensionality and her homeodynamic principles of helicy, integrality, and resonance" (Fawcett, 2005, p. 473); and the existential phenomenological philosophies of Heidegger (1962), Sartre (1966), and Merleau-Ponty (1974). The human becoming theory is a revision of Parse's (1981) previous work "Man-Living Health: A theory of nursing," for which the basic tenets of the theory were not changed. The review became necessary in 1991, after the dictionary definition of "man" was changed, to a definition that was not congruent with neither the title nor the assumptions of the theory (Parse, 1992; 1997).

The human becoming theory refers to an ongoing construction of reality by assigning significance to the experiences of the many realms that are lived all at once

(Fawcett, 2005). Human becoming "reflects the unity of the construct man-living-health" (Parse, 1992, p. 37). According to Parse (1981, 1997), the theory is a human science which focuses on human being's participative experience in the world" (p. 37). The theory is rooted in the belief that:

Human-universe experiences are connected uniquely to give meaning to an individual's life ... humans participate with the universe in the cocreation of health ... that human beings live their health incarnating personal values which are each individual's unique connectedness with the universe ... the theory is embedded in meanings, patterns in relationships, and in hopes and dreams (Parse, 1992, p. 37).

According to Parse (1997), "human becoming is a unitary construct referring to the human being's living health" (p. 32). The assumptions of the theory are as follows:

- Human becoming is freely choosing personal meaning in situations in the intersubjective process of relating value priority;
- Human becoming is cocreating rhythmical patterns of relating in mutual process with the universe;
- 3. Human becoming is cotranscending multidimensionally with the emerging possible" (Parse, 1997, p. 33).

These assumptions led to three underlying principles and related concepts.

Principle #1 - Meaning

According to Parse (1981, 1992, and 1997):

The structuring of meaning multidimensionally is cocreating reality through the language of valuing and imaging: Human beings construct a personal significance

by choosing options from the various realms of the universe ... what is real for each individual is structured by that individual. (Parse, 1981, p. 69; Parse, 1992, p. 37; Parse, 1997, p. 33)

The corresponding concepts/paradoxes of meaning are imaging: explicit-tactic, reflective-prereflective; valuing: confirming-not confirming; and languaging: speaking-being silent, moving-being still.

Principle #2 - Rhythmicity

"Cocreating rhythmical patterns of relating is living the paradoxical unity of revealing-concealing and enabling-limiting while connecting-separating" (Parse, 1981, p. 69; Parse, 1992, p. 37; Parse, 1997, p. 33). According to Parse (1992), "the rhythmical patterns of relating are paradoxical in nature ... the rhythmical patterns are not opposite; they are two sides of the same rhythm that coexists all at once" (Parse, 1992, p. 38). The corresponding concepts/paradoxes of rhythmicity are revealing-concealing: disclosing-not disclosing; enabling-limiting: potentiating-restricting; and connecting-separating: attending-distancing.

Principle #3 - Cotranscendence

"Co-transcending with the possible is powering unique ways of originating in the process of transforming" (Parse, 1981, p. 69; Parse, 1992, p. 37; Parse, 1997, p. 33). According to Parse (1992), "human beings move beyond with intended hopes and dreams through pushing-resisting in creating news ways of viewing the familiar" (p. 38). The corresponding concepts/paradoxes of cotranscendence are powering: pushing-resisting; originating: certainty-uncertainty, conforming-not conforming; and transforming: familiar-unfamiliar.

The principles and concepts of the human becoming theory, which include Principle #1 Meaning – imaging, valuing, and languaging; Principle #2 Rhythmicity – revealing- concealing, enabling-limiting and connecting-separating; and Principle #3 Cotranscendence – powering, originating, and transforming, were connected to the emerged study themes of *Panorama of Living With HIV; Consciousness*, and its subthemes *Kinship, Concealing* and *Paradox*; *Realities of Living With HIV; and Affirming Milestones*. The connection between the principles and corresponding concepts of the human becoming theory and sub-themes of this study are illustrated in Figure 32.

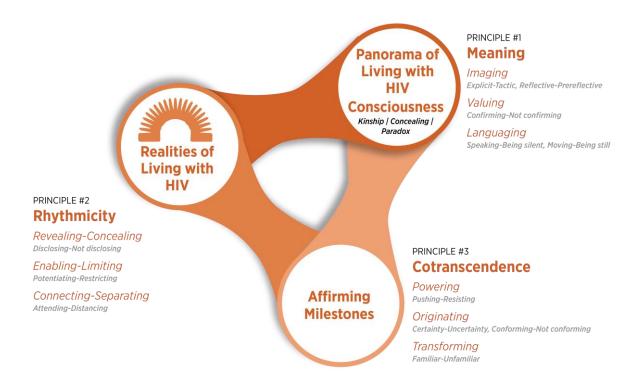


Figure 32. The human becoming theory (Wright, 2018, partially adopted from Parse, 1981, 1992, 1997, 1999).

Figure 32 shows the links between the principles and corresponding concepts/paradoxes of the human becoming theory and the emerged themes and sub-themes of the study.

Principle #1 - Meaning: Panorama of Living with HIV

The principle of meaning and the concepts/paradoxes (imaging: explicit-tactic, reflective-prereflective; valuing: confirming-not confirming; and languaging: speakingbeing silent, moving-being still) as described by Parse (1981, 1992, and 1997) in the human becoming theory were connected to the theme *Panorama of Living With HIV* in this study. Meaning as described by Frankl (1967), is concerned with what man basically is and what man should be because man can only actualize himself to the extent to which he fulfils meaning, after which self-actualization occurs spontaneously. Meaning has also been shown to be a perception of significance, which leads to less psychological stress and greater life satisfaction, better adjustment, and the ability to move on (Fillion et al., 2009). Meaning has two distinguishing levels (global and situational), where global meaning encompasses a person's enduring beliefs and valued goals, while situational meaning refers to the significance of a particular occurrence in terms of its relevance (Park & Folkman, 1997). It is the meaning that is formed in the interaction between a person's global meaning and the circumstances of a person-environment transaction, which encompasses an initial appraisal of the meaning of the event and the search for meaning (Park & Folkman, 1997). The connection of Principle #1 Meaning to the theme Panorama of Living With HIV is discussed in the subsequent section.

Participants' structured meanings of their reality of being an emerging adult with PAHIV are partially depicted in their description of their *Panorama of Living With HIV* as represented in their overall view (common thoughts) of living with HIV from birth,

their experiences with HIV, and the effects of HIV on their entire lives. These images have defined the values they ascribed to their reality of living with the disease.

Participants described their *Panorama of Living With HIV* as not being the easiest thing to do because they were often lonely and the only member of their household with the disease. They also described their lives growing up as being normal because it was the only life that they knew. They become more accepting of having the disease after they realized that having the disease did not make them bad people, it was just a part of their lives. Participants remained hopeful as long as others did not know that they have the disease. They were enjoying successes, and they described a typical day in their Panorama of Living With HIV as involving the normal activities of daily living (personal hygiene, eating); attending regular activities (school, work, doctor's visit); spending time with relatives or intimate partners; relaxing; self-love/care; taking care of their children; and taking their medications. Participants believed that their lives would be the same with or without HIV. They pledged not to allow themselves to be defeated and that they would remain hopeful. Participants does not consider their lives to be any different from their HIV negative peers. The connection of Principle #1 Meaning to the theme *Panorama of* Living With HIV are further illustrated in study participants' verbatim accounts.

Blessed discussed her structured meaning of *Panorama of Living With HIV* by sharing her images of the experience of growing up with the disease and the values or lessons learned from those experiences. She stated:

It was [pause], it was really hard growing up, because I thought I was like something disgusted [pause]. I honestly, I hated it, I hated life, because I felt like, how, why, I was the only one who was taking medicine. Why do I have to

go through this? Honestly, having a health issue shouldn't stop you from doing what you should do, that's honestly, that's just another excuse for you to make yourself depressed and everything, you shouldn't hold back or anything. My life would still be the same either way [pause] because I already go through a lot with my disability. I accomplish having a beautiful healthy daughter, and I accomplished just being here and taking my medicine every day. So, I accomplish a lot by having, by having HIV. I think even if I have HIV I am still able to do everything, if I set my mind to it, just not think about what I have, just do it as long as you are safe.

Keisha spoke about her structured meaning of *Panorama of Living With HIV* by sharing her images of growing up with the disease and the values she ascribed to her experiences. She expressed:

In my younger days, I had this thought about what it would be like. Like, Oh I can't get married, I can't have kids, [pause] but [pause] that's all I really thought about. It's when I became, towards my teen years and towards my young adult years, like now is when it really was a challenge. Like relationships, making sure I am on top of my health, being an adult.... I have to make sure I know what all the terms mean, medically, and I am taking my meds. Normal living was regular as a child ... a typical day ... when I wake up I have to remember, before class, to take my pills, so I always keep like a bottle of water in my room ... then I go to class. I come home study, I watch TV, and then I go to sleep and then do it all over. Yes, and the fact that I wouldn't need to remember to always take pills, but ... I don't really see a difference, [from HIV negative peers] [silence] ... I think that's

one thing that makes me, or living with HIV different from a normal person, because there are some information that's reserved.

Loren shared the structured meaning of *Panoramic View of Living With HIV* by explaining her images of living with HIV since birth and the values she attributed to her experiences. She verbalized:

I feel like certain people [pause] will treat you differently ... whereas when you [they] don't know, people treat you like ... your' a regular person. I feel like, aah, its different [from HIV negative peers] because, you have to take medication ... and I was dealing with it since I was little ... I would be so happy like I won't have to think about aam if I missed a dose, aah I got to take my medication or be concerned that my health, you know, be affected ... I feel like it, it's kind of normal living with it ... because I was born with it ... I don't really see it as, you know, out of [pause], something abnormal. I wake up, brush my teeth ... take a shower, ash I either go to work, or go to school or go hang out with one of my sisters. I think relationships would be different, and the fact that, it would be less pressure when you meet someone to figure out when to disclose and aahm, the time frame and if the person is even worth telling ... Peers my age tends to be sexually active and aahm [pause] ... the average peer doesn't have to think about it, or they are not as concerned, whereas for me I feel like it's different because I have to make sure that, aahm, I am safe if I am sexually active. I just have to be more careful.

Participants' essence of living with HIV since birth as described in *Panorama of Living With HIV* is their perception of life growing up being difficult in the early years

and becoming normal and similar to their HIV uninfected peers as they got older. Normalcy was demonstrated in their typical day involving regular activities, except for having to take their medications daily and on schedule, frequent doctor's visits and hospitalizations. Participants acknowledged that their lives are different from their HIV negative peers in some regards. They have to be more cautious by practicing safe sex; keep their HIV status a secret; and disclose their HIV status to intimate partners. Their essence of living with HIV since birth as portrayed in *Panorama of Living With HIV* were also compared with findings in research studies conducted by Madiba and Mokgatle (2016), Mutumba et al. (2015), and Williams et al. (2017).

Principle #1 - Meaning: Consciousness

Meaning and its concepts and paradoxes (imaging: explicit-tactic, reflective-prereflective; valuing: confirming-not confirming; and languaging: speaking-being silent, moving-being still) as described by Parse (1981, 1992, and1997) in the human becoming theory were connected to the theme *Consciousness*. The emerging adults in this study shared their experience of their HIV status coming into their *Consciousness* and their construction of their own reality of living with HIV. Participants' experiences were based on their knowledge of the disease at the time their HIV diagnosis came into their *Consciousness*; concerns that they had before being informed of their diagnosis; their response to the HIV diagnosis; and the impact of the disease. Participants' HIV status came into their *Consciousness* at varying ages, but all were informed by the age of 15 years. Ahmazin is an anomaly because she was diagnosed with the disease at the approximate age of 15 years. Other participants conveyed that when their HIV status came into their *Consciousness*, they did not know what HIV was, and their caregivers had

limited knowledge about HIV. They also reported that caregivers delayed disclosing their HIV status to them by withholding information, avoiding answering related questions, or being deceptive. Prior to their HIV status coming into their *Consciousness*, participants reported events in their lives, which were of concern to them. They also conveyed that their lives were normal before associating events with HIV.

Participants' reported their responses to their HIV diagnosis coming into their Consciousness as being challenging, frustrating, shocking, and crushing. Their Consciousness left them feeling depressed and with suicidal thoughts without attempt; sad; crying; refraining from having sex until a later age; and the feeling that they were going to die. Participants reported eventually embracing the news, forgetting about the diagnosis and going on with their lives, with the perspective that things happen to people in life. In structuring the meaning of their HIV status coming into their Consciousness, participants have also considered their Kinship relationships, the Concealment of their HIV diagnosis from family members and close friends, and their Paradoxical relationship with their medications, by assigning values to those experiences in the context of their connection with their universe.

The connection of Principle #1's meaning to the theme *Consciousness* is further reflected in participants' accounts. **Ahmazin** shared her structured meaning of her HIV status coming into her *Consciousness* by describing her image of coming into that knowledge and the values she attributed to it:

When I was diagnosed I was a teenager ... they had also did a HIV/AIDS test.

My tests came back positive and that's when they notified my parents. My

parents probably told me a month after I got out of the hospital, when I had my

first appointment at the ZT [immunology clinic]. I was unaware [pause] of everything [parent's HIV status].... I was frustrated and upset, I felt like aahm ... I was being punished.... Aahm, around that time I lost my faith and everything.... And it's like, "why me of all people?" ... [she] didn't know why I was getting shingles. At first, it was very challenging ... Added to my depression [pause] ... suicidal thoughts - I want to kill myself, I never attempted anything, but I did have those thoughts ... as far as how it changed my life, aahm, after I got out of my depression ... at the end of the day I can't change it, unfortunately ... so overtime I started to transition to a more positive mind frame; It's actually, aah, push me and encourage me to do more things.

Bryan discussed his structured meaning of his HIV status coming into his *Consciousness* by reflecting on his image or knowledge of being informed and the values he attributed to his *Consciousness*:

So, at first ... you don't really know you actually have this thing, you just think that you are a normal kid ... growing up with it you're a normal person.

I found I had it when I was in the fifth grade ... I keep asking him [father] why I was taking the medication and he didn't tell me, so I refused. So, he felt like "I have to tell him so he can start take the medication" ... That's how I found out.

After I told my dad, he didn't really say anything. He just started crying because he didn't think that I was gonna figure it [how his mom got HIV] out, or even if I am right or wrong. I never shamed my mother for it I'll never thought it was her fault ... I never was like you ruin my life. I was like it's fine, something always happen to everybody, somebody's life but you can't blame somebody for it. You

have to embrace and live with it. When my mother passes I had a lot of anger build up in me ... I am not letting it hinder me.

Jamie explored her structured meaning of her HIV status coming into her *Consciousness* by delving into her image of coming into knowledge of her HIV status and the values she attributed to her *Consciousness*. She reflected:

I used to always ask myself, why do I always take medicine, why do I take medicine? I finally asked my cousin, why did I take medicine? And she told me ... I got to be knowledgeable about it, because you know, I am in a situation, and aahm, ... it's position of where I have to know about this disease too [pause] you know? Pass it on. I was very shocked, but I took that, and I embraced it and I just dealt with it. The disease itself do not bother me, it bothers me but it don't ... I don't let it affect me ...

Kayden explored his structured meaning of his HIV status coming into his *Consciousness* by considering his image of knowing and the values he attached to his *Consciousness*. He mentioned:

I honestly don't recall not knowing that I was HIV positive. I always knew as a kid ... I always feel like I am sick, in a sense ... a slightest headache, or the slightest stomach pain and I feel like, Oh, maybe if I didn't have HIV ... I probably wouldn't feel like this every day.

Participants' essence of living with HIV since birth as described in *Consciousness* is becoming aware of their HIV status, which describes how and when they were informed of their HIV diagnosis; their knowledge of HIV at the time; their concerns before being informed; their response to their HIV diagnosis; and the impact that their knowledge of

having the disease had on them. Participants' HIV status came into their *Conscious* at varying ages, by the age of 15 years. Their essence of living with HIV since birth as described in *Consciousness* were compared to the findings in research studies conducted by Madiba and Mokgatle (2016), Namukwaya et al. (2017), Proulx-Boucher, et al. (2017), Stangl et al. (2015), and Williams et al. (2017).

Principle #1 - Meaning: *Kinship - Sub-Theme of Consciousness*

Participants' structured meaning of their interconnectedness with others in their universe were also illustrated in their *Kinship* relationships. The *Kinship* or familial-type relationship that participants enjoys comes in various forms, biological parents (divorced, single mothers, widows); adoptive parents (married, separated), siblings (sisters, brothers); and relatives (aunts and uncles; cousin, godparent, step-relative). Participants also shared *Kinship* relationship with siblings (biological, adoptive, and step siblings), in which they fall either in between or at the end in birth order. They reported siblings being the only other family member besides their parents being aware of their HIV diagnosis and of their siblings keeping their secrets and being very protective. Siblings have also been reported to have taken on the responsibilities of primary caregiver and of finding participants ways out of difficult situations, even when they themselves have their own responsibilities of life.

Participants shared their structured meaning of *Kinship* in their perceptions and experiences and the values they ascribed to them. **Ahmazin** described her structured meaning of *Kinship* with her parents by exploring her image of the relationship she shares with each parent and the values she places on those relationships. She stated, "Me and my dad's relationship is gotten way better ... me and my mom is pretty cool. On my

mom's side I have, its four of us ... On my dad's side I have one sister." **Ashley** discussed her structured meaning of *Kinship* in her relationship with her adoptive parents by expounding on her images, and the values she places on their relationships. She shared:

I am aahm with my, adoptive parents now ... from 6 around 5 or ... They give me like a life, like you know, outside of what I knew.... So around fourish, my dad [biological] died.... my mom [biological] ... She died. She [adoptive mother] told my older brother and he basically, so he is the only one that knows, besides my parents...

Brittany explored her structured meaning of *Kinship* in the relationship she shares with her sister as her primary caregiver, her image of their relationship, and the value of appreciation that she ascribes to it. She disclosed:

Aaah, they are good, well they [biological parents] passed away. She is a good big sister [caregiver]? ... Yes, she takes care of me. She make sure I be straight ... Like she is helping me go to class for wigs, makeup and aah, she is a very big supporter.

Bryan described his structured meaning of *Kinship* in the relationship he shares with his godmother, his image of their relationship and the value of loyalty that he places on it. He echoed:

I always consider her my mom especially, consider that she is already my godmother, and the fact that she is my mother's biological sister and I never saw anything different of her.... Even her husband ... at the end of the day I saw him as a second dad as well ...

Jamie divulged her structured meaning of *Kinship* in the relationship she shares with her sister and her relatives by expressing her images of those relationships and the values she ascribes to them. She reported:

My mom died when I was six, and ... he [father] is somewhere, me and my sister we're close ... she still feels like aahm ... I am still that little girl when I am 24 years old ... [pause].... My aunt used to always [emphasis and pause] ... have me drink out of a different cup ... eat out of different spoon, like dishes completely. ... she would be having me miss doctor's appointment. I have 2 brothers and my sister.

Kayden discussed his structured meaning of *Kinship* in his relationship with his mother's cousin as his caregiver, his image of their relationship, and the value of appreciation that he places on it. He affirmed:

My mom's cousin took us in ... me and my brothers, there is 3 of us.... she has a daughter which I call my sister. It was [pause] it was really good, I mean, I don't really have no complaints ... I mean we are really close, aahm, I felt like we have gotten closer as I got older, I guess?

Keisha relayed her structured meaning of *Kinship* in her relationship with her aunt as primary caregiver, her image of their relationship, and the values she places on it. She articulated:

My relationship with my aunt, she is like, she is like a second mom to me ... So, it's the same as it would be with my mom ... she is a big part of my life. Well, my mom is passed. Ahm, I am older than all of them [aunt's children] ... so, they got it together [both chuckled].

Loren explained her structured meaning of *Kinship* in her relationship with her parents and siblings, the images of their relationships and the values she assigns them. She explored:

My real father passed away years ago ... My mom has always been there... She is definitely supportive, helpful too ... but, my Mom has always been there for me ... She always make sure I always have food on the table, take care of me, clothes. Make sure I was brought up right, how to take care for myself as a woman, young adult, a girl. She took me to church aahm, yeh! [pause] ... three sisters, one brother ... One, one of my sisters passed away, so right now I have 3 siblings ...

Lovely shared her structured meaning of *Kinship* in her relationship with her biological family when she stated:

I have a nice family, [pause] ... my mom [adoptive mom takes care of her] ... and I have birth mom, and she was really, really sick. She had HIV and she couldn't [pause] take care of me no more.... I had a brother and an older sister I never knew who they were [silence].

Margarita explained her structured meaning of *Kinship* in her relationship with her relatives as caregivers, her image of their relationships and the value of sadness that she assigns them. She revealed:

When I was 14 I lost my mom, and then I found out ... am going from different school, to school, to foster care And my aunts still didn't want to take care of me because [pause].... They didn't want me around their children. Seven, my mom had 7 [children] ... I am my mom's only daughter so.

Melissa discussed her structured meaning of *Kinship* in her relationship with her sisters as caregivers and siblings by complementing their virtutes in her image of their relationships and the values she attributed to them when she expressed:

My sister, Monica [name changed], she took care of me ... they like my best friends. She had like the mom figure, so it's like I couldn't, I know that was my sister and stuff, but I still respected her like a mother figure ... My two older sisters did took care of me and everything.

Rashad commented on his structured meaning of *Kinship* in his relationship with his mother by applauding his image of their relationship and the values he associates with it. He revealed:

I love my mom ... She is a single mom with 3 kids. So that kind of give me the drive and the motivation to, you know, get up She give me hope ... even when I felt like, I want to give up, she was there to, you know, kick me in my butt and tell me "push on, you got to go." I am the middle child and I am the only one that was infected.

Travis discussed his structured meaning of *Kinship* in his relationship with his adoptive parents by professing his gratitude for their relationships and the values he attributed to them. He reported:

I was raised by my parents [adoptive] ... I am still in touch with my mom, I am still really close to her, my dad, not so much ... I still love him, I still keep in contact with him.

Participants' essence of living with HIV since birth as described in *Kinship* is the familial type relationship they enjoy, which comes in different forms (parents, adoptive

parents, relatives, and siblings). These relationships features both good and bad experiences; however, participants have reported receiving love, encouragement, and motivation in these relationships. Most participants have experienced the loss of one or both biological parents and some have reported the loss of a sibling. They reported positively on their relationship with their siblings, some of whom have taken on the responsibility of primary caregivers, and often being the only other family member besides the parents who were aware of their HIV diagnosis. Participants' essence of living with HIV since birth as described in *Kinship* were compared with results in research studies by Silva-Suarez et al. (2016) and Grant et al. (2013).

Principle #1 - Meaning: Concealing – Sub-Theme of Consciousness

Participants' structured meaning of their interconnectedness with the universe and others were further illustrated in their structured meaning of *Concealing* their HIV status from close family members and friends. They reported that caregivers raised them to be *Concealing* by deliberately keep their HIV diagnosis from close family members, friends, and intimate partner's family. They often *Concealed* their medication or intentionally left them at home and not take them to stayovers. Now that participants are older and more independent, they now have the responsibility to decide whether to *Conceal* or not *Conceal* their HIV status. Participants shared their structured meaning of *Concealing* their HIV status. Ahmazin shared her structured meaning of *Concealing* her HIV diagnosis by hiding her medications and the values she placed on the secrecy, "I didn't want anyone to see me taking my meds, I would intentionally leave them home, and not take them."

Ashley explained her structured meaning of her parents *Concealing* her HIV diagnosis and the values she attributed to it, "Mom would always, she would always make up a lie

... now my parents left it up to me to basically tell people ... they even raise me to be that way." **Edward** shared his structured meaning of *Concealing* his HIV status by being deceptiveness and the values he associated with keeping his secret:

It's very say like sneaky... you hang out with your friends and you grow up just like a regular guy I would always have my little napkin with my pills in it, and I would sneak off to the bathroom with some water or something and go take my pills.

Travis divulged his structured meaning of *Concealing* his HIV diagnosis by protecting his secret and the values he ascribed to keeping the secret, "At church camp, I would be kind of afraid of like bringing my meds ... I didn't want people to ask; I just felt like it was, it was a secret I wanted to be kept."

Participants' essence of living with HIV since birth as described in *Concealing* is their experience of the secrecy and stigma associated with the disease. They reported that their caregivers raised them to be secretive by keeping their HIV status from intimate partner's family, other close family members and friends. These actions have led to isolation and mistrust. As participants become older and more independent, they now have the choice to disclose their HIV status to whoever they want. Participants' essence of living with HIV since birth as described in *Concealing* was compared to other research studies conducted by Namukwaya et al. (2017).

Principle #1 - Meaning: Paradox – Sub-Theme of Consciousness

Participants also demonstrated their structure meaning of *Paradox* in their reflections of their relationship with their medications and the values they ascribed to the efficacy of the medications. Their *Paradoxical* relationship with medication (ART) lies

in the significant improvements in the medications over the years; however, participants still have to maintain a rigid schedule. Additionally, while the medications have improved and extended their lives, it also has side effects and contraindications, which participants have to contend with. Similarly, although taking their medications have become second nature to them, participants still miss doses, and the act of taking the medications are a consistent reminder of their HIV status. The following participants' experiences exemplified their structured meaning of their *Paradoxical* relationship with medication. Ahmazin discussed her structured meaning of the *Paradoxical* relationship she shared with her medication by describing her changing attitudes towards her medications and the values she ascribed to having the medications available. She communicated:

Because I didn't want anyone to see me taking my meds, I would intentionally leave them home, and not take them. I started off on seven pills. I am actually down to one now ... I started taking my meds consistently, because I also went through this rebellion stage ... I didn't want to take my pills.

Jamie explained her structured meaning of the *Paradoxical* relationship she shares with her medications by discussing her daily experience of the side effects of the medications. She elaborated:

I take two times a day, five pills, two times a day ... Aah getting up, take my medication [pause], relaxing [pause] until work ... Because it has a side effects as in dizziness, feeling sick, so ill lay down and try to take a nap wake up go work.

Kayden also discussed his structure meaning of the *Paradoxical* relationship he shares with his medications by explaining his experience with the side effects of the medications. He revealed:

Having HIV like with my meds, my stomach, every morning it's like irritated, because, you know, I take it at night before I go to bed. When I wake up it like annoyed and agitated, to me aahm ... sometimes I do try to take it with meals, aahm. I would be between two jobs and sometimes I forget to package ... I forget to replace what's in my keychain then that night I would probably miss it.

Loren relayed her structured meaning of her *Paradoxical* relationship with her medications by exploring the virtues of the medication in maintaining her health and the values she ascribes to its efficacy. She extolled:

Twice a day, once when I get up, once when I go to bed. Sometimes I skip doses ... I really need to work on that ... But if you're taking care of yourself, you're taking your medication like you're suppose to, or you're just resistance aahm, your body is able to fight off the virus, aahm, and it doesn't physically show aahm, then [silence] people will just see you, like you walk out the door and people would treat you regularly...

Melissa illustrated a portrait of her structured meaning of her *Paradoxical* relationship with her medications and the values she attaches to it. She highlighted:

Years ago I used to take like 10 pills a day ... I had to take it like bout five different medicines to maintain, but now I only took two. She [her Physician] just call me yesterday and said that, aahm, you know, the medicine that I am taking will have a birth effect on the baby, so she was like "don't get pregnant."

Rashad explained his structured meaning of the *Paradoxical* relationship he shares with his medications in the precautions he has to take to ensure its efficacy, and the values he places on having the medications. He responded by saying:

You can't drink alcohol while on your medicine. You can't, you know, do certain type of things, some people can't even put on, like lotion, different types of lotion. Twice a day, once when I get up, once when I go to bed.... sometimes you just don't feel like taking your medicine, just too tire to take it ... you're forced to face reality every single day you take medicine.

Participants' essence of living with HIV since birth as described in *Paradox* is the thankfulness, burdensomeness [appreciation-disfavor] relationship that they experience with the medications (anti-retroviral therapy [ART]). They described conflicting emotions between their appreciation of the benefits of the medications in extending and improving their lives and the difficulties they experience in maintaining the almost rigid schedule and the debilitating side effects. Participants' essence of living with HIV since birth as described in *Paradox* were compared to the findings in research studies carried out by Fields et al. (2017), Newman et al. (2016), Stangl et al. (2015), and Williams et al. (2017),

Principle #2 - Rhythmicity: Realities of Living with HIV

Principle #2 Rhythmicity and the corresponding concepts and paradoxes (revealing-concealing: disclosing-not disclosing; enabling-limiting: potentiating-restricting; and connecting-separating: attending-distancing), as described by Parse (1981, 1992, and 1997), were connected to the emerged theme *Realities of Living With HIV*. Rhythmicity is described as a noun meaning "the state of being rhythmic or of

responding rhythmically" as in the rhythmicity of the heart. According to Blood, Studdert, and Gay (2007), rhythmicity in cardiology is the ability to beat, or the state of beating rhythmically without external stimuli. Ciccone (2013) described rhythmicity in infants as concerning the interactions, adjustments, and attunements that take place within the bonds that parents develop with their infants. He identified three types of rhythmic experiences, related to the infant's development: (a) an alternation between openness to the world and withdrawal; (b) interactive and intersubjective exchanges; and (c) the object's presence and absence.

Ciccone (2013) further asserted that the alternating movements of openness and retreat as well as the withdrawal that follows a period of exchange and contact with the world allows the infant to construct subjectivity. Interactions and interactive exchanges with the infant allow for "the infant's own rhythm in order to sustain the process of internalization and avoid overexcitement" (p. 287). Ciccone (2013) advised that external rhythmicity should be in step and in tune with the infant's inner rhythm to allow the infant to engage in "the dance or choreography of their encounters" (p. 288).

Maier (2013) wrote that there are a great number of rhythmic-prone opportunities available to us, for example, greeting someone by fully entering the rhythm by an embrace, handshake, or casual wave; the built-in rhythmicity of a ball toss; walking in unison; or in giving a backrub, which are opportunities for blending each other's rhythms. Maier (2013) also communicated that true rhythmicity "requires a process of mutual engagement and inclusion" (para. 19) and that "rhythmic experience can be impactful in furthering a sense of wellbeing and internal cohesion" (para. 23). According to Maier (2013), "rituals may constitute an institutionalized form of rhythmicity by

culturally conforming to repeated and valued practices, which brings the participants an experience of togetherness" (para. 25).

In this study, participants cocreated rhythmical patterns of relating to facilitate their coexistence in the universe in their Realities of Living With HIV, which includes their involvement in normal activities of life such as post-secondary education, jobs, residential arrangements, volunteering, and intimate relationships. Study participants are actively pursuing post-secondary education, and some have already attained degrees at various levels. Participants are employed in different capacities in community outreach, administration, guest services, retail sales, banking, warehousing and security, school counseling/life coach, and telemarketing. Participants presently live in different residential arrangements: with parents (biological, adoptive, or foster); relatives; and sharing accommodations with a sibling or a partner. They are volunteering by assisting others who can benefit from their experience. Participants' cocreated rhythmical patterns of relating to others in their universe in their Realities of Living With HIV also includes being involved in intimate relationships, particularly HIV sero-discordant relationships, and having to navigate disclosing their HIV status to their intimate partners while being uncertain of the partner's reaction. Cocreated rhythmical patterns of interaction with others in their world are also evident in participants' resilience as described. **Brittany** shared the cocreated rhythmicity of her *Realities of Living With HIV* by revealing her involvement in the normal activities of life, that enabled her to connect and coexist with her HIV negative peers and others in her universe. She remarked:

I am studying for cosmetology after cosmetology I am going to, I am going to actually be an assistant for one of my friend's beauty salon. I see myself getting

involved ... I don't want the person ... to judge me when I tell them. I would like, tell the person first, before having sex, and I would want to wait until I am ready.... I want to take my time, get to know the person and tell them, when we are ready [pause]. So, I just be scared about like what they are gonna say. Are they going tell somebody, if they do, everybody is gonna call me bad words and all that stuff.

Jamie articulated the cocreated rhythmic associations of her *Realities of Living With HIV* by revealing her achievements and current situation, which enables her to maintain a connection to the real world. She also affirmed that *Concealing* her HIV status has limited her involvement in intimate relationships. **Jamie** revealed:

I had graduated from FCC ... last year September [2017] with aahm, MA- medical assistant and I wanted to do that but I couldn't [pause] take the job offer ... Me and my sister we stay together.... It's hard to like, to even like, if you waan like you know, have sex or like whatever?" You feel different sometimes, like you feel like you can't do things ... like couples they can live with each other without like secret and you have this secret that you wanna tell your partner ... and it's like you don't wanna [pause] tell them because you are scared of their reaction. ... and you tell that person so Oh! I am HIV positive, and they just look at you like. Like pause] you just you basically scaring them off ... so you just stay to yourself, you just don't have sex.

Participants' cocreated rhythmical patterns of relating with others in their universe as described in their essence of living with HIV since birth in their *Realities of Living*With HIV. These are demonstrated their presence in the normal activities of life: post-secondary education, work, residence, volunteer, and intimate relationships that their

HIV-negative peers are involved in, and the consequences of such involvement. Their essences were compared to results in research studies conducted by Galano et al. (2016), Gaudet (2007), Godsay et al. (2012), Greenhalgh et al. (2016), Lopez (2004), Morton, et al. (2017), Newman et al. (2018), Stangl et al. (2015), Weintraub et al. (2016), and Williams et al. (2017).

Principle #3 - Cotranscendence: Affirming Milestones

The principle of *Cotranscendence* and the corresponding concepts and paradoxes (powering: pushing-resisting; originating: certainty-uncertainty, conforming-not conforming; and transforming: familiar-unfamiliar), as described by Parse (1981, 1992, and1997) in the human becoming theory, demonstrates a connection with the theme *Affirming Milestones*. According to Levinas (1999), transcendence indicates a movement of crossing over or of ascent, which leads to the notion of going beyond or of upward movement, or a gesture that moves beyond itself. Frankl (1967) further wrote that existence falters unless it is lived in terms of transcendence towards something beyond self; since man is responsible for the fulfillment of the specific meaning of his personal life; and to or for something (society, humanity, mankind, his own conscience) other than himself.

According to Frankl (1967), life can be meaningful through what we give to life (our creative work); what we take from the world (or experiencing value); or by the stand we take toward a fate that we can no longer change (incurable diseases). In the theory of self-transcendence, Reed (2014) asserted that self-transcendence embodies experiences that connect rather than separate a person from self, others, and the environment and that self-transcendence "facilitates the integration of complex and conflicting elements of

living, aging and dying ... can help the person gain new perspectives and organize these challenges into some meaningful systems to sustain well-being and a sense of wholeness" (p. 110). The connections or integration of the elements of living aging and dying were further demonstrated in Coward's (1996) quantitative study among 152 elderly women (17-85 years). The purpose of the study was to document the presence of self-transcendence perspectives in a healthy population and to compare self-transcendence and related concepts with previous findings.

Coward (1996) concluded that higher scores on the self-transcendence scale were associated with older age, being female, having better health, and reporting better financial status. This finding supports Reed's (1991) theory that self-transcendence views and behaviors are associated with mental health. Coward (1996) also concluded that the association of self-transcendence with emotional well-being in their healthy sample supports the promotion of perspectives and activities that expand self-boundaries. Participants in this study were not expected to survive infancy; however, they are now emerging adults, who have cotranscended those expectations, with *Affirming Milestones* of furthering their education; having a successful career; having children; helping people (altruism); and what their future looks like, in preparation for their future. As a foundation to those *Affirming Milestones*, 100% (n = 15) of the participants have earned the minimum of a high school diploma; 66.67 % (n = 10) have attempted post-secondary education; 26.67% (n = 4) have already earned a degree; and 73.33% (n = 11) have plans to either continue or further their education in the future.

Participants have *Affirming Milestones* for their careers to become entrepreneurs, business owners, social workers or drug counselors, professional photographers,

cosmetologists, tenured professors, nurses, public administrators or a career in criminal justice, medical doctors, teachers, occupational therapist assistants, and musicians. Two participants are already parent who also *Affirms* to have more children in the future. One participant had a child on the way (due to be born September 2018); 10 participants had *Affirming Milestones* of having children in the future; and two participants had no desire to have children. All participants who *Affirmed* to have children in the future also *Affirms* that their children will be born HIV negative. Participants does not wish for their children to go through life having to confront the same issues that they have confronted. Study participants are fully aware that they can have heathy, HIV negative children by doing their part in keeping their viral load undetectable, which may be achieved by taking their medications as prescribed and by planning their pregnancies.

Participants also have *Affirming Milestones* to have children with partners who understands their condition. They have also voiced uncertainty about having children because of their own health status; their questionable longevity; and not wanting their children to be left with the feelings of abandonment that their parents left them with. Participants have also indicated that they have experienced complications with having children. They also have *Affirming Milestones* to use their experiences to help others who are newly diagnosed; to establish and operate non-profit organizations that will provide a platform to encourage people to open up and seek help; to change the outcomes for those affected by the child welfare system and drug use; and to provide education.

Participants also have *Affirming Milestones* of taking vacations, going on mission trips, travel, having successful careers, becoming business owners, having a home and family; being financially stable; basically, anything that anybody else would dream of.

They Affirmed that they will have normal and healthy lives by maintaining an undetectable viral load. They also have Affirming Milestones to be alive the next 5-10 years, live long enough to have grandchildren, and achieve their life's goals. Participants are not limiting themselves as they Affirmed to become successful and not just be another statistic in this world. Principle #3 Cotranscendence was connected to the emerged theme Affirming Milestones as reflected in the determination of participants to become successful by creating new pathways in transforming their lives for a successful future.

Bryan discussed the cotranscendence of Affirming Milestones in transforming his future successes. He pontificated:

Normal life! I would like to get married, I would like to have children, have my own house. Have my own stable job ... I may feel that I am going to mess up their life as well.... Due to modern medicine I can, my wife can take a pill every month, every week or every day or something like that. Neither herself or the child that she is having of mine cannot get the virus.

Loren elaborated on the cotranscendence of *Affirming Milestones* in transforming her future when she expressed:

I want to go for and what best fits me for a bachelor's degree, and then after that I want to [pause], maybe get my master's degree. I want a job that doesn't require me to socialize too much. [I] want to have children ... Someone that has your DNA Take care of them, you know, watch them grow.... I want to do something that is helpful towards other but [pause] it behind the scenes so I am not directly interacting with them. Whatever I paint it to be [the next 5-10]

years]... I want to be financially stable ... long term healthy relationship ... I want to be married. I want to have 2 kids.

Rashad explored the cotranscendence of *Affirming Milestones* in transforming his future. He divulged:

My career goal is ... occupational therapy assistant ... I picture me having kids when I was set in my career and financially stable. But I mean things happen ... making sure that my child has the best life that it possibly have ... She takes care of herself and the baby should come out ... shouldn't have a problem. I don't know [what life will be like in 5-10 years], the sky is the limit at this point ... My options are open. I don't limit myself or, my future ... I won't be unsuccessful ... I would get married when the time comes, when I know it's right. I am not saying that it will come in the next 10 or 15 years ... I just like for it to just happen naturally.

Participants' essence of living with HIV since birth as described in *Affirming Milestones* are their goals to achieve and maintain a healthy and economically stable future. Study participants have plans to further their education as they aspire to become professionals; have healthy, HIV uninfected children; help others who are having a difficult transition (altruism) and destignatize the disease; and have a positive outlook on what their lives will be like in 5 to 10 years. Participants' essence of living with HIV since birth as described in *Affirming Milestones* were also compared with findings from research studies conducted by Evangeli et al. (2013), Fair et al. (2017), Kirby et al. (2009), Li et al. (2016), Malinowski (1930), Marta & Pozzi (2008), Silver-Suarez et al. (2016), and Stangl et al. (2015),

The lyrics of the song "I Will Survive" is reflective of the connections made by the researcher between the Human Becoming Theory and the themes and sub-themes of this study, which highlights the emerging adults' essences of the experience of perinatally acquired HIV.

I Will Survive

At first I was afraid, I was petrified

Kept thinking I could never live without you by my side

But then I spent so many nights thinking how you did me wrong

And I grew strong

And I learned how to get along

And so you're back

From outer space

I just walked in to find you here with that sad look upon your face

I should have changed that stupid lock, I should have made you leave your key

If I'd known for just one second you'd be back to bother me

Go on now, go, walk out the door

Just turn around now

'Cause you're not welcome anymore

Weren't you the one who tried to hurt me with goodbye

Do you think I'd crumble

Did you think I'd lay down and die?

Oh no, not I, I will survive

Oh, as long as I know how to love, I know I'll stay alive

I've got all my life to live

And I've got all my love to give and I'll survive

I will survive, hey, hey

It took all the strength I had not to fall apart

Kept trying hard to mend the pieces of my broken heart

And I spent oh-so many nights just feeling sorry for myself

I used to cry

But now I hold my head up high and you see me

Somebody new

I'm not that chained-up little person and still in love with you

And so you felt like dropping in and just expect me to be free

Well, now I'm saving all my loving for someone who's loving me

Go on now, go, walk out the door

Just turn around now

'Cause you're not welcome anymore

Weren't you the one who tried to break me with goodbye

Do you think I'd crumble

Did you think I'd lay down and die?

Oh no, not I, I will survive

Oh, as long as I know how to love, I know I'll stay alive

I've got all my life to live

And I've got all my love to give and I'll survive

I will survive Oh

Go on now, go, walk out the door

Just turn around now

'Cause you're not welcome anymore

Weren't you the one who tried to break me with goodbye

Do you think I'd crumble

Did you think I'd lay down and die?

Oh no, not I, I will survive

Oh, as long as I know how to love, I know I'll stay alive

I've got all my life to live

And I've got all my love to give and I'll survive

I will survive

I will survive

(Singer: Gloria Gaynor; Songwriters: Dino Fekaris / Frederick J. Perren, 1978)

Significance of the Study

The significance of this qualitative heuristic study was to explore the lived experience of the emerging adult with perinatally acquired HIV to elucidate their essences of the experience of living with the virus since birth. The emerging adults with perinatally acquired HIV have survived into the developmental stage and not much is known about the effects of their exposure to ART since in utero; the physiological, psychological, and sociological challenges they encounter; and whether they have met the benchmarks of their developmental stage. The emerged themes from this study:

Panorama of Living With HIV; Consciousness and sub-themes Kinship, Concealing, and Paradox; Realities of Living With HIV; and Affirming Milestones, and their association to the Human Becoming Theory provides new insights and a philosophical perspective of the essences of participants' experience. The results of the study also indicates that the emerging adults with perinatally acquired HIV (PAHIV) are meeting the benchmarks of

the developmental stage. The study findings further add to the body of knowledge related to emerging adulthood, PAHIV, and the emerging adult with PAHIV.

Significance of the Study to Nursing

Human Immunodeficiency Virus and Acquired Immunodeficiency Syndrome (HIV/AIDS) and perinatally acquired HIV (PAHIV) continues to be a global problem and the discipline of nursing remains in position to play a vital role in the health outcomes of this global population of people living with HIV/AIDS (PLWHA), particularly the PAHIV population. The emerging adult with PAHIV was not expected to survive infancy; consequently, few studies have been done about them, their experiences, and their specific needs (Hazra et al., 2010; Levine et al., 2006; Phillips et al., 2011). A review of the literature indicates that they have physiological, psychological, and sociological challenges. Understanding these challenges facilitates the integration of this population into mainstream society and provide directions to the discipline of nursing on measures to strengthen the nursing workforce to meet the demands of a prepared healthcare workforce, as outlined in the initiatives of the World Health Organization (WHO, 2016) Global Strategy on Human Resources for Health (HRH): Workforce 2030. The emerged themes from the study, Panorama of Living With HIV and Consciousness and sub-themes Kinship, Concealing, and Paradox; Realities of Living With HIV; and Affirming Milestones provides further insights into the emerging adults' essences of their experience of PAHIV to better inform the evidence-based care and service needs of this population.

Participants used language to express their structured meaning of *Panorama of Living With HIV* associated with their reality of growing up and having HIV. The values

and beliefs they attribute to their structured meanings are depicted in the normal activities of their typical day, except for having to take their daily medications. They consider their lives to be normal, and they resolve to be not defeated but to remain hopeful.

Participants' structured meaning of their HIV diagnosis coming into their Consciousness at varying stages but all by the age of 15 years. Their Consciousness left them sad, depressed, and fearful that they were going to die; however, they refused to give value to those responses, instead they resolved to live and to have a normal life. Participants also structured meaning of Kinship in their relationships with caregivers and siblings. They expressed in language the values they attributed to those relationships that have provided care, support, protection, and directions throughout their lives and to which they have remained attached.

Participants' structured meaning of *Concealing* their HIV diagnosis is connected to the values they attribute to keeping their HIV diagnosis a secret by not sharing their information and by intentionally leaving their medications at home when they were out on stayovers. Participants also structure meaning of *Paradox* in their relationship with medications (ART); for which they value the efficacy of the medication in maintaining their health and extending their lives, although they still have to maintain a rigid schedule and contend with the side effects. Participants co-created meaning of living with HIV in rhythm with the universe (Sitzman & Wright-Eichelberger, 2011) in their *Realities of Living With HIV*. This was demonstrated in their cocreation of patterns of interactions with their universe, through their choices of taking advantage of opportunities to continue their education after high school, to be employed, to live in different residential situations, to help others, and to being involved in romantic relationships. These choices

enabled them to rhythmically integrate into the wider society that forms the universe that they live in. Participants are co-transcending *Affirming Milestones* (higher education, career, children, helping others, a bright future) to live productive, healthy, meaningful, and happy lives. They have defied the odds by outliving their life expectancy and decisively creating a path to a successful future that is comparable to that of their HIV uninfected peers.

Participants fall within the three psychosocial tasks of emerging adulthood, where "power is share, mutual and responsibility for care and support gain in reciprocity" (Tanner and Arnett, 2009, p. 40). Their commitment to roles and relationships are temporary in some aspects and enduring in other responsibilities. Participants are involved in sexual risk-taking behaviors; enjoys various living arrangements; are in pursuit of higher education at varying levels; and have difficulty associating themselves with young adulthood because they do not consider themselves in a position to accept full responsibility for themselves. Their worldviews vacillate from that of their parents to others, which is reflected in their exploration of love and career. They have developed a deeper level of intimacy and work, which provides the experience for future relationships and careers.

Implications for Nursing Education

HIV/AIDS continues to impact the global population. In 2017, there were 36.9 million people worldwide living with the disease; of which 1.8 million were children younger than 15 years of age, most of whom acquired the virus from their mothers (UNAIDS, 2018). This increase in the global population of people living with HIV/AIDS (PLWHA) is the result of improvements in the management and treatment of

the disease, which has extended and improved the quality of life of people living with HIV/AIDS. Nursing may become instrumental in meeting the projected needs of approximately 40 million new health and social care jobs globally by 2030. This may be accomplished by establishing a competent nurse workforce to bridge the gap in the over 18 million additional health workers who will be needed, primarily in low-resource settings, to cover the broad range of health services needed to ensure healthy lives for all (WHO, 2016, p. 12).

Preparing nurses through the integration of HIV/AIDS care in nursing curriculum and continuing nursing education requirements are critically needed at all levels of nursing preparation in all geographic regions where nursing is practiced. The results of the study indicated that nursing education is needed to prepare nurses to address the physiological, psychological, and sociological needs of this population to become proficient and confident healthcare providers to this vulnerable population. The preparation of Advanced Practice Registered Nurses (APRN) in particular may play a role in closing the Health Care Provider gap created by the shortage of Primary Care Physicians, especially in regions both nationally and globally where healthcare costs are excessive, and the human resources are limited. An initiative of this nature would ensure that nurses globally are prepared to meet the World Health Organization's Global Strategy on Human Resource for Health: Workforce 2030's (GSHRH 2030) target in each region, by optimizing the performance of nurses in providing evidence-based care and services to this population, while ensuring the quality of the available workforce. By preparing nurses through education and training, the profession would further solidify its

seat at the global policy decision tables towards meeting the overall objective of improving the health of the global population.

Implications for Nursing Practice

Although the results of this study cannot be transferred to other populations, it supports the literature, which indicates that a high incidence of HIV sero-discordant relationships. This is potentially a public health crisis waiting to happen, if effective measures are not put in place to educate parties involved on preventing the transmission of HIV to their unaffected partners and children. Consequently, nursing practice needs to provide patient education, access to Pre-Exposure Prophylaxis (PrEP), and other resources to both the HIV affected and the general population. Patient education should be initiated in the pediatric care setting and throughout the lifespan and healthcare settings to ensure that everyone have access to the information before making the decision to become involved in a HIV sero-discordant relationship or try and become pregnant. By providing PrEP education to the general populous, it would potentially remove some of the burden of HIV disclosure to partners from the HIV positive partner and empower the HIV negative partner to be more accountable for their own health outcomes and prevent a potential public health crisis.

Implications for Nursing Research

It has already been established that not much is known about the perinatally acquired HIV (PAHIV) population since few studies have been done because they were not expected to survive infancy (Hazra et al., 2010; Levine et al., 2006; Phillips et al., 2011). They have defied the odds by living much longer into the development stage of emerging adulthood. They have unique needs and faces physiological, psychological,

and sociological challenges requiring evidence-based healthcare and social services to facilitate their integration in the normal society. The results of this study provide new knowledge on the emerging adults' essences of the experience of perinatally acquired HIV (PAHIV); and the perspective of a new researcher. The results of this study further indicated the need for further studies of longer duration and varied methodologies, with larger sample size and ethnic diversity for which the results of this study may also be a catalyst.

Implications for Health and Public Policy

Nursing may influence global health and the health of the PAHIV emerging adult through public and health policies by translating the findings of this research study and others into language that policy makers can understand to facilitate their policy decisions. However, in order to conduct these studies, statistical data need to be available to inform the studies. The difficulties experienced in obtaining statistical and other data related to the perinatally acquired HIV (PAHIV) population in general and the emerging adults with PAHIV in particular to inform this study was alarming. This is an indication of the needs for a more inclusive data collection and accounting system that incorporates this population as a group. This is imperative because of the global impact of HIV/AIDS in general and the implications of a maturing PAHIV population in particular, especially in resource poor regions of the world. Consequently, this study has highlighted the needs for local, national, regional and global data collection and reporting systems, which incorporate the PAHIV population as a group to facilitate their inclusion in health and public policy decisions.

The need for a global data collecting and accounting systems that includes specific data collection on children less than 15 years of age with HIV/AIDS and on the PAHIV population specifically were also demonstrated in Pegurri et al.'s (2015) analysis of the national HIV data for Ethiopia. The lack of available data dictated the authors use of the "Spectrum/Estimation and Projection Package (EPP) [version 4.7], and primary data on children living in households with at least one HIV-positive adult" (p. 1) to provide estimates for their study. Pegurri et al. (2015) reported that there were no population-based HIV prevalence survey existing for children below the age of 15; the data for the study were estimated; and modelling was used to determine the age distribution of children with PAHIV in Ethiopia.

Ethiopia, the wider East African communities where the incidence and prevalence of HIV are hardest hit, and the global community would benefit greatly from a local, national, regional, and global data collection and accounting system. Accounting for the PAHIV population is of great importance to achieving the World Health Organization's (WHO's) 2020 targets towards ending the AIDS epidemic as a public threat by 2030, as outlined in the Global Health Strategy on HIV 2016 – 2021. The results of this study may further influence health and public policy by requiring pre exposure prophylaxis (PrEP) education and access at the point of care for individuals beginning in prepubescent years and though out the developmental stages. This action will empower the HIV negative individual to protect themselves from acquiring the virus, while protecting the community at large by preventing a potential public health crisis.

Strengths and Limitations of the Study

There are strengths of this study, which include the participants being assured that their privacy would be maintained. In each case, the researcher provided a safe place in a reassuring atmosphere to conduct the interviews. This reassurance encouraged participants to openly share their experience of living with HIV since birth, often sharing some of their most deeply held secrets and confidences. **Jamie** confided in the researcher off audio that this interview was the first time that she had ever spoken to anyone as openly about her HIV. **Loren** was hopeful about this study, saying:

Your research allows those who are positive to speak about their experiences which allows the public to get a better understanding of us because it's directly from a first person's perspective, this research allows our voices to be heard in a positive way.

Travis was also encouraged by his experience, he confided, "I see myself doing more interviews about this." The participants' privacy were further maintained by having each participant select a pseudonym, which was then used for all communications, and on all reports, lists, and documentations. Further efforts to protect the privacy of the participants and their associates included changing the names of all family members, associates, and places occurring in the transcribed audio recorded data.

Limitations are common to studies in general. The limitations to this study include the study design specific to the access and recruitment of participants, which was inadequate for this population. The population is surrounded by a wall of protectiveness from Health Insurance Portability and Accountability Act [HIPPA] (1996) and their health care providers. This protective environment limits access to the population from

outside of their network. Transferability of this study to other populations and settings is limited by the lack of ethnic diversity in the sample population. The novice researcher as an instrument of this study may also have contributed to bias in the data collection and analysis processes.

Recommendations

Further studies are needed to explore health care providers attitudes and their protectiveness toward this population to determine if their attitudes and protectiveness are barriers that contribute to the gap in nursing knowledge and the continues level of stigma associated with this PAHIV population. Future studies are also needed to explore the factor that influences an individual's decision to commit to a HIV sero-discordant relationship; and the effects of such decision on their social connections (immediate family, relatives, and friends) who are invested in their health and well-being. Most participants referred to stigma or wanting to keep their diagnosis a secret, while they overwhelmingly indicated that their lives are normal, and not any different from their HIV negative peers. Those who have made such assertions have set goals for their future and plans to achieve those goals.

Further studies are needed to determine the foundation for those motivations, the effects of stigma, and their health outcomes on their ability to achieve their goals.

Studies with larger sample size, ethnic diversity, and mixed method design are also recommended. Capturing the perspectives of a larger emerging adult with perinatally acquired HIV (PAHIV) population will facilitate the transferability of the study's results to other settings or groups. Studies of longer duration are also needed to track the accomplishments of this population to determine their ability to achieve their long-term

goals and to appraise their quality of life. Recommendation for future studies to determine the effects of losing either one or both biological parents on the health outcomes and aspirations of this population. Most participants are in care and their successes can be attributed to their orientation to and staying in care. Studies are needed to track the health outcomes, and achievements of those, who have been transferred to adult care and have been lost to care and follow-up.

Conclusions

This study explored the lived experience of 15 emerging adults with perinatally acquired HIV (PAHIV) to gain their essence of the experience of living with the disease from birth and to determine if they are meeting the benchmarks of their developmental stage, as coined by Arnett (2000, 2006). The Heuristic research method (Moustakas, 1990) was used to guide the exploration of their essences of the experience. The 15 participants were recruited from physicians' offices and immunology clinics in Miami-Dade, Broward, and Palm Beach Counties in South Florida. Demographic data were organized and presented, as well an individual depiction for each participant. The participants' essences of the experience of living with HIV since birth as depicted in the themes: Panorama of Living With HIV; Consciousness and sub-themes Kinship, Concealing, and Paradox; Realities of Living With HIV; and Affirming Milestones were elucidated in a composite depiction; exemplary portraits of three participants (Melissa, **Keisha**, and **Kayden**) and a creative synthesis. Participants falls within the three psychosocial tasks of emerging adulthood and are committed to worldviews that influences their decisions to pursue higher education, delay marriage and parenthood, and participation in premarital sex. The emerged essences – themes and sub-themes were

further connected to the constructs of the human becoming theory (Parse 1981, 1992, and 1997), placing them in a theoretical/philosophical perspective.

Infants born with HIV during the AIDS epidemic of the 1980s were not expected to survive infancy. With the emergence of ART and healthcare providers' training; these infants are now emerging adults about whom not much information is available, because not many studies have been done to understand their unique challenges and to provide healthcare and social services specific to their needs (Levine et al., 2006; Hazra et al., 2010; Phillips et al., 2011). The results of this study indicated that this population has structured meaning of their Panorama of Living With HIV, claiming that their lives with HIV are normal and not different from their HIV negative peers. They have also structured meaning in the *Consciousness* of their HIV status; their *Kinship* with caregivers and siblings; Concealing their HIV status from close family members and friends; and in their *Paradoxical* relationship with medications [ART]. All participants' HIV status came into their *Consciousness* by the age of 15 years. Their *Kinship* relationships provided the care and support that they needed. Concealing their HIV status allowed participants to keep their secret and avoid HIV stigma. Their medication Paradox highlighted the complexity in their relationship with the medications [ART], which are effective in extending their lives and improves their health, yet having unbearable side effects, contraindications, and a burdensome schedule.

The results of the study revealed the cocreated rhythmicity of participants'

Realities of Living With HIV, in their interactions in the process of everyday living, by
going college; working; living in varied residential situations; volunteering; and
participating in intimate relationships and having to go through the emotional process of

disclosing their HIV status to intimate partners. Participants are cotranscending into the future though their *Affirming Milestones* of furthering their education in preparation for a career; plans for having children; hope for the future; and altruistically wanting to help others whom their experience may benefit. Having attained some features of emerging adulthood in their commitment to enduring roles and responsibilities in career, marriage, and partnership none of the 15 participants can be considered as having completely entered into adulthood, but more correctly transitioning into adulthood. Therefore, they remain as emerging adults. These results add to the body of nursing knowledge regarding this population through nursing education, nursing practice, nursing research, and health and public policy.

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Appendix A

BARRY UNIVERSITY

INSTITUTIONAL REVIEW BOARD APPROVAL

Barry University

Division of Academic Affairs

Research with Human Subjects Protocol Review Institutional Review Board
11300 NE 2nd Avenue
Miami, FL 33161
P: 305.899.3020 or 1.800.756.6000, ext. 3020
F: 305.899.3026
www.barry.edu

Date:

October 30, 2017

Protocol Number:

170906

Title:

"Emerging Adults' Lived Experience of Perinatally Acquired

Human Immunodeficiency Virus."

Name:

Angela Marie Wright

Faculty Sponsor:

Dr. Claudette Chin

Dear Ms. Wright:

On behalf of the Barry University Institutional Review Board (IRB), I have verified that the specific changes requested by the convened IRB on October 18, 2017 have been made.

It is the IRB's judgment that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with requirements and that the potential benefits to participants and to others warrant the risks participants may choose to incur. You may therefore proceed with data collection.

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

It is a condition of this approval that you report promptly to the IRB any serious, unanticipated adverse events experienced by participants in the course of this research, whether or not they are directly related to the study protocol. These adverse events include, but may not be limited to, any experience that is fatal or immediately life-threatening, is permanently disabling, requires (or prolongs) inpatient hospitalization, or is a congenital anomaly cancer or overdose.

The approval granted expires on October 31, 2018. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately three months before the anniversary date of your current approval.

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB point of contact, Mrs. Jasmine Trana at an e-mail to edu. Finally, please review your professional liability insurance to make sure your coverage includes the activities in this study.

Sincerely

David M. Feldman, PhD Chair, Institutional Review Board Barry University Department of Psychology 11300 NE 2nd Avenue Miami Shores, FL 33161

to follow the research protocol as approved and will hold Barry University harmless from all claims against it arising from said deviation or failure.

Appendix B

BARRY UNIVERSITY

INFORMED CONSENT FORM

Approved by Barry, University IRB a

Date a 1/5/18

Signature a

Institutional Review Board
Protocol Form
September 2017 9

BARRY UNIVERSITY INFORMED CONSENT FORM

APPENDIX B

Your participation in a research project is requested. The title of the study is, "Emerging Adults' Lived Experience of Perinatally Acquired Human Immunodeficiency Virus." The research is being conducted by Angela M. Wright, MSN/Ed., ARNP, FNP-BC a student in the College of Nursing and Health Sciences department at Barry University. The researcher is seeking information that will be useful in the field of nursing. The purpose of this qualitative study is to explore the emerging adult's lived experience of perinatally acquired HIV. The aim of the research is to give voice to the Perinatally Acquired Human Immunodeficiency Virus (PAHIV) emerging adult by gaining an understanding of their essence of the experience of PAHIV. In accordance with this aim, the following procedures will be used: a researcherprepared demographic questionnaire; an audiotaped interview, participant's reflection, a followup meeting, and researcher's reflexive journal. The anticipated number of participants will be a maximum of 20 emerging adults or until data saturation is reached. If you decide to participate in this research, you will be asked to do the following: to complete a demographic questionnaire that will take a maximum of 15 minutes; to participate in a face-to-face, semi-structured, conversational audiotaped interview lasting a maximum of 50 minutes; to reflect on the interview and document your thoughts either in writing, poetry, song, picture, movie or journaling for a maximum of 15 minutes; and to attend a follow-up meeting for the purposes of member checking, lasting a maximum of 30 minutes. The total time commitment to participate in the study is 110 minutes.

Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no penalty. There are no known benefits associated with this study. There are no known risks associated with this study. As a token of appreciation for participating in the study, the researcher will give you a \$20.00 Publix gift card at the beginning of the interview after signing the consent. You may keep this even if you withdraw from the study.

As a research participant, information you provide will be held in confidence to the extent permitted by law. Any published results of the research will be reported in aggregate format and

Institutional Review Board
Protocol Form
September 2017 10

identified with pseudonyms. Data will be kept in a separate locked file in the researcher's home office. Demographic questionnaire and transcription data will be scanned and the information stored on the researcher's secured, password-protected personal computer. Audiotape recordings will be erased after the follow-up meeting after you agree that the researcher's transcription of the data is consistent with the information that you wanted to share at the first interview. Your signed consent form will be kept separate from the data. It will be scanned and stored on the researcher's secured, password protected personal computer. All data will be retained for 5 years upon completion of the study and then indefinitely by the researcher.

If you have any que	stions or concern	ns regarding the study or you	ir participation in the
study, you may contact the	researcher, Ange	ela Wright, at	, or by email at:
	; Faculty	sponsor: Dr. Claudette Chir	n, at or
or the Ins	stitutional Review	w Board point of contact, Ja	smine Trana, at
	If you are sa	tisfied with the information	provided and are willing
to participate in this researc	- 3		
Voluntary Consent			
I acknowledge that I have b Angela Wright and that I ha			
have received a copy of this			
this experiment.			
Signature of Participant	Date		
Researcher	 Date	Witness	
(Witness signature is required only if minimal risk is present.)	research involves pre	gnant women, children, other vulnera	able populations, or if more than

Appendix C

BARRY UNIVERSITY

LETTER OF ACCESS

Angela Wright



Dear Sir,

My name is Angela Wright, a doctoral student at Barry University College of Nursing and Health Sciences, in Miami Shores, Florida. I am conducting a study titled, *Emerging Adults' Lived Experience of Perinatally Acquired Human Immunodeficiency Virus*. This study is for my dissertation in partial fulfillment of a PhD. The purpose of this study is to explore the emerging adult's lived experience of perinatally acquired HIV.

I am requesting assistance in gaining access to emerging adults (18-25 years) who acquired HIV from their mother and who will be willing to share their experiences about having HIV since birth. They will be asked to complete a demographic questionnaire. In addition, they will be asked to participate in a face-to-face, semi-structured conversational audiotaped interview. They will also be asked to reflect on the interview and document their thoughts either in writing, poetry, song, picture, movie or journal for a maximum of 15 minutes and take it to the follow up meeting. This will be followed by a follow up meeting for a maximum of 30 minutes 3 weeks from the interview to review and verify the transcribed data. Participants will engage in the study voluntarily, and they can withdraw at any time without penalty. Each participant will be given a \$20.00 Publix gift card as a token of appreciation.

I am requesting permission to place a flyer in approved locations which are accessible and visible to prospective volunteers. The study was approved to begin on November 1st, 2017. I will comply with all requirements of your establishment.

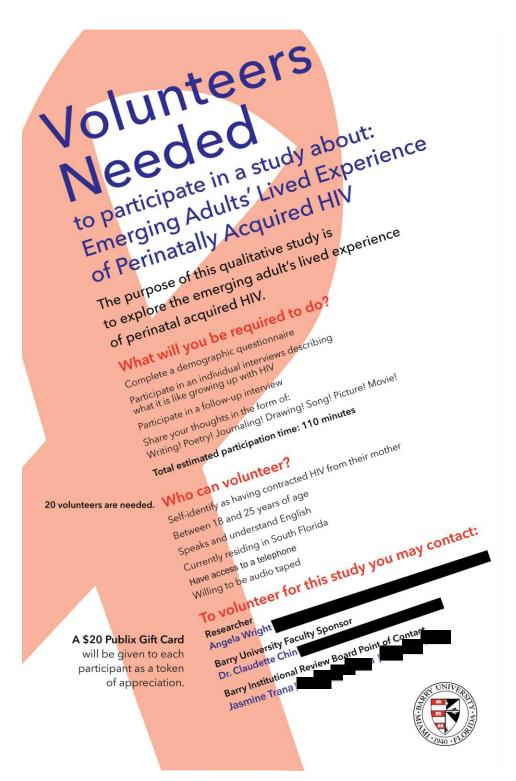
Please contact me Angela Wright at							
f	or any	questions	or conce	erns.	You may	also	contact
my faculty sponsor, Dr. Claudette R.	Chin,	at					

Trana who can be reached at or email to Trana who can be reached at or email to Trana who can be reached at or email to Trana who can be reached at or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana or email to Trana who can be reached at Trana or email to Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana who can be reached at Trana or email to Trana who can be reached at Trana or email to Trana who can be reached at Trana or email to Tr
Respectfully Yours,
Angela Marie Wright
Angela M. Wright, MSN/Ed., ARNP, FNP-BC

Appendix D

BARRY UNIVERSITY

RECRUITMENT FLYER



Appendix E

BARRY UNIVESITY

DEMOGRAPHIC INFORMATION

Instruct	tion: Please provide an answer to each of the following questions.
Date/Ti	ime:
Pseudo	nym:
1.	What is your age?
	18-20 years 21-23 years 23-25 years
2.	What gender do you identify with? Male: Female: Transgender
	Other
3.	Which ethnic group do you identify with?
	White Non-Hispanic Hispanic Black Non-HispanicOther
4.	What is the highest education level you have attained?
	Primary Elementary High School Associate/Technical College
	Graduate
5.	Are you presently employed? Yes No
6.	What does your job entail?
7.	Is this an area that you would want to work as an adult? Yes No
8.	What is your living arrangement? Living with family (home) Living alone _
	Shared rental Living on Campus Living with a Partner Other
	Are you involved in a romantic relationship?Yes No
10.	If yes, does your partner know your HIV status? Yes No
11.	If yes, when did you disclose your HIV status to your intimate partner?
12.	When do you think is a good time to start having sex? 18 years or before
	19-20 years 21-22 years 23-24 years 25-26 years 27- 28 years
	29 years and older

13. Are you sexually active? Yes No
14. If yes, at what age did you first become sexually active? $(16-18)$ $(19-21)$
(22 – 23) (24-25)
15. What do you think about marriage? Already married Want to get married
Planning to get married Don't want to get married
Other
16. Are you planning to have children? Yes No
17. If yes, at what age do you think that you will be ready to start having children?
18-20 years 21-23 years 24-26 years 27- 29 years
30 years and over
18. Are you involved in any organized sporting or recreational activities?
Yes No
19. If yes, how are you involved? Player Organizer Management
Board member
20. Are you involved with any religious organization? Yes No
21. If yes, do you play an active role? Yes No
22. Are you involved with any civic or community organization? Yes No
23. If yes, do you play an active role? Yes No
24. Do you volunteer? Yes No
25. If yes, where do you volunteer?
26. Do you participate in any peer program? Yes No
27. If yes, in which peer program do you participate?
28. Do you play an active role within any of these organizations? Yes No
29. If yes, please state what role?

Appendix F

BARRY UNIVERTIY

INTERVIEW QUESTIONS AND PROMPTS

1. Primary Question:

What is it like growing up and having HIV?

2. Potential Follow-up Questions:

- a. What does a typical day look like for you?
- b. How do you see yourself when compared with your peers who do not have HIV?
- c. What do you think your life would be like if you did not have HIV?
- d. What are your plans for your education and career?
- e. How does having HIV affect your intimate relationship?
- f. What is your experience or opinion on having sex?
- g. Considering that you have HIV, what do you think your future will be like?
- h. What do you think about having children?
- i. How were you related to your primary caregiver growing up?
- j. What is your relationship with your caregiver/parent like today?

Appendix G

BARRY UNIVERSITY

THIRD-PARTY CONFIDENTIALITY FORM

BARRY UNIVERSITY Third Party Confidentiality Form

Confidentiality Agreement

As a member of the research team investigating Emerging Adults' lived experience of Perinatally Acquired Human Immunodeficiency Virus, I understand that I will have access to confidential information about study participants. By signing this statement, I am indicating my understanding of my obligation to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to
 the public any information obtained during this research project that could identify the
 persons who participated in the study.
- I understand that all information about study participants obtained or accessed by me
 during my work is confidential. I agree not to divulge or otherwise make known to
 unauthorized persons any of this information unless specifically authorized to do so by
 office protocol or by a supervisor acting in response to applicable protocol or court order,
 or otherwise, as required by law.
- I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I understand that a breach of confidentiality may be grounds for disciplinary action, and may include termination of employment.
- I agree to notify my supervisor immediately should I become aware of an actual breach
 of confidentiality or situation which could potentially result in a breach, whether this be
 on my part or on the part of another person.

5/4/18 Jennifer Ferris
Printed Name

S/4/18 Award Whilett

Date Printed Name

Appendix H

BARRY UNIVERSITY

VITA

EDUCATION

Barry University Miami Shores, Florida
Doctor of Philosophy (PhD) December 2018

Florida International University

Doctor of Philosophy (PhD) – Withdrew

Master of Science Nursing (MSN)

2011

Family Nurse Practitioner (FNP)

Post Masters Certificate: Culturally Competent Nursing Education (Ed.)

Florida International University

Bachelor of Science in Nursing (BSN)

Miami, Florida

2000

Broward Community College Ft. Lauderdale, Florida Associate of Arts Degree 1998

WORK EXPERIENCE

Jackson Health Systems Clinical Staff Nurse (CSN) 2000 - Present

Miami, Florida

Medical Staffing Network Per-diem Critical Care Nurse 2002- 2007

Hialeah, Florida

Capscare Academy Nurse Consultant August 2011- Present

Lake Worth, Florida

South University Adjunct Faculty January 2012–Present

Royal Palm Beach, Florida