LISTENING TO THE VOICES OF EMERGING ADULTS: THE EXPERIENCE OF LIVING WITH PHIV

By

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ABSTRACT
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The purpose of this descriptive study was to explore the research question: "As an emerging adult what is your everyday experience of living with PHIV?" The purposive sample consisted of six emerging adults living with perinatally acquired HIV (PHIV), who are 18-29 years of age, speak English, and live in the greater Chicago area.

This was an exploratory study using a participatory action approach of photovoice. Photovoice methodology combines photography and participatory action to provide images and the participants' interpretations of their everyday health realities. Five themes which describe the everyday experience of living with PHIV emerged from the thematic analysis of the data: refusal to be defined by HIV, living life to the fullest, empowerment through social connections, the need for political support, and hope. Refusal to be defined by HIV emerged as the rejection of being solely described as a person with the virus. Secondly, living life to the fullest is valuing every past, present, and future moment despite living with PHIV. Empowerment through social connections describes how emerging adults with PHIV gain power through engagement with others such as peers living with HIV, romantic partners, family, and community. The fourth

theme to emerge is the need for political support. Political support is the need for assistance in ways to achieve funding, promote advocacy (voice), and feel secure. Lastly, hope is the belief that desires and dreams can be achieved despite living with PHIV through education, spiritual beliefs, and self-preservation.

Findings are consistent with the theory of Emerging Adulthood and describe the sample as doing well, pursuing education, being connected to health care and engaging in relationships. Results indicate additional research is needed to address gaps in our knowledge including how emerging adults living with PHIV deal with stress and anxiety as well as engage in decision-making about health, love, and work. Finally, we need to further understand how these emerging adults handle change in love relationships and how spiritual practices and behaviors influence sexual attitudes and beliefs and activities.

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Chapter 1 - Introduction and Statement of Problem

I am the future, and I have AIDS. I am Hydeia L. Broadbent. I can do anything I put my mind to. I am the next doctor. I am the next lawyer. I am the next Maya Angelou. I might even be the first woman president. You can't crush my dreams. I am the future, and I have AIDS.

Hydeia L. Broadbent, 26 year old AIDS activist with perinatally acquired HIV. (http://www.hydeiabroadbent.com/#!__bio)

There are approximately 1.2 million people in the United States living with Human Immunodeficiency Virus (CDC, 2011). In the United States, Human Immunodeficiency Virus (HIV) prevalence rates are high in the African American and Hispanic communities. The Centers for Disease Control (2011) reports HIV prevalence in African Americans (1,819.0 per 100,000 population) and Hispanics (592.9) are approximately eight times and two and half times the rate among Caucasians (238.4).

Human Immunodeficiency Virus (HIV) is a retrovirus that causes AIDS. Upon infection, the virus invades the host and multiplies in the white blood cells called CD4+ or T cells (Fanales-Belasio, Raimondo, Suligoi, & Butto, 2010). The CD4+ or T cells helps protect the host from disease, but are destroyed by HIV. An individual is diagnosed with AIDS when the CD4+ count is below 200 cubic millimeters of blood and there is one or more opportunistic diseases present (Fanales-Belasio, et al, 2010).

Adolescents with perinatally acquired HIV (PHIV) are emerging into adulthood in greater numbers. The notion of HIV as terminal for individuals who acquired the virus perinatally has changed. In the United States, HIV/AIDS is viewed as a chronic illness

versus a terminal illness. Emerging adults with chronic conditions have the same developmental changes and concerns as emerging adults living without chronic conditions (Taylor, Gibson, & Franck 2008); however, emerging adults with chronic conditions are forced to contemplate their physical differences and areas of competence as they transition to adulthood (King, Cathers, Polgar, MacKinnon & Havens, 2000). Another unique aspect regarding emerging adults with PHIV is that they live with a terminal transmittable disease unlike emerging adults with other chronic conditions.

Nurses have the opportunity to assist emerging adults with PHIV navigate the complexities of transition from adolescence to adulthood. As adolescents emerge into adulthood, specific elements of identity explorations, instability, self-focus, feeling in-between, and age of possibilities arise (Arnett, 2004). It is essential that nurses and health providers listen to and understand the concerns of emerging adults with PHIV.

As nurses and health providers, we listen to the stories individuals tell, both spoken and unspoken, to uncover the true meaning and feelings that are part of the message. Narratives provide insight into an individual's everyday life and how they derive meaning from their experiences. Riessman (2008) identifies narratives as "event-centered-depicting human action-and they are experience-centered" (p.22). Individual stories provide rich insight into ways of knowing everyday events (Riessman, 2008). The American Nurses Association (ANA) Nursing's Social Policy Statement recognizes, "Nursing practice is supported on understanding the human condition across the life span and the relationship of the individual within the environment" (p.13). It is vital that nurses and health providers understand, affirm, and value all individuals. Pilkington (2008) affirms, "Without listening, there can be no understanding and, moreover, those

who speak are denied the sense of affirmation that comes with feeling listened to and understood" (p.104).

Background of PHIV

In 1982, the first AIDS cases in children were reported (CDC, 1982). Perinatally acquired HIV (PHIV) infection peaked in 1992 and steadily declined in the United States between 1993 and 1997 (Kang, Mellins, Ng, Robinson, & Abrams, 2008). In 1994, AZT was proven effective to prevent mother to child HIV transmission in infected pregnant mothers (Scott, et al., 1994).

Throughout the past two decades, the advancement of medical technology and treatments has increased life expectancy for children and adolescents with chronic illness (Rosen, Blum, Britto, Sawyer, & Siegel 2003). The life expectancy for an individual with Cystic Fibrosis has increased to 50 years of age (Dodge, Lewis, Stanton, & Wilsher, 2007). The survival rates of emerging adults with perinatally acquired HIV (PHIV) have increased due to the advancement of highly active antiretroviral therapy (HAART) (Abrams et al, 2001; McConnell et al., 2005). The average life expectancy of individuals with PHIV is unknown. However, data collected in 25 states showed that individuals with HIV, who were > 13 years of age, had an increased life expectancy from 10.5 years to 22.5 years from 1996 to 2005 (Harrison, Song, & Zhang 2009). The data did not differentiate if individuals acquired HIV behaviorally or perinatally.

In 1987, AZT was the initial medication approved to treat HIV (Peralta, 2006). During the mid-1990s, pregnant women living with HIV received AZT to decrease *in utero* transmission of HIV to the neonate. AZT was successful in reducing perinatal transmission by 70% (Connor, et al., 1994). In the most recent decade, there have been

less than 200 HIV-infected births in the United States each year (CDC, 2006).

AZT is a nucleoside reverse transcriptase inhibitor (NRTIs). NRTIs disrupt the HIV replication process by inhibiting the reverse transcriptase protein (Peralta, 2006). AZT was found to disrupt the HIV protein replication process but was unsuccessful to produce long-term sustainable results (Peralta, 2006). Protein inhibitors (PIs) emerged in the mid-1990s and are effective to inhibit protease production in the HIV replication process (Gavin & Yogev, 2002; Peralta, 2006). Non-nucleoside reverse transcriptase inhibitors (NNRTIs) also impede the replication process of HIV (Peralta, 2006). Clinicians discovered that combination medication therapy of NRTIs, NNRTIs, and PIs were extremely effective in treating HIV (Gavin & Yogev, 2002; Peralta, 2006). HAART is a highly effective therapy that consists of two NRTIs and one PI medication regimen (Gavin & Yogev, 2002; Peralta, 2006).

Significance

Individuals currently living with PHIV are the first generation emerging into adulthood. These young people are unique compared to their peers living with other chronic illnesses. HIV is transmittable and unlike those living with chronic conditions such as asthma or diabetes, individuals with PHIV may experience social stigma. Social stigma may occur due to lack of understanding about HIV and how it's transmitted. Since the onset of HIV pandemic, society has often related HIV to individuals engaged in insalubrious behaviors such as illicit drug use or risky sexual activities (Rintamaki, Davis, Skripkauskas, Bennett, & Wolf, 2006). Individuals with PHIV may be challenged with disclosing status to friends, workplace, school, and sexual partners for fear of being stigmatized and possible rejection.

Another challenge for individuals with PHIV is pill burden and medication resistance. The medication regimen for individuals with PHIV is arduous. HAART medication therapy is a life-long regimen that requires the individual with PHIV to take three or more, timed daily medications. The side effects of medication therapy may include nausea, vomiting, diarrhea, abdominal pain, headaches, lipodystrophy, increased blood lipids, rash, and peripheral neuropathy (Gavin & Yogev, 2002).

Individuals with PHIV are challenged with medication resistance more than their peers with behaviorally acquired HIV (BHIV). The life- long use of ARVs may limit the available medication treatment options for individuals with PHIV versus individuals with BHIV. Medication resistance occurs when HIV is no longer effectively controlled by the prescribed antiretroviral treatment. Individuals with PHIV may be more susceptible to develop viral resistance due to life-long use of intricate ARV drug regimen (Chandwani, Abramowitz, Koenig, Barnes, & D'Angelo, 2011).

As individuals with PHIV foster independence they may be challenged with self-management of medication therapy due to pill burden, and unpleasant medication side effects. Difficulty taking medications consistently can facilitate medication resistance in individuals with PHIV (Malee, et al., 2011). Individuals with PHIV who are not able to implement medication regimen consistently can experience decreased treatment efficacy and treatment options, develop viral resistant mutations, and have an increased risk of HIV transmission to sexual partner (Malee, et al., 2011). Individuals with PHIV who have problems implementing the medication regimen may be more susceptible to opportunistic diseases and develop AIDS.

Another area of significance is that individuals with PHIV are disproportionately

ethnic minorities from urban settings who are impacted by various socioeconomic stressors (Havens & Mellins, 2008). African American and Hispanic communities in the United States are greatly impacted by HIV. Individuals with PHIV socioeconomic stressors in an African American urban community include poverty, lower education levels, increased health disparities (Williams, 1998) and substance abuse (Havens & Mellins, 2008). During the early 1990s, young, ethnic minorities living with PHIV were mostly offspring of crack-cocaine abusers from economically depressed urban communities (Havens & Mellins, 2008). Young adults with PHIV often struggle with limited education and incomes that are below the poverty line (Dodds, et al., 2003). Individuals with PHIV may be challenged with disorganized social environments, poverty, limited access to care, and obtaining adequate education and employment.

Finally, individuals with PHIV are sexually active. The average age of initial sexual activity for individuals living with PHIV is 12-14 years of age (Bauermeister, et al., 2008; Ezeanolue, et al., 2006; Koenig, et al., 2010). Alarmingly, more than half (60%) of all new HIV infections reported in the U.S. in 2006 occurred in African-American young people 13-24 years of age. The prevalence of pregnancy in unmarried adolescents and young adults is high in geographic areas that are also disproportionately affected by HIV/AIDS (Koeing, Espinoza, Hodge, & Ruffo, 2007). Individuals with PHIV may be challenged with limited sexual knowledge regarding transmission and how to negotiate condom use with sexual partners.

Conceptual Framework – Emerging Adulthood

Emerging adulthood framework will provide the theoretical underpinnings for this study. A unique developmental period between adolescence and adulthood is

emerging adulthood. Emerging adulthood is an industrialized societal developmental period between 18-29 years of age (Arnett, 2006). Emerging adults are no longer adolescents; they have completed puberty, secondary school, and most live separate from their parents (Tanner, Arnett, & Leis, 2009). Adolescence into adulthood has increased in western industrialized cultures due to transformation in societal norms. Emerging adults 18-29 years old are choosing to pursue higher levels of education and explore life opportunities in work and relationships prior to considering marriage and children (Arnett, 2006; Arnett, 2004; Murphy, Blustein, Bohlig, & Platt, 2010). Increasingly, women are pursing higher education and delaying childbirth (Arnett, 2004). The average age at first birth is 25 years in the United States (Matthews & Hamilton, 2009).

During 18-29 years of age, individuals seek to explore new possibilities in love (relationships), work, and become more independent of their parents or guardians (Arnett, 2006). The age of possibilities encompasses big dreams and high expectations. Arnett (2004) suggests that emerging adults leave their families, but are not committed to a new network of relationships and responsibilities. Emerging adults who have been raised in challenging conditions may have difficulty with commitment in a new network of relationships and responsibilities (i.e. work or education) (Arnett, 2004). Emerging adults with PHIV may particularly have difficulty establishing a network of relationships and sustaining responsibilities due to health and social challenges. Arnett suggests a chaotic or despondent family is challenging for children and adolescents because they return to a family environment where the family's every day tribulations are frequently reflected in troubles of their own.

The literature does not adequately reflect the "voice" of emerging adults living

with PHIV. The notions, experiences, and perceptions of emerging adult with PHIV is limited. HIV/AIDS is connected with societal, psychological, and behavioral stressors that greatly influence coping patterns, psychosocial aspects, and health status (Conner, Wilson, & Lyon, 2006). There is a need to explore the perceptions of emerging adults with PHIV with regards to relationships, work, independence, and health. Additional inquiries are needed to enhance meanings, insights, and understandings about transition to adult care from the perspective of emerging adults with PHIV.

Emerging adults with HIV expressed not feeling ready or prepared to transition to adult care (Wiener et al, 2007). The barriers noted in the literature include: perceived lack of autonomy, perceptions and experiences of stigma, difficulty letting go of pediatric providers, availability of adult community physician, and lack of knowledge regarding health management (Vijayan, et al., 2009; Wiener, et al., 2007).

Gaining knowledge about transition to adult care from emerging adults with PHIV perspective could inform health providers about ways to support young people for a successful transition. It is imperative that health providers value the meaning of experiences from the perspective of the individuals receiving care. Notions may arise from additional inquiries exploring the emerging adults with PHIV experiences with relationships, work, health; and transition to adult care that inform practice, policy, and enhance support systems.

Purpose and Research Questions

Emerging adults living with the chronic condition PHIV have unique physical and social challenges as PHIV is a transmittable and potentially fatal condition. Understanding how emerging adults are living with PHIV and how they envision

adulthood will enhance health care knowledge and practice. The purpose of this study is to understand the everyday experience of living with PHIV as emerging adults. Specifically the study will explore emerging adults with PHIV everyday realities and provide emerging adults with PHIV an opportunity to record and reflect their personal community strengths and concerns as it relates to living with PHIV. The research question is “As an emerging adult what is your everyday experience of living with PHIV?”

Chapter 2 - Review of the Literature

Emerging adults with PHIV is a dynamic phenomenon, not fully understood in nursing science. The utilization of HAART has significantly enhanced the lifespan for PHIV children and adolescents (Abrams, et al., 2001; McConnell, et al., 2005); yet, the challenges of living with PHIV remain numerous. To expand understanding of what is known about the experience of emerging adults with PHIV, a review of nursing, medicine, psychology, and sociology literature was implemented. There are limited inquiries that have exclusively examined experiences of emerging adults with PHIV. Thus the review of literature will include experiences of emerging adults with PHIV that occurred during childhood and adolescence. The review of literature is written in four sections. The initial section will cover the conceptual framework, *Emerging Adulthood*, which guides this study. The second section will identify six themes in relation to emerging adults with PHIV and discuss how the themes correspond with emerging adulthood theory. The third section explores gaps in literature of emerging adults with PHIV. Lastly, the fourth section will discuss HIV empirical outcomes associated with Photovoice methodology.

Review of Literature Methodology

There are 16 quantitative, 10 qualitative, and one mixed method studies in the following literature review. Eight exploratory, descriptive studies analyze the demographics, perceptions of sexual behaviors, disclosure, and mental health. Three of the inquiries were comparative studies. The identified variables within the studies compared emerging adults living with PHIV with peers who had behaviorally acquired HIV or with peers who were HIV negative. Furthermore, there were four predictive

studies that explored the causal relationships between disclosure and psychological adjustment, social support and spirituality, and sexual behavior and HIV positive status. Reliability and validity of tools was not consistently addressed in the inquiries.

Six of the 10 qualitative inquiries used semi-structured interviews to investigate concerns of emerging adults with PHIV. Interviews were conducted on average from 45 min to 2 hours. Interviews were recorded and transcribed. Thematic analysis was commonly used to analyze the data. Qualitative inquiries were frequently conducted with adolescents and emerging adults with PHIV in regards to disclosure and sexual behaviors. There are two case studies that evaluated pregnancy and spirituality in adolescents and emerging adults with PHIV.

African Americans (> 70%) were predominately represented throughout all inquiries. There are limited studies that solely address emerging adults with PHIV. Most studies include children and adolescents with PHIV. Purposive sampling was frequently implemented throughout studies. Sample sizes were adequate in the majority of quantitative (n range = 57 to 2864) and qualitative inquiries. Several studies obtained participants from established US and UK cohorts of children, adolescents, and emerging adults with PHIV.

Conceptual Framework

Adolescents emerging into adulthood are in a unique developmental period that differs from adolescence and young adulthood. Emerging adults are no longer adolescents; they have completed puberty, secondary school, and most live separate from their parents (Tanner, Arnett, & Leis, 2009). Arnett (2004) suggest Emerging Adulthood has five main components: “the age of identity explorations, of trying out various

possibilities, especially in love and work; the age of instability; the most self-focused age of life; the age of feeling in between, in transition, neither adolescent nor adult; and the age of possibilities, when hopes flourish, when people have an unparalleled opportunity to transform their lives" (p.7).

The Emerging Adulthood (Arnett 2004, 2006) conceptual framework was used as the orientation for this review of the literature. Emerging adulthood is a stage theory that occurs in 18-29 year olds living in industrialized countries between adolescence and adulthood (Arnett, 2006; Hendry & Kloep, 2010). The emergence of adolescence into adulthood has extended in western industrialized cultures due to changes in societal norms. Young people 18-29 years old are choosing to pursue higher education and explore life options in work and relationships prior to considering marriage and children (Arnett, 2006; Arnett, 2004; Murphy, Blustein, Bohlig, & Platt, 2010). Increasingly women are pursing higher education and delaying childbirth (Arnett, 2004): average age at first birth is 25 years old (Matthews & Hamilton, 2009).

The age of identity explorations.

Personal identity is a developmental marker during late adolescence (Erickson, 1968). Erickson (1980) suggests that when adolescence ends and a sense of identity is established, one enters into exploration of higher education, work, and intimate relationships. Emerging adults begin to develop their worldviews and who they are in work, love, and life. They foster independence from their parents as they engage in higher education and delve into careers. Self exploration during emerging adulthood allows individuals to discover more of themselves and "what they want out of life" (Arnett, 2006).

During the age of identity exploration emerging adults also begin to define their religious beliefs. Emerging adults religious beliefs are highly individualized (Arnett and Jensen, 2002). Arnett and Jensen (2002) suggest emerging adults' religious practices and beliefs in childhood has minimal relationship with current religious practices and ideologies. Religious practices and behaviors in emerging adults influence sexual attitudes and behaviors. Emerging adults who adhere to daily religious ideology in regards to sexual behaviors tend to embody conservative sexual attitudes (Lefkowitz, Gillen, Shearer, and Boone, 2004).

The age of instability.

The age of instability is an exceptionally unstable period during emerging adulthood (Arnett, 2006). Emerging adults move frequently as they explore various opportunities in relation to work, education, and love. Residential changes occur upon leaving the parents house to attend college, leaving college to enter the workforce, and/or to cohabitate with romantic partner (Arnett, 2006).

Emerging adults are increasingly engaging in cohabitation prior to marriage (Arnett, 2006; Manning, Cohen, and Smock, 2011). Cohabitation allows the emerging adult couple to spend more time together, test compatibility, and reduce living expenses (Arnett, 2004; Huang, Smock, Manning, and Lynch, 2011). Cohabitation significantly increases the risk for relationships ending within five years (Bumpass and Hsen-Hen, 2000).

The self-focused age.

Emerging adults tend to have increased autonomy and minimal societal obligations and commitments (Arnett, 2006). Arnett, Ramos, and Jensen (2001) suggest,

"Autonomy defines the individual as the primary moral authority, unrestricted in choices except by his or her own preferences" (p.70). There is a sense of freedom during emerging adulthood to be self-focused and to satisfy personal dreams and desires prior to settling into adult responsibilities. Emerging adults are able to contemplate "who am I" in relation to work, education, and love (Arnett, 2006). During the self-focused age the ultimate goal of the emerging adult is to achieve self-sufficiency (Arnett, 2006).

The age of feeling in-between.

Throughout the age of feeling in-between emerging adults gradually begin to accept responsibility for self, initiate independent decision making, and attempt financial independence (Arnett, 2004). Emerging adults do not perceive themselves as adults. Emerging adults are neither adult nor adolescent but are increasingly engaging in roles and responsibilities leading to adulthood (Arnett, 2004).

The age of possibilities.

There is an era of optimism about one's future during emerging adulthood. The age of possibilities present with high hopes and expectations and various paths for self-exploration in love and occupation (Arnett, 2004). This age is associated with the notion of self transformation and becoming the person they envision (Arnett, 2004).

Experiences of Emerging Adults Living with PHIV

To assist the reader in integrating the themes identified from the literature on living with PHIV with the conceptual framework, a matrix of emerging adulthood concepts and literature themes was created (Table 1). The themes are presented below.

Disclosure in emerging adults with PHIV.

There were 15 studies that addressed aspects of disclosure in young people with

PHIV. Disclosure of HIV has emerged in studies that directly investigated the phenomenon in children, adolescents, and emerging adults with PHIV (Bachanas, et al., 2001; Fernet, et al., 2011; Lester, et al., 2002; Michaud, et al., 2009; Phebe, et al., 2007; Santamaria, et al., 2011; Sopena, et al., 2010). Themes regarding fear of stigma, lack of trust toward peer groups and social support surfaced in studies not directly investigating disclosure in children, adolescents, and emerging adults with PHIV (Butler, et al., 2009; Di Risio, et al., 2011; Fielden, et al., 2011; Koenig, et al, 2010; Lester, et al., 1999; Marhefka, et al., 2011; Merzel, et al., 2008; Vijayan, et al., 2009).

There are three types of disclosure found in the literature in regards to children, adolescents, and emerging adults with PHIV. The first type of disclosure is the chronological age that individuals with PHIV are informed of their HIV positive status by parent or guardian (Lester, et al., 2002; Santamaria, et al., 2011). The disclosure of HIV positive status to the infected child by the parent or guardian is a challenging dilemma. Parents or guardian may struggle with knowing the appropriate time and age to discuss the child's HIV positive status. Parents or guardian may fear the child may not keep the secret of their HIV status, which could have a negative impact on the family (Fielden, et al., 2011). The average ages of disclosure to the child by the parent/guardian is seven to twelve years old (Butler, et al, 2008; Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006; Lester, et al., 2002; Santamaria, et al., 2011; Sopena, et al. 2010).

The second disclosure found in the literature in regards to individuals with PHIV is disclosure to friends, school, and/or work (Di Risio, et al, 2011; Fielden, et al., 2011; Michaud, et al., 2009). During the age of identity explorations, emerging adults cultivate new relationships in work and educational environments. Emerging adults exert

independence from parents or guardians while establishing relationships. Furthermore, they engage in “active disclosure” versus “passive disclosure” (Michaud, et al., 2009). Active disclosure is the decision of the emerging adult to share their HIV status with friends, relatives, place of employment and/or educational setting (Michaud, et al., 2009). Passive disclosure involves parents or guardians full involvement with sharing HIV positive status and they can also serve as an advisor to the young adult regarding this disclosure (Michaud, et al., 2009). Emerging adults with PHIV struggle to disclose their status due to fear of stigma (Fielden et al., 2011; Leonard et al., 2010) and fear of rejection (Michaud, et al., 2009). Fear of negative reaction from others can hinder disclosure (Fielden et al., 2011; Leonard et al., 2010; Michaud, et al., 2009). Some emerging adults with PHIV do not disclose their status, because they do not view it as something vital to share with others (Di Risio, et al., 2011). Others choose to disclose their status to friends and relatives, so that they can have the support to decrease the burden of isolation (Di Risio, 2011; Leonard et, al., 2010).

An exemplar descriptive, exploratory study investigated the level of disclosure of status among adolescents and emerging adults (12-20 years old) who have acquired a vertically transmitted HIV infection, and the reasons for choosing to disclose or not to disclose their status (Michaud, et al., 2009). The study was conducted in Switzerland with 29 adolescents and emerging adults with PHIV (22 were female). Semi-structured interviews were conducted with encounters lasting 40-110 minutes. The interviews included discussions about participants’ health status, feelings about the disease and treatment, medical adherence, social life, and disclosure. The investigators used the principles of grounded theory and identified through content analyses categories related

to selected topics.

There were 20 participants enrolled in school and six were employed. Half of the participants' HIV status was known by at least one school official (head teacher, nurse). The older adolescents and emerging adults appear to drive the decision-making process regarding disclosure of status to school officials and at workplace. Medication adherence did not seem to be related to the decision to share status with school officials or in the workplace. There were two participants who decided to publicly disclose their status due to gossip in the workplace and an accident that involved bleeding at school. All 29 adolescents and emerging adults have selectively disclosed their status to a few close friends. The group of informed friends was described as "restricted". Fear of rejection and negative reactions from peers were reasons the adolescents and emerging adults decided not to disclose their HIV status.

Lastly, disclosure emerged in the literature in relation to individuals with PHIV and their sexual partners or significant other (Di Risio, et al., 2011; Fernet, et al., 2011; Fielden, et al., 2011; Koenig, 2010; Michaud, et al., 2009). During the age of instability emerging adults experience change in love relationships, work, and educational endeavors (Arnett, 2006). Emerging adulthood parallels as a period of young people who are sexually active and not married (Lefkowitz & Gillen, 2006). Emerging adults with PHIV are sexually active and are challenged with disclosing their status to sexual partners (Fernet, et al., 2011; Fielden, et al, 2011; Koenig, et al., 2010; Marhefka, et al., 2011).

Emerging adults with PHIV engage in sexual activities knowing that they are HIV positive. Koenig, et al. (2010) explored sexual transmission risk behavior of adolescents

and emerging adults with PHIV and behaviorally acquired HIV (BHIV). The study revealed that 79.3% of participants' with PHIV did not disclose their status to their sexual partners. Adolescents and emerging adults with PHIV mention fear of rejection as a main reason for non-disclosure of status to sexual partner (Fernet, et al., 2011; Fielden, et al., 2011; Koenig, et al., 2010).

Emerging adults with PHIV are challenged with condom negotiation and disclosure of status to sexual partner (Fernet, et al., 2011; Marhefka, et al., 2011). The risk of disclosure to sexual partner leads to fear of rejection and loss of "love" (Fernet, et al. 2011). An 18 year old female shared, "Everything changed after that (disclosure). He told me I don't want a woman like you […]. He was really mean to me and I was really scared" (Fernet, et al., 2011).

Further, PHIV disclosure was viewed as an opportunity to transfer responsibility for condom use to partner (Marhefka, et al., 2011) and as an opportunity to educate individuals in ways to prevent infection (Leonard, Markham, Bui, Shegog, & Paul, 2010). A participant in the study stated, "If she already told the person that she's with that she has HIV and he says that he doesn't care and he didn't put on a condom, then it's his fault…" (Marhefka, et al., 2011, p.1324).

In summary, emerging adults with PHIV are challenged with disclosure of their seropositive HIV status to sexual partners (intimate relationships), friends, and the public (work or school). Fear of rejection and negative reaction, stigma, isolation, and lack of trust are reasons that hinder individuals with PHIV to disclose their HIV positive status to others. There is limited knowledge regarding how emerging adults with PHIV disclose their status as they explore establishing social networks, love, occupational and education

paths. There is also limited understanding of how emerging adults with PHIV deal with the stress of disclosure and handle stigma and rejection.

Sexual behaviors in emerging adults with PHIV.

The age of identity explorations in emerging adulthood involves determining sexual values in regards to premarital sex, monogamy, contraception, abstinence, sexual behaviors and sexual orientation (Lefkowitz & Gillen, 2006). The age of instability in emerging adults is a period of change. During this period they experience change in various areas of life including love relationships (Arnett, 2006). The self-focused age consists of the emerging adult's goal to obtain self-sufficiency and be liberated to make decisions without consulting others (Arnett, 2006). Emerging adults may choose and establish love relationships without the interference of parents or guardians. Throughout emerging adulthood individuals may engage in sexual relationships. Emerging adults are more likely than older adults to have two or more sexual partners (Lefkowitz & Gillen, 2006).

There were ten studies that address aspects of sexual behaviors in adolescents and emerging adults with PHIV (Bauermeister, Elkington, Bracis-Cott, Dolezal & Mellins, 2008; Ezeanolue, 2006; Fernet, et al., 2011; Kenny, Williams, Prime, Tookey, & Foster, 2011; Koenig, Espinoza, Hodge, & Ruffo, 2007; Koenig, et al., 2010; Leonard, et al., 2010; Marhefka, et al., 2011; Meloni, et al., 2009; Williams, Keane-Tarchichi, Bettica, Dieudonne, & Bardeguez, 2009). Sexual risk behaviors in adolescents and emerging adults with PHIV were directly examined in five inquires (Fernet, et al., 2011; Koeing, et al., 2010; Leonard, et al., 2010; Marhefka, et al., 2011). Procreation intentions and pregnancy has been explored in five inquiries (Ezeanolue, et al., 2006; Kenny, et al.,

2011; Koenig, et al., 2007; Meloni, et al., 2009: Williams, et al., 2009).

There were two qualitative (Leonard, et al., 2010; Marhefka, et al., 2011), two quantitative (Bauermeister, et al., 2009; Koenig, et al., 2010), and one mixed method (Fernet, et al., 2011) inquiries that have explored sexual behaviors and attitudes in adolescents and emerging adults with PHIV (Bauermeister, et al., 2009; Fernet, et al., 2011; Koenig, 2010; Leonard, et al., 2010). Emerging adults with PHIV engage in sexual behaviors that include kissing, touching and oral, anal, or vaginal penetration (Bauermeister, et al., 2008; Fernet, et al., 2011; Marhefka, et al., 2011). Emerging adults with PHIV were more likely to participate in non-penetrative sexual activities compared to peers with behavioral acquired HIV (Koenig, 2010) and peers who are HIV negative (Bauermeister, et al., 2008). Bauermeister, et al., (2008) study discovered that individuals with PHIV were four times less likely to participate in penetrative sex and are three times more likely to engage in touching behavior (Bauermeister, et al., 2009). The number of lifetime partners for sexually active emerging adults with PHIV averages three to six partners (Fielden, et al., 2011; Koenig, et al., 2010).

At-risk sexual behaviors for adolescent and emerging adults with PHIV include sexual relation with partner during menstruation (Fernet, et al., 2011), inebriated from drugs or alcohol during sexual relations (Fernet, et al., 2011; Koenig, et al., 2010) and unprotected sex (Fernet, et al., 2011; Koenig, et al., 2010; Leonard, et al., 2010). Adolescent and emerging adults' attitudes toward condom negotiation use vary. Some individuals with PHIV suggest use of condoms to avoid transmission of virus (Fernet, et al., 2011; Marhefka, et al., 2011), avoid re-infection of virus, avoid risk of acquiring another STD, and pregnancy (Leonard, et al., 2010). Individuals with PHIV who chose

not to use condoms expressed difficulty negotiating condom use with sexual partner (Leonard, et al, 2010), discussed past sexual experiences with no obvious consequences (Fernet, et al., 2011) and fear of rejection (Fernet, et al., 2011; Leonard, et al., 2010).

An exemplar mixed method descriptive study examined romantic relationships and sexual activities in 18 adolescents and emerging adults with PHIV (Fernet, et al., 2011). Adolescents and emerging adults with PHIV (13-22 years old) expressed that HIV had impacted their sexual experiences. All participants who were sexually active (10/18) reported having used a condom at least once. Condom use was implemented more consistently with regular sexual partners (8/10) versus with casual sexual partners (7/10). The participants articulated difficulties to continue having protected sex in a romantic relationship due to lack of intimacy. An 18 year old female shared, "We didn't use anything that time […] it was spontaneous, it wasn't planned. Using a condom, it makes it so that you're a bit distant from the person."

There are three quantitative studies that explored pregnancy outcomes (Ezeanolue, et al., 2006; Kenny, et al., 2012; Williams, et al., 2009), one quantitative study explored psychosocial and behavioral characteristics (Koenig, et al., 2007), and one qualitative study described pregnancy care in pregnant adolescents and emerging adults with PHIV (Meloni, et al., 2009). Emerging adults with PHIV plan to procreate (Ezeanolue, et al., 2006; Leonard, et al., 2010). The success of antiretroviral therapy in decreasing mother to child transmission of HIV infection may influence emerging adults with PHIV desire to procreate.

Ezeanolue, et al., (2006) conducted a descriptive, exploratory study to assess the sexual knowledge and behaviors, determine the procreational intentions, and determine

the impact of age, gender, race, ethnicity, and perception of maternal-to-child transmission risk on adolescents and emerging adults with PHIV procreational intent. The investigators hypothesized that adolescents with PHIV would have less intent to have children than the general U.S. adolescent population, and the perception of maternal-to-child transmission risk would affect the procreational intentions of adolescents with PHIV. A 22-item questionnaire was administered to 57 adolescents and emerging adults with PHIV (13-24 years of age). The questionnaire contains five items that address sexual knowledge, 15- items that address sexual behavior, and three items that address procreational intention. There was no discussion regarding validity and reliability of the questionnaire. The questionnaire was piloted prior to the study among ten 12 year olds; pilot data were not included in the analysis. Investigators could have pilot the study with desired sample (13-24 years of age) at a similar clinic to ascertain appropriateness of tool. Demographic data were obtained from medical records.

Seventy-four percent of adolescents and emerging adults (13-24 years of age) with PHIV consented and completed the survey. The investigators found 89% of the participants had received sex education; however, only 28.1% received education from their provider (physician or nurse practitioner). Eighty-two percent of the participants correctly identified sex as a mode of HIV transmission. Seventy-nine percent of the participants reported having a boyfriend or girlfriend and 33% reported that they had penile-vaginal intercourse. The majority of the participants (89%) who had their initial sexual encounter after becoming aware their HIV diagnosis and 55% of sexually active female participants had been pregnant. In regards to desire to procreate and age, 75% of emerging adults with PHIV desire to have children. Females (71%) and males (69.2%)

with PHIV equally desire to have children. Interestingly, Caucasian participants (80%) desire to have children more than African Americans (69%) and Hispanics (63%). Seventy – one percent of the participants who desired to have children were knowledgeable of maternal to child transmission. Neither of the two hypotheses was supported. Adolescents and emerging adults with PHIV desire to procreate (32/35) was higher than counterparts. The perception of maternal-to-child transmission risk had no bearing on the intent to procreate (71.7% are knowledgeable of maternal-to-child transmission risk.

Adolescents and emerging adults with PHIV had successful pregnancy outcomes with proper antiretroviral treatment (Ezeanolue, et al., 2006; Kenny, et al., 2011; Koenig, et al., 2007; Meloni, et al, 2009; Williams, et al., 2009). Pregnant women who were HIV positive and take antiretrovirals (ARVS) as prescribed had positive pregnancy outcomes compared to pregnant HIV positive women who were not able to take the antiretrovirals as prescribed (Kenny, et al., 2011; Meloni, et al., 2009; Williams, et al., 2009). There are two quantitative studies that abstracted medical records pregnancy data of adolescents and emerging adults with PHIV between 1997-2007 in New Jersey (Williams, et al., 2009) and between 2003-2007 in the UK and Ireland (Kenny, et al., 2011). Neonatal outcomes were favorable with 92% (Williams, et al., 2009) and 95% (Kenny, et al., 2011) of infants born HIV negative.

In conclusion, sexual behaviors, attitudes, and pregnancy have been minimally explored in emerging adults with PHIV. Emerging adults with PHIV desire to engage in sexual relationships. What is not known is how emerging adults with PHIV handle condom negotiation with sexual partners. Furthermore, there is limited knowledge

regarding procreation choices and sexual behaviors in emerging adults with PHIV. Emerging adults with PHIV desire to procreate, but are fearful of transmitting HIV to significant other and child. There is a gap in discerning emerging adults with PHIV knowledge regarding reducing risk of transmission during conception and pregnancy. There were no interventional studies found that addressed decreasing risky sexual behaviors, condom negotiation, or the challenges of taking medications as prescribed during pregnancy.

Spirituality in emerging adults with PHIV.

The age of identity explorations allow emerging adults to cultivate spiritual identity. Vital aspects of emerging adulthood are experimentation and exploration in love, work and development of worldview (Arnett, et al., 2001). Spiritual experiences may influence attitudes and behaviors regarding love and work.

There are two studies that have explored spirituality in relation to sexual attitudes and beliefs in emerging adults (James, et al., 2011; Lefkowitz, et al., 2004). There are no inquiries that have solely explored spirituality in emerging adults with PHIV. However, one exemplar study explored spiritual and social support on treatment adherence among HIV/AIDS patients by race/ethnicity (Sunil & McGehee, 2007). It is unclear how many of the 2864 participants (18-50+ years) within the study were emerging adults with PHIV. The investigators hypothesize that religious support and social support will be advantageous to treatment adherence for Caucasian, African–American, and Hispanic with religious support being especially favorable for African Americans. There was no positive relationship between religious variables and treatment adherence. However, African Americans (1.25 more likely) and Hispanics (2.06 more likely) seek comfort

through religion than Caucasians. Ethnicity and age had an association with treatment adherence. Participants who were 50+ years and older were more likely to be adherent to treatment than participants between 18-34 years in all ethnicities (Hispanic 7.41 times more likely, Caucasian 1.62 times more likely, and African Americans 3.17 more likely).

In conclusion, there is minimal knowledge regarding spirituality in emerging adults with PHIV. Religious practices and behaviors may influence sexual attitudes and beliefs in emerging adults with PHIV. Spirituality has been investigated in relation to sexual attitudes and beliefs in emerging adults. There are no inquiries that have solely explored spirituality in emerging adults with PHIV. Spirituality has been minimally explored in emerging adults with PHIV in relation to love and work. What is not fully understood is how emerging adults with PHIV spiritual beliefs influence decisions regarding work, education, and love.

Social support in emerging adults with PHIV.

During the age of instability emerging adults frequently experience change. Changes occur in work and educational endeavors, love relationships, and place of residence (Tanner, et al., 2009). Emerging adults with PHIV may experience difficulty with establishing social support due to the instability.

Social support has been investigated in one study in relation to mental health (Lam, et al., 2007) and two inquiries regarding lived experiences in adolescents and emerging adults with PHIV (Abramovitz, 2009; et al., Di Risio, et al., 2011). Themes of social support emerged in a study with adolescents and emerging adults with PHIV transitioning to adult health care providers (Vijayan, et al., 2009). The study revealed caring for adolescents and emerging adults with PHIV is associated with disorganized

social environments. Disorganized social environments surfaced as adolescents with PHIV experiences of being taken away from their biological parent(s), witnessing the death of family members due to HIV, and being socially isolated due to HIV.

A study explored social support (family and friends) in adolescents and emerging adults with HIV/AIDS (Abramovitz, et al., 2009). The investigators sought to study the nature, type, and source of social support available to adolescents and emerging adults with PHIV and the relationship between social support and depression. The participants included 166 HIV-infected youth (60% PHIV and 40% BHIV), ages 13-21 years old and predominately minority race and ethnicity (72% black/black-multicultural and 20% Hispanic). The investigators used the HIV-Specific Social Support Questionnaire (validity and reliability of tool was not provided), The Medical Outcomes Study (MOS) Social Support Survey, and Beck Depression Inventory.

The adolescents' social networks consisted of household members, close friends, and friends who knew their HIV status. Adolescents and emerging adults with PHIV reported having family members (53%) to remind them to attend or to bring them to clinic and 91% reported that family would care for them if they were sick. Few adolescents and emerging adults with PHIV reported being encouraged (5%), reminded (4%), or brought to clinic (3%) by friends.

In summary, limited inquiries have explored social support in emerging adults with PHIV. Emerging adults with PHIV may experience difficulty with establishing social support due to the instability in this period and fear of stigma and rejection. It is unclear how emerging adults with PHIV establish social supports as they cultivate independence. Furthermore, it is not known how emerging adults with PHIV will disclose

their status as they develop new relationships.

Mental health in emerging adults with PHIV.

During the age of instability the emerging adult is involved in frequent periods of change that can create additional stress and anxiety (Tanner, et al., 2009). Emerging adults change frequently as they explore various opportunities in relation to work, education, and love. The age of instability can be emotionally challenging for emerging adults with PHIV.

Mental health has been explored in children and adolescents with PHIV in relation to neuropsychological issues and education (Mialky,Vagnoni, & Rutstein, 2001), coping and psychological adjustment (Sopena, et al., 2010), disclosure (Santamaria, et al., 2011), psychotropic drug therapy and behavioral treatment patterns (Chernoff, et al., 2009), and substance use association with psychiatric symptoms (Williams, et al., 2010). Mental health predictors have also been explored in relation to disclosure and social support in emerging adults with PHIV (Lam, et al., 2007).

Historically, children and adolescents with PHIV have been challenged with high rates of psychological disorders (Chernoff, et al., 2009; Gadow, et al., 2010; Mellins, Brackis-Cott, Dolezal, & Abrams, 2006). Encephalopathy is more commonly found in children with PHIV than in adults with HIV: it can cause microcephaly, cognitive and motor dysfunctions, and mental retardation (Mitchell, 2001). Early aggressive treatment of zidovudine can reverse the encephalopathy (Mitchell, 2001).

Children and adolescents with PHIV frequently struggle with depression and attention deficits (Chernoff, et al., 2009; Gadow, et al., 2010; Mellins, Brackis-Cott, Dolezal, & Abrams, 2006). Chernoff, et al (2009) discovered more children and

adolescents with PHIV versus peers who were HIV negative (37% versus 22%) received behavior or medication interventions for emotional and behavioral problems. Another study described some of the medical, educational, and psychosocial aspects of school age children with PHIV (Mialky, et al, 2001). There was a retrospective medical records review of 85 children with PHIV. Thirty-seven of the children with PHIV (43.5%) had a diagnosis of attention deficit disorder (ADHD) or significant neurologic or emotional disorder.

The majority of studies regarding mental health issues in individuals with PHIV have occurred with young people under the age of 18 years of age. One study examined social support and disclosure as predictors of mental health in adolescents and emerging adults with HIV (Lam, et al., 2007). The study did not differentiate if the participants acquired the virus perinatally or behavioral. There were 66 enrolled participants with HIV, 16-25 years (mean age 21.2 years [SD]=2.71). The majority of the participants were African American (87%). The mean education was 11.35 (SD=1.62) less than high school education. The investigators hypothesized that HIV-positive youth would express high levels of mental health symptoms compared to the general population of youth in the US. Also mental health symptoms would be positively associated with poor health status while HIV-status disclosure and social support (family and friends) would be protective factors.

The 53-item Brief Symptom Inventory (alpha=0.97) and 12 items Social Provision Scale (alpha=0.86) both showed good reliability. The adolescents and emerging adults with HIV had higher levels of depression (32% above) and anxiety (29% above) than the normative population. Disclosure to family and close friends were not associated

with psychological distress.

In conclusion, children and adolescents with PHIV frequently struggle with depression and attention deficit disorders. The age of instability can be emotionally challenging for emerging adults related to frequent periods of change in work, education, and love. The instability can foster additional stress, anxiety, and depression. There are limited inquiries that have solely examined mental illness in emerging adults with PHIV. It is not known how emerging adults with PHIV deal with stress, anxiety, and depression. Furthermore, it is not known how long-term mental health issues impact emerging adults ability to cultivate social networks, job and education trajectories, and intimate relationships.

Transition to adult care in emerging adults with PHIV.

Limited inquiries have investigated transition to adult care in emerging adults with PHIV. There are six inquiries that have explored transition to adult care in adolescents and emerging adults with PHIV (Bundock, et al., 2011; Fair, Sullivan, & Gatto, 2010; Gilliam, et al., 2011; Maturo, et. al, 2011; Wiener, Zobel, Battles, & Ryder, 2007; Vijayan, et al., 2009). Inquiries were conducted to exam satisfaction with transition to adult health (Bundock, et al., 2011); readiness to transition (Wiener, et al., 2007) and barriers to transition to adult care (Vijayan, et al., 2009: Wiener, et al., 2007); transition practices and protocols (Fair, et al., 2010; Gilliam, et al., 2011; Maturo, et al., 2011).

Emerging adults with PHIV are forced to contemplate transition to adult care issues that are unique to their community. The long-term complications of HIV and effects of HAART treatment are unknown, and emerging adults have a chronic illness that is potentially transmittable to sexual partner and child (Bundock, et al., 2011).

Emerging adults with PHIV are challenged with barriers to transition. Identified barriers include: the need for a multidisciplinary team (provider, social work, and pharmacy) in the community, inadequate health insurance, and limited finances to cover out of pocket cost, and knowledge deficit related to HIV disease and treatment (Weiner, et al., 2007).

During the self-focused age emerging adults are free to make decisions without consulting others, seek to attain the goal of self-sufficiency, and can structure their daily lives without being inhibited by social roles (Arnett, 2006). Due to the complexities of HIV (rigid treatment adherence, medical appointments, and intermittent illness) emerging adults with PHIV may struggle with structuring their daily health lives independently. The age of feeling in-between in emerging adults with PHIV may be intensified due to prolonged assistance from others (family and health care providers) which fosters lack of independent decision making.

The study by Gilliam et al (2011) described the current practices and characteristics of 14 Adolescent Trials Networks (ATN) for HIV/AIDS. There was a principal investigator appointed at each site. The investigators interviewed one to three staff that was proficient in transition to adult care. There were six ATN clinics that created structured transition programs that gradually exposed the emerging adult to the prospective adult provider. A case manger or peer educator accompany would accompany the emerging adult to the adult clinic. There were four sites that continued contact with emerging adult with PHIV up to a year after they transition to adult care.

In summary, emerging adults with PHIV are challenged with barriers to transition due to the complexities of HIV. What is not known is how emerging adults with PHIV will structure their daily health lives independently. Furthermore, what is not known is

how emerging adults with PHIV perceive accepting responsibility for their health, foster independent decision making, and financial independence.

Photovoice Empirical Outcomes in Individuals Living with HIV

The photovoice process enables individuals to identify, represent, and enhance their community through photographic imagery (Wang & Burris, 1997). Photovoice provides a means for individuals to be active participants in identifying, characterizing, and educating others about their realities (Jacobs & Harley, 2008). Participants are able to give "voice" to their experiences and concerns through the lens of a camera. The method provides disadvantaged individuals access to document and initiate change within their communities.

Photovoice has been used to gain understanding of individuals living with HIV. Inquiries have been conducted with volunteers who provide support to individuals living with HIV in South Africa (Jacobs & Harley, 2008), with indigent persons living with HIV in the southern region of the United States (Rhodes, Hergenrather, Wilkin, & Jolly, 2006), and with African-American males who have sex with males (Mamary, Mccright, & Roe, 2007). Additional photovoice inquiries have explored employment seeking behaviors in individuals living with HIV (Hergenrather, Rhodes, & Clark, 2006) and to bridge relational understanding between individuals living with HIV and future dentists (Schrader, Deering, Zahl, & Wallace, 2011).

Photovoice inquiries have been conducted with adolescents (Jacobs & Harley, 2008), emerging adults, and adults living with HIV (Hergenrather, 2006; Mamary, et al., 2007; Rhodes, et al., 2007; Schrader, et al., 2011). More than 80% of the participants living with HIV in the photovoice inquiries are African American (Hergenrather, et al.,

2006; Mamary, et al., 2007; Rhodes, et al., 2006; Schrader, et al., 2011) or African descent (Jacobs & Harley, 2008). Participants are challenged with unemployment, low incomes and the majority received some government financial assistance (Hergenrather, et al., 2006; Jacobs & Harley, 2008; Rhodes, et al., 2007; Schrader, et al., 2011).

There were several common themes that emerged from the photovoice inquiries. Individuals living with HIV valued independence and autonomy (Hergenrather, et al., 2006; Rhodes, et al., Schrader, et al., 2011) and valued social support received from friends and family (Hergenrather, et al., 2006; Mamary, et al., 2007; Rhodes, et al., 2007; Schrader, et al., 2011), providers and volunteers (Hergenrather, et al., 2006; Rhodes, et al., 2007; Schrader, et al, 2011) and peers living with HIV (Rhodes, et al., 2007: Schrader, et al., 2011). Spirituality and places that foster spirituality was viewed favorably by participants living with HIV (Rhodes, et al., 2007; Schrader, et al., 2011).

Individuals living with HIV expressed concerns regarding medication adherence in relation to inability to afford medications and debilitating side effects (Schrader, et al., 2011) and challenged with adherence while working (Hergenrather, et al., 2006). Additional challenges included living in inadequate housing (Jacobs & Harley, 2008; Schrader, et al., 2006), maintaining sobriety from substance use (Mamary, et al., 2006; Rhodes, et al., 2007; Schrader, et al., 2011), and mental health issues (Schrader, et al., 2011). Participants also expressed concerns of stigma in regards to negative associations attached to living with HIV (Rhodes, et al., 2007; Schrader, et al., 2011).

The following study is an exemplar of photovoice process with participants living with HIV. Photovoice was used to educate future dental providers about the daily biological and psychosocial challenges involved in living with HIV/AIDS (Schrader, et

al., 2011). The question posed by the investigators was: How can visual methodologies help in the development of educational materials that will educate dental students about the everyday lives and experiences of people living with HIV and AIDS? The participants consisted of 15 adults living with HIV or AIDS associated with an Indianapolis HIV service center. There were 12 participants who completed the study (three dropped related to extensive time commitment, loss camera, and no longer wanted to participate).

Each participant was provided a disposable digital camera. Participants were instructed on use of camera, oriented to the study, and instructed to exclude minors or incriminating activities in photographs. Over four months, participants were assigned to photograph events, people, places, and things involved in their daily living with HIV/AIDS and to maintain a reflexive field journal about the meanings associated with the photographs and details about where, when, and who was displayed within the pictures.

Two months into the study, participants were engaged in a photo discussion using SHOWED to reveal developing themes from their photographs and reflections. The 12 participants acquired 257 photographs (averaged 21 photos per participant) over a two week period. The participants and the research team identified 10 themes from the 257 photographs (social support, places, family, staff, group, recovery tools, transportation, friends, medications, and food).

Social support consists of individuals who provide people living with HIV/AIDS various forms of support. A place characterizes one's home and other physical spaces for relaxation and support spirituality, peace, and stability. Family is defined in relation to

biological and social ‘families’ and includes pets. Staff encompasses personnel at care coordination centers (social service and mental health services). Medication symbolizes the individuals who are accountable for providing HIV-related medications and know how they may interact in one’s body. Group refers to the support center where the study was conducted. Recovery tools are different resources to support sobriety and peace to handle mismanagement of emotions. Transportation is means of transferring to and from appointments. Friends are individuals who support people with HIV/AIDS at the various health centers. Food is displayed as vital in the maintenance of overall health and wellness. Throughout the process of creating themes, participants provided supportive and stressful attributes of specific themes (staff, medication, transportation, and places).

The participants shared that the staff was instrumental in obtaining housing, food, mental health resources, and helped with mail. However, staff at various care coordination centers can also be a source of stress and not always helpful (changes with case managers, understaffed). Medications are seen as providing health but also complicating an individual’s life and cause discomfort due to cost and physical side effects. Transportation fosters independence and allows participants to attend health related appointments on “ones’ own terms”. Participants’ also noted various transportation stressors (unavailable funds for gas, delays in public transportation, car repairs). Finally, a place was characterized as a “place of peace” in which one can escape. Participants were grateful for housing however some viewed as a stressor (paying bills, obtaining food, housecleaning, living in undesirable communities, living with infestation of pests, and living with individuals who are disruptive).

Lastly, three key meta-themes emerged (stigma, maintenance of health, and pride)

as important indicators regarding the supports and stressors in the lives of people living with HIV/AIDS. The meta-themes were presented to the participants and their feedback was solicited. The meta-themes were used to educate the future dental providers about the social barriers and challenges that limit people living with HIV/AIDS access to oral health care. The investigators, with insight from the participants, developed three, four by five feet photo narrative posters that outlined each meta-theme. The photo narrative posters were provided to dental education programs to lend insight into the lives of people living with HIV/AIDS.

The photovoice process was viewed positively by participants living with HIV (Hergenrather, et al., 2006; Mamary, et al., 2007; Rhodes, et al., 2007; Schrader, et al., 2011). Photovoice exposed the vulnerability of social and structural components of the participants' everyday lives. Participants viewed the process as valuable, empowering, and provided a venue to voice their concerns.

Photovoice methodology has been successfully implemented with individuals living with HIV and emerging adults. Photovoice empowers disenfranchised communities to give voice to their everyday experiences and concerns. There are no studies that have implemented photovoice with emerging adults living with PHIV.

Gaps in the Literature: Emerging Adults Living with PHIV

There were minimal inquiries that directly investigated emerging adults with PHIV (18-29 years) experiences in work and educational endeavors and how they deal dealt with disclosure within these settings. The majority of all inquiries conducted with emerging adults with PHIV included adolescents. There is a need to explore the experiences of emerging adults with PHIV separate from other developmental cohorts.

Emerging adults with PHIV are unique compared to peers living with other chronic illnesses as those with PHIV have a transmittable disease. Both the chronic nature of PHIV and its transmission patterns are problematic for the key developmental issues of emerging adults that is as an age of identity explorations, instability, self focus, feeling in between, and an age of possibilities (Arnett, 2004). The integration of these two challenges, emerging adulthood and living with PHIV has led to a substantial gap in the literature (see Table 1).

Additional inquiries are needed to discern how emerging adults with PHIV disclose their status as they explore love, occupational and educational paths during the age of identity explorations. How do emerging adults with PHIV deal with fear of rejection and negative reactions, stigma, and isolation in regards to disclosure of their HIV positive status? Little is known regarding emerging adults with PHIV religious practices and beliefs influence when exploring relationships and occupational and educational paths.

In the age of instability, emerging adults experience changes in residential environments, love, relationships, work and educational endeavors (Arnett, 2004). Emerging adults may experience stress and anxiety throughout this period. Emerging adults with PHIV have been found to be high risk for mental illness due to HIV related illnesses and/or social issues. Behavioral changes are commonly experienced by adolescents, but were often exacerbated in adolescents and emerging adults with HIV/AIDS. It is not known how emerging adults with PHIV deal with changes in residential environments, love, relationships, work and educational pursuits. How do emerging adults with PHIV experience stress and anxiety during this period?

The self-focused age represents the least structured age for emerging adults. Emerging adults are free to make decisions without consulting others and they seek to attain the goal of self sufficiency (Arnett, 2004). Emerging adults are free to structure daily activities and are not constrained by social roles (Arnett, 2004). There is gap in knowing how emerging adults with PHIV perceive social support as they seek more independence. Further, little is known about how emerging adults with PHIV make decisions regarding love (sexual relationships), work and education choices, and transitioning to adult health care. There is also need to explore how emerging adults with PHIV seek to attain self- sufficiency.

The age of feeling in between represents the emerging adult not feeling they have reached adulthood. Adulthood is not perceived as transition events such as marriage and completing education. Emerging adults perceive achieving adulthood as accepting responsibility for self, independent decision making, and financial independence: becoming an adult is a gradual process (Arnett, 2004). What is not known is how emerging adults with PHIV perceive accepting responsibility for themselves, foster independent decision making, and financial independence.

There is a gap in knowledge regarding emerging adults with PHIV perception of love and procreation. Emerging adults with PHIV engage in sexual relationships. There are inquiries that explored sexual behaviors and procreational issues in adolescents and emerging adults with PHIV. There is a gap in knowing love, sexual behaviors, and procreational views solely through the lens of emerging adults with PHIV.

The age of possibilities in emerging adulthood is a period of optimism and

fulfillment of hopes and dreams (Arnett, 2004). Emerging adults are open to transform their lives and liberate themselves. What is not known are the hopes and dreams of emerging adults with PHIV or how they envision transformation in their lives. These gaps in the literature that arise from the integration of a unique state of development, emerging adulthood, and a challenging chronic condition, PHIV, are compelling. The gaps present multiple opportunities to advance the scientific knowledge, enhance health care, and improve the lives of those living with PHIV.

Photovoice is an ideal methodology to gain insight into the lives of emerging adults with PHIV. The process would allow them to document and share their everyday realities and perceived health through visualization and stories. Furthermore, photovoice will provide emerging adults with PHIV an opportunity to educate others about the experiences within their community.

Chapter 3 – Research Design and Method

Research Design

Emerging adults living with the chronic condition PHIV have unique physical and social challenges as PHIV is a transmittable and potentially terminal condition. Understanding how emerging adults are living with PHIV will enhance health care knowledge and practice. The purpose of this study is to understand the everyday experience of living with PHIV as emerging adults. Specifically the study explored emerging adults with PHIV everyday realities and provided emerging adults with PHIV an opportunity to record and reflect their personal and community strengths and concerns as it relates to living with PHIV. The research question is "As an emerging adult what is your everyday experience of living with PHIV?"

Research Approach

Participatory action research enables investigators to obtain local knowledge and perceptions by engaging community participants as active contributors (Stevens & Hall, 1998). Participatory action research differs from traditional research by allowing participants to collect and analyze data, then establish what action should follow (Baum, MacDougall, & Smith, 2006). The process enables researchers and participants to understand and enhance daily practices in which they participate and the situations in which they find themselves (Baum, et al., 2006). Given this information, implementation of participatory action approaches was found beneficial to gain insight into the lived experiences of emerging adults with PHIV. The study was reviewed and approved by the University of Wisconsin-Milwaukee Institutional Review Board (UWM IRB).

Photovoice.

Photovoice methodology combines photography and participatory action to provide images of the participant's everyday health realities (Wang & Burris, 1997). The process allows individuals to document and share their everyday realities and perceived health through visualization and stories. The three main goals of photovoice are: to enable individuals to document and reflect about their personal and community strengths and concerns, to promote critical discourse and knowledge about vital community concerns through group discussions of photographs, and to engage policy makers and individuals in the community, who can influence change (Wang, 1999; Wang & Burris, 1997).

Photovoice theoretical tenets were developed from critical consciousness, feminist theory, and documentary photography (Wang & Burris, 1997). The initial theoretical tenet of photovoice is Freire's education for critical consciousness. Freire (1973/2002) suggests individuals need increased critical consciousness to engage in societal change. Freire proposes to position individuals in "consciously critical confrontation with their problems, to make them the agents of their own recuperation" (p.12). Individuals are empowered to share communal experiences and to influence community change.

The second theoretical tenet captured within photovoice is feminist theory. Feminist theory is gender specific and provides female – centered perspective versus the traditional dominant male-centered experience (Harding, 1986). Feminist theory and practice has illuminated "male bias" that has prejudiced participatory research (Wang & Burris, 1997). Women's lives are socially rich similar to men's lives; however,

"theoretical discourses" lack the women's perspective (Harding, 1986). Similar to feminism, photovoice recognizes individuals in disenfranchised groups as experts of their communities that can provide "voice" to their experience (Wang & Burris, 1997).

The last theoretical tenet articulated in photovoice is documentary photography. Historically, photographs have informed others of social events. Documentary photographs are visual experiences of social events captured by individuals not living the experience (Duganne, 2011). According to Wang & Burris (1997), "Documentary photography has been characterized as the social conscience presented in visual imagery"(p. 371).

Photovoice implementation.

There are various phases inherent to the photovoice process. The phases consist of recruiting participants, defining project goals, training the participants, taking pictures and sharing stories, evaluating, and disseminating findings (Wang, Yi, Tao, & Carovano, 1998). The phases associated with the photovoice process will be discussed.

Photovoice sessions are guided by facilitators who are responsible and committed to foster social change within a group or community (Wang & Burris, 1997). The photovoice process starts with recruitment of participants and policymakers or community leaders. The participants are engaged in all stages of the photovoice process. Policymakers or community leaders are ad hoc members: they have the authority to make decisions that can improve the participants' situation (Wang, 1999).

The next step involves participants naming the problem, concern, or notions that are relevant to their community (Wang, 1999). The project goals and objectives are also collectively defined with members of the group. During the initial session the facilitator

obtains a written consent, provides an overview of the project, and presents potential risk and benefits. The photovoice concept and method is introduced. There is a discussion regarding cameras, ethics, and power and how the project can influence policymakers, community leaders (Wang, 1999). The participants and facilitator collaborate to determine guidelines for imagery content (Schrader, et al., 2011). The group discusses acceptable ways to approach individuals and obtain consent prior to taking pictures. The participants are educated on the mechanical use of cameras. There is additional discussion to establish criteria on how to evaluate photographs. The participants may wish to give their photographs to other individuals: the group discusses possible implications of sharing photographs (Wang and Burris, 1997).

The participants engage in taking photographs after the theme is established by the group. Wang, et al (1998) suggests it can be beneficial to establish the theme at the beginning of the project of what individuals might photograph. A prearranged specific theme would provide direction and the participants could discuss how to visually portray it (Wang, et al., 1998). The participants are provided a camera and instructed on use. Facilitators encourage photographers to be creative and not avoid placing the topic of interest in the middle of each photograph (Wang, et al., 1999). An agreed time is established for participants to take pictures and return to facilitator for developing.

Subsequent sessions consist of selecting photographs, sharing stories about the photographs, and identifying issues, themes, or theories within the photographs (Wang, 1999). Each participant is encouraged to select and discuss one or two photographs. Photograph selection should be based on what resonated with the individual. The participants define the meaning of their images through stories. Stories are structured

through a series of questions described as SHOWED (see Appendix J). After the participants share their stories they may identify the issues, themes, or theories that emerge from their photographs. Wang (1999) suggest participants may highlight issues because photovoice is able to promote the development of practical guidelines. Following the identification of issues, themes, or theories the participators write their stories.

Participants and facilitators collaborate to determine how to disseminate photographs, stories, and recommendations to policy makers and community leaders (Wang, 1999). The group selects pictures and stores to share in public presentation. In addition, the participants provide written consent to approve public sharing of photographs and stories.

Photovoice advantages.

Photovoice is a powerful tool that provides individuals an opportunity to voice their perceived needs. There are several advantages for using photovoice. This section will discuss the advantages of using photovoice.

All individuals involved in a photovoice project may acquire various benefits. Policymakers, community leaders, and researchers' benefits differ from participants who "voice" the issues within their community (Wang, et al., 1998). The influential policymaker, community leader, and researcher have an opportunity to learn from the individuals within the community and gain fulfillment for engaging in respected work (Wang, et al., 1998). Furthermore, they are able to enhance visibility through publications and speaking engagements. Policymakers, community leaders, and researchers may begin to recognize participants fully as persons (Wang, et al., 1998).

The participants are provided a means to have a "voice" and provide insight into

their community through visuals and stories. Photovoice allows the participant to identify and define their community concerns and advocate for change (Wang, et al., 1998). Through the process the participant finds their "voice" and may improve self esteem (Wang, et al., 1998). The participant may be seen as an informal leader within their community which may increase access to power (Wang, et al., 1998). In addition, the participant is able to provide tangible experiences through photographs.

Photovoice provides instant and obtainable benefits for individuals and their community (Wang & Burris, 1997). The process provides a way to confirm the resourcefulness and insightfulness of disenfranchised individuals. Photovoice allows individuals to portray their community needs and assets (Wang & Burris, 1997).

Photovoice limitations.

Photovoice can require extensive amount of resources and logistical support (Schrader, et al., 2011). The requirement of participant involvement can be laborious and participation may diminish. Furthermore, the expense of cameras, picture development, writing tools and additional resources may be a deterrent (Wang & Burris, 1997). Photographs may be simple to obtain but challenging to analyze and summarize due to the complexity of data embedded within the photos (Wang & Burris, 1997). Lastly, there may be a potential risk of sharing photos to the public (Wang & Burris, 1997). The dissemination of photos to the public may expose participants to unwanted social duress.

In summary photovoice is an accepted empowerment method for disenfranchised groups. Participants are authorized to give "voice" to their experiences and concerns. Policymakers and community leaders can discover meaning through the lens of the participants who gives "voice" to their experiences. Photovoice helps participants

develop richer connections to their experiences and community through reflection, visualization, and narrative. Photovoice provides an opportunity to educate others about the experiences within their community.

Research Site

The Provident Foundation in Chicago was the site for the study. The Provident Foundation (PF) is a non-profit organization located on the south side of Chicago. Provident Foundation was founded in 1995 to perpetuate the history and legacy of Dr. Daniel Hale Williams, who in 1891 addressed the healthcare crisis African Americans faced with the founding of the Provident Hospital (PH). Since then, the Foundation has supported various charitable causes and community based service programs. The foundation has given priority to programs involving health and medical education, and other social service programs dealing with the welfare of children, the elderly, domestic abuse, housing and nutrition.

The PF is the driving force of the Future Doctors-Future Nurses Project that has been established in seven Chicago Public high schools since 2005, partially funded by the Chicago Public Schools Careers to Education Department. PF is the owner of the PH historical collection of archives and the Medical Miracles Exhibit of PH graduating classes dated back to 1893. The mission of the foundation is to passionately ensure the future health of the African American community. The PF has provided a conference room to conduct Photovoice Workshops and a letter of support.

Recruitment Procedure

Purposive and snowball sampling were implemented to direct recruitment of study participants. Participants were recruited from two HIV/AIDS health and

community agencies located in the greater Chicago area and by participants enrolled in the study. A flyer (see Appendix A) and recruitment letter (see Appendix B), approved by UWM IRB, were provided to a community group leader that trains women with HIV to become HIV peer educators. The Ruth Rothstein CORE Center staff also received verbal and written information to share with potential participants. IRB flyers provided study and participant requirements. The inclusion criteria consist of the following: emerging adults with PHIV, 18-29 years of age, English speaking, and live in the greater Chicago area are eligible to participate. The recruitment letter contained a description of the study and contact information for those interested to participate.

There were two participants that enrolled in the study from the HIV peer educator community group. Both participants expressed knowing peers with PHIV who would be interested in the study and would have their peers to contact this researcher. This researcher was contacted by five of their peers to participate in this study.

Sample

Morse (2000) suggested the following when determining sample size: the scope of the study, nature of the topic, quality of data, and study design. This study addressed a focused population and developmental period in life and collected in-depth data through visual and narrative. A sample of seven to ten participants was proposed to be sufficient for the study. Initially, seven emerging adults with PHIV showed interest in engaging in the study. Due to prior commitments one potential participant was unable to enroll in the study. A total of six emerging adults with PHIV committed to participate in this study. All participants are 18-29 years of age, speak English, and live in the greater Chicago area.

Informed Consent

The UWM short version consent form (see Appendix C) was provided to participants in session one. The participants were reassured both in written documents and verbally that their participation in the study is confidential and will not be shared with anyone. All volunteers had adult status (no legal guardian and capable of giving consent for participation). Because individuals with PHIV may present with some neurocognitive or learning disabilities, an evaluation to sign consent tool (ESC) was implemented. The ESC determines if potential participant understands his or her rights prior to signing the consent. All six participants successfully passed the ESC tool and understood their rights prior to signing their consents. The signed consent forms were obtained by the researcher at the beginning of the initial photovoice session and subsequently secured in a locked location. All participants received a copy of their signed consent forms.

All six participants consented to release selected photographs (Appendix D) to use in dissemination of study findings. The photo release consent forms were obtained by the researcher throughout the study and these consents were secured in a locked location. Participants were informed that they could withdraw their permission to disseminate photos anytime before the photos were used by notifying this researcher in writing through email (hill8@uwm.edu) or by letter. Participants received a copy of their signed photo release consent.

Retention

Participants were strongly encouraged to attend all five sessions. The participants had to attend three out of the five sessions to have their data included in the study. There

were five participants who attend all five sessions. Make-up sessions were allowed for participants. One participant missed session five but met with the researcher at a later date to provide input about the Photovoice Workshops and ideas for next steps. All participants received a digital camera to take photographs. Participants kept the digital cameras at the conclusion of the study. Each participant received $10.00 per session attended; a total of $50.00 for five sessions. Finally, all participants received a picture book of personal photos and narratives.

Photovoice Workshop

The participants completed a demographic questionnaire (see Appendix E). The six participants engaged in a five-session Photovoice Workshop. Each session lasted approximately 1½ to 2 hours. The researcher developed a photovoice training manual (see Appendix F) to guide the workshop. The first session was not conducted as a group, but was facilitated separately with each participant by the researcher. Session one's individual photovoice workshops, on average, lasted 1½ hours and were conducted on Friday, July 20, 2012, Saturday, July 21, 2012, Tuesday, July 24, 2012, Thursday, July 26, 2012, and Friday, July 27, 2012.

The subsequent sessions, two through five, were conducted as a group. Session two was held on Saturday, July 28, 2012, sessions three and four were on Saturday, August 4, 2012 and session five was on Saturday, August 11, 2012. Sessions two and five were held 11:00 a.m. to 1:00 p.m. Sessions three and four occurred on the same day and were held 11:00 a.m. to 3:30 p.m.

Sessions three, four, and five were digitally recorded. Sessions one and two were not digitally recorded. The initial session was directed toward explaining study, assessing

writing and comprehension ability, and obtaining consent. Session two was not recorded due to malfunction of the digital recorder. The researcher purchased a new digital recorder to obtain dialogue during focused discussions in sessions three, four, and five.

There was a research assistant present during sessions two through five. The research assistant was a graduate student in public health whose education had a emphasis on emerging adults with HIV and thus provided additional support in the team conducting the study and analyzing the data. The assistant supported with downloading photographs from participants' digital cameras to the researcher's password encrypted laptop. Furthermore, the assistant printed photos for the participants to use during photovoice sessions two, three, and four. Finally, the assistant organized handouts, materials, and set up refreshments for sessions two through five.

Session one.

The researcher conducted one on one session with each participant. The first workshop was conducted on days and times that were established by each participant. The initial session consisted of an introduction and explanation of what is Photovoice (see Appendix G), overview of SHOWED (see Appendix J), and assessment of the individual's ability to participate, and obtain consent for participation. The participants were also asked to complete a Demographic Information Questionnaire (see Appendix E). The questionnaire asked for their age, ethnicity, gender, level of education completed, and yearly income.

In addition, each participant was provided a digital camera along with verbal and written instruction on camera use. Participants received photography training, which included verbal and written information regarding the power of pictures. All participants

were able to demonstrate understanding of camera use by practicing taking pictures. The researcher reviewed the photo release forms (see Appendix D). The participants were informed that a consent form must be signed prior to taking pictures of people. The participants received verbal suggestions on how to ask for permission.

Additionally, the participants engaged in a writing exercise. Each participant was presented a picture of a purple butterfly sitting on a yellow flower that was surrounded by a fir tree. During the writing exercise the participants were instructed to write about what they saw in the picture and what they really thought was happening in the picture on a sheet of paper. The participants were informed that the writing exercise would be discussed in session two.

Finally, participants were instructed to practice taking pictures prior to session two. The participants were asked to take a picture in response to the following question: What is your experience living with PHIV as it relates to your health? The experience provided the participants an opportunity to practice using the digital camera and identify areas of interest to photograph. The participants were informed that they will share one practice photo with the group during session two in relation to the aforementioned question. They were also instructed to bring digital their camera to every Photovoice session.

Session two.

Session two occurred on Saturday, July 21, 2012. All participants were present throughout the session. There were two participants that were approximately 20 minutes late. The session started upon the two participants' arrival. Upon arrival, participants

were instructed to give cameras to the research assistant, so their pictures could be downloaded into the researcher's computer.

Initially, the researcher reviewed "What is Photovoice" (see Appendix G). The group was asked if they had any questions. The participants were asked to share thoughts regarding the writing exercise from session one with the group. The next discussion explored their photography practice experience. The participants were asked to share their experiences. Following the discussion about the photography experience, participants shared a photo captured during their practice shoot. The researcher displayed their selected photos onto a projector screen. The participants were encouraged to share their pictures in response to the question: "What is your experience living with PHIV as it relates to your health?"

The researcher explained SHOWED (see Appendix J) and used their photographs to demonstrate how SHOWED would be applied. Following the SHOWED demonstration, the participants practiced applying SHOWED to one of their photographs during a writing exercise. At the end of the session, the researcher reviewed and answered questions regarding photo release consents. The participants were asked to take a minimum of 20 pictures, prior to the third session, to address the following question: "As an emerging adult what is your everyday experience of living with PHIV?" The participants were also encouraged to think about an additional question that was of interest to photograph.

Session three.

Session three occurred on Saturday, July 28, 2012. All participants were present and one participant arrived 10 minutes late. Upon arrival, participants were instructed to

give cameras to the research assistant so their pictures could be downloaded into the researcher's computer.

Initially, the researcher reviewed "What is Photovoice" (see Appendix G). The group was asked if they had any questions. The researcher shared a photograph of a well-known African-American family to demonstrate how SHOWED would be applied. Following the demonstration, another picture of a well-known African-American family was presented and the participants were asked to demonstrate SHOWED.

Secondly, the participants were asked if they had an additional question they wanted to explore through photographs. The group stated they had no additional questions to explore. The participants were asked to select two photographs in relation to the question: "As an emerging adult, what is your everyday experience of living with PHIV?" The participants were provided time to reflect and write about their selected photos.

Finally the participants were asked to select an additional three photos. The participants were provided a folder with five photo reflection sheets (see Appendix H) to write a brief description of their photos. The researcher reinforced the following questions to write about: why they want to share the photo, what's the real story these photos tell, how does each photo relate to your life and/or the lives of people in your community, and how can these photos be used to educate others. Folders were collected at the end of the session and stored in a secured location. The participants took a break before returning for session four. There were two participants, who requested to have their cameras, so they could take additional pictures during the break.

Session four.

Session four occurred the afternoon of Saturday, July 28, 2012. All the participants returned to session four after attending session three earlier in the day. Upon arrival, two participants were instructed to give cameras to the research assistant, so their pictures could be downloaded into the researcher's computer.

The researcher reviewed "What is Photovoice" (see Appendix G) at the beginning of the session. The group was asked if they had any questions. The researcher reviewed SHOWED (see Appendix J) and shared a photograph of an ocean front landscape to demonstrate how SHOWED would be applied. The participants were encouraged to share two new photographs in relation to the question: "As an emerging adult what is your everyday experience of living with PHIV?"

The group was asked to reflect and continue writing about pictures selected in session three and the new pictures selected during this session. Overall each participant selected three to five pictures to write a narrative. The assistant distributed the assigned folders to the participants along with additional photo reflection sheets to write their narratives. The researcher reinforced the following questions to write about: why they want to share the photo, what's the real story these photos tell, how does each photo relate to your life and/or the lives of people in your community, and how can these photos be used to educate others. Folders were collected at the end of the session and stored in a secured location.

Session five.

Session five occurred on August 11, 2012. There were five participants present in session five. Two participants were 30 minutes late due to a delay on the Chicago Transit

Authority Bus. The session started upon the arrival of the two late participants. The researcher received prior notification from one participate that he was unable to attend due to college visit. Arrangements were made to meet with the participant at a later date.

Initially, participants who arrived on time were given time to complete photo reflection sheets. The assistant distributed the assigned folders to the participants that contained their personal narratives. The researcher reinforced the following questions to write about: why they want to share the photo, what's the real story these photos tell, how does each photo relate to your life and/or the lives of people in your community, and how can these photos be used to educate others. There was one late participant who had an opportunity to complete her personal narratives upon arrival. The other late participant had completed her narratives in session four. Folders will be collected at the end of the end of the session.

Each participant was informed they would receive a personalized book of his or her photos. The participants had an opportunity to reflect on photovoice experience in a group discussion and by completing the Photovoice Workshop evaluation (see Appendix I). Collectively, participants and the researcher discussed ways to inform and educate the community of the group's concerns and decide how the group would want to share photographs and concerns in the community. Participants were given the option to permit researcher to use photos and share findings from the study to inform professionals and other appropriate individuals. All participants, including the participant who was absent, consented for the researcher to use photos and share narratives in dissemination forums.

Data Analysis

Visual and thematic analysis was implemented. Photograph representations were

interpreted through the lens of each participant throughout the photovoice process. The participants individually and collectively selected photographs, provide meaning of photographs through narrative, and identify the issues and themes that arise from their photographs (Wang, 1999). Riessman (2008) suggests that visual representation experiences in various art forms can enable others to see through the lens of the participant. Thematic analysis focuses on "what" is said and keeps a story "intact" (Riessman, 2008). Participants used SHOWED (see Appendix J) to depict what is being expressed in the photographs.

The researcher and research assistant read and reread the participant's explanation of each photograph during four separate intervals. The participants' photovoice writings were initially coded by the researcher and research assistant after the third read. Mutually, the researcher and research assistant highlighted meaningful sections, sentences or phrases, and assign a code. The researcher and research assistant coded a sample of the photovoice narratives to confirm consistency in coding. Dr. Sawin, committee chair, reviewed codes to ensure coding reflect the participants photovoice narratives. The researcher and the research assistant completed a fourth read of the photovoice narratives. Coding was completed on photovoice narratives. The researcher and research assistant met a second time to discuss photovoice narrative codes. The researcher and research assistant summarized each participant's story and identify overarching themes and sub-themes. A participant in the study performed insider validation of themes and sub-themes.

The researcher and research assistant met after sessions two through five to discuss dynamics of the sessions, participant engagement, and researcher's role as

facilitator. After sessions three, four, and five the researcher listened to the digital recordings of each session. The researcher submitted sessions three, four, and five to a transcription service to transcribe discussions. Transcripts and field notes were read during four separate intervals by the researcher. Coding of transcripts and field notes were conducted by the researcher. Dr. Sawin, committee chair, reviewed codes to ensure that the coding reflects the voice of the participant. Additionally, the investigator had extensive discussions with the committee chair reviewing codes for the photovoice selections, transcripts and field notes. Refinements were made to the definitions, thematic labels and exemplars to reach consensus. A participant in the study performed insider validation of themes and sub-themes.

The 26 photovoice narratives and coding performed from photovoice narratives, field notes, and sessions three, four, and five transcripts were also compiled in an excel file by participant's assigned pseudo name. Data were analyzed across data source to identify themes and sub-themes, develop thematic definitions, and identify exemplar quotes. This data file has been kept on a secure password-protected server at the University of Wisconsin-Milwaukee. The client non-disclosure agreement for sessions three, four, and five is located on this secure server.

Scientific rigor.

Hall and Stevens (1991) criteria (dependency, adequacy, reflexivity, credibility, rapport, coherence, complexity, consensus, relevance, honesty and mutuality, naming, and relationality), was used to ensure scientific adequacy. Dependability involves the investigators being transparent throughout the research process; methodically recording all actions connected to every aspect of the study (Hall &Stevens, 1991). All actions

connected with data collection, sampling, analysis, and outcomes are transparent to the reader.

Adequacy ensures that research processes and outcomes are relevant, meaningful to the problem being explored (Hall & Stevens, 1991). Photovoice is an appropriate methodology to understand the experiences of emerging adults living with PHIV. Participants are able to document and share their everyday realities and perceived health through visualization and stories. Additionally, photovoice provides emerging adults with PHIV a way to educate others about their experiences.

Reflexivity is essential throughout the process and requires the investigators to assess their individual values, beliefs in relation to all aspects of the research study (Hall & Stevens, 1991). The researcher has prior experience working with emerging adults in the community and in a pilot project at Children's Memorial Hospital in Chicago. Prior experience provided the researcher with sensitivity and the ability to listen well to this population. The researcher was careful about procedures that allowed her to check beliefs and experiences to ensure all aspects of the participants' perspectives were fully captured. After sessions two through five the researcher and research assistant discussed the dynamics of the sessions, participant engagement, and researcher's role as facilitator. Furthermore, The researcher reflected after each session to address potential personal assumptions and values that may influence the study.

Credibility ensures that an authentic account of experiences has been captured and is validated by a member of the community being studied (Hall & Stevens, 1991). A participant volunteered to review the researcher and research assistant findings. Rapport is the researcher's ability to develop and maintain a trusting relationship with the

participants so that a credible description of their experiences is attained (Hall & Stevens, 1991). Throughout this study the researcher was a co-participant and actively involved with participants during photovoice workshop. The researcher was able to retain all six participants during study and participants expressed positive feedback regarding photovoice workshop in evaluations.

There were frequent coherence checks throughout the research process. Coherence checks involve questioning the data and analytical insights (Hall and Stevens, 1991). The researcher was committed to activities, which ensured the complexity of the participants' experiences was captured through practice writing exercises and discussion of photographs during each session. The researcher listened to digital recordings of photovoice sessions three, four, and five after sessions. The researcher and research assistant discussed observations and participant engagement after sessions two through five. All data was read and re-read at four separate intervals.

Complexity involves capturing the rich, complex realities of participants that are influenced by socio-cultural, political, economic, and historical situations (Hall & Stevens, 1991). Participants' similarities and differences emerged from photovoice photos, text, and discussions based upon their various contextual experiences. The researcher was mindful to capture the meaningful complexities expressed in the lives of emerging adults living with PHIV.

Consensus is a primary verifier that enables the researcher to compare verbal responses, observations and written records and ascertain possible motives behind participants' actions and notions (Hall & Stevens, 1991). The researcher was able to ascertain participants' possible intentions in photovoice selections, session transcripts,

and field notes. Furthermore, the researcher was able to identify recurring themes in regards to emerging adults with PHIV lived experiences.

Relevance involves whether the questions address the participants' concerns and if the questions can address their interests and improve the conditions of their lives (Hall & Stevens, 1991). The research question is "As an emerging adult what is your everyday experience of living with PHIV?" The participants' were uninhibited and free to define their everyday lived experience through visualization and text. Moreover, the participants were able to voice their interests and concerns. An opportunity was given to the participants to identify an additional question of interest. All six participants expressed satisfaction with research question presented by the researcher and did not express another question to explore.

Honesty and mutuality were maintained throughout the study: information was freely exchanged between the researcher and participants throughout photovoice workshop. The participants are the "truthtellers" and are considered peers rather than "objects of study" (Hall & Stevens, 1991). Naming involves selecting, defining, and unfolding concepts and significance of the findings (Hall & Stevens, 1991). The participants were able to select, define, and describe concepts that were revealed through their photos. Furthermore, the participants exchanged notions about peers photos and narratives throughout photovoice sessions two through five.

Relationality involves collaborating with other researchers and members of the group being studied in designing and analyzing to enhance adequacy throughout the research process (Hall & Stevens, 1991). Dialogue is inherent to photovoice as it promotes critical discourse regarding personal and community strengths and concerns.

Throughout the photovoice workshop participants captured their personal and community strengths and concerns through photo and defined their voice through text and critical discourse. In session five, the participants determined how they would voice their story to policy makers and identified community leaders. Finally, participants engaged in data analysis by providing meaning of photovoice selections and validation of themes and sub-themes.

Ethical Considerations

The study was guided by both ethical and legal considerations. The questions within the study could evoke sad feelings. Participants received informed consents that cover the following areas: details about the study, why he/she is eligible to participate in the study, significance of the research, potential risks and benefits to the emerging adult, a statement that he/she may choose to participate and can withdraw from the study at any time without negative consequences, an invitation to ask questions at any time, and key contact name, phone number and email address. The participant does not have to respond if he or she does not want to answer the questions. IRB approval will be obtained through the University of Wisconsin–Milwaukee.

The researcher fully explained the study to the participants, including the purpose and aims of the study, the procedure for data collection, and the process for protection of confidentiality. Verbal and written informed consent for participation was obtained from each participant. Ethical issues related to taking photographs were covered in detail including obtaining informed consent from people depicted in images throughout sessions one to four.

Chapter 4: Research Results

The purpose of this study was to understand the everyday experience of living with PHIV as emerging adults. This chapter will provide analysis of data generated from Photovoice Workshop. The six participants, who engaged in the study, reflected on their experiences of living with PHIV as an emerging adult. Each participant's data were individually analyzed and the data consisted of (1) demographics, (2) photovoice selections, (3) transcripts from digitally recorded sessions, and (4) field notes. The demographic data was collected from all six participants in photovoice session one. The participants captured a total of 55 images during the study. There are 26 images and narratives generated from this study that will be presented.

The analyses of the data are presented in five phases. First, presumptions of the researcher will be explored. Secondly, a summation of participant descriptive data, including demographics, will be discussed. An introduction to themes identified in the analysis follows. Next, participant profile analysis based on photovoice selections, field notes, transcripts, and a presentation of individual findings will be provided. The voice of the participants is present throughout the report through descriptive narratives and statements generated by the participants. All participants provided the titles for their photovoice selections. The faces in the photovoice selections were blocked to assure confidentiality. Themes presented in each profile are introduced in the order of participant's emphasis. Photovoice selections that are applicable to the themes are presented in the participants' profile. All photovoice selections are presented as Figures 1 through 26. Lastly, a summary of thematic findings across participants is presented.

Presumptions/Activities of the Researcher

I will never forget the fall of 1992. I had only been out of nursing school for approximately 10 months and I was still adjusting to my new role as a RN on a busy general medical unit at Children's Memorial in Chicago. During the fall, we were seeing more and more children being admitted with unexplained recurrent pneumonias and fevers. The children would receive a battery of test and work ups. Consultations were ordered.

I provided care for one of these patients. A beautiful 2–year old African-American girl, I'll call her Kianna, admitted with recurrent pneumonias. I remember asking one of my co-workers, "Wasn't she just here several weeks ago?" She nodded her head in agreement. I felt compelled to become her primary nurse.

Kianna's mom was a single parent who had an older teen son. At the time, I was separated from my husband and fully understood the demands on the single parent. Kianna's mom and I developed a solid relationship and I informed her that I would notify her if there were any changes or questions.

About one week into Kianna care, I saw members from the Special Infectious Disease team on the unit. The attending and his team seemed somber and ask to speak to Kianna's primary nurse. As I approach the team, I felt this overwhelming sense of dread. The attending informed me that they must inform mom that Kianna was HIV positive and they would like for me to be present. I became numb. In my mind I thought, WOW…Kianna's mom doesn't appear sick…in fact she's what you would call a big woman, most likely weighs 200lbs. or more. I felt ashamed of the stereotypes that I had regarding HIV. For goodness sake I was a nurse!

As we walked to the room, I was waiting for mom to turn in her chair and look at me, but she did the opposite. She picked up Kianna, did not make eye contact and started rocking. The closer we came to the room, the more she rocked. I saw tears roll down her cheek. She knew she had to know. She sensed the inevitable as they disclosed Kianna's status.

That day has resonated with me for 20 years. In 2010, I received a card from mom. In my excitement, I tore open the card and saw a picture of Kianna as a beautiful young woman. She was 18 years old. Yet, when I read the card, mom was thanking me and several other nurses for caring for Kianna and then notified us of her death.

My experience with Kianna and several other children through the years encouraged me to explore their lived experiences as emerging adults. Several biases emerged that I knew needed to be address as I conducted the study. I envisioned that the emerging adults with PHIV would be feeble, ill due to poor medication compliance and overall years living with HIV.

Another perception I had to address was inner city emerging adults not being well educated and would have difficulty articulating future goals. I'm truly ashamed of this confession; yet, the literature tends to support this thought. Additionally, I wondered if it would be extremely challenging to engage participants in the study. I also questioned if the participants had the skills to effectively write their experiences. I addressed biases by networking with co-workers, who work with adolescents and emerging adults living with HIV. I was able to volunteer with some community support groups and had an opportunity to develop relationships with adolescents and emerging adults living with

PHIV. Prior to this study, I conducted a photovoice pilot at Children's Memorial Hospital in Chicago with four emerging adults living with PHIV.

Although I come to this study with prior experience working with emerging adults in the community and in a pilot project, which I believe provided me with sensitivity and the ability to listen well to this population, I was thoughtful about procedures that allowed me to suspend my pre-determined beliefs and experiences and ensure that I managed the process to fully capture and analyze all aspects of the participants' perspectives. In this study, my role as researcher was to facilitate all five photovoice sessions, observe participant behavior, write field notes, and conduct analysis. At the end of each session, the research assistant and I discussed dynamics of the sessions, participant engagement, and researcher's role as facilitator. I read and reread all photovoice selections, field notes, and session transcripts. I used an audit trail to address interpretation of data. Further, three additional sources: participant, research assistant, and committee chair authenticated analysis.

Participants' Descriptive Data

The participants' demographics were obtained from completed demographic forms in session one and from session transcripts. The following is a summary of the six participants' demographics (Table 2). Participants are four females and two males. The ages range 19–24 years of age: the mean is 21.3 years. All six participants are African–American. The highest level of education completed is as follows: four completed some college, one has a high school diploma, and one obtained a general equivalency degree. The four participants who completed some college are all enrolled in college. Out of the four participants with some college, one participant was recently admitted and received a

scholarship to attend this fall as a freshman. The yearly income for all six participants is less than $5,000. Four participants live with a parent or guardian and two live independently. There are three participants who live in the south and western suburbs and three live in Chicago. Five out of the six participants live in impoverished communities with high crime rates. All six of the participants receive care at a clinic specialized in HIV care. One participant receives care at a major pediatric center and the remaining five participants receive care from adult providers who specialize in HIV/AIDS care.

Introduction to Themes

There are five themes and sixteen sub-themes that emerged (Table 3). The five themes are: refusal to be defined by HIV, living life to the fullest, empowerment through social connections, the need for political support, and hope. The themes and sub-themes that surfaced for each emerging adult will be presented in their participant profile analysis. The following section and Table 3 provides an overview and definitions of themes and sub-themes.

First, refusal to be defined by HIV is the rejection of being solely described as a person with the virus. Refusal to be defined by HIV emerged in three (50%) of the participant profiles. Stigma is a sub-theme of refusal to be defined by HIV. Stigma is the attachment of a negative label imposed by society in regards to living with the virus. Society views those with HIV as having brought it upon themselves through the acts of unchaste behaviors. Unlike those who acquired HIV behaviorally, emerging adults with HIV were born with the virus and did not participate in behaviors that could lead to infection.

Another sub-theme is sexuality. Sexuality is the expression of sexual exploration despite of living with HIV. Emerging adults with PHIV do not allow the virus to inhibit the expression of their own sexuality.

Secondly, living life to the fullest is valuing every past, present, and future moment despite living with PHIV. All six participants (100%) expressed living life to the fullest in their profiles. There are three identified sub-themes of living life to the fullest: celebrating every moment, cherishing the beauty, and choosing careers. Celebrating every moment is living each moment of life as special whether it's a moment of joy or of growing through pain. Emerging adults with PHIV celebrate each day as an accomplishment even when challenges arise. Cherishing the beauty is the ability to see the beauty in people, nature, situations, and self throughout everyday lived experiences. The participants are in tuned to the beauty in their surroundings and hold unique perspective about their experiences. Lastly, choosing careers is the acknowledgement that life is not over by selecting future a career path.

Thirdly, Empowerment through social connections is how emerging adults with PHIV gain power through engagement with others. There are five participants (83%) articulated empowerment through social connections. Furthermore, five sub-themes emerged from empowerment through social connection: engaging with peers living with HIV, intimate relationships, family, and community. Engaging with peers living with HIV is the interaction between emerging adults with PHIV and peers with HIV. An intimate relationship is the establishment of a romantic relationship with a significant other. The family defined by emerging adults living with PHIV includes mother, father, grandmother, aunt or biological children. The community consists of key individuals who

are not peers, family, or romantic partner. Additionally, the community is viewed as society as a whole.

The fourth theme is the need for political support. The need for political support is the need for assistance in ways to achieve funding, promote advocacy (voice), and feel secure. All six participants (100%) articulated the need for political support in the profiles. The four sub-themes that emerged are: funding, advocacy (voice), security, and transportation. Advocacy (Voice) is the ability to voice concerns to appropriate policymakers and the community. Furthermore, advocacy is learning to convey their viewpoints. Funding is defined as the need for finances to support programs and events. Emerging adults with PHIV view funding as financial support to fund their causes. Security is the ability to access help when needed. Moreover, security is fostering a secure environment. Transportation emerged as means of securing reliable travel.

Finally, hope is the belief that desires and dreams can be achieved despite living with PHIV. Hope was expressed in four (67%) participant profiles. Education, spiritual beliefs, and self-perseveration are sub-themes of hope. Education promotes that hope can be attained through higher education and training. Emerging adults with PHIV envision that obtaining more education will enable them to secure a better future. Spiritual beliefs embodies that hope is obtained through spiritual values and beliefs. Lastly, self-preservation is the innate ability to keep oneself from harm. Emerging adults with PHIV

Participant Profile: Hannah

Hannah is an articulate and physically striking 19-year old African-American female that lives in the Englewood community in Chicago. Englewood has been recognized nationally as a high crime, impoverished community. Hannah has a primary

physician and receives health care at a major HIV center in Chicago. She learned about the study and contacted me by phone. On the phone, she sounded excited to meet with me and I was just as excited to get to know her. She has a bubbly personality. Initially, when I met Hannah, I was impressed with her model-like features. During session one, I asked her if anyone ever mentioned that she could model. She stated that she gets that a lot and that she loves to watch America's Next Top Model.

Throughout the Photovoice Workshop, Hannah and I had an opportunity to connect and learn more about each other. In session one, I shared with Hannah my background as a nurse at Children's Memorial Hospital and my passion for partnering with young people living with HIV. She expressed excitement when I mentioned being a pediatric nurse and shared her desire to become a pediatric nurse and eventually a pediatric nurse practitioner. Hannah also wants to work with young people living with HIV. She attends a reputable 4-year university in Chicago.

Hannah lives with her mom and likes to spend time with her boyfriend and friends. Occasionally she works seasonal jobs through the Chicago Youth Workforce, but has no steady employment. She enjoys participating in "special projects" and is active in a young women HIV support group. As a peer educator she has provided presentations to peers at local colleges. She mentioned that she feels awkward after presenting because they are so close to her age but she is willing to continue with presentations. She stated, "I want everyone to know that you can live with HIV and not let it stop you from becoming who you want to be in life".

Throughout the photovoice workshop, Hannah created five photovoice selections. Five theme emerged from the photovoice selections: Living life to the fullest, Refusal to

be defined by HIV, The need for political support, Empowerment through social connections, and Hope. There were also several sub-themes that emerged from each theme. Hannah's photovoice selections, session transcripts and field notes will be discussed in relation to the identified themes and sub-themes.

Living life to the fullest.

Hannah captured living life to the fullest in her photovoice piece "Moving Time". She expressed the following in "Moving Time" (Figure 1):

I feel like time waits for no one, so you must live life. Sometimes I ignore that time is ticking or don't even realize that I am getting older. This picture is a reminder that everything is moving including time, so I have to live my life.

The participant photovoice piece "Moving Time" is a photo of a brick temple on the side of the road. The participant has an appreciation for the nature and the various objects surrounding her. People and cars are moving pass the temple with no acknowledgement of its presence. This is a picture in motion. Evolution and moving forward is a part of life. There is movement behind the scenes. The cars are moving, clouds are floating, and people are walking. The photo is a representation of time in motion. "…time waits for no one so you must live life." Hannah acknowledges that time is moving forward and that she is aging. Aging is something to celebrate. The picture is a reminder that time and everything waits for no one and that you must live your life.

Living life to the fullest emerged in various discussions throughout the photovoice workshop. Key milestones in past experiences are remembered and celebrated. During session two a participant shared that her daughter might be infected

with chicken pox. This topic led to an impromptu discussion among he participants' about past experiences with chicken pox. There were moments of questions and laughter as participants' recalled their experiences. She shared in the discussion as she remembered her childhood experience with chicken pox.

Emergence of living life to the fullest occurred during session five reflection of photovoice workshop experience. Hannah's outlook on people and circumstances has changed since her participation in the photovoice workshop. She stated, "It is deep. I look at pictures differently, much differently now and even when I'm looking at people and circumstances, situations, even if it's not a picture I'm envisioning in my head without taking that picture, what would that look like and what's really going on." Hannah now envisions what is really happening behind every experience that is encountered in everyday life.

Lastly, choosing careers also appeared as a sub-theme of living life to the fullest. Hannah's acknowledgement and appreciation of time propels her to move forward and not remain stagnate. Her pursuit to become a pediatric nurse, active engagement in studies, and role as a peer leader fosters her living life to the fullest and cherishing the present and what is yet to come.

Refusal to be defined by HIV.

Living with HIV does not define you, steal your joy, or stop you from becoming who you want to be in life. Refusal to be defined by HIV is the rejection of being solely described as a person with HIV. Hannah states, "I want everyone to know that you can live with HIV and not let it stop you from becoming who you want to be in life." She refuses to be labeled by people and society. Emerging adults with PHIV embody a

positive perspective, outlook, and message to convey. During session five she explained, "I want to put out that this how things look in our ads of being positive, but I am trying to figure out a way to word that, but I want to show that we are positive people, HIV positive people. I want people to look into what we see in our everyday life". Hannah eventually coined the phrase: "A Positive View, A Positive Mindset, a Positive Voice" as a name to describe who they were as emerging adults living with PHIV.

Stigma appeared as a sub-theme of refusal to be defined by HIV. Stigma was captured in two of Hannah's photovoice selections "Stamped" (Figure 4) and "Higher Ground" (Figure 3). In "Stamped", there are two men who are intimately close to one another. Shadows covering their faces represent stigma that separates them from individuals and society. Their relationship and love for one another can never fully be understood. People who are different become stigmatized by society. Society can't accept or understand different people's truth. The couple in the photo can't live their truth in society with being stigmatized as homosexual. This photo relates to Hannah, because she carries the burden of being stigmatized due to her HIV status. So instead of just being Hannah she is forced to be the girl with HIV. She suggest the following in "Stamped" (see Figure 4):

The story is society doesn't accept/understand the truth about someone because a stigma creates a meaning/definition on it's own. They can't just be a couple yet they are forced to be a homosexual couple. This relates to me because society created a stigma for who I am. I stigma of being diagnosed with HIV takes away from who I am as a person. So, instead of me being Hannah, I am the girl with HIV. Who defines the norm of people?

Hannah also recognizes stigma in relation to where you reside. In "Higher Ground" the urban setting is an environment that is generally not valued by society. It's a setting where people learn from the streets. Hannah relates to the photo, because she grew up and still resides in the same challenging urban environment and it has always been a struggle. She states the following in "Higher Ground" (see Figure 3):

I feel that growing up in the Englewood area of Chicago dealing with my surrounding has always been a struggle for me. My environment weighed heavey on my mind, but I tried to separate who I am and what I want from life from my situation. Though I live in Englewood, I am not Englewood and that doesn't define my life.

Hannah shared that she desires to show society a "different side" of emerging adults with PHIV. Living with PHIV is only part of her story and does not fully define her. During session five she expressed that displaying their photovoice selections in a gallery setting would show a different side of the PHIV lived experience.

Finally, in Session 3, there was a discussion about a famous celebrity family photo. Hannah noted that the family refused to be labeled by the public as having to consistently be a certain way. She shared, "The real story is that they are human beings who have emotions and it looks like they don't mind showing, and how down to earth…they are human beings and have emotions and they don't mind showing how down to earth and fun loving and silly they really are." She has a positive perspective and outlook to convey to society. Similar to the celebrity family, she yearns to be seen as a human being minus the labels imposed by society.

Empowerment through social connections.

Emerging adults with PHIV gain power through communal engagement with others. Social connections provide strength and support to emerging adults living with PHIV. When an emerging adult with PHIV connects with peers living HIV there is a sense of validation. Hannah voiced her enjoyment participating in "special projects" and actively participating in a young women HIV support group. Peer recognition of accomplishments is noted throughout the photovoice workshop. During session five a conversation occurred regarding David and his achievements. She along with her peers expressed positive feedback as David's accomplishments were shared.

The community is viewed as individuals who are not peers living with HIV, family, or partners in intimate relationship. The community may include health providers and leaders. Throughout session five the participants determined how they wanted to share their photovoice selections. Hannah referenced the women's HIV support group leader and anticipates her recognition and approval regarding sharing their "voice". She stated, "She's going to be proud of us." The community provides an additional level of support and validation for the emerging adult living with PHIV.

Hannah desires to belong in an intimate relationship yet remain independent to pursue personal interest in life. The following photovoice selection "Self Love" (Figure 2) provides insights into her perspectives about intimate relationship.

There is a boy and a girl sitting on a beach at a park. The scenery is beautiful. There is a bridge and a pond right across from them. These two looks as if they are a couple spending time together. The lady is sitting enjoying the scene as if she is admiring it, yet her boyfriend has his arm around her and he is staring in a completely different direction. This shows that eventhough they are a couple, they are on differ pages. They don't have common interests. What appears to be a moment together, is a moment with themselves. This relates to me because it makes a statement to me reguarding a loved one in my life. Because I feel that I deserve to have someone/ a love in my life, I fail to appreciate/ recognize myself growth. Just as the girl is enjoying the moment on her on, it shows I don't have to lach on to a man.

The picture shows the experience of an intimate couple in beautiful surroundings. Quality time in an intimate relationship is an experience that is valued by Hannah. The couple appears engaged yet distant staring in different directions. The woman is fully engaged with scenery. Different interests captivate them. Everyone should be allowed to express his or her own direction in life. Individuality is something that she values in an intimate relationship. The picture reminds her of her loved one and reinforces that she deserves to engage in an intimate relationship. Self-awareness is symbolic of growth. Hannah fails to appreciate or recognize her growth yet can relate to the woman's ability to love a man yet remain independent.

The need for political support.

The need for political support surfaced in regards to advocacy (voice), and funding. Advocacy is the ability to voice concerns and educate appropriate policymakers and the community. Advocacy is demonstrated as taking initiative to establish venues to educate others about emerging adults with PHIV lived experiences. During session five

Hannah and her peers expressed various ways to advocate. The group was trying to determine who should attend and how to reach the identified policymakers and stakeholders. She shared, “We should come up with an idea on how to invite them, like a postcard.” She further notes, “In some type of way, we just got to make a list and figure it out from here.” Hannah suggested the theme should be “Behind the Camera” to name the photovoice event. She expressed that it prompts the audience about who is “voicing” their stories.

Funding also emerged by the group as a need. Hannah and the group sought to understand how to create short term funding. She mentioned the idea of creating note cards and post cards from their photovoice pieces to address short term funding needs to sponsor the photovoice event.

The need for support in development of voice was articulated. Hannah expressed the need for a formal process of certifying the photovoice experience and accomplishment so that the participants could support other emerging adults with PHIV in developing their voice. Hannah suggest, “If that is the case, then we should have a graduation, not a graduation, but like a certificate for photovoice like to move us to the next step.”

Hope

Hope is observed through self-preservation. Self–preservation is the innate ability to keep oneself from ruin. Furthermore, self-preservation is the “will power” to continue regardless of what comes your way. Hope represents the light at the end of the tunnel in the face of adversity. It is also seen as resilience. Hannah’s photovoice selection “Will Power” (Figure 5) shares the following:

There is a young boy holding a sweat towel…he is tired because I see a slight slouch like he is a little weary. But I see a sense of ambition in from his eyes…I see that he is tired but I see hope in his eyes. The real story is that, although things may seem tough, you have to remain hopeful. This is a representation of that light at the end of the dark tunnel. This relates to me because will power will get you through any situation. My environment or situation may be bad, but I use my will power to control that situation and turn it into something positive.

Hope is also seen through education. Education provides hope to overcome negative environments. Hannah values education and is determined in spite of her surroundings to obtain her college education. In Hannah's photovoice selection "Higher Ground" (Figure 3) she states, "I feel this picture makes a statement reguarding education. This picture reads determination for education."

Participant Profile: Esther

Esther is a vibrant 24-year old African American female, who lives in the south suburb of Dalton. She exudes streetwise commonsense and is very knowledgeable about various communities embedded in the south side of Chicago. Esther can come across very authoritative yet has an engaging, non-threatening side to her.

Esther lives with her auntie, who she call momma, and grandma. Her birth mother died when she was 4 years old. Esther shared, "I don't remember my mom, she was always gone." "I had to grow up quick." Esther's mom was a drug addict and she worked as a prostitute to support her habit. Esther discovered that she was HIV positive at 9 years of age. She shared, "I never understood why I took medicine all the time." "My family didn't treat me different. I always was able to do things."

During session one I shared with Esther my background and why I wanted to perform the study. She shared her dreams of becoming a pediatrician one day and hopes to work with others who are infected with HIV. Esther expressed wanting to participate in the study because she wants to voice her opinions to who anyone who listens. She revealed she has traveled to Springfield for AIDS day and has talked to a legislature about living with HIV. Esther stated, "I'm not working now but I stay busy participating in a lot of projects." "I like things like this."

Empowerment through social connections.

Support is gain through communal engagement with others. Esther highly values engaging with peers living with HIV. The photovoice piece "Retreat May" (Figure 8) reflects her desire to an ongoing connection with peers living with HIV:

What I see in the pic is everyone happy to be with ea. Other + having fun enjoying our weekend together. I see everyone just to have had A ball together with no drama. What is really happening here is we are on our way back home to Chicago but we had fun together (dram free) weekend. This pic relate to our lives because no matter of lifes obstacles we learned to accept ea. Other + have fun living life. This situation is a strength + concern. The strength is that no matter what we may go through, we are still a family at the end of the day.

Esther's opportunity to engage with peers living with HIV offers her an escape from the "drama" of life. Peace and a "drama free" situation is something that she cherishes. Life can be enjoyable with peers who embody like experiences regardless of obstacles they face. Strong bonds with peers are important in order get through life.

Engaging with peers living with HIV fosters validation. Esther recognized the accomplishments of David and provided positive feedback regarding his opportunity to attend the International AIDS Conference and funding to attend school. She expressed, "That's awesome…he was visiting and he got that scholarship part. That's good." During session two a participant Spirit was concerned that her daughter might have chicken pox. Esther and the participant Spirit are good friends. Esther shows genuine concern as she listens to Spirit talk and she acknowledges that chicken pox is going around.

Community emerged in relation to empowerment through social connections. Esther recognizes the importance of key stakeholders in the community and the value of connecting with them. She states in regards to the International AIDS Conference, "Oh that is so big. I always wanted to go…there where the big perform." Esther further expressed how her community women's group leader would embrace the photovoice project and may want to adopt photovoice. Esther mentions, " She is going to try to add her two cents in…now they may want to decide to do the Voice."

Intimate relationships are vital part of Esther's support system. Intimate relationship is the establishment of romantic relationship with a significant other. In Esther's photovoice selection, "My Husband" (Figure 7), she mentions the importance of him in her life:

What I see is my husband. What is really happening is he is posing for a pic for my photovoice project. This relate to our lives because he is an important part of my support system. If he wasn't there supporting me. I would only have my family. This situation is a strength for me because he has never left my side throughout our trials + tribulations. Even when I took his chose from him he still decided to stay with me. Without many resources I wouldn't have this strong support system. As young mature adults can be blessed by this + continue to do right things.

Intimate relationships provide strength during trials and tribulations. Dedication in relationships is valued. "He has never left her side." In spite that she may not fully disclosed her status to him prior to becoming intimate. She states, Even when I took his chose from him he still decided to stay with me." Loyalty and dedication in relationships are valued. Others can learn the meaning of love by seeing how much her husband loves her.

The need for political support.

Esther expressed concern about lack of funding for support group initiatives. She believes her story might help policymakers understand why funding is necessary for these programs. The following excerpt is from "Retreat May" (Figure 8):

> My concern is that funding will be cut + that WAS the last teen retreat for us. This image can educate policymakers + the community because if others from the community look at this pic they will see us having fun drama free. Policymakers should know we need these retreats to keep us smiling + stress free, for the moment.

Esther needs opportunities to interact with her peers. Recognition of her needs by public officials in control is important. Policymakers and the community can recognize the need to support programs that promote peer engagement for emerging adults with PHIV. These programs provide a way for emerging adults with PHIV to de-stress and relax. Funding is needed to foster therapeutic peer relations.

Funding also surfaced as a way to cover expenses for photovoice event. Esther agreed with suggestions to create cards to sell at AIDS walk and other events to sponsor possible photovoice event that was discussed in session five. Esther also inquired about cost to patent the group name "A Positive View, A Positive Mindset, A Positive Voice". She stated, "I like that, I really like that, and I am feeling that. How much it cost to patent, like $5,000? We need to because that is a hard quote, that is a hard thing right there. Security also surfaced in relation to the patent discussion. Esther notes, "I don't want nobody else to steal it. We will not call it a title, but as long as we did that."

Lastly, the development of voice and advocacy also emerged with the need for political support. Esther led the discussion in session five on ways to strategize to contact policymakers and development of key messages. She suggests, " We can do that. We can do that by our own different district, I am talking like Linda Cone: I am talking whomever she may know, like…our own argument and our legislatures in our communities, she lives west." Furthermore, Esther helped her peers determine appropriate policymakers for their districts and methods to deliver the invites. She shared, "What's your community called? Englewood, and you live in whatever, and I live out in Dalton, and what is it called? East whatever you want to call it…That's why I skipped over you, but I didn't know what it's called, your neighborhood or whatever. Get your

legislature or whatever. South Shore legislature involved. Right mail and e-mail."

Through previous experience, Esther identified a strong advocate in state legislature to provide support. Esther volunteered to contact the legislature. Esther shared, "I'm not sure if …but we went to Springfield not too long ago and we went to speak to some of the legislatives down there. There was this one legislature and she was very passionate…so I might try to get her, maybe go to Linda Cone and see if she can get her involved."

Esther is excited to voice her concerns through innovative means and "name" their voice. She shared, "Behind the camera, right. A Positive View, A Positive Mindset, A Positive Voice behind the camera. That is nice. We are going with that. This is hot."

Living life to the fullest.

Emerging adults with PHIV hold a positive perspective, outlook, and message to convey and want to live life to the fullest. Living life to the fullest emerged in Esther's photovoice selections, session transcripts, and field notes as celebrating every moment, cherishing the beauty and choosing career.

Celebrating every moment is an appreciation of time. Esther acknowledges that life is precious and emerging adults with PHIV are trying to move forward and progress. She states, "Our life is on this line and that's what we're trying to move forward to. We're trying to progress to them, to let them know all the time of doing this trying to being past or whatever." Progression is a symbol of success. She's resilient and able to make progress regardless of living with PHIV. Others can learn resilience through her lived experience. In her photovoice selection "Retreat May 5th" (see Figure 10) she states, "This situation is a strength that I am to continue to move forward + progress in life. This

can educate others that thought because of the past history with (HIV) I wouldn't survive that I lived 23 years (my life) with it + continuing on my road to success."

Esther's photovoice selection "Retreat Last Day" (Figure 9) celebrates and cherishes the memories she has with peers living with HIV who are no longer living. She reflects the following:

What really happening is that all of candles were (memorial) made by us teens for all of those who were with us once upon a time + has gone on to the next life. This relates to us because even though the person is not in presence with us we still think + have them in our heart everyday. This situation strengths because it just lets me know even though they may be gone we will always love + never 4get them. This image can educate the community + policymakers because we just don't let past be gone we keep it new + rebirth. We can keep ea. Other healthy + communicate more often.

Esther is grateful to celebrate and experience life. The photovoice selection "Retreat May 5th" (Figure 10) reveals her gratitude to celebrate life. She celebrates her life "birthday" versus imposed "death date". She states, "This picture relates to my life because I spent my 23rd b-day with many including myself that was given a death date. It makes me happy + blessed to have this experience."

Cherishing beauty is observed in Esther's everyday lived experiences. Esther's "Moon Rising" (Figure 6) represents a new unique experience to cherish. She notes, "Not many people including me have had the chance to see a moon rise." There is natural beauty in everyday life. This is powerful because it influenced Esther to look at something that she always seen differently. She shares, "It made me realize how much nature has so much beauty to offer everyday living."

Esther shared an encounter she had with an older man she didn't know. She regrets that she did not ask the man permission to take his picture. He reminded her of her mom (aunt) who is 63 years of age yet he appeared young for his age. She was intrigued with his look and the cloths that he wore. She believes that he would of allowed her to take his picture and that he would make an interesting story.

Lastly, choosing a career is an expression of living life to the fullest. Esther desires to become a pediatrician someday though she is not enrolled in school. She states, "My ambition is to become a pediatrician. So I got to work on that, I haven't started yet, but in another two or three years I'll be there." Esther's thoughts toward what she wants to do in the future acknowledges her wish to fully participate in cultivating an abundant life.

Refusal to be defined by HIV.

Stigma emerged as a sub-theme. Esther shared that she had no control over being born with HIV. Esther express, "One of the things is, I say that, just to give everybody something to think about, that we had nothing to do with the era of time. I was being born, we had to deal with the era of our time, so we are suffering from that era of time. We are suffering from that era of time". Esther notes that females may get labeled more than the males who are also HIV. She notes that the time, which they were born, is important but another area of importance is the topic of men living with PHIV. She shares, "This message is behaviorally or through, but like I said the era of time is very important because, I want to say it is very important because men it is men. Not only is it us, the five of us in here, it is men and women and it is two times men than it is women living with it, not living with it, but was born with it."

Sexuality also emerged as a sub-theme of refusal to be defined by HIV. Esther makes a distinction during a session regarding women who are ready to engage in sexual activity. She also briefly mentions some women just know their bodies. The topic of sexuality is approached without limitations. HIV is not a factor during the discussion. Esther shared, “Some girls do it. Some girls don’t. Some girls just be ready, just ready.” There was no discussion what this statement meant to Esther. She shared this comment with her peers while engaging in writing her photovoice narratives.

Hope.

Spirituality is a sub-theme of hope. Hope is the belief that desires and dreams can be achieved in spite of living with PHIV. Hope is facilitated through spiritual values and beliefs. Throughout session five the group’s dialogue about creating an event to display photovoice selections to key policymakers and stakeholder generated a lot of excitement and big ideas. Optimistic about the future of the project, Esther suggests to her peers to pray. She stated, “This is going to happen. We are going to happen. We are going to pray about it.” Prayer is seen as an effective tool.

Finally, hope surfaced as self-preservation. During session one Esther participates in a practice writing exercise about a down tree that is surrounded by clovers and covered in mold. She notes that even though the tree is down and covered in moss it is surrounded by 3 leaf clovers that is symbolic of good luck. She states, “Even though the tree is down I think the leaves symbolize hope and that the tree will continue to live.” Resilience to persevere in spite of what is going on in your internal and external environment is symbolic of hope.

Participant Profile: Spirit

Spirit is a soft-spoken, mature 24-year old African American female. She is a mother of a 1½-year old daughter. I had an opportunity to meet Spirit's daughter at session one. Spirit was running late for our initial meeting. She called and informed me that her daughter would accompany her. Spirit's boyfriend, daughter's father, was to meet her at the center and pick to pick up their daughter. I told her no worries and to take her time. Upon her arrival to the meeting she apologized profusely and again I reassured her that it was alright. Spirit's boyfriend arrived approximately five minutes after her arrival. I was impressed with Spirit and her boyfriend's maturity as they exchanged information and dealt with their daughter. Spirit kissed her daughter good-bye as she left with her father.

During session one Spirit disclosed that she lives in an apartment with her daughter in the south suburbs of Chicago. She's in a relationship with her daughter's father. Both Spirit's daughter and daughter's father are HIV negative. Spirit and her daughter's father dated for 2½ years. Initially, she did not disclose her status to her daughter's father when they started their relationship. She was scared of what he would think. Several months into their relationship she decided to disclose her status to him. Spirit expressed the need to inform him because their physical intimacy was increasing. Eventually, she disclosed her HIV positive status to him. Spirit was relieved that he expressed that he loved her in spite of her HIV status.

Spirit has a high school general equivalency diploma (G.E.D.). Eventually, she aspires to become a chef and plans to attend culinary program at City Colleges of

Chicago. Spirit is unemployed and is receiving governmental assistance. She is active in various local HIV support groups in Chicago.

Living life to the fullest.

Spirit describes living life to the fullest as cherishing the beauty in self and celebrating past, present, and future experiences. Cherishing the beauty is the ability to see beauty in self throughout every day lived experiences. Spirit's photovoice selection, "My Star Side" (Figure 13) affirms her confidence in who she is and proud of her natural beauty. She's proud of her resilience in face of life's pain and sorrow. Her inner beauty is her strength to smile whenever she is down regardless of the situation she encounters. The following is an excerpt from "My Star Side":

Me on the 4th of July. Me!!! I want to share this photo because I was able to spend the 4th with my daughter. Also because it shows my star side no make no ear rings and my pure beauty. Real story is how I can smile whenever im down no matter the situation. Looking into my eyes in it says that I have pain and unhappiness at times but yet I smile. The sparkle says to me that I have a little bomb waiting to explode sometimes. But I am going to hold it and live life any way.

Positivity is her approach to navigating daily life struggles. Her smile masks the pain. Perseverance gives her the ability to push forward through difficult times. Her eyes are the window to her emotions of pain and sorrow yet her smile exhibits strength and resilience. She's able to suppress "the bomb within" in spite of life's pain and sorrow. She desires to live life.

Every moment of life is special whether it is a moment of joy or of growing through pain. Spirit describes celebrating past childhood experiences and how these

events evoke feelings of deep meaning for present and future experiences. “I’m Almost There” (Figure 14) reflects how Spirit’s past parallels with her present.

This photo is a picture that have the 55 Garfield train stop on it. A House in the background. I want to share this photo because it says a lot about me. What’s the real story this tells That’s it’s a train stop but has deep meaning to me. This photo relate to my life. being that Garfield was the very first stop on the train I went alone. I remember Garfield meant we where almost there. Even though she’s Gone Now I still feel that happiness when I see Garfield. How Im almost There I always wanted a family in I have that and wont to continue my education In Im in the process of that so my life is moving like a train and im Almost there at the Stop I want.

The neighborhood and train reflects Spirit’s life. It evokes feelings of “deep meaning”. Spirit has memories of navigating the train alone and happy thoughts of traveling to her grandmother’s house. The sign symbolizes that her destination is almost complete and goals are almost met. Spirit has dreamed of having a family and now she has a daughter and a boyfriend. She wants to complete her education and she is in the process of establishing herself in culinary school. Her life is moving forward quickly and she’s almost at the destination she envisioned.

Living life to the fullest also consists of choosing a career. Choosing a career is the acknowledgement that life is not over. It reflects Spirit desire to move forward and imagine the possibilities of the future. Spirit aspires to become a chef. She shared, “I love cooking and think this would be a great way for me to make a living.” “My ambition is to become a chef or a type of cook. Maybe even like a caterer”.

Refusal to be defined by HIV.

Stigma emerged as a sub-theme of refusal to be defined by HIV. Stigma is an attachment of a negative label imposed by society in regards to living with HIV. During session two a picture of the moon's reflection captured in a puddle of water embedded in a sidewalk, shaped as a heart, led to a discussion about how stories can present in layers. Spirit state, " Oh, that's the heart. It's the heart. I was thinking you were talking about the other. I was going off of your moon. Oh I get it, the moon. Okay. Yes, that's nice. Like telling two stories in one." Similar to living with PHIV, the virus is only one part of the emerging adult life but it does not define the totality of his or her life. Spirit's photovoice selection, "my City Stand together" (Figure 11) shows how imperfections may be present but do not define the individual. She states:

My photo has building of downtown in it. It shows the Willis tower. River center in others. I want to share this photo because it Shows how beautiful our city is. To me the real story says that even though Chicago has flaws it can still be beautiful, strong, In Stand together. This realates to my by showing that having HIV is Just a small detail The strength is what comes out of it like how I wont to educate others or just tell those who are goin through this that its not over. How the buildings stands together in are tall and strong I wont to be like that able to work together to show to the world that HIV is not being taken litely.

Spirit shows pride in the beauty, strength, and togetherness of Chicago in spite of the city's imperfections. She acknowledges that she's strong regardless of having HIV. HIV does not define Spirit. Educating others will strengthen societal understanding and

encourage those who are living with HIV. Spirit desires to symbolize strength, togetherness while living with HIV.

Stigma also emerged in Spirit's photovoice selection "The Elephant Face" (Figure 15). Spirit sees an image of an elephant among the white clouds, blue skies, and green trees. The elephant looks a "little crazy" or "screaming" in the clouds. The image of the elephant among the trees is not perfect and reminds her that imperfections can make an individual unique. The trees in the photo represent HIV. The presence of HIV does not define the individual but it is a detail that exists. The detail in Spirit's life brings forth beauty and strength. She states, "The trees represent my statics it says no matter what may be inside the photo that you can hardly see it's a strong detail it kinda brings out the beauty the strength."

The need for political support.

Spirit expressed advocacy as the ability to voice for her daughter's need and having the resources available to assist her in advocacy. Spirit's photovoice selection "Brown Eyes" (Figure 12) shares what her daughter means to her. Despite of living with HIV she is able to raise her daughter. Her daughter inspires her and reminds her that life is not over. Spirit's daughter is a reflection of her and they are happy together. Spirit states, "I want to share this photo because it shows how much m daughter means to me it mean to her in that being positive does not mean my life is over. It really tells how happy we both are to spend time together & how much we look alike our eyes can tells Stories just by look into them."

During session two, Spirit was appropriately concerned about her daughter's health. She articulated, "I'm taking my daughter to the doctor. A little rash, MmHmm.

Yes, she had the fever. She had a little rash that pooped up after the fever went away…her voice is kind of hoarse…I did take her to Roseland…I'm thinking chicken pox not that early." Spirit sought medical care for her daughter and appropriately questioned if her daughter had chicken pox.

Advocacy (voice) was presented in session five as necessary means to educate policy makers about the lived experience of emerging adults with PHIV. Spirit and her peers want to challenge legislatures to understand the importance of listening to their voice. Spirit states, "the fact that we're even trying to challenge legislatures…". Funding also emerged in the conversation as an opportunity to generate revenue to cover expenses for photovoice events. Spirit knows how to create postcards and notecards from photographs. She stated, "Yes. I do postcards. We can generate that by October 1st. I could see that on a card."

Finally, transportation was identified as a need. Spirit expressed the Chicago Public transit is unreliable. There are long wait times and lack of communication about delays. She causes her to be late for appointments and unnecessary delays. She expressed the need to secure reliable transportation. She shared, "The CTA is a mess. I need to get a car ASAP…we had to get off the train, then we had to reroute another train. Yes, that's what we said. We're sorry. We aint't going to be on time. Ugly out there."

Empowerment through social connections.

Spirit values quality family time and her daughter motivates her to persevere through life. During session three a picture of a famous African American family was presented and participants were asked to write about the picture. Spirit shared, "Sort of like their conservative look, and the fact their relationship or their family is sort of public,

so instead of like their family bond or whatever being sacred and within the family, it is like shown to the world. It relates to my life because the only thing I can think about is that it represents family bonding, but mine is not so public. I value spending time with my family." Community also emerged through empowerment through social connections. The community consists of influential people who are not family, peers living with HIV, or intimate partners. During session five, Spirit identified the facilitator of the University of Chicago young women's HIV support group who could offer support with photovoice event.

Participant Profile: David

David is an articulate, out-going 19-year old African American male, who lives in the western suburbs of Chicago. Prior to session one I had an opportunity to talk with David by phone. I was initially impressed with his level of maturity that he displayed throughout occur conversation. In person he's just as charming. He has what the young people call "swag", which is urban terminology for a cool disposition. He stood up as I approached the table and had purchased an extra tea at Starbucks. I said, "That wasn't necessary, but was a very nice gesture."

I shared an overview of my background as a nurse, various community involvements with young people living with HIV, and research interest. When I mentioned that I had worked at Children's Memorial Hospital he stated, "I know that place very well." "I receive care their and I'm sure I will transfer from there soon."

David lives with his mother, two brothers, and cousin in a three-bedroom home. He has a car and works part-time as a caddy at a suburban country club. David has been accepted to attend a state university starting the fall of 2012. He is excited about

attending college and seeks to major in business. After college, David desires to go to law school and eventually become a full time advocate for underserved communities. Recently, he received a scholarship to attend the International Worlds AIDS Conference in Washington D.C. As a peer educator, he is frequently asked to speak locally and nationally about living with HIV. He mentioned that he has to go to Omaha, Nebraska for an event. He shared that he is connected to a great mentor that has supported him in the past year to apply for various opportunities. He stated, "I keep my bags packed and ready to go." "It's a good thing that I live close to the airport."

Empowerment through social connections.

Family emerged as a sub-theme for empowerment through social connections. An intact family equates strength and each member brings a unique dynamic that compliments each other. Family suggests strong community and the possibility for change. During session three David and his peers were asked to describe what they saw in a photo of a famous African-American family. David shared, "I also said that husband and wife, and their child, strength is in family because there is a strong family, strong community, change is possible."

At the forefront of change in a family is the woman. David sees the woman as the backbone and nurturer. Women exude beauty as they endure life challenges. They are influential and are able to bring forth change in their communities. David's photovoice selection "Flower = Beauty" (see Figure 19) demonstrates how he envisions women as change agents in the community. David shares:

It is good to identify beauty when its noticed. When beauty is seen it hard to compare it. A woman is flawless just like a pedal. This image is important to me because when I see a flower I see a woman. I think of all of the support I have received and love I was given by a woman. Women have the power the alter the very fabric of our culture. If government official rallied women on their side, they could have a ocean wave of support. The voice of a woman is vatal to the success of our up bringing and very lives. The women nurtiors to child and teaches it. If a women was given the right tools to eduacate the child, it would be so much more successful in life.

David believes women possess the power to influence cultural change and public officials need to engage women in initiatives to enhance communal support. Women have a powerful voice are you vital to the success of young people. Equipped with the right tools, women can successfully educate youth and the community.

The community is another identified sub-theme of empowerment through social connections. The community is viewed as society as a whole. David envisions community as communal places that are memorable and important especially when conveying messages. The “Barbershop” (Figure 18) photo selection piece conjures thoughts of past events, emotions, and people. The barbershop is a staple in the African–American community and is known as a place to exchange ideas and messages. David shares:

I look at the swirling colors and I'm remembered of my old barbershop, I was really little and I remember using a booster seat and crying every time the clippers touched my head. The barbershop was always packed with so many people. A barbershop would be a good place to reach a different audience and a large population. If a speaker came into a barbershop a lot of motivation and inspiration can be sparked amongst the listening ears.

The barbershop is an inviting place to motivate and inspire others. There is an opportunity to educate in places like barbershops. Educating others in these places is what is helpful to reach the community.

David also views the community as support system for an emerging adult with PHIV. The community can provide mentorship and guidance. Furthermore the community can support emerging adults with PHIV in focusing and establishing daily goals and priorities. The photovoice selection "Hours of Operation" (Figure 17) explores how the community can cultivate support for an emerging adult with PHIV. David reflects:

The picture replicate's my lifestyle. Everyday I work and I'm focused thinking of the next project. My schedule is similar to this picture. I don't sleep at night. We as a community can make sure they are focused and accomplished the goal and set out to do within the 24hrs were given. As a society we are in constant movement. We hope to achieve to much in the time we are given but life is and time is not guaranteed. If the individuals in power actually took advantage of the time given, so much more can be accomplished. There are many distractions that make it difficult for people to stay on track. Programs should be created to help focus people and guide them to success.

David envisions that people in power such as policymakers can develop programs to foster support for emerging adults living with PHIV. He recognizes that often those in powerful positions waste the precious time and resources that are at their disposal. Powerful people need to use their time wisely to impact societal changes and enhance social connections.

The need for political support.

Security is the sub-theme that emerged from the need for political support. As expressed in "Hours of Operation" emerging adults with PHIV need support with establishing daily routines that will assist them to stay on track and avoid distractions. Mentorship provides a sense of security for David as he navigates through the emerging adult years. David has a great mentor who offers encouragement and support. David reflects upon a time when he did not have mentorship support in "I'm Lost" (Figure 20).

There was a point in my life where I didn't know where my next step would led me. I was confused, I was lost. That moment of my life was filled with many hardships and cloudy days. I took this picture because of the word lost and then I recognized something else that connected to me which was NOTICE. During the time in my life that I felt lost, I wanted someone to notice me.

Another way security is understood is having a safe environment to grow and develop without threat of loss. David recognizes his life as valuable and worthy of protection. Society has not been effective in protecting the valuable lives of young African-American males. Public officials are not doing enough to prevent young African-American males lives from being stolen prematurely. Community support systems are needed to provide assistance to prevent poor societal outcomes in the African-American community. African-American communities need access to the innovation and changes that occur in mainstream society. "I'm Lost" (Figure 20) depicts the feelings of David's experience.

> Elected officials showed step away from their desk and from behind their computers and try to influence the individuals I was once liked. There is so much crime because someone is lost. There is so much violence because someone is lost. A person needs to take notice and take action to make the world we live better.

The photovoice selection, "Locked Bike" (Figure 16), also reflects the aforementioned.

I see a bike locked to a post. The bike is a means of transportation. The vehicle with two wheels, handle bars, and a seat. I see years of history and a transformation from training wheels to a mountain bike. The bike being locked to the post is security and the reality of wrong doing. The bike symbolize the mobility of our culture and of innovation we have created. This society is in constant movement. We have to live in a world where it's possible that something will be stolen. The fact is that the things that are valued must be protected. Elected officials are not protecting its people. I am not saying lock everyone up but, have something in place to avoid them from being taken. If a support system was created where everyone can have a helping hand or just someone to speak to much more can be prevented.

Living life to the fullest.

Choosing a career emerged as a sub-theme for living life to the fullest. David's acceptance and scholarship to a 4–year state university has fostered his desire to major in business. He wishes to one day go into business for himself and somehow mix advocacy with his profession.

Participant Profile: Boaz

Boaz is a reserved 23-year old African-American male who lives in the Englewood community. He is soft-spoken. Boaz is approximately 5"11 and somewhat slender build. He's dark complexion and wears the traditional "hip-hop" gear sagging pants and big shirt, baseball cap. Boaz found out about the study through Hannah and called me for additional details. He shared that he was surprised that someone would want to hear his story. He shared that he's never been in a project like this and looked forward to "doing this".

He lives at home with his mother. Boaz dates but is not in a relationship at this time. Boaz attends a local college and plans to graduate in 2013. He did not disclose his major. He also works part-time during the summer and school breaks at a food depository. He recognizes the need for more positive males in his community. Boaz hopes to be a positive influence to youth in his community.

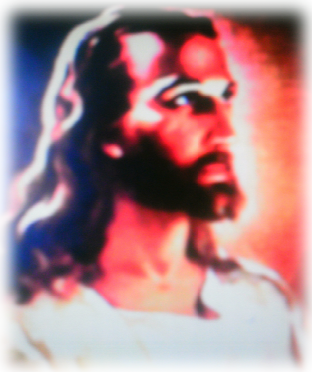
Hope.

Hope can be attained through higher education and training. Education is valued as an avenue to reach abundant living. Boaz is an advocate for education in his community and sees it as a means to avoid the streets. Some young people lose their rights to education because of wrong doing in the streets. However, Boaz is focused and determined not to lose himself to the streets. The photovoice selection, "The Dimploma" (Figure 23) reflects his pride in avoiding the "streets" and to pursue education.

This is a picture of my high school dimploma. I did something with life. And made something of myself. I was a young man, who made it through school. I'm happy for myself. Most kids don't get to see school because they doing something stupid in the street. That this is a man with his head on rite. He' not out here doing dumb shit. He's going to work or having fun with his family and friends, he went to school, like a young was surpose to do with his life. everybody should stay in school, because life is hard out here, because if you drope out, nobody is not going to deal with you at all. So I'm telling my neighborhood stay in school in become for self.

Hope is facilitated through spiritual values and beliefs. Faith sustains an individual when they face various challenges living with PHIV. Boaz believes in the teachings of Christianity, and reverences Jesus Christ, and God's Word. He believes that

all things are existence because of God however nothing can survive apart from God or it dies. “Our Savior” (Figure 22) reflects his beliefs. Boaz shares:



This is a picture of Jesus Christ. I want everybody to know that this man gave his life for us, in we can’t do rite at all. God saw all that He had made, and behold, it was very good…All things come into being through Him, and apart from Him nothing came into being that has come into being. I can just say people can Learn from Jesus. because we need him in our lives.

The need for political support.

Advocacy is the ability to voice concerns to the community. The opportunity to share their story helps the emerging adult with PHIV develop voice. Mentors are vital to provide direction and help uncover hidden passions and talents. Throughout the photovoice workshop Boaz was appreciative about having the opportunity to participate in this study. He stated, “I look forward to sharing my story and taking pictures.” “Thanks for this opportunity.” The photovoice selection “53rd Street” (Figure 21) demonstrate the importance of mentorship and how mentors can inspire others to dream the impossible. If you can dream it, then you can do it. Boaz shares how a man, through his paintings, has made his mark in the community. The man’s painting is an inspiration. Boaz is inspired to make his mark in his community. Inspiration is what drives him to be better. Boaz suggests:

Reproductions of truck paintings, underneath the Metra train tracks in Hyde Park, Chicago. Because it gives Kids something to do. With there time when they are not in school, because we don't want our kids in these streets doing dumb stuff, They need something to do with there time. That people can put there minds to something they love to do. It brings out the inter people. He save's lives with this picture. this is a man with a mind to do this. This picture say if I think of something I can do it. This picture is all over Chicago. It makes me want to put my work around Chicago.

Living life to the fullest.

Choosing a career emerged as a sub-theme. Selecting and planning future career paths acknowledge that life is not over. As described in his photovoice selection "Dimploma" Boaz values education and has established plans for the future through accomplishments in education. He's currently attending a four- year university in Chicago.

Participant Profile: Sarah

Sarah is a vibrant, outgoing 20-year old, who lives in the South Shore Community of Chicago. Upon meeting Sarah for session one I noticed her bright smile and warm disposition. Sarah said she heard so much about the study from "the girls" who enrolled that she also wanted to participate. I shared with her my story and how I decided to engage in this project to learn about emerging adults with PHIV experiences.

Sarah shared her journey of obtaining her first apartment by herself. She started having issues with the landlord after only living in the apartment for one month. Her place needs repairs. She stated, "the place was filthy, nasty when I moved in I had to clean it real good and I can't ever really get the tub clean." She mentioned how she would

call the repairman who lives in the building and he was slow to perform any work. Furthermore she expressed, “He’s always trying to hit on me.” He sort of scares me when he’s around.” Sarah has shared her living situation with her case manager and in spite of her issue she loves living on her own.

Sarah has a boyfriend but did not discuss their relationship. Sarah has a high school diploma and has completed some college course work. She hopes to attend cosmetology school when she can obtain some financial assistance. She mentioned that she messed up her opportunity to attend school this fall. Sarah desires to be a cosmetologist and even open a daycare and own her businesses.

Living life to the fullest.

Living life to the fullest was articulated as valuing every past, present, and future moment and event in life despite living with PHIV. Sarah participates in a discussion about chicken pox during with peers. Sarah remembers having chicken pox as a child and recalls the marks that were left from the illness. She further recalls the treatment used to heal the scars. She shared, “I used calamine once. I had 13, mom I remember said I had 13 chicken pox. That was me.” Sarah also celebrated the fact that she knows her body and that she knows what’s happening with her body. She acknowledged, “I can remember my body right That’s good though….as a woman, we need to be all the time. We’ve got in our bodies.” Sarah also celebrates participation in the photovoice workshop. Photovoice provided a new way to look at things. Sarah shared that the photovoice event should be held in an art gallery. She stated, “I think the gallery it’s more comfortable setting than if we were just display on a power point at a conference.”

Cherishing the beauty in everyday experiences also emerged. Beauty is found in unique situations and can be found daily experiences if you search for it. The photovoice selection "Heart" (Figure 26) reflects beauty in unique situations.

Wen I first took this picture I thought it was beautiful and unique and it stood out to me because it's showing a puddle of water turned into a heart and the moon inside of it. I want to share this photo because eit stood out because it's beautiful wiyh passion and it could bring you joy depending on how you look at it. What's relally happen is I feel as tho the heart is talking to me and trying to tell me something and the moon is there to back up to confirm thats its real!! Some may say this relate other not so much but in all I think it relates because its giving people a sign of happens wisdom and so on

Sarah also notes that beauty can be a vehicle for confirmation. Confirmation is reassuring and it provides hope for happiness and wisdom.

Choosing a career surfaced from living life to the fullest. Sarah has plans to become a cosmetologist and eventually own a daycare as well. Sarah acknowledged that she messed up her opportunity to attend school this fall but looks forward to resume school next year.

Empowerment through social connections.

Family, intimate relationships, engaging with peers living with HIV, and community emerged from Sarah's data. An intact family is equivalent to strength and each family member compliments the family unit. Sarah and her peers were asked to write about a famous African American family depicted in a photo. Sarah articulated that the family gives hope regarding marriage, She stated, "This makes you think like they

can do it…wait; if they can do it, you can do it." The father's love for his daughter and wife also resonated with Sarah.

Collaboration on project fosters innovation and cohesiveness with peers living with HIV. Sarah values the ability to connect with peers living with PHIV. Connection with peers strengthens and validates her abilities and foster creativity. Sarah provided various insights during session five regarding ways to display photovoice selections. She suggests, "This could be a set, like we could show that moon this one and the one where it was setting, like they could be a group together. This could be a separate like the moon in my heart or name it something else."

Community provides familiarity, a sense of belonging, and connection. Individuals with positive outlook encourage Sarah to be positive. Sarah appreciates genuine people who are consistent. Sarah shared a photo, which was not submitted with her photovoice selection, during session four about a young boy that makes her smile.

> "My title is smiling, because he's smiling. In this picture I'm holding my little man because he wanted to be in my lap. I believe he was singing the Diego song, and of course I was too. He looks really happy. This relates to me because every time I am around him my face lights up and so does his. When he sings and does little crazy things, it's cute and funny. If he was around people he didn't know, he would be the same and he would put smiles on everybody's face because of what he does."

The need for political support.

The need for political support illuminates in various forms. Sarah is excited about the opportunity to voice her concerns through innovative means and name her voice.

Sarah embodies the group name “Positive View, Positive Mindset, a Positive Voice”. The name emerged out of session five discussion regarding next steps. Sarah expressed that he phrase will provide further insight into the voice of emerging adults living with PHIV. She suggest, “I think that would give people something actually to come in and se what happening with those sayings.”

Sarah wants to seek clarity in everyday situations. She hopes to voice her position in everyday situations but doesn’t know how to start. The photovoice selection “Polish” (Figure 24) illuminates this perspective.

Pink heart thats dripping. I want to share this picture because when I seen it on my friend floor I was like what but then when I took a closer look at it I seen that I could be dripping tears happiness or anything. To me tha real story is that its fingernail polish and its trying to tell a story but don’t quite know how to start it off. I think this will relate to sum ppl becuz different ppl will get a different view on how it look to them but in a way they will still realte to them.

Furthermore, Sarah needs a sense of security and reassurance that she can access and receive assistance as needed. Responsiveness to health concerns is important to her and peers living with PHIV. Photovoice selection “Help” (Figure 25) is a photo of a medical helicopter transporting a child to the hospital. Sarah shares, “This can relate to so many ways because we might need this help or someone we know may need the help so you never know what will happen.” Funding is also a concern for Sarah and she provides input on ways to fund photovoice event during session five.

Hope.

Sarah views hope through education. Education is seen as an opportunity to advance one's life. Sarah is determined to enroll in school in 2013 in spite of mistake that prevented her from attending this fall. She did not apply in time for financial assistance. She shares, "Seeing as how I can't go to school this year, I have to wait all the way to next summer, that's my fault but I'll get over it. When next year comes, I'll get in school, and I'll do what I got to do."

Summary of Thematic Analysis Addressing the Research Question

This section will present the summary of data analysis across participants that addressed the research question "As an emerging adult what is your everyday experience of living with PHIV?" Five themes emerged from the analysis of the photovoice selections and narratives created by the participants, digital recordings, and researcher's field notes during the Photovoice Workshop. The themes are (1) Refusal to be Defined by HIV, (2) Living Life to the Fullest, (3) Empowerment through Social Connections, (4) The Need for Political Support, and (5) Hope.

Refusal to be defined by HIV.

Living with a chronic illness can be burdensome. Knowing the potentials and the realities of living with chronic illness can be especially daunting for an emerging adult with PHIV. As an emerging adult with PHIV establishes their identity in work, love, and education, they are reminded of the presence of living with HIV. One participant described HIV as "a little bomb waiting to explode".

The emerging adults in this study expressed that HIV does not define them. Regardless of the illness within them, the participants are able to persevere and foster

their identities in life. Participants symbolize strength while living with PHIV. Strength comes from the determination to get through everyday life and the refusal to be defined by HIV.

Stigma also emerged in refusal to being defined by HIV. Stigma was seen as an unfair label imposed by society in defining individuals as "good or bad" or "right or wrong". The participants refuse to be labeled in regards to living with HIV.

The emerging adults, in this study, refuse to be defined by HIV. Instead, they seek to overcome the boundaries and labels that society imposes and excel in all aspects of their lives. The participants also seek to educate others on how to overcome adversities and not be defined by a situation.

Living life to the fullest.

Emerging adults with PHIV, in this study, desire to live life to the fullest. They are learning to cherish every moment in the present, past, and future. Life is not taken for granted. Celebrations such as birthdays and graduations are significant milestones for the participants' in this study. Living an abundant life includes work, education, and having fun with family and peers living with HIV.

Participants are living their dreams and having fun. Life is something they respect and cherish. Aging is something to honor and progression is a symbol of success. The participants are resilient and able to make progress and embrace life regardless of living with PHIV.

The emerging adults in this study expressed the ability to see beauty in life experiences. Beauty is depicted in nature, people, events, and themselves. There is

natural beauty in everyday life. Beauty is simplistic and noted in unique situations. Comparisons of nature and people are made in regards to beauty.

People tend to ignore the natural beauty in everyday life; however, the participants' value these experiences. Individuals should be educated to enjoy the natural beauty in everyday life events and the importance of cherishing these experiences. Individuality emerged as beautiful. The ability to express confidence and uniqueness regardless of your situation is beautiful.

Empowerment through social connections.

The emerging adults, in this study, articulated empowerment through social connections as intimate relationships, relationships with peers living with HIV, and community. Social connections are vital in the lives of the participants. Social connections play a vital role in the participants' support system.

Loyalty and dedication in relationships are valued. Intimate relationships provide strength during "trials and tribulations". Emerging adults, in this study, treasure connecting with peers living with HIV. Strong bonds with peers living with HIV are important to escape the "drama" of life. There is a special acceptance and understanding when the participants connect with peers living with HIV. Opportunities to interact with peers living with HIV help relieve the stress experienced in participants' daily lives. Peer relationships help emerging adults with PHIV develop the ability to be accountable for each other. Communities provide a sense of belonging, connection, and support. Familiar communities evoke thoughts of past events, emotions, and people.

The need for political support.

The need for political support emerged in the participants' photovoice narratives as assistance with advocacy (voice), fostering security, funding, and transportation. The emerging adults in this study desire clarity in everyday situations. The participants are learning how to voice their position in everyday situations. Mentorship is also valued and is seen as a way to prevent confusion, provide direction, and reassurance. Mentors help others dream the impossible. Unclear direction leads to moments of hardships and uncertainty. Life distractions can make it difficult for emerging adults with PHIV "to stay on track". Participants suggest in their narratives that people of authority, policymakers, in the public sector can create programs and allocate funding to help guide emerging adults with PHIV to success.

The need for reliable public transportation is a concern. Public transportation was seen as unreliable. Unreliable transportation was a stressor and made it difficult for participant to know if she could arrive to commitments on time.

Fostering security is also vital to the emerging adults in this study. Security is based on feeling safe within the community. Several of the participants live in communities with high crime rates. Assurance of assistance is needed. The responsiveness of public officials in relation to maintaining a secure environment and reacting to health needs is of concern.

Hope.

The participants envision hope through education, family, beliefs, and self-preservation. Emerging adults, with PHIV embrace hope in the face of difficulty. Hope is also projected as desire to love and be loved. A participant shared, "I deserve to have

someone/a love in my life." The ability to have a family evokes hope for some of the female participants. Another participant captured a picture of herself and her daughter. Her daughter encourages her to continue the journey. Family bonds and happiness are to be cherished. The participant's daughter is a reflection of her and they're happy to be together. Lastly, hope is exhibited in the participants' beliefs. Spiritual beliefs in religion and religious practices propel hope in the lives of emerging adults with PHIV.

Chapter 5 - Discussion

The purpose of this study was to gain understanding of the everyday experience of living with PHIV as emerging adults. This study revealed new insights about the everyday experience of emerging adults living with PHIV. The major contribution of this study is that it presents an alternative and more positive view of emerging adults living with PHIV than the prevailing perception held by many health care providers. There are five themes and sixteen sub-themes that emerged from the data.

In this chapter the author will address the results in relation to the categories in the emerging adulthood framework (see Appendix K) and the literature reviewed in chapter 2 of emerging adults living with PHIV. Furthermore, advocacy will be discussed in conjunction with the group's desire to educate others through their photovoice selections. Finally, limitations of the study, gaps in the science, implications for future research, and implications for practice will be explored.

Study Findings in Relation to Emerging Adulthood Theory

The experiences of emerging adults living with PHIV were explored in which five well-defined themes emerged: refusal to be defined by HIV, living life to the fullest, empowerment through social connections, the need for support, and hope. Aspects of these themes coincided with pre-understandings of emerging adults living with PHIV.

Identity explorations in emerging adults with PHIV.

Throughout the age of identity explorations emerging adults explore various possibilities for their lives in love, work, and education (Arnett, 2006). Emerging adults pursue independence and begin to separate from parents or guardians. Furthermore, they begin to form a worldview about religious beliefs and values.

Throughout the age of identity explorations emerging adults cultivate spiritual identity. Spirituality has been investigated in relation to sexual attitudes and beliefs in emerging adults (James, et al., 2011; Lefkowitz, et al., 2004). Lefkowitz, et al., 2004 recognize that most studies conducted with emerging adults consist of a convenience sample of Caucasian, college students, which restricts researchers from understanding various aspects among minority individuals. Additionally, there are no inquiries that have solely explored spirituality in emerging adults with PHIV.

Spirituality also surfaced as a sub-theme of hope. There was a participant who valued prayer and another participant valued his faith in Jesus. There was no discussion regarding the influence of spirituality in relation to sexual attitudes and beliefs. Furthermore, no discussions or narratives explored religious practices and beliefs influences when choosing work, education paths and establishing social connections.

The emerging adults in this study refuse to be defined by HIV. The participants are fully aware of the strong presence of HIV in their life yet refuse to allow the virus to cultivate their identity. Sexuality emerged as a sub-theme of refusal to be defined by HIV. Several of the females in the study shared satisfaction in knowing their bodies. Additionally, there were expressions of sexual activity that emerged during discussions. Tassiopoulos, et al., 2012 reported that adolescents with PHIV (13-18 years of age) not living with biological parent have higher probability of participating in unprotected sex. Furthermore, only 33% of the adolescents with PHIV disclose their HIV status to their initial sexual partner. This finding reflects a participant in this study who had unprotected sex with her boyfriend and as a result became pregnant. The participant notes that her daughter and boyfriend are HIV negative. She shared that was challenged with disclosing

her HIV seropositive status with her boyfriend. Lastly there was no discussion regarding condom negotiation. Emerging adults with PHIV are challenged with condom negotiation and disclosure of status to sexual partner (Fernet, et al., 2011; Marhefka, et al., 2011).

During the age of identity explorations, emerging adults with PHIV are challenged with disclosure of their HIV status to sexual partners and the public due to fear of rejection and stigma. The findings of this study showed emerging adults with PHIV are hesitant to disclose their seropositive HIV status to their intimate partners. This finding reflects Koenig, et al. (2010) study that revealed 79.3% of participants with PHIV did not disclose their status to their sexual partners. Disclosure appears to happen closer to sexual intimacy or after sexual intimacy has occurred. Two female participants discussed disclosure of status to their boyfriends. One participant may have disclosed her status after sexual intimacy and another participant stated that she informed her boyfriend of her status as they neared sexual intimacy. The risk of disclosure to sexual partner leads to fear of rejection and loss of "love" (Fernet, et al. 2011).

Disclosure surfaced as the time when participant was informed of their HIV positive status by a parent or guardian. The average ages of disclosure in the literature to the child by the parent/guardian is seven to twelve years old (Butler, et al, 2008; Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006; Lester, et al., 2002; Santamaria, et al., 2011; Sopena, et al. 2010). One participant discussed learning about her HIV positive status at 9 years of age. She remembers not being stigmatized or treated differently by her family. The remaining participants did not discuss the age their status was disclosed to them by a parent or guardian.

The age of instability.

During the age of instability emerging adults experience frequent residential changes related to attending college or foster independence. Additionally they experience changes in love relationships, work, and educational endeavors. Emerging adults may experience stress and anxiety throughout this period.

Children and adolescents with PHIV frequently struggle with depression and attention deficits (Chernoff, et al., 2009; Gadow, et al., 2010; Mellins, Brackis-Cott, Dolezal, & Abrams, 2006). One participant shared his experience of feeling lost and confused, not knowing what path to follow several years ago. During this period, he lived with depression and expressed that having a mentor could of alleviated the confusion. Emerging adults are susceptible to stress and anxiety during this age (Tanner, et al., 2009). The discussion of battling long–term mental health issues did not manifest in the current study.

There have been limited inquiries regarding empowerment through social connections in emerging adults with PHIV (Abramovitz, 2009; et al., Di Risio, et al., 2011). The presence of social connections for adolescents and emerging adults with PHIV provides better outcomes of adherence to attend clinic appointments (Abramovitz, et al., 2009). The ability to connect with peers living with PHIV strengthens the participants' ability to cope with daily life experiences. In this study, emerging adults with PHIV shared experiences of establishing social connections with peers living with HIV and intimate relationships. There was no discussion by participants about forming friendships with people whose HIV status is unknown.

Lastly, the participants desire assistance in cultivating their voice (advocacy) as they foster independence. Furthermore, the participants sought a sense of security in their environment and reassurance that they could access and receive assistance as needed. In this study, the emerging adults with PHIV expressed that support can be found through policymakers and other influential people in society. Policymakers and influential people have access to funds that can support programs and initiatives for emerging adults living with PHIV.

The self-focused age.

The self-focused age represents the least structured and the least obligations for emerging adults. Emerging adults are free to make decisions without consulting others (Arnett, 2006). They seek to attain the goal of self-sufficiency and can structure daily activities freely due to not being constrained by social roles.

Access to health care emerged as a sense of security in knowing that assistance is available, if needed. Emerging adults with PHIV are challenged with barriers to transition which include: the need for a multidisciplinary team (provider, social work, and pharmacy) in the community, inadequate health insurance, and limited finances to cover out of pocket cost, and knowledge deficit related to HIV disease and treatment (Weiner, et al., 2007). All the participants in this study had access to ongoing care. Discussion regarding health did not emerge in relation to transition to adult health care. One participant mentioned that he still receives care at a pediatric center and realize that he will transition soon. However, he did not discuss how he plans to make decisions about his health or select adult services.

The age of feeling in-between.

Emerging adults do not feel they reached adulthood. Feelings of attaining adulthood are not based on transition events such as marriage or completing education (Arnett, 2006). Emerging adults perceive accepting responsibility for self, independent decision-making, and financial independence to being an adult. Becoming an adult is perceived as a gradual process.

In this study, the emerging adults with PHIV disclosed aspects of how they perceive responsibility emerged. One participant perceived the ability to care for her daughter and advocate for daughter's health needs as being responsible. Another participant is navigating through landlord issues by voicing her concerns and seeking assistance through a case manager. A third participant took responsibility for mistakes that led to her missing the opportunity to apply for training this year but has a plan for applying next year. Although taking responsibility was reflected in most narratives with the exception of the parent in the sample, most were examples of early emerging responsibility activities and not yet full responsibility for independent or financial independence.

The age of possibilities.

The age of possibilities is a period of optimism and hope. Emerging adults are free to transform their lives and liberate themselves (Arnett, 2006). The participants embodied hope and saw opportunities to achieve their dreams through education, intimate relationship, family, and beliefs. Through embracing life to the fullest, emerging adults with PHIV envisioned transformation in their lives as an honorable journey that is not to be taken for granted.

In conclusion, the study reinforces that individuals with PHIV desired to live life to the fullest and did not want to be defined by HIV. Emerging adults with PHIV sought to overcome the boundaries and labels that society imposed and exceled in all aspects of their lives. Furthermore, the study emphasize that emerging adults with PHIV engaged in sexual explorations. Spirituality emerged as a sub-theme to hope but was not discussed in relation to sexual behavior, attitudes, and behaviors. Empowerment through social connections reinforced that emerging adults with PHIV valued support from peers, family, romantic partner, and community. Disclosure of seropositive status emerged as age of disclosure by parent or guardian and disclosure to romantic partner. Disclosure of HIV seropositive status to a romantic partner supports was a challenge for emerging adults with PHIV. Furthermore, there was no discussion regarding condom negotiation.

Advocacy

Throughout session five, the participants expressed that the photovoice workshop was more than a study but was impactful and life changing. The emerging adults shared that they were glad that they had an opportunity to voice their lived experience. Participants stated that it helped them to captured their lives through photos and show what they valued in life. Furthermore, they learned about others through their stories, they learned to appreciate the beauty that they see in life, learned that everything within their life defines who they are and they want to make the best of their lives. Some of the participants expressed the following about what they like about the photovoice workshop:

> "I was always given the opportunity to express how I feel and to express what I thought. I like that we did group discussions and we got to collaborate our different perspectives."

"It has given me a better look of my life how I can look back at things that may not have much meaning to others, but means a lot to me."

"I liked that I got to do the photovoice sessions. Everyone was nice. I would do it again."

"Learning how to look at the photos in a better view and learning how to take photos."

"What I learned I can give more opinions in life as for photovoice and I would like to think the ladies for showing another side."

The photovoice workshop helped the participants "tell my side of the story."

"I like telling and talking to people about my life. It gives me and them a chance to know about HIV. And what it to do to people. I had HIV for 23 years now and I look good."

During session five, the group was asked, "would you like to share your voice and if so how would you want to share your voice?" And "if yes, who is your audience?" The group articulated that they want to share their voice and display their photovoice selections in an art gallery setting. The stakeholders were identified as policymakers and other community leaders. I was impressed how the emerging adults actively participated in sharing ideas and identifying next steps. The group titled the event, "Behind the Camera" and also identified a name for their work, "A Positive View, A Positive Mindset, A Positive Voice."

The target date for the event was World AIDS Day December 1, 2012. Several possible gallery locations were mentioned along with ideas on how to display the photovoice selections. As the conversation continued, the topic of funding the event

surfaced. Immediately, several members suggested creating notecards and postcards from their photovoice selections and selling their items at the Chicago AIDS walk and other AIDS events. There was a suggestion to contact the University of Chicago Infectious Disease to inquire about sponsorship. The female participants are active participants in a young woman's group sponsored by the medical center. They had an upcoming meeting and were planning to ask the leader if she would meet to discuss possible partnership.

The leader from the young women's HIV group contacted me and expressed excitement that her group was excited about the project. She stated that the HIV Directors Board at the University of Chicago would be interested in sponsoring the event. The photovoice presentation would coincide with women, young people and stigma event scheduled for March 2013. The event will occur in the new Reva and David Logan Art Center located on the University of Chicago campus. The participants have agreed to partner with the University of Chicago team to plan the event.

Study Limitations

The findings of this study are limited to emerging adults living with PHIV and who live in the Chicago area. The participants' experiences may not be generalizable; however, the purpose of this descriptive, exploratory research study is to understand the experiences of emerging adults living with PHIV and how they envision their transition to adulthood.

The emerging adults with PHIV in this study differ from what is known of individuals living with PHIV. The African-American emerging adults with PHIV do not represent the experiences that are in literature. All of the participants' have completed

high school or G.E.D. and three out of the six participants are actively engaged in college coursework. The three who are not school plan to return to vocational training or college within 1-2 years.

The participants in this study did not represent the age compliment of emerging adulthood. The participants age range between 19–24 years. Thus, the study provides insight into the lived experiences of younger emerging adults with PHIV and not of older emerging adults with PHIV. Most were "in process" and working on the early tasks of emerging adults.

Furthermore, the participants in this study have been active in various advocacy activities. Several of the emerging adults participated in local, state, and national HIV advocacy initiatives. The participants in this study may not reflect other peers with PHIV. Many peers with PHIV may not experience opportunities to engage in advocacy.

Medication adherence and resistance did not emerge in this study. The participants shared that they are connected to health care providers but did not discuss medication treatment if there were problems taking medication consistently or if there were resistance issues. The emerging adults in this study expressed living life to the fullest, but did not provide photos, narratives, or discussion regarding their medication treatment.

Many emerging adults with PHIV often have challenges with cognitive limitations especially learning disabilities. However, the participants in this study functioned at a high level. Thus the experiences of participants in this study may not reflect the experiences of others who have different characteristics. The participants did not express difficulty taking pictures, operating the camera or adhering to the instructions

given concerning what the photographs should depict. The researcher provided hands on demonstration and written instructions on camera use and repeatedly provide visual examples as well as verbal and written instructions related to the methodology SHOWED. The participants in this study were able to capture pictures describing their lives and name their pictures. However, the writing skills in the narratives did not match the education level of the participants. Misspelled words and grammar errors were frequent. The participants in this study used paper and pen when writing their narratives. In addition many have learned a "shorthand" communication through texting. These technology-based modes of communication are equipped with spell checks and other features that can enhance writing. The written narratives may be similar to others writing products in this technology era. The articulateness with which the subjects discussed their narratives, however, made it clear that cognition was not an issue limiting the expression of participants in the study.

Additionally, Strack, Magill, and McDonagh (2004) encouraged youth to capture pictures describing their lives and to envision who they are within a particular social context, noted that young people preferred to take pictures of friends and families instead of their community assets and strengths. This may be the case with this sample as they clearly valued peers and family. However, the theme "the need for political support" would suggest that these participants were aware of and valued community assets. Another possible limitation is the participants' ability to express thoughts in writing. Emerging adults might not want to disclose their personal feelings about their photographs in a group setting. Initially, splitting participants into small groups might facilitate robust discussions about photographs (Strack, et al., 2004). Hesitancy to express

personal feelings about sensitive subjects may be due to the relative number of the five sessions. Additional sessions might lead to comfort with sensitive issues. The combination of both written and discussion of the photovoice selections did support the participants' ability to articulate notions, priorities, and feelings. However, use of probes to guide the participants to discuss aspects not identified by their pictures might have yielded fuller data. Probes such as "What do you think about your experience would be important for others to know?" might have yielded data that participants did not capture with their pictures.

Implications for Future Research

Ongoing research endeavors are necessary to address the gaps in knowledge of emerging adults living with PHIV. The participants in this study did not address many specific gaps in the literature in Table 1 as their salient issues in living with PHIV. It is possible that to address those gaps, studies that specifically address these issues will need to be conducted.

Emerging adults with PHIV desire to live life to the fullest. However, life challenges and stressors are inevitable and could impede emerging adults with PHIV ability to fully engage in life. Studies that explore how emerging adults living with PHIV deal with stressors and make decisions about health, love, work, and education are needed. Researchers could study emerging adults with PHIV perceived stressors and behaviors that are exhibited when stressors are present. Furthermore, researchers could recognize interventions that may promote effective decision-making during stressful periods. Emerging adults with PHIV are high risk for long- term mental issues such as ADHD and depression. Studies are needed to understand the effects of long-term mental

health issues as individuals living with PHIV emerge into adulthood.

Emerging adults with PHIV refuse to be defined by HIV however the stress associated with stigma and disclosure of status to an intimate partner may cause anxiety and depression. In general, little is known how emerging adults with PHIV experience anxiety and depression during this period. Researchers can explore the effects of stigma in relation to mental health in emerging adults with PHIV. Additional studies can determine ways emerging adults with PHIV disclose their HIV seropositive status to romantic partners. Moreover, it is unclear how emerging adults with PHIV handle change in love relationships and how spiritual beliefs, practices, and behaviors influence sexual beliefs, attitudes, and behaviors. Researchers could explore how spiritual beliefs, practices, and behaviors effect sexual beliefs, attitudes, and behaviors in emerging adults with PHIV.

As emerging adults with PHIV transition from pediatric care, they may lack resources to access and pay for medical care. Emerging adults with PHIV, who received comprehensive care at a specialized pediatric center, may have difficulty navigating the complex systems associated with adult care. Studies can explore how these emerging adults seek to solidify and sustain self-sufficiency.

The emerging adulthood theory may not be an adequate framework for emerging adults with PHIV. Emerging adulthood has been predominately explored in Caucasian Americans and may not be applicable to an ethnic group such as African-Americans. Furthermore, the majority of studies that use emerging adulthood theory did not use with and emerging adult population who lives with chronic illness. Additional studies are needed to explore the appropriate fit of emerging adulthood in relation to various ethnic

populations and individuals living with chronic illness within industrialized countries. Lastly, this study did provide a useful overview of the emerging adult with PHIV, who was doing well as defined by living life to the fullest, refusal to be defined by HIV, and hope. Understanding others, who trajectory is not as positive, is also important and needs to be addressed.

Implications for Practice

Emerging adults engage in relationships and have a desire to be listened to, understood, and valued as they voice their daily lived experiences. Emerging adults with PHIV are the first generation to transition to adulthood. Social connections are highly valued by emerging adults with PHIV and the connections equip them to navigate through daily life experiences. Key community individuals such as health care providers and support group leaders are instrumental in the lives of emerging adults with PHIV.

The findings of this study have implications for practice involving nursing and other interdisciplinary health professionals who care for emerging adults with PHIV. Health care professionals should challenge their own negative attitudes about emerging adults with PHIV. As one participant notes she has suffered for something she had no control over for simply being born with HIV. Health care professionals should avoid biases and labels and create ways to understand aspects of emerging adults with PHIV. For example, a primary health care provider can provide a camera or ask the patient to use his or her phone to take photos of what is important for the provider to know about their health realities. Health providers can use this to develop therapeutic relationship, ongoing assessments, and provide the emerging adult with PHIV a voice in his or her care.

Furthermore, practice models need to be culturally sensitive. Emerging adults with PHIV are disproportionally African–American. It is important that practice models are not created in silos but include the perceived needs of emerging adults with PHIV. Practice models need to address the comprehensive needs of the emerging adult living with HIV. While the United States may be one of the primary countries where those with PHIV are emerging into adulthood, developing countries which look to industrialized nations for effective practice models are not far behind. For example, it is estimated that the increasing use of ARVs in Kenya may see an emergence of individuals with PHIV transitioning to adulthood in 10 years. Articulating effective practice initiatives will assist countries, such as Kenya, who will then be able to examine and adopt practice models from the United States and other industrialized nations.

Hope is associated with education, spirituality and self-preservation in emerging adults with PHIV. The participants in this study dispel the notion that emerging adults with PHIV lives are riddled with insurmountable challenges that produce negative outcomes. It is important for health care professionals to explore ways to engage those living with PHIV at a younger age and assist with cultivating desires for the future in education, work, and love. Health care professionals can co-create with the emerging adult with PHIV a self-management plan and be open to innovative solutions to self-management of medications and other aspects of daily health experiences. Nurses can assist with care coordination and facilitate community support systems that are not limited to physical care, but incorporate educational, mental and spiritual support.

Another major concern to address is sexuality and unprotected sex in emerging adults with PHIV. Emerging adults with PHIV desire to fully connect with all aspects of

life and do not want to be defined by PHIV. As emerging adults with PHIV begin to develop intimate relationships and engage in sexual activities they may not fully understand the implications they and their partners may face with unprotected sex. Health care professionals are key to providing education about sexual activities and ways to implement safe sex practice. Furthermore, health care professionals need to cultivate a safe environment, where emerging adults can freely explore topics in regards to their sexuality and sexual behaviors without feeling shame.

In attempt to better understand the uniqueness of emerging adults with PHIV, nurses and health professionals should be knowledgeable about emerging adults with PHIV concerns as they cultivate independence. By taking the time to listen, nurses and health professionals convey respect, concern, and understanding.

Implications for Community Action

Emerging adults with PHIV value opportunities to cultivate their voice. All the participants in this study expressed the need for political support. Health care professionals can identify opportunities to partner with emerging adults with PHIV on local or national advocacy initiatives. Health care professionals can be instrumental in the development of individuals with PHIV voice at an early age. The child or adolescent with PHIV can partner with a HIV advocate from clinical practice or community and learn how to identify and share their perceived health needs verbally and written. Furthermore, they can shadow HIV advocates and leaders to learn how to lobby and introduce health policy. Additionally, emerging adults with PHIV can become familiar with local and national policymakers that represent their district or who champion HIV initiatives.

Governmental processes can be reinforced through various interactions with policymakers.

Lastly, establishing a train-the–trainer program can teach older emerging adults living with PHIV to be mentors to younger emerging adults living with PHIV. The emerging adults with PHIV in this study are younger, mean age 21.3 years, and they expressed a need for mentoring. Peer mentorship can be valuable in providing younger emerging adults with PHIV ways to handle stressors, develop self-sufficiency, and navigate adult health care while reinforcing behaviors in older peer mentors.

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Figure 1. Moving Time

This photo is of a brick temple on the side of the road. Cars are driving pass and people are walking pass. The sky is beautiful and white + blue with nice clouds. This photo is a captured moment, but it looks as if the image is moving. The cars are moving, the clouds are floating, and people are walking. This is a caption of moving time. Even though the picture is frozen, the time is still moving and this picture is a representation of this. I feel like time waits for no one, so you must live life. Sometimes I ignore that time is ticking or don't even realize that I am getting older. This picture is a reminder that everything is moving including time, so I have to live my life.

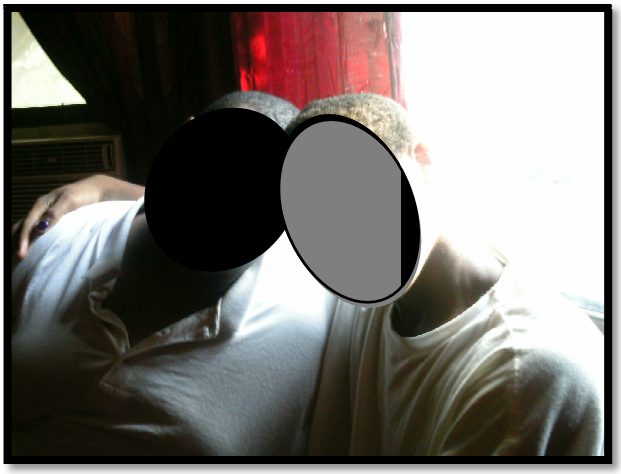
Figure 2. Self Love

There is a boy and a girl sitting on a beach at a park. The scenery is beautiful. There is a bridge and a pond right across from them. These two looks as if they are a couple spending time together. The lady is sitting enjoying the scene as if she is admiring it, yet her boyfriend has his arm around her and he is staring in a completely different direction. This shows that eventhough they are a couple, they are on differ pages. They don't have common interests. What appears to be a moment together, is a moment with thereselves. This relates to me because it makes a statement to me reguarding a loved one in my life. Because I feel that I deserve to have someone / a love in my life, I fail to appreciate/ recognize myself growth. Just as the girl is enjoying the moment on her on, it shows I don't have to lach on to a man.

Figure 3. Higher Ground

I see a boy with his back turned and is he is walking down the street wearing a bookbag and he has his hat in his hand. He is walking in an urban setting. He looks like he is headed to school. I feel like this picture makes a statement reguarding education. This picture reads determination for education. The urban setting shows that he lives in the hood/ an environment where education isn't completely valued. This is the setting where people learn from the streets. I also see a sign in the picture [cold] and that gives off a negative tone, and that represents his surroundings, yet he takes off his "cool" hat and continues to walk to school. I feel that growing up in the englewood area of Chicago dealing with my surrounding has always been a struggle for me. My environment weighed heavey on my mind, but I tried to separate who I am and what I want from life from my situation. Though I live in englewood, I am not englewood and that doesn't define my life.

Figure 4. Stamped

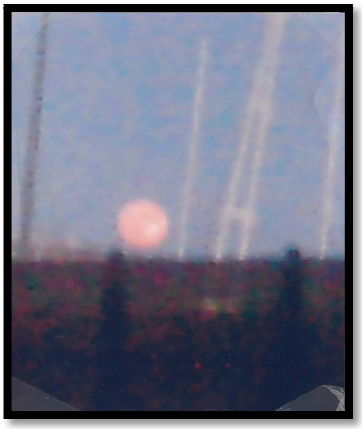


There are two mean posing with their hands/arms around each others neck and their heads are leaning on one another. Their faces are dark/shadow, yet I sense affection between the two men. This is a photo of a homosexual couple. The shadow in there face is symbolic of a shield from thoes around them. People/Society will never fully understand their relationship or the love they have for one another. Homosexuality is like a stamp that separates them from the rest. The story is society doesn't accept/understand the truth about someone because a stigma creates a meaning/definition on it's own. They can't just be a couple, yet they are forced to be a homosexual couple. This relates to me because society created a stigma for who I am. I stigma of being diagnosed with HIV takes away from who I am as a person. So, instead of me being Hannah, I am the girl with HIV. Who defines the norm of people?

Figure 5. Will Power

There is a young boy holding a sweat towel around his neck. He is wearing a bright pink shirt. He is starring as if he is tired because I see a slight slouch like he is a little weary. But I see a sense of ambition in from his eyes. As I anaylize this photo, I see that he is tired but I see hope in his eyes. The bright pink gives off hope. He is holding the towel tight, which shows strength. Lastly the light gleams in his background, like an angel watchs over him. The real story is that, although things may seem tough, you have to remain hopeful. This is a representation of that light at the end of the dark tunnel. This relates to me because will power will get you through any situation. My environment or situation may be bad, but I use my will power to control that situation and turn it into something positive.

Figure 6. Moon Rising



I see a moon rising from a horizon. What is really happening is the sun is setting + the moon is rising. The moon is rising from the bottom of the horizon. This relates to our lives because not many people including myself haven't had the chance to see a moon rise. This situation is strength to me because it made me realize how much nature has so much beauty to offer everyday living. This image can educate by exposing that moon uprising really takes place + how often it does happen. As people we can continue to study the uprising of the moon + times in specific.

Figure 7. <u>My Husband</u>

What I see is a my husband. What is really happening is he is posing for a pic for my photovoice project. This relate to our lives because he is an important part of my support system. If he wasn't there supporting me. I would only have my family. This situation is a strength for me because he has never left my side throughout our trials + tribulations. Even when I took his chose from him he still decided to stay with me through it all. This image can educate the many just showing how much this person loves + supports me. Without many resources I wouldn't have this strong support system. As young mature adults can be blessed by this + continue to do the right things.

Figure 8. <u>Retreat May</u>

What I see in this pic is everyone happy to be with ea. other + having fun enjoying our weekend together. I see everyone just to have had A ball together with no drama. What is really happening here is we are on our way back home to Chicago but we had fun together (drama free) weekend. This pic relate to our lives because no matter of lifes obstacles we learned to accept ea. other + have fun living life. This situation is a strength + concern. The strength is that no matta what we may go through, we are still a family at the end of the day. My concern is that funding will be cut + and that WAS the last teen retreat for us. This image can educate policymakers + the community because if others from the community look at this pic they will see us having fun drama free. Policymakers can see we need ea. other + have known ea. other awhile that our brand can't be broken. Policymakers should know we need these retreats to keep us smiling + stress free; for the moment.

Figure 9. Retreat Last Day

What really happening is that all of candles were (memorial) made by us teens for all of those who were with us once upon a time + has gone on to the next life. This relates to us because even though the person is not in presence with us we still think + have them in our heart everyday.This situation strengths because it just lets me know even though they may be gone we will always love + never 4get them. This image can educate the community + policymakers because we just don't let past be gone we keep it new + rebirth. We can keep ea. other healthy + communicate more often.

Figure 10. Retreat May 5th

What I see in this pic is me having fun at a expensive resturant I only dreamed of going. What I see in this pic is me having fun at a expensive resturant I only dreamed of going. What really happening here is we are all eating + before I ate I had to strike A pose for the camera. This relates to my life because I spent my 23 b-day with many including myself that was given a death date. It makes me happy + blessed to have had this experience. This situation is a strength that I am to continue to move forward + progress in life. This can educate others that thought because of the past history with (HIV) I wouldn't survive that I lived 23yrs (my life) with it + continuing on my road to success. And policymakers that are oppose to keep funding I as well as many others need this support from them policymakers.

Figure 11. <u>"my City Stand together"</u>

My photo has building of downtown in it. It shows the Willis tower. River center in others.
I want to share this photo because It Shows how beautiful our city is.
To me the real story says that even though Chicago has flaws it can still be beautiful, strong, In Stand together.
This relate to my by showing that having HIV is Just a small detail The strength is what comes out of it like how I wont to educate others or just tell those who are goin through this that its not over. How the buildings stands together in are tall and strong I wont to be like that able to work together to show to the world that HIV is not being taken litely.

Figure 12. <u>"Brown Eyes"</u>

My daughter & Myself sitting on my coach. I want to share this photo because It shows how much my daughter means to me it I mean to her in that being positive does not mean my life is over. It Really tells how happy we both are to spend time together & how much we look alike our eyes can tells Stories Just by look into them. This Photo Relate to me by showing how even being time a positive mother I am more happy then some . my joy comes out of her happiness in it shows on this photo.

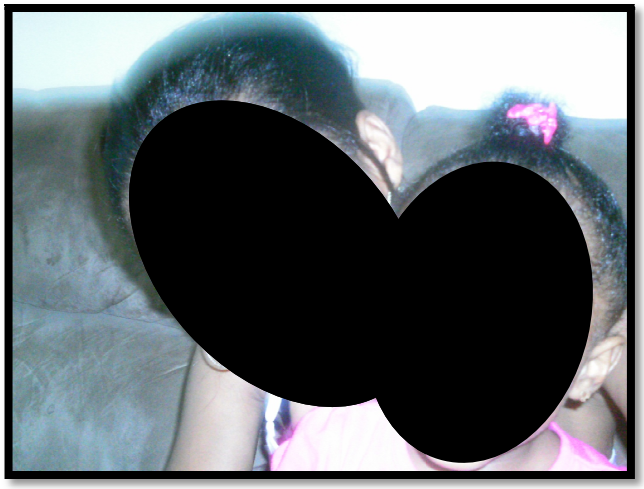


Figure 13. "My Star Side"

Me on the 4th of July. Me!!! I want to share this photo because I was able to spend the 4th with my daughter. Also because it shows my star side no make no ear rings and my pure beauty. Real story is how I can smile when ever im down no matter the situation. Looking into my eyes in it says that I have pain and unhappiness at times but yet I smile The sparkle says to me that I have a little bomb waiting to explode sometimes. But I am going to hold it and live life any way.

Figure 14. "I'm almost There"

The Photo is a picture that have the 55 Garfield train stop on it. A House in the background. I want to share this photo because It says a lot about me. What's the real story this tells That's it's a train stop but has a deep meaning to me. This Photo relate to my life. being that Garfield was the very first stop on the train I went alone. I remember going on the train in getting off going to my Grandmothers house a million times. I remember Garfield meant we where almost there. even though she's Gone Now I still feel that happiness when I see Garfield. How Im almost There I always wanted a family In I have that and I wont to continue my education In Im in the process of that so my life is moving like a train and Im Almost there at the Stop I want.

Figure 15. <u>"The elephants Face"</u>

White clouds, blue sky, Green Trees It looks as the clouds framed a Elephant & a face that looks a little crazy or screaming, I want to share this photo because It tell me how my life is it says that my life can have a couple flaws like the trees but it can make the picture special. What's the real story this tells That it's a clear sky no Gray no Rain Just Clear with the trees looking as though they are touching the heavens, This relate to me because as the clouds take different shapes I take different Journey living with HIV. The trees Represents my statics it says no matter what may be inside the photo that you can hardly see its a strong detail it kinda brings out the beauty the strength.

Figure 16. <u>Locked Bike:</u>

I see a bike locked to a post. The bike is a means of transportation. The vehicle with two wheels, handle bars, and a seat. I see years of history and a transformation from training wheels to a mountain bike. The bike being locked to the post is security and the reality of wrong doing. The bike symbolize the mobility of our culture and innovations we have created. This society is in constant movement. We have to live in a world where it's possible that something will be stolen. The fact is that the things that are valued must be protected. Elected officials are not protecting its people. I am not saying lock everyone up but, have something in place to avoid them from being taken. If a support system was created where everyone can have a helping hand or just someone to speak to some much more can be prevented.

Figure 17. Hours of operation:

The picture replicate's my life style. Every day I work and I'm focused thinking of the next project. My schedule is similar to this picture. I don't sleep at night. We as a community can make sure they are focused and accomplished the goal set out to do within the 24hrs were given As a society we are in constant movement. We hope to achieve so much in the time we are given but life is and time is not guaranteed. If the individuals in power actually took advantage of the time given, so much more can be accomplished. There are many distractions that make it difficult for people to stay on track. 8. Programs should be created to help focus people and guide them to success.

Figure 18. Barbershop:

We visit barbershops and salons constantly wanting to look a current way. Perfection can never be achieve even if we try and try again. I look at the swirling colors and I'm remembered of my old barbershop. I was really little and I remember using a booster seat and crying every time the clippers touched my head. The barbershop was always packed with so many people. A barbershop would be a good place to reach a different audience and a large population. If a speaker came into a barbershop a lot of motivation and inspiration can be sparked amongst the listening ears.

Figure 19. Flower = Beauty

It is good to identify beauty when its noticed. When beauty is seen it hard to compare it. A woman is flawless just like a pedal. This image is important to me because when I see a flower I see a woman. I think of all of the support I have received and love I was given by a woman. Women have the power the alter the very fabric of our culture. If government offical rallied women on their side, they would have a ocean wave of support. The voice of a woman is vatal to the success of our upbring and very lives. The women nurtiors to child and teachs it. If a women was given the right tools to eduacate the child, it would be so much more successful in life.

Figure 20. I'm lost

There was a point in my life where I didn't know where my next step would led me. I was confused, I was lost. That moment of my life was filled with many hardships and cloudy days. I took this picture because of the word lost and then I recognized something else that connected to me which was NOTICE. During the time in my life that I felt lost, I wanted someone to notice me. Elected officials showed step away from their desk and from behind their computers and try to influence the individuals I was once liked. There is so much crime because someone is lost. There is so much violence because someone is lost. A person need to take notice and take action to make the world we live in better.

Figure 21. 53rd Street

Reproductions of truck paintings, underneath the Metra train tracks in Hyde Park, Chicago. Because it gives Kids something to do. With there time when they are not in school, because we don't want our kids in these streets doing dumb stuff, They need something to do with there time. That people can put there minds to something they love to do. It bring s out the inter people. He save's lives with this picture. this is a man with a mind to do this. This picture say if I think of something I can do it. This picture is all over Chicago. It makes me want to put my work around Chicago.

Figure 22. Our Savior

This is a picture of Jesus Christ. I want everybody to know that this man gave his life for us, in we can't do rite at all. God saw all that He had made, and behold, it was very good. And the man and his wife were both naked and were not ashamed. In the beginning was the world, and the word was with god, and the Word was god. He was in the beginning with god. All things come into being through Him, and apart from his Him nothing came into being that has come into being. I can just say people can Learn from Jesus. because we need him in our lives.

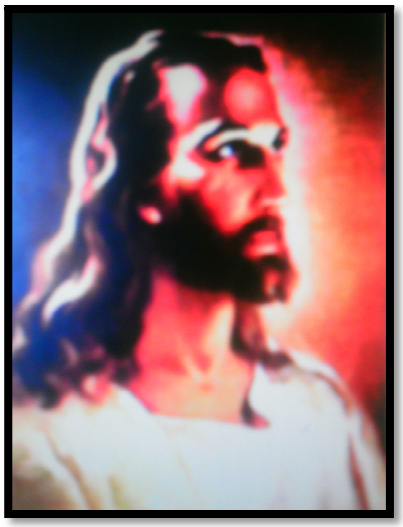


Figure 23. <u>The Dimploma</u>

This is a picture of my high school dimploma. I did something with life. And made something of myself. I was a young man, who made it through school. I'm happy for myself. Most kids don't get to see school because they doing something stupid in the street. That this is a man with his head on rite. He' not out here doing dumb shit. he's going to work or having fun with his family and freinds, he went to school, like a young was surpose to do with his life. everybody should stay in school, because life is hard out here, because if you drope out, nobody is not going to deal with you at all So I'm telling my neighborhood stay in school in become for self.

Figure 24. <u>Polish</u>

Pink heart thats dripping. I want to share this picture because when i seen it on my friend floor i was like what but then when i took a closer look at it i seen that i could be dripping tears happiness or anything. To me tha real story is that its fingernail polish and its trying to tell a story but don't quite know how to start it off. I think this will relate to sum ppl becuz different ppl will get a different view on how it look to them but in a way they will still relate to them.

Figure 25. Help

Theres a Helicopter and police truck in the middle of the grass they landed here to take a lil kid to the Hospital so he or she can get the help he/she needed. I want to share this because this shows how they help wen they really need to. The real story is they rushed a Kid to the Hospital so he or she can be looked at. This can relate to so many ways because we might need this help or someone we know may need the help so you never know what will happen.

Figure 26. Heart

Wen I first took the picture I thought it was beautiful and unique and it stood out to me because it's showing a puddle of water turned into a heart and the moon inside of it. I want to share this photo because It stood out because it's beautiful with passion and it could bring you joy depending on how you look at it. What's relally happen is I feel as tho the heart is talking to me and trying to tell me something and the moon is there to back up to confirm thats its real!! Some may say this relate other not so much but in all I think it relates because its giving people a sign of happens wisdom and so on

Table 1

Emerging Adulthood: Emerging Adults with PHIV

Arnett (2004, 2006) Emerging Adulthood (18 years – 29 years)	**Emerging Adulthood Definitions**	**Experiences of Emerging Adults with PHIV**	**Emerging Adults with PHIV (Gaps in Literature)**
The Age of Identity Explorations	Emerging adults explore different possibilities for their lives in love, work, education, and various areas. They become more independent of parents and guardians. They start to form a worldview about religious beliefs and values.	**Disclosure**: Emerging adults with PHIV are challenged with disclosure of their seropositive HIV status to sexual partners (romantic relationship), friends, and the public (work or school) due to fear of rejection and stigma. **Sexual Behaviors**: Emerging adults desire romantic relationships and are sexually active. They may have had several sexual partners. They hope to eventually procreate, but are fearful of HIV transmission to significant other and child. **Spirituality**: Religious practices and behaviors influence sexual attitudes and beliefs in emerging adults with PHIV.	Little is known how emerging adults with PHIV disclose their status as they explore love, occupational and education paths. Little is known about their religious practices and beliefs influence when exploring occupational, education paths and social networks.
The Age of Instability	Emerging adults experience frequent residential changes related to attending college or foster independence. They experience changes in love relationships, work, and educational endeavors. They may experience stress and anxiety throughout this period related to instability.	**Disclosure**: Emerging adults with PHIV are challenged with disclosure of their seropositive HIV status to sexual partners (romantic relationship), friends, and the public (work or school) due to fear of rejection and stigma. **Social Support**: Social network consist of immediate family (parent/guardian and/or close friends). They may experience hardship within social environments due to death of parent and social isolation related to illness. **Sexual Behaviors**: Emerging adults may have several sexual partners and intimate relationships are often temporary. **Mental Health**: Emerging adults with PHIV are high risk for mental illness due to HIV related illnesses and/or societal issues.	How do emerging adults with PHIV choose to disclose their HIV positive status while immersed in a period of frequent change? What is not known is how emerging adults with PHIV deal with changes in love relationships, work, and educational endeavors. How do they experience stress and anxiety during this period? It is not known how long-term mental health issues impact emerging adults ability to cultivate social networks, job and education trajectories, and intimate relationships.

The Age of Self-Focused	Self-focused age represents the least structured and the least obligations for emerging adults. They are free to make decisions without consulting others. They seek to attain the goal of self-sufficiency. Emerging adults can structure daily activities freely due to not being constrained by social roles.	**Transition to Adult Care**: Barriers transitioning to adult care include disorganized social environments and difficulty letting go of pediatric providers. **Sexual Behaviors**: Emerging adults desire romantic relationships and are sexually active. They are free to engage in various sexual relations that may be risky.	As emerging adults with PHIV transition to adult care, how do they make decisions about their health and selecting services? How do they make decisions about love (sexual relationships), work, and education? How do they seek to attain self-sufficiency?
The Age of Feeling In-Between	Emerging adults do not feel they reached adulthood. Feeling of attaining adulthood is not based on transition events (marriage, completing education, etc.). They perceive accepting responsibility for self, independent decision making, and financial independence equates to being an adult. They perceive becoming an adult is a gradual process.	**Transition to Adult Care**: Emerging adults with PHIV may struggle with advocating for self as they transition from pediatric to adult health care. They may be challenged with independent decision making regarding their health.	What is not known is how emerging adults with PHIV perceive accepting responsibility for their health, foster independent decision making, and financial independence.
The Age of Possibilities	Period of optimism and fulfillment of hopes and dreams. Emerging adults are free to transform their lives and liberate themselves.	**Sexual Behaviors and Social Support:** Emerging adults are free to cultivate new relationships and social supports to further pursue their hopes and dreams.	What is not known are the hopes and dreams of emerging adults with PHIV or how they envision transformation in their lives?

Note. Adapted from "Emerging Adulthood: Understanding the New Way of Coming of Age," by J. Arnett, 2006, p. 319 and "Emerging Adulthood: The Winding Road from the Late Teens through the Twenties," by J. Arnett, 2004.

Table 2

Emerging Adults with PHIV Demographics

	Hannah	**Esther**	**Spirit**	**David**	**Boaz**	**Sarah**
Age	19	24	23	19	23	20
Gender	Female	Female	Female	Male	Male	Female
Race/ Ethnicity	African American	African American	African American	African American	African American	African American
Education	Some College	High School	High School/GED	Some College	Some College	Some College
Yearly Income	Less than $5,000	Less than $5,000	Less than $5,000	Less than $5,000	Less than $5,000	Less than $5,000
Housing	Lives with Parents	Lives with Guardian	Lives on Her Own	Lives with Parents	Lives with Parent	Lives on Her Own

Note. Participant Descriptive Data

Table 3

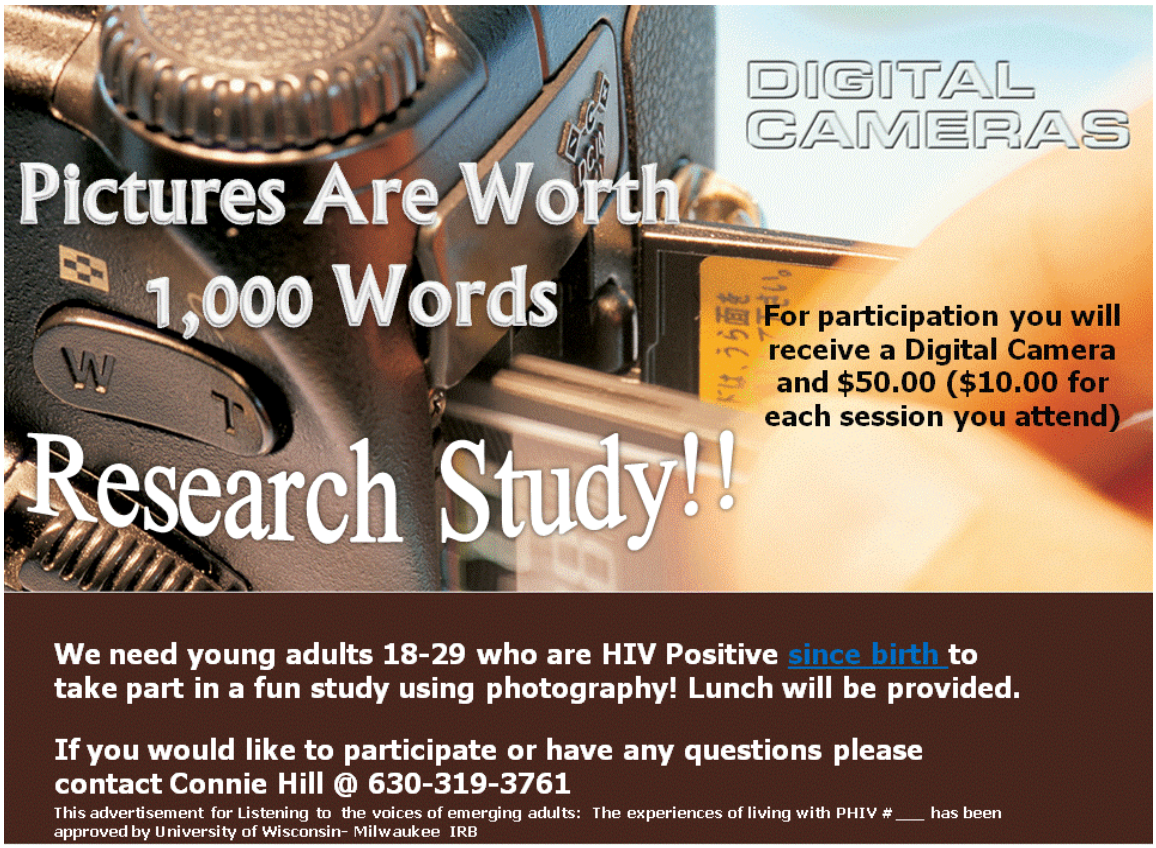
Emerging Adults with PHIV Themes and Sub-Themes

THEMES	THEME DEFINITION	SUB-THEMES	SUB-THEME DEFINITION
Refusal to be Defined by HIV	The rejection of being solely described as a person with HIV.	**Stigma**	The attachment of a negative label imposed by society in regards to living with HIV.
		Sexuality	HIV does not hinder sexual exploration.
Living Life to the Fullest	Valuing every past, present, and future moment and event in life despite living with PHIV.	**Celebrating Every Moment**	Every moment of life is special whether it is a moment of joy or of growing through pain.
		Cherishing the Beauty	The ability to see the beauty in people, nature, situations, and self throughout everyday lived experiences.
		Choosing Careers	The acknowledgement that life is not over by selecting future career paths.

Empowerment through Social Connections	Emerging adults with PHIV gain power through communal engagement others.	**Engaging with Peers Living with HIV**	Emerging adult living with PHIV interacts with others living with PHIV.
		Intimate Relationships	Establishment of romantic relationship with a significant other.
		Family	Defined by emerging adults with PHIV as mother, father, grandmother, aunt, and their biological children.
		Community	Defined as key individuals who are not peers, family, or romantic partner. Also defined as society as a whole.
The Need for Political Support	Identified need for assistance in ways to achieve funding, promote advocacy/voice, and feel secure.	**Funding**	Defined as finances to support programs and events.
		Advocacy/Voice	The ability to voice concerns to appropriate policymakers and the community.
		Security	Ability to access help when needed. Also fostering a secure environment.
		Transportation	Means of securing reliable travel.

Hope	The belief that desired and dreams can be achieved despite living with PHIV.	**Education**	Hope can be attained through higher education and training.
		Spiritual Beliefs	Hope is facilitated through spiritual values and beliefs.
		Self-Preservation	The innate ability to keep oneself from harm.

Appendix A


DIGITAL CAMERAS
Pictures Are Worth 1,000 Words
Research Study!!
For participation you will receive a Digital Camera and $50.00 ($10.00 for each session you attend)
We need young adults 18-29 who are HIV Positive since birth to take part in a fun study using photography! Lunch will be provided.
If you would like to participate or have any questions please contact Connie Hill @ 630-319-3761
This advertisement for Listening to the voices of emerging adults: The experiences of living with PHIV # ___ has been approved by University of Wisconsin- Milwaukee IRB

Appendix B

Dear Potential Participant:

Have you ever heard that a picture is worth a 1,000 words? Pictures are powerful! I would like to invite you to participate in a study that will allow you to tell your story through pictures! The purpose of this study is to understand the everyday experience of 18-29 year olds who have HIV since birth. **There will be up to 15 participants in this study**. If you agree to participate, you will be asked to participate in 5 group sessions. **During the first session you will be asked questions to determine eligibility to participate in the study. You will also be asked to consent to participate in the study, discuss camera use and photo instruction.** You will be asked to use a camera to take pictures, take part in writing stories about pictures, and share pictures and story experiences during the sessions. Each session will last no longer than 2 hours**. The total of all 5 group sessions will take approximately 10 hours of your time. The approximate time for taking photos may be 1 ½ to 2 additional hours. All 5 sessions will be audio recorded.** At the end of the study you will be able to keep the camera, receive a photo book of your pictures, and $50.00 ($10.00/per session attended).

Please contact Connie Hill @ 630-319-3761 to sign up or to find out more about the study.

Thanks for your consideration.

This advertisement for Listening to the voices of emerging adults: The experience of living with PHIV #13.010 has been approved by University of Wisconsin- Milwaukee IRB

Appendix C

Informed Consent
UW - Milwaukee

IRB Protocol Number: 13.010

IRB Approval date:

University of Wisconsin – Milwaukee
Consent to Participate in Research

Study Title: Listening to the Voices of Emerging Adults: The Experience of Living with PHIV

Person Responsible for Research: Constance D. Hill MSN, RN (PhD Candidate College of Nursing) and Kathleen Sawin, PhD, CPNP-PC, FAAN

Study Description: The purpose of this research study is to understand the everyday experience of 18-29 year olds who have HIV since birth. There will be up to 15 people taking part in this study. If you agree, you will be asked to take part in 5 group sessions. You will be asked to use a camera to take pictures, take part in writing stories about pictures, and share pictures and story experiences during the sessions. Each session will last no longer than 2 hours. This will take about 10 hours of your time.

Risks/Benefits: Risks that you may experience from taking part are "considered minimal". Certain discussions may make you feel sad or embarrassed. You do not have to respond if you feel uncomfortable. There will be no cost to take part in this study. Benefits of taking part include being able to share your experiences within your community and decide how to educate others about your experiences. Your experiences will further research and help others understand your daily life.

Confidentiality: Your information collected for this study is completely confidential and no individual person will ever be identified with his/her research information. Photographs and stories from this study will be saved on password encrypted protected computer for 6 months. Only the primary researcher and research assistant will have access to the information. However, Dr. Kathleen Sawin, Dr. Patricia Stevens, Dr. Virginia Stoffel, the Institutional Review Board at UW-Milwaukee or appropriate federal agencies like the Office for Human Research Protections may review this study's records.

Voluntary Participation: Taking part in this study is voluntary. You may choose not to take part in this study, or if you decide to take part, you can change your mind later and withdraw from the study. You can choose to not answer any questions or quit the study at any time. Your chose will not change any present or future relationships with the University of Wisconsin Milwaukee.

Who do I contact for questions about the study: For more information about the study or study procedures, contact Constance Hill at hill8@uwm.edu or 630-319-3761.

Who do I contact for questions about my rights or complaints towards my treatment as a research subject? Contact the UWM IRB at 414-229-3173 or irbinfo@uwm.edu.

Research Subject's Consent to Participate in Research:
To voluntarily agree to take part in this study, you must be 18 years of age or older. By signing the consent form, you are giving your consent to voluntarily take part in this research project.

_____
Printed Name of Subject/Legally Authorized Representative

_____ _____
Signature of Subject/Legally Authorized Representative Date

Appendix D

University of Wisconsin - Milwaukee | **IRB# 13.010**

Photo Release Form
Using Photovoice to Explore the Experiences of Young People Emerging into Adulthood

I give permission for public display of my photograph and narrative titled:

_____

I took this photo and wrote this story as a participant in the emerging adult Photovoice study conducted by Constance Hill MSN, RN. I understand that this photo and story may be included in a research report and then professional publications and other exhibits at local, state, national or international health care, public, or professional conferences. The purpose of will be to share findings from the study to inform professionals and other appropriate individuals. I understand that photos and stories will be displayed anonymously (your name will not be mentioned) or a different name will be used.

_____ Include this photo and story in the research report and then professional publications without my name listed as the photographer and writer.

_____ Include this photo and story in the research report and then professional publications as taken by a photographer and writer with a (pseudo) different name.

_____ Include this photo and story in any exhibit/presentation without my name listed as the photographer and writer.

_____ Include this photo and story in any exhibit/presentation as taken by a photographer and writer with a (pseudo) different name.

I understand at any time before the printing of the research report I may choose to withdraw my consent for this photo and story to be included. I understand I may withdraw my permission for this photo to be included in exhibits at local, state, national or international health care, public, or professional conferences. I understand that I am being given a copy of this consent form for my own records.

_____ _____

Photographer/Writer Signature Date

Reprinted with the permission of Virginia Stoffel PhD, University of Wisconsin- Milwaukee

Appendix E

STUDY ID NUMBER 13.010

Demographic Information Questionnaire

1. What is your age? _____

2. What is your gender (please circle one)? Male or Female

3. What is your race (please circle one)?
   Non-Hispanic (White)
   Non- Hispanic (African American)
   Hispanic
   Asian or Pacific Islander
   American Indian or Alaskan American
   Mixed or Multiracial

4. What is your highest education level (please circle one)?
   Elementary
   Middle School
   High School
   Some College
   College Graduate

5. What is your yearly income (please circle one)?
   Less than $5,000
   $5,000 - $10,000
   $10,000 - $15,000
   $15,000 - $20,000
   Greater than $20,000

Appendix F

SESSIONS OVERVIEW

SESSION I

- What is Photovoice? (10 minutes)
- The Power of Pictures (10 minutes)
- Photography Training (10 minutes)
- Photography Picture Activity (15 minutes)
- Session Break (10 minutes)
- Introduction to Forms (10 minutes)
- Writing Exercise (20 minutes)

SESSION II

- Review "What is Photovoice?" (5 minutes)
- Share a Photograph and Discuss Photography Experience (15 minutes)
- Discuss Writing Exercise from Session 1 (10 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Writing Exercise Using SHOWED (20 minutes)
- Discuss Photovoice Question(s) for Session 3 (15 minutes)
- Review Forms (5 minutes)

SESSION III

- Review "What is Photovoice?" (5 minutes)
- Review "What is SHOWED?" (5 minutes)
- Share and Discuss Two (2) Photographs in Response to Question(s) (20 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Select Five (5) Photos and Write Brief Descriptions for Each Photo (40 minutes)

SESSION IV

- Review "What is Photovoice?" (5 minutes)
- Review "What is SHOWED?" (5 minutes)
- Share and Discuss Two (2) Photographs in Response to Question(s) (20 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Select Five (5) Photos and Write Brief Descriptions for Each Photo (40 minutes)

SESSION V

- Complete Writing Exercise (40 minutes)
- Session Break (10 minutes)
- Discussion About Ways to Inform and Educate the Community (40 minutes)

SESSION I

Agenda

- Group Introduction (5 minutes)
- What is Photovoice? (10 minutes)
- The Power of Pictures (10 minutes)
- Photography Training (20 minutes)
- Photography Picture Activity (20 minutes)
- Session Break (10 minutes)
- Introduction to Forms (15 minutes)
- Writing Exercise (30 minutes)

SESSION I

Practice Question

Congratulations! You have completed the first session of training for Photovoice. The following is a practice question to help you with understanding the steps of Photovoice.

The practice question is:

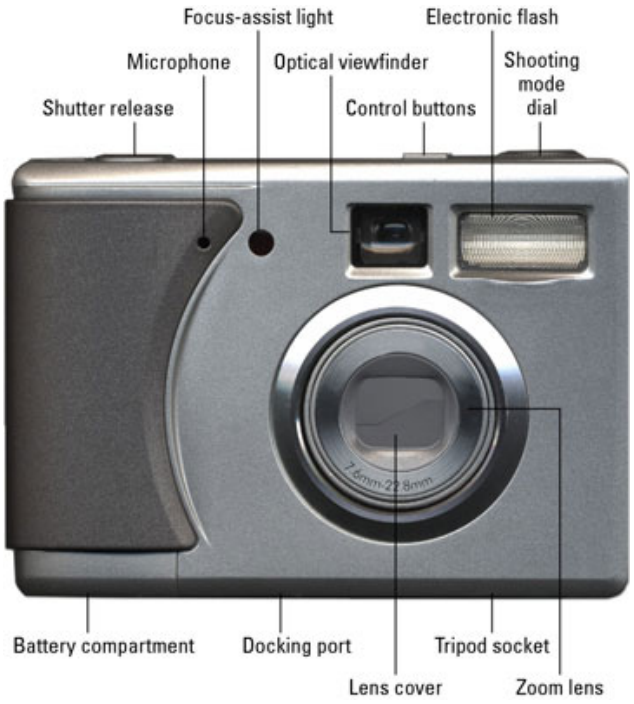
ıtes to your

Please review the information in your folder to assist with taking pictures and make sure that you bring your camera to Session 2.

TAKING PICTURES

We want you to take good pictures of objects, people and places that reflect what you feel answer the questions given. Let's review how the camera works.

The following are the basic components of a digital camera:



Here are some important points to remember while taking pictures:

- ***Is it near or far?*** Remember that being too far away to take a picture may cause it to become blurry and very hard to see. Try t obe no more than 20 steps from your target.
- ***Do I have the flash on?*** Remember to check to make sure that the flash is on by pressing the flash button. The flash light will shine in the flash window.
- ***Can I take your picture, please?*** If you are taking pictures of a person or business, you must ask the person or business owner/manager to sign the photo release form. This form is used to make sure that the person agrees that you had permission to take the picture.
- ***Where did I place the camera?*** Place the camera where you can always find it. The digital camera can stop working if it is stored in places that are too hot or too cold. Make sure it is in a place where the temperature is moderate and safe from physical damage.

SESSION II

Agenda

- Review “What is Photovoice?” (5 minutes)
- Share a Photograph and Discuss Photography Experience (25 minutes)
- Discuss Writing Exercise from Session 1 (10 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Writing Exercise Using SHOWED (25 minutes)
- Discuss Photovoice Question(s) for Session 3 (25 minutes)
- Review Forms (10 minutes)

SESSION III

Agenda

- Review “What is Photovoice?” (5 minutes)
- Review “What is SHOWED?” (5 minutes)
- Share and Discuss Two (2) Photographs in Response to Question(s) (30 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Select Five (5) Photos and Write Brief Descriptions for Each Photo (60 minutes)

SESSION IV

Agenda

- Review “What is Photovoice?” (5 minutes)
- Review “What is SHOWED?” (5 minutes)
- Share and Discuss Two (2) Photographs in Response to Question(s) (30 minutes)
- What is SHOWED? (10 minutes)
- Session Break (10 minutes)
- Select Five (5) Photos and Write Brief Descriptions for Each Photo (60 minutes)

SESSION V

Agenda

- Complete Writing Exercise (60 minutes)
- Session Break (10 minutes)
- Discussion About Ways to Inform and Educate the Community (50 minutes)

Appendix G

WHAT IS PHOTOVOICE?

A picture is worth a thousand words. A photograph can describe what is happening at a specific time.

Photovoice is defined as a process in which people...

- Photograph their everyday health realities.
- Participate in group discussions about the photographs that spotlight your concerns.
- Reach health professionals, community leaders, and others who can assist to make needed changes.

Why use pictures?

- Pictures teach.
- Pictures influence programs.
- Pictures help define the issue.
- Pictures help others **see** the issue.

Appendix H

PHOTO REFLECTION SHEET

Participant's Name:	Participant #: Week #: Exposure #:
Brief description of photo:	
I want to share this photo because:	
What's the real story this photo tells?	
How does this relate to your life and/or the lives of people in your neighborhood?	

Developed by B.L. Nowell, University of Michigan, 2004

Appendix I

Photovoice Workshop Evaluation

- What did you like about Photovoice Sessions?

- What did you like the least about the Photovoice Sessions?

- How has the Photovoice Sessions help you share your experiences of living with Perinatally Acquired HIV?

Appendix J

SHOWED

The acronym SHOWED represents:

What do you See here?

What is really Happening here?

How does this relate to Our lives?

Why does this situation, concern, or strength exist?

How can this image educate the community and policymakers?

What can we Do about it?

Note. Adapted from "Photovoice: a Participatory Action Research Strategy Applied to Women's Health," by C. Wang, 1999, p. 188.

Appendix K

Findings in Relation to Emerging Adulthood Theory

Identity explorations

- Spirituality
- Sexuality
- Disclosure

The age of instability

- Mental Health
- Social Connections
- Advocacy (Voice)

The self-focused age

- Security

The age of feeling in-between

- Perception of Responsibility

The age of possibilities

- Hope

CURRICULUM VITAE

Constance D. Hill

Place of Birth: Oklahoma City, Oklahoma

Education

- B.S., St. Francis University, December 1991
  - Major: Nursing

- M.S., Olivet Nazarene University, August 2005
  - Major: Nursing

Dissertation Title: Listening to the Voices of Emerging Adults: The Experience of Living with PHIV

Licensure and Certification

- State of Illinois, Active
- State of California, Active
- Certified in Pediatric Advanced Life Support (PALS), Current

Professional Academic Experience

- Illinois Benedictine University, 2010 and 2012
  - Adjunct Instructor-Nursing Research Instruction to RN/BSN Students

- Olivet Nazarene University, 2005 – 2007
  - Adjunct Instructor-Health Assessment/Pathophysiology, Nursing Research, and Ethics/Legal Issues in Nursing Instruction to RN/BSN Students

Clinical Experience

Children's Memorial Hospital in Chicago, Illinois

- *Administrator, Critical Care Services*, 2010 – 2012
  - Created LEAN workflows to enhance patient throughput, family-centered rounding, and discharge optimization for the new Lurie's Children 23-floor, 288-bed licensed facility opening June 9, 2012. Developed zone concept and Team Leader role (budget neutral) to support family centered rounding and staff nurses in new decentralized care environment.
  - Developed staffing model for the new Lurie's Children 42-bed Comprehensive Cardiac Care Unit (CCU). Mentored CCU Leadership to successfully recruit 90% experienced RN staff in 2 months.
  - Co-Magnet Program Director (MPD) and led nursing staff to receive 3rd Magnet Re-Designation August, 2010. Children's Memorial was the first freestanding children's hospital in the nation, to receive the prestigious Magnet Award for Nursing Excellence.

- Established partnership with the Chicago City Colleges to create RN mentorship program for nursing students interested in a career in pediatrics. Twenty-five nursing students have been partnered with RN mentors and 10 students have been hired into RN externship program.

- *Director, Pulmonary/Allergy/Transitional Care Unit*, 2002 – 2010
  - Responsible for executing leadership, fiscal control, customer satisfaction, quality care, and overall direction for a 30-bed pediatric inpatient unit. Managed a staff of 52.8 FTEs.
  - Nursing turnover less than 6.75%. Patient Satisfaction Press Ganey Nursing score average 91.0.
  - Developed and facilitated Medically Complex Discharge Task Force to address social and community concerns for patients with a Length of Stay (LOS) totaling 20 days or more. The LOS for medically complex patients decreased from 63.1 days to 54.3 days in 3 quarters with a cost savings of $104,200.
  - Spearheaded Illinois Consortium for the Medically Complex Child. The consortium was established as a coalition of medical professionals, governmental agencies, community activists and parents dedicated to enhancing the quality of life for children with special health care needs. The consortium was spotlighted in *American Journal of Nursing (AJN),* Osterlund, H (2006). "Helping them get home: A Chicago nurse makes a difference for children with medically complex needs." *AJN*, 106(6), 102-103.
  - Led Institute for the Healthcare Improvement (IHI)/Robert Woods Johnson Foundation *Transforming Care at the Bedside* (TCAB) initial pilot program at Children's Memorial.
  - Developed a 15-minute chair massage program for Inpatient frontline nurses; it successfully expanded to 23 departments and served 1,200 employee throughout the institution.

- *Clinical Manager, Pulmonary/Allergy/Transitional Care Unit*, 1996 – 2002
  - Coordinated patient care delivery utilizing staff expertise, patient acuity, and budgetary guidelines.
  - Collaborated with Director and Educator to assess and provide educational activities for staff.
  - Implemented and monitored team projects in collaboration with staff.

- *Staff Nurse, Allergy/Endocrine/Immunology Unit*, 1991 – 1996
  - Coordinated care for neonatal, pediatric, and adolescent patients with pulmonary, immunology, and endocrine disorders.

Recognition and Honors

- Featured in medical publication, *The Future of Nursing: Leading Change, Advance Health* (ISBN-10: 0-309-15823-0) by the RWJF Initiative on the Future of Nursing, 2011

- Child Health Corporation of America (CHCA) Faculty Advisor for *Revitalizing Beside Care*, 2010

- Recipient, Shaw Grant Award $15,000 for *Listening to the Voices of Emerging Adults: The experience of living with perinatally acquired HIV (PHIV)*, 2009

- Recipient, Children's Memorial Hospital (CMH) Nurse Researcher Exemplar Award, 2008

- Honoree, Northwestern Memorial Hospital *Speaking of Women Health*, 2007

- Recipient, Shaw Grant Award $25,000 for *Development of an instrument to measure mothers' caregiving for their children assisted with medical technologies: An application of functional caregiving*, 2007

- Recipient, Sigma Theta Tau, Kappa Sigma Chapter, Student of Excellence Award, 2005

- Nominee, CMH Nurse Exemplar for Nursing Leadership Award, 2000

Professional Memberships

- Sigma Theta Tau Nursing Honor Society, 2011
- Midwest Nurse Research Society, 2011
- American Organization of Nurse Executives (AONE), 2011

Presentations

- 2008
  - *Development of an Instrument to Measure Mothers' Caregiving for their Children Assisted with Medical Technologies: An Application of Functional Caregiving Poster and Discussion*
    Midwest Nursing Research Society Meeting
    Indianapolis, Indiana

- 2005
  - *Collaborative Advocacy for Children with Special Health Care Needs Poster*
    National Association of Children Hospital and Related Institutions Annual (NACHRI) Meeting
    Indian Wells, California

- 2004
  - *Discharge Process Improvement for Children with Social, Financial, and Medical Needs*
    Poster
    NACHRI Meeting
  - Miami, Florida

- 2001
  - *Implementation of a Shared Governance Leadership Model*
    Poster
    Nursing Congress Annual Meeting
    Orlando, Florida

- 2000
  - *Collaborative Approach in Improving Asthma Care in Chicago Public Schools*
    Poster
    Nursing 2000 Convention
    Orlando, Florida

Community Affiliations

- *Board Member*, Provident Foundation (Future Doctors/Future Nurses Program) in Chicago, Illinois, 2009 – Present

- Global Outreach NFP and B-Unity Christian Summer Health Missions (Zimbabwe and Kenya), 2007 – Present

- *Representative*, Churches United to Fight Against AIDS (CUFAA), 2006 – 2007

- *Executive Board Member*, Regional Care HIV/AIDS Center in Joliet, Illinois, 2005 – 2006

- Ruth Rothstein CORE Center – HIV/AIDS Initiatives with the City of Chicago Community Colleges, 2004 – 2006

- Alpha Kappa Alpha Sorority Incorporated, Chi Omega Omega Chapter Health and Education Initiatives in the Bronzeville and Englewood Communities, 2003 – 2007

- *Family Congregational Nurse*, Alpha Missionary Baptist Church in Bolingbrook, Illinois, 1998 - 2012