2021

Challenges to Successful Health Care Transition Among HIV Positive Youth With Perinatal Acquisition

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Abstract

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MS, Walden University, 2010

BFA, Otterbein University, 2005

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

Doctor of Philosophy

Public Policy and Public Administration

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May 2021

Abstract

To ensure stability in the continuum of health care for HIV-positive youth with perinatal acquisition, there is a need for a successful transition from pediatric to adult primary care. However, there are a growing number of perinatally infected HIV-positive young persons remaining in pediatric care beyond the age of 21. Using Mohr's program theory and a phenomenological approach, the lived experiences of Ohio HIV clinicians were examined to determine why many perinatally infected HIV-positive youths are remaining in pediatric care beyond the age of 21. Audio recorded video interviews via SKYPE were conducted with 12 participants, transcribed, underwent thematic analysis, and were coupled with review of existing policy documents from Ohio-based Ryan White Part C and D clinics. Three themes emerged: (a) lack of awareness or absence of formal policies, (b) barriers created by the hand-holding nature of the pediatric system, and (c) the relationship dynamics between the young person and their HIV care team. This research supporting an HIV clinicians' unique viewpoints and perceived challenges of health care transition for this population by the age of 21 could affect positive social change by assisting health systems in the development of new policies and practices that facilitate successful reduction in the number of adolescents that are lost in their HIV care continuum.

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Dedication

First and foremost, I dedicate this study to all of the young people living with HIV that I have had the honor of knowing and serving in my adult life. Their stories and their passion for life have helped build the foundation of my strength and resilience to keep going, even when the odds against us have seemed insurmountable. To Billy, Geneva, Justin, Michael, Ricky Shelton and to the countless others that I cannot muster the strength to share, your light lives on in my daily fight.

To my mother, Terrie TerMeer, the strongest and most resilient woman I know. She is my rock, system of support and confidant. Thank you for all the sacrifices you have made for our family over the years to ensure that we could achieve anything that we set our hearts and minds on. Thank you for teaching me patience, dedication, and resolve. Thank you for believing in me and supporting me throughout this very long and difficult journey.

To Kevin, losing you changed my life forever. You were kind, compassionate, and had a passion for making the world a better place like no one I have ever met. You were the epitome of a great man. Thank you for your constant presence, sacrifice, and advice. Thank you for showing the world and me the power of unconditional love, support and encouragement.

Acknowledgments

To my dissertation committee, thank you for your willingness to partake on this important journey with me. Specifically, to my Committee Chair, Dr. Steven Matarelli, thank you for your patience, your support, your guidance, and your encouragement. To Dr. Gary Kelsey and Dr. Lydia Forsythe thank you for your insight, support and suggestions.

To my Walden colleagues and friends that I have made along the way, thank you for your guidance and support along this journey.

To my second family, my team at Cascade AIDS Project and Prism Health, thank you for your constant support and encouragement as I completed this journey.

To my chosen family, I couldn’t have done this without your friendship and unconditional love and support.

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Chapter 1: Introduction to the Study

Background

According to the Centers for Disease Control (CDC; 2020), youth comprise 7% of the more than 1 million people living with HIV in the United States. The CDC stated that “Youth with HIV are the least likely out of any age group to be linked to care and have a suppressed viral load” (para. 1). The HIV care continuum represents the planned progression of health care by which a person living with HIV can expect to follow and includes linkage, engagement, medication prescription, adherence, and viral suppression (Zaboni & Meyer, 2014). Disruption of care at any point along the continuum may adversely impact health status associated with HIV treatment and may increase the risk of transmission if viral loads are unsuppressed (Crowley et al., 2011). The majority of young persons born with a chronic illness will survive until adulthood and should transition to the adult health care system (American Academy of Pediatrics [AAP], 2011). These factors underscore the importance of engagement and the need for policies and infrastructure that support successful transition from pediatric to adult systems of care.

The movement from pediatric to adult-focused health care for individuals living with chronic disease (e.g., congenital heart conditions, cystic fibrosis, or diabetes mellitus) is clearly challenging for youth, families, and providers (Chu et al., 2015). Hussen et al. (2015) found that “transition from adolescent-specific to adult HIV care may have even lower rates of successful transition than that of youth with other diverse chronic conditions” (p. 921). The transition process can raise a number of issues for the patient. The nurturing culture of support offered within the pediatric setting is often different in adult care settings where patients are assumed to be autonomous individuals who should possess the self-management skills to make decisions regarding their own (Watson, 2012).

According to the AAP (2011), “Young adults with disabilities and chronic medical conditions are more vulnerable to failures in the transition of health care services and require more attention from providers and the health care system” (p. 196). However, the AAP found that, “caring for young adults with special health care needs may represent a challenge that some adult primary care practices are currently not prepared to meet” (p. 197). Interviews with Ohio HIV clinicians and the review of existing policies and procedures within Ryan White Part C and D clinics as they relate to health care transition could create a stronger understanding of systemic challenges and serve as the foundation for the further development of new and existing policies that support the successful transition of young persons born with HIV from pediatric to adult care in similar clinics across the United States.

Problem Statement

As a result of medical advances in the care and treatment of HIV, both perinatally and behaviorally infected youth are living longer (Gibson & Garcia, 2009). Tanner et al. (2016) reported that “Many youths living with HIV, especially those with co-occurring issues (e.g., substance use, insecure housing, and mental health), disengage at some point from care” (p. 2). A noteworthy point of disengagement occurs during the transition from pediatric to adult care (Crowley et al., 2011). Transition issues for individuals living with a chronic illness are complex and can create anxiety for the young person, the parent or guardian, and the clinician; therefore, transition to adult care needs to be a planned process occurring over many years with the viewpoints of all involved (Watson, 2012).

Over the next decade, 25,000 youth will transition from adolescent to adult care (Cervia, 2013). A well-timed, well-planned transition from child to adult-oriented health care, ideally occurring between the ages of 18 to 21, enables youth to optimize their ability to assume adult roles and activities; however, many adult providers feel unprepared to care for young adults with chronic conditions (AAP, 2011).

Hepburn et al. (2015) stated, “Although transitions of care have received much attention in the child health community, little government attention has been paid to this complex health system issue” (p. 5). The little research that does exist related to HIV health care transition primarily focuses on the perspectives of the perinatally infected HIV-positive adolescent and the perceived challenges of shifting from a pediatric to adult care clinic (Tanner et al., 2016). According to the AAP (2011),

> A key component of supporting the transition process is the primary care medical home having an explicit office policy that describes the practices approach to health care transition, including the age and process at which youth shift to an adult model of care. (p. 187)

Hepburn et al. (2015) concluded that “while policy frameworks are not sufficient for change, they are an important first step in improving transition from pediatric to adult care” (p. 5). Examination of policy-specific implementation processes at the provider level are lacking the perspectives of HIV clinicians on the opportunities for systemic or policy-level changes that could help prepare both the young person, caregiver, and provider for an earlier, more supportive continuum of care.

Purpose of the Study

The purpose of this study was to fill a gap in the existing literature by examining the viewpoints of Ohio HIV clinicians on the challenges of transitioning perinatally infected HIV positive youths to adult primary care by age 21. Using a qualitative, phenomenological approach, I conducted a study in Ryan White Part C and D funded clinics throughout Ohio. The expected research plan was to examine the policies and procedures of these health systems related to health care transition for young people born with HIV infection and interview key stakeholders that inform policies and practices surrounding the transition of these young persons from pediatric to adult care. Upon conducting my research, I discovered that either no policies and procedures existed at facility levels or that these clinics were unwilling to electronically transmit policy documents. See Chapter 4 for further discussion.

Research Question

The following research question (RQ) guided this study:

> RQ: How will understanding the lived experiences of Ohio HIV clinicians inform why many perinatally infected HIV-positive youths are remaining in pediatric care beyond the age of 21?

Theoretical Framework

According to Watson (2012), “The transfer process from pediatric to adult care needs to be individualized and agreed upon with each patient and his/her family in conjunction with the pediatric and adult team” (p. 3). The AAP (2011) found that

> because both transition and transfer are influenced by environmental, socioeconomic, medical and other factors it is the responsibility of the medical home – in partnership with patients and their families – to coordinate efforts that ensure the optimal outcomes for every patient. (p. 184)

The AAP continued, reporting, “To achieve the goal of transitioning as a standard of care, the medical home team must receive training and technical assistance to implement transitions effectively and adopt transition-related practices” (p. 187).

I used Mohr’s (1995) program theory, which be detailed further in Chapter 2, as a guiding theory while examining the multitude of factors that influence HIV health care transition for the perinatally infected HIV-positive youth and the variety of stakeholders detailed in the literature.

Nature of the Study

I used a phenomenological approach in order to gain a better understanding of the everyday lived experiences and viewpoints of HIV clinicians serving perinatally infected HIV-positive youths in four Ryan White Part C and D clinics throughout Ohio. First, I intended to conduct a review of clinic policies as they related to the health care transition of young person’s born with HIV from pediatric to adult care (see Chapter 4 for revised research approach). Secondly, key stakeholder interviews were conducted with HIV clinicians within these clinics to gain a better understanding of their viewpoints on the challenges and opportunities for the successful health care transition to adult care by age 21. A purposeful criterion sample of stakeholders was used to assist in highlighting different perspectives on this issue.

Definitions

For clarity and understanding of issues pertaining to the health care transition of youths born with HIV from pediatric to adult-focused care and to establish a common vocabulary, I used the operational definitions provided in this section in the study.

Federally qualified health centers (FQHC): Community-based health care providers that receive funds from the Health Resources and Services Administration (HRSA) Health Center Program to provide primary care services in underserved areas (HRSA, 2020c).

Medical home or patient-HIV continuum of care: A model that outlines the sequential steps or stages of HIV medical care that people living with HIV go through from initial diagnosis to achieving the goal of viral suppression and shows the proportion of individuals living with HIV who are engaged at each state (U.S. Department of Health and Human Services [HHS], 2020a).

Patient centered medical home: An initiative that supports health centers working towards better care and lower costs for patients (HRSA, 2020d).

Medication adherence: Sticking firmly to an HIV regimen – taking HIV medicines every day exactly as prescribed (HHS, 2020b).

Ryan White Program: A program providing a comprehensive system of care that includes primary medical care and essential support services for people living with HIV who are uninsured or underinsured (HRSA, 2020a).

Standards of HIV care: A series of guidelines issued by the HHS to help doctors provide care and treatment to people living with HIV in the United States. The HRSA has developed complementary clinical protocols and practices that provide detailed information the effective delivery of HIV care (HRSA, 2020b).

Viral suppression: When antiretroviral therapy (ART) reduces a person's viral load (i.e., HIV RNA) to an undetectable level. Viral suppression does not mean a person is cured because HIV still remains in the body (HHS, 2020c).

Assumptions

An important assumption made in this study was that the timing of transition is a decision happening in partnership between the young person, their parent or caregiver, and the HIV clinician. According to the AAP (2011), "Coordination of patient, family, and provider responsibilities enables youth to optimize their ability to assume adult roles and activities" (p. 182). I also assumed that Ohio Ryan White Part C and D clinics were aware of the AAP transition recommendations for HIV positive youth. Another assumption was that HIV clinicians working in Ryan White Part C and D funded clinics throughout Ohio would have a willingness to participate in this study and approval from the larger medical homes where they were located to do so.

Scope and Delimitations

I conducted this study in four HRSA-funded Ryan White Part C and D clinics throughout Ohio. I intended the study to involve a review of existing policies and procedures designed to support the unique health care transition of young persons born with HIV as they enter early adulthood as well as key stakeholder interviews with HIV clinicians about their lived experiences within these unique clinic settings (see Chapter 4 for revised research approach). The study did not involve collecting data directly from HIV-positive young persons. A high likelihood of transferability exists because what was learned from Ohio HIV clinicians about the challenges and opportunities of this period of health care transition for HIV-positive youths could be applied to other Ryan White Part C and D clinics throughout the United States.

Limitations

The first limitation was that the 10 HRSA-funded Ryan White Part C and D clinics in Ohio were located throughout the state in a combination of rural, suburban, and urban communities. In a more rural community, the HIV clinician may be one of the only providers of infectious disease health care in the region, whereas in an urban center the patient may have many options in their transition from pediatric to adult care. This limitation may have impacted the HIV clinician’s availability to participate.

Another limitation was that clinics either existed as a stand-alone practice or within a larger health system or FQHC. I planned to conduct a review of policies and procedures and found none existed at the clinic level or that these clinics were unwilling to electronically transmit policy documents. I also planned to conduct key stakeholder interviews only within these Ryan White clinics and not within the larger health systems. The viewpoints of individual HIV clinicians may not reflect that of the larger health system.

As a person living with and working in the field of HIV over the last 17 years, my own personal and professional experience bring potential bias. This potential bias was acknowledged to participants in the informed consent process. In order to eliminate this bias, I did not collect qualitative data from any organization where I was currently or have previously been employed.

Significance

Research exploring existing models of health care transition among young persons born with HIV is centered on the experiences of the patient rather than their providers or caregivers. The AAP (2011) stated,

> A key component of supporting the transition process of the primary medical home is having an explicit office policy that describes the practice's approach to health care transition, including the age and process at which you the shift to an adult model of care. (p. 187)

The results of this study may fill a gap in understanding the importance of establishing policies and infrastructure to support health care transition programs in the care and treatment of perinatally infected HIV-positive young persons. According to the AAP,

> Transition planning, when present at all, can be inexplicit, incomplete, or late, and when necessary the transfer of care to adult medical home and to adult medical

> subspecialists involve more of a drift away from pediatric care rather than a clearly planned and executed handoff. (p. 182)

Research supporting the HIV clinicians' unique viewpoints and perceived challenges of health care transition for this population by the age of 21 could assist in the development of new policies and systems that facilitate a reduction in the number of adolescents that are lost in the care continuum.

Summary

Young adults with chronic conditions are vulnerable to increased barriers in their transition from pediatric to adult care (AAP, 2011). In order to best ensure ongoing engagement in the continuum of care, treatment, and medication adherence, HIV clinicians will need to have a stronger understanding of the policy- and systemic-level barriers related to successful health care transition (Tanner et al., 2016).

The purpose of this study was to fill a gap in literature by examining the viewpoints of and challenges perceived by HIV clinicians for the successful transition of perinatally infected HIV-positive youth from pediatric to adult health care by age 21. I conducted this qualitative, phenomenological study in four HRSA-funded Ryan White Part C and D clinics throughout Ohio. I used program theory as the theoretical framework for this study. Limitations were centered around the availability of providers to participate, especially in more rural areas of Ohio, and the viewpoints of HIV clinicians that may differ from the larger health systems from which they are employed. The findings of this study may fill a gap in understanding the policy- and system-level challenges that impact Ohio HIV clinicians in successfully transitioning young persons born with HIV into adult-focused systems of care. In Chapter 2, I provide a restatement of the problem and the purpose of the study as well as a detailed review of the literature on the subject and the theoretical framework.

Chapter 2: Literature Review

In this chapter, I provide a review of the available literature. The second section includes additional background information regarding progress made in the care and treatment of perinatally infected HIV-positive adolescents. In the third section, the importance of engagement in the spectrum of the HIV continuum of care for the achievement of optimal health outcomes is highlighted. The fourth section contains a description of the goals of the National HIV/AIDS Strategy (NHAS). In the fifth section, I analyze the need for transition in health care, while in the sixth section I detail the obstacles of transition for perinatally infected HIV-positive youth from pediatric to adult care. The following sections include a description of the theory, methodology, and variables as they pertain to this research. The chapter concludes with a summary.

Literature Search Strategy

I located literature for this review from a number of sources: Academic Search Premier, EBSCOhost, Google Scholar, and ProQuest. Websites directly related to HIV that were searched included: AAP, CDC, the White House Office of National AIDS Policy (ONAP), the World Health Organization (WHO), and the HHS. Google Scholar was the primary search engine employed in this literature search and was used except when the internal search engine of a particular database was required.

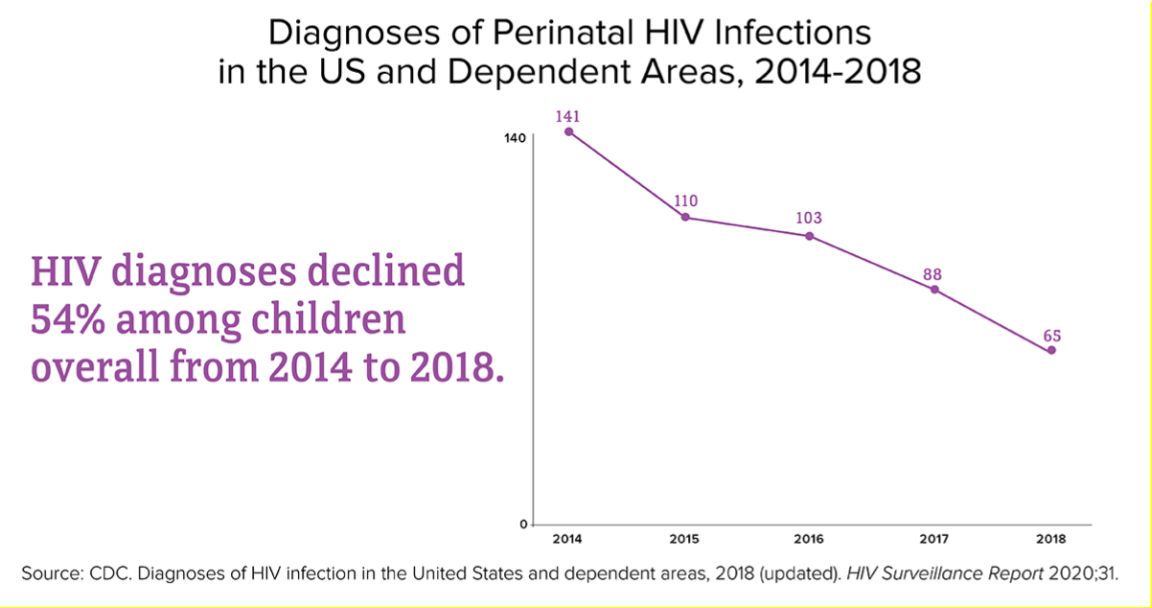
I searched databases and websites using the following keywords: *perinatal HIV infection, health care transition for youth with chronic illness, perinatally HIV-infected youth and health care transition, HIV/AIDS policy, HIV continuum of care*, *HIV/AIDS and youth transition, born with HIV, obstacles in youth health care transition, HIV* *stigma and youth, HIV mental health and youth, perinatally infected HIV positive young people and sexual health,* and *program theory*. Additional keywords and key search terms were developed as a result of the initial searches. The literature review included peer-reviewed journal articles, books, and related research that was published between 2009 to 2020.

Background

Today, more than 3 decades since the first reported cases of HIV in the United States, progress in treatment options, access to affordable health care, and specialized training for clinicians have improved the prognosis of young persons born with HIV infection (Wiener et al., 2011, p. 141). As early as 1982, the diagnosis of pediatric AIDS cases began to appear (Achievements in Public Health, 2014), in which potential mother-to-child transmission occurred during pregnancy, labor, delivery, or breastfeeding. The CDC (2020) reported that from 2014 to 2018, perinatal HIV diagnoses decreased by 54% (see Figure 1). Figure 2 further shows that from 2014 to 2018, the disparity in perinatal HIV diagnoses by race/ethnicity (CDC, 2020). The CDC (2020) attributed this reduction to routine HIV screening of pregnant women, use of antiretroviral drugs for treatment and prophylaxis, avoidance of breastfeeding, and use of elective cesarean delivery when appropriate (see Figure 3). Collectively, these strategies have significantly decreased HIV transmission among newborns, while simultaneously the advent of combination ART has increased the probability of these young persons living into adulthood with chronic HIV infection. The CDC reported that “When HIV is diagnosed before or during pregnancy, perinatal transmission can be reduced to less than 1% if appropriate medical treatment is given, the virus becomes undetectable, and breastfeeding is avoided” (para. 15).

Figure 1.

Diagnosis of Perinatal Infections in the United States and Dependent Areas, 2014–2018



Diagnoses of Perinatal HIV Infections
in the US and Dependent Areas, 2014-2018

HIV diagnoses declined 54% among children overall from 2014 to 2018.

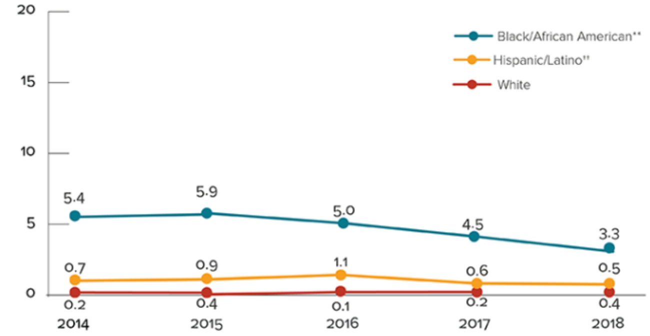
Source: CDC. Diagnoses of HIV infection in the United States and dependent areas, 2018 (updated). *HIV Surveillance Report* 2020;31.

Note. From “HIV and Pregnant Women, Infants, and Children,” by CDC, 2020 (https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html).

Figure 2.

Rates of Perinatally Acquired HIV Infections in the United States, by Year of Birth and Mother's Race/Ethnicity, 2014–2018

Rates of Perinatally-Acquired HIV Infections Among Persons Born in the United States, by Year of Birth and Mother's Race/Ethnicity, 2014-2018 *†‡



*Data include only persons born in the United States (50 states and District of Columbia). Data accounted for delays between birth and diagnosis, as well as between diagnosis and reporting.
†Rates are per 100,000 live births.
‡Live-birth data reflect race/ethnicity of the infant's mother.
***Black* refers to people having origins in any of the Black racial groups of Africa. *African American* is a term often used for Americans of African descent with ancestry in North America.
††Hispanics/Latinos can be of any race.

Source: Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas, 2018. *HIV Surveillance Supplemental Report* 2020;25(2).

Note. "From "HIV and Pregnant Women, Infants, and Children," by CDC, 2020 (https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html).

Figure 3.

What can you do if you are Pregnant and Have HIV

What You Can Do If You Are Pregnant and Have HIV

Visit your health care provider regularly.

Take HIV medicine as prescribed to stay healthy, protect your partner, and protect your baby.

Taking HIV medicine reduces the amount of HIV in the body (viral load) to a very low level, called *viral suppression* or an *undetectable viral load*.* Getting and keeping an undetectable viral load is the best thing you can do to stay healthy and help prevent transmission to your baby.

The risk of transmitting HIV to your baby can be 1% or less if you:

- Take HIV medicine daily as prescribed throughout pregnancy, labor, and delivery.
- Give HIV medicine to your baby for 4-6 weeks after giving birth.

If your HIV viral load is not adequately reduced, a Cesarean delivery can also help prevent HIV transmission.

Do not breastfeed or pre-chew your baby's food.

Keeping an undetectable viral load substantially reduces, but does not eliminate, the risk of transmitting HIV through breastfeeding. The current recommendation in the U.S. is that mothers with HIV should not breastfeed their babies.

Note. "From "HIV and Pregnant Women, Infants, and Children," by CDC, 2020 (https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html).

At the beginning of the epidemic, such longevity was not anticipated; however, "HIV testing and preventive interventions have resulted in more than a 96% decline in the number of children perinatally infected with HIV in the United States since the early 1990's" (CDC, 2019, para. 2). Ross et al. (2010) reported that "Many perinatally infected children have survived into their second or third decade of life because of the advent of combination antiretroviral therapy (ART) and effective viral suppression with immunologic reconstitution" (p. 1). Despite this progress, considerable challenges remain in the successful transition of young persons from pediatric health care to adult health care settings.

The health and well-being of youth with chronic illnesses, particularly HIV/AIDS, hinges on uninterrupted and successful transition to adult care (Wiener et al., 2011, p. 141); however, a rising number of HIV positive young persons remain in pediatric care long after the age of 21. Greifinger (2012) stated, "Advances in medication mean that these young people have long and healthy lives ahead of them, but for years they were not expected to survive and so were never prepared for adulthood" (p. 2). At the same time, pediatric HIV clinicians and primary caregivers may be unprepared to allow for these adolescents to transition to an independently monitored system of adult care (Peter et al., 2009). This transformative juncture in the epidemic has created an unexpected phenomenon for the young person, their caregiver, and medical providers that will require a multifaceted approach for a smooth continuum of care.

Ross et al. (2010) found anxiety within adolescents with chronic illness at the time of transition and stressed the importance of addressing the intersectionality of medical and psychosocial treatment strategies. Reiss et al. (2005) added that "Transition requires managing and adjusting to significant changes in the organization of care, family involvement in care, and patient-physician communication" (p. 115). However, there is minimal research that focuses specifically on the viewpoints of HIV clinicians with patient populations of young persons born with HIV and the distinctive barriers to transition to adult care.

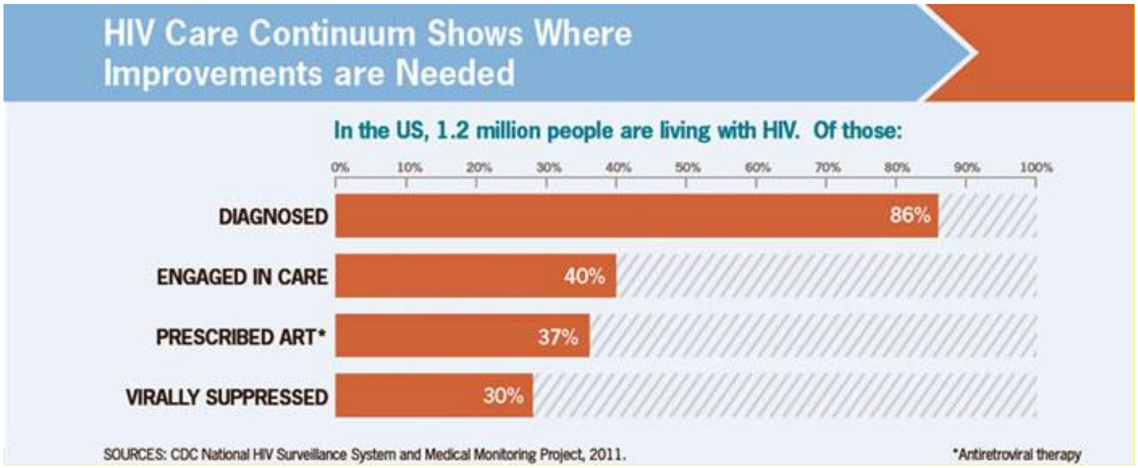
The HIV Care Continuum

Advancement in treatment options for individuals with HIV infection has allowed most individuals living with the virus to achieve undetectable plasma HIV-RNA levels or an undetectable amount of the virus in their lab results; however, “for an individual to fully benefit from potent combination antiretroviral therapy, they need to know that they are HIV infected, be engaged in regular HIV care, and receive and adhere to effective antiretroviral therapy” (Gardner et al., 2011, p. 794). These test-and-treat strategies have facilitated a shift towards high impact HIV prevention activities, which are inclusive of expanded testing and the earlier treatment of HIV infection, with a goal of decreasing ongoing HIV transmission (CDC, 2018). Gardner et al. (2011) reported that “Late HIV diagnosis, suboptimal linkage to and retention in HIV care, insufficient use of antiretroviral therapy, and suboptimal adherence to therapy pose significant barriers to achieving optimal treatment outcomes” (p. 794).

The HIV/AIDS care continuum, depicted in Figure 4), illustrates how few HIV infected individuals have the virus under control. According to Gardner et al. (2011), among the 1.2 million HIV-positive Americans, nearly 1 in 5 is unaware they are infected, just over one third are retained in care, only one third are on ART, and only one fourth achieve viral suppression. In other words, of the 1.2 million Americans with HIV, 18% do not know their status, 66% are linked to care, 37% are retained in care, and only 25% receive adequate treatment to achieve viral suppression. The CDC (2014) released additional analysis (see Figure 5) of these data that provided further information about the 70% of people living with HIV who did not have their virus under control in 2011.

Figure 4.

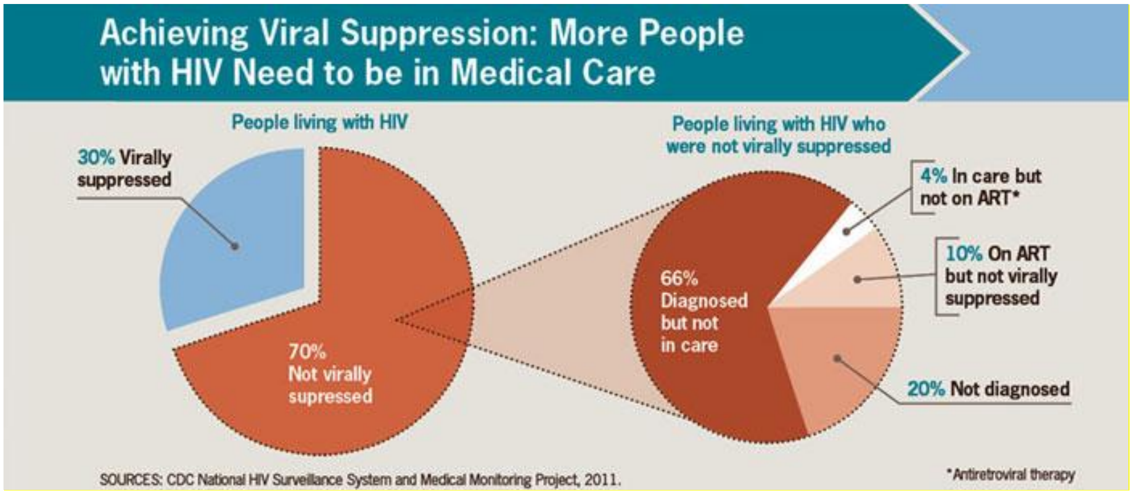
Continuum of HIV Care



Note. "From "Continuum of HIV care,describing the spectrum of engagement in HIV care," by HRSA (https://www.aids.gov/federal-resources/policies/care-continuum/)

Figure 5.

Continuum of Care Describing the Spectrum of Engagement in HIV Care



Note. "From "Continuum of HIV care, describing the spectrum of engagement in HIV care," by HRSA (https://www.aids.gov/federal-resources/policies/care-continuum/)

The National HIV/AIDS Strategy

While the overall number of new infections in the United States has begun to stabilize, the CDC (2020) estimated that 21% of all new HIV infections occur among young people between the ages of 13 and 24, with many social drivers, including, but not limited to, stigma, racism, poverty, homelessness, sexism, genderism, misogyny, homophobia, and transphobia, continuing to fuel the epidemic. These factors further underscore the critical need to develop protocols to successfully transition perinatally infected HIV positive youth to adult care. President Obama made domestic HIV/AIDS policy one of his highest priorities as evidenced by the 2010 development and implementation of a NHAS (ONAP, 2010, p. 2).

The ONAP (2010) described the vision for a national strategy as a macro-level blueprint by which states must establish their individualized plans and effectively translate these goals for addressing the epidemic at the local and state levels. The ONAP (2010) went on to describe that, “the document provides a roadmap to move the nation forward in responding to the domestic HIV epidemic. It is not intended to be a comprehensive list of all activities needed to address HIV/AIDS in the United States but is intended to be a concise plan that identifies a set of priorities and strategic action steps tied to measurable outcomes” (p. 3). To achieve this vision, the strategy focused on four goals: (a) reducing new HIV infections; (b) increasing access to care and improving health outcomes for people living with HIV; (c) reducing HIV-related disparities, and (d) coordinating a national response. The success of the NHAS would revolve around local-level implementation whether they fully embrace these goals and find effective means of translating them into public health practice within particular communities.

Youth and the NHAS

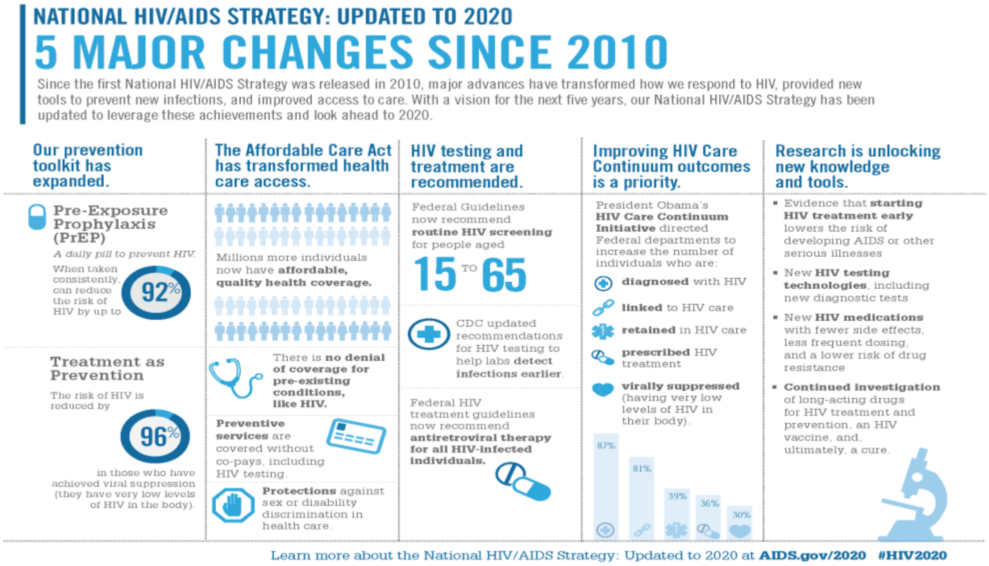
AFY (2010) released a statement that said, “thee NHAS shines a spotlight on the central fact of the current epidemic--that HIV disproportionately impacts those most affected by poverty, racism, homophobia and health care disparities” (para. 3). The original strategy, released in 2010, had little mention of youth or policy recommendations on how to address the epidemic among young people, let alone mention of strategies for successful health care transition. AFY’s statement further stated that, “while public health experts have worked to address the reality of health disparities for some time, the NHAS brought a long overdue shift in the political framework that underpins our country’s response to HIV and AIDS” (para. 3).

With one out of every four people diagnosed with HIV in the United States being between ages 13 and 29, the oversight of meaningful youth inclusion in the NHAS caused community concern and criticism directed at the ONAP. The community advocated for the engagement of young people as partners throughout the implementation of the NHAS, with a particular focus on youth most at risk of infection and those already living with HIV and AIDS. Specifically, AFY (2010) was advocating on behalf of the community for the inclusion of policy recommendations within the NHAS that would “support the creation, evaluation, and implementation of programs and services that specifically address the needs young women of color and young men who have sex with men, especially young men of color who have sex with men” (para. 6).

Across the United States, advocates were asking for a stronger commitment to the provision of comprehensive sex education, as well as access to prevention methods, HIV screening, and health services for young persons. AFY (2010) stated that, “If we are truly committed to changing the tide of HIV/AIDS in the United States, young people offer our best opportunity for success. America must not cede another generation to this epidemic” (para. 7). An updated version of the strategy was released in July of 2015 that provided updates to the necessary actions to achieve its goals by 2020. The 2015 updated strategy changes, pictured below in Figure 6, are centered on the same four goals. While there has been an improvement in the inclusion of young people within the strategy, policy recommendations on the health care transition of youth living with HIV remains absent from the strategy.

Figure 6.

NHAS: Updated to 2020



NATIONAL HIV/AIDS STRATEGY: UPDATED TO 2020

5 MAJOR CHANGES SINCE 2010

Since the first National HIV/AIDS Strategy was released in 2010, major advances have transformed how we respond to HIV, provided new tools to prevent new infections, and improved access to care. With a vision for the next five years, our National HIV/AIDS Strategy has been updated to leverage these achievements and look ahead to 2020.

Our prevention toolkit has expanded.

Pre-Exposure Prophylaxis (PrEP)

A daily pill to prevent HIV.

When taken consistently, can reduce the risk of HIV by up to 92%

Treatment as Prevention

The risk of HIV is reduced by 96% in those who have achieved viral suppression (they have very low levels of HIV in the body).

The Affordable Care Act has transformed health care access.

Millions more individuals now have **affordable, quality health coverage.**

There is **no denial of coverage for pre-existing conditions, like HIV.**

Preventive services are covered without co-pays, including HIV testing.

Protections against sex or disability discrimination in health care.

HIV testing and treatment are recommended.

Federal Guidelines now recommend **routine HIV screening** for people aged 15 TO 65

CDC updated recommendations for HIV testing to help labs **detect infections earlier.**

Federal HIV treatment guidelines now recommend **antiretroviral therapy for all HIV-infected individuals.**

Improving HIV Care Continuum outcomes is a priority.

President Obama's **HIV Care Continuum Initiative** directed Federal departments to increase the number of individuals who are:

- **diagnosed** with HIV
- **linked** to HIV care
- **retained** in HIV care
- **prescribed** HIV treatment
- **virally suppressed** (having very low levels of HIV in their body).

Research is unlocking new knowledge and tools.

- Evidence that **starting HIV treatment early** lowers the risk of developing AIDS or other serious illnesses
- New **HIV testing technologies**, including new diagnostic tests
- New **HIV medications** with fewer side effects, less frequent dosing, and a lower risk of drug resistance
- **Continued investigation** of long-acting drugs for HIV treatment and prevention, an HIV vaccine, and, ultimately, a cure.

Learn more about the National HIV/AIDS Strategy: Updated to 2020 at **AIDS.gov/2020** **#HIV2020**

Note: “From “NHAS: Major Changes Since 2010,” by ONAP (https://www.aids.gov/federal-resources/national-hiv-aids-strategy/documents/)

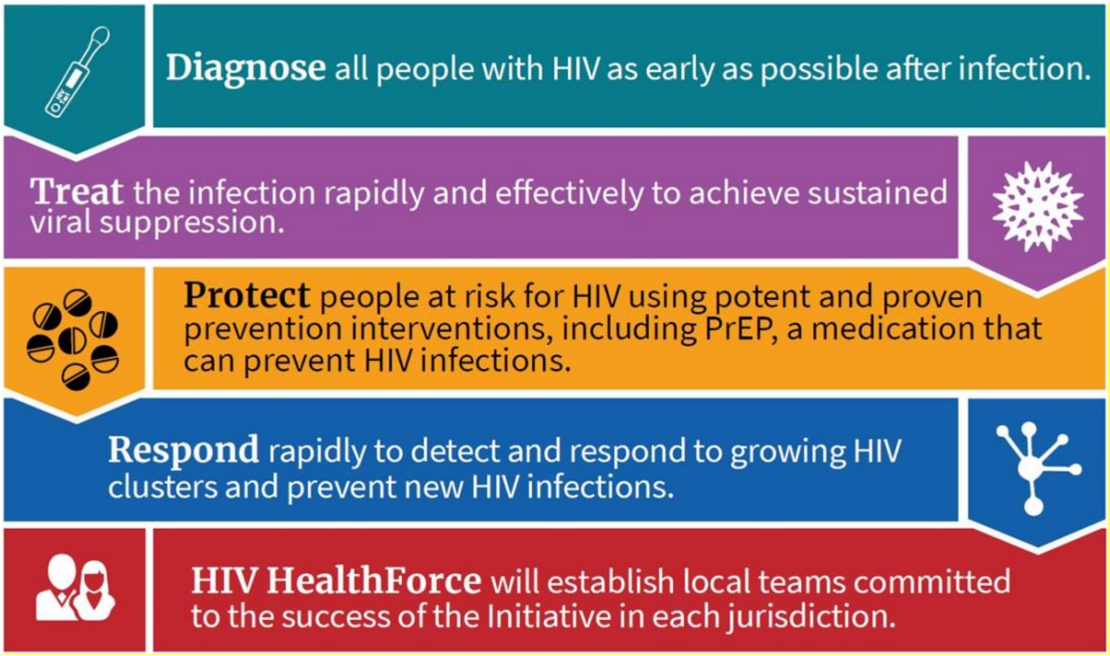
AFY (2015) reported that, “Importantly, the new strategy includes explicit focus on young people, identifying youth aged 13-24 as a population for targeted interventions” (para. 3). The updated NHAS places a strong emphasis on policy recommendations that support young men who have sex with men of color as well as advocating for comprehensive sex education. AFY’s statement went on to state that, “the strategy specifically mentions universal integration of HIV information in education, defining this need as one that includes scientifically-accurate and accessible information” (para. 4). The greater inclusion of young persons in the 2015 Strategy underscores a commitment to improving their health and well-being. AFY also underscored that, “youth activists are hopeful for additional recognition of some specific problems facing their own communities, including care access and non-discrimination in housing and shelter for youth with HIV experiencing homelessness; effective needle exchange programs; and training primary care physicians on cultural competence and treating people living with HIV” (para. 7). Continued advocacy would be necessary for the development and inclusion of policy recommendations centered on youth health care transition.

Ending the HIV Epidemic: A Plan for America

During the 2019 State of the Union address the Trump administration announced a new initiative beginning in fiscal year 2020 with the goal of ending the HIV epidemic in the United States within 10 years (HRSA; 2019). HRSA (2019) reported that, “to achieves this goal and address the ongoing public health crisis of HIV, the proposed *Ending the HIV Epidemic: A Plan for America* will leverage the powerful data and tools now available to reduce new HIV infections in the United States by 75 percent in five years and by 90 percent by 2030" (para 1). The initiative is focused on 48 counties, plus Washington, DC and San Juan, Puerto Rico where greater than 50% of HIV diagnoses occurred in 2016 and 2017 as well as an additional seven states with a substantial number of HIV diagnoses in rural areas (HRSA; 2019, para 2). The initiative focused on four key strategies that together can end the HIV epidemic in the United States: diagnose, treat, protect, and respond (see Figure 7).

Figure 7.

Ending the HIV epidemic: A plan for America



Diagnose all people with HIV as early as possible after infection.

Treat the infection rapidly and effectively to achieve sustained viral suppression.

Protect people at risk for HIV using potent and proven prevention interventions, including PrEP, a medication that can prevent HIV infections.

Respond rapidly to detect and respond to growing HIV clusters and prevent new HIV infections.

HIV HealthForce will establish local teams committed to the success of the Initiative in each jurisdiction.

Note: "From "Ending the HIV epidemic: A plan for America," by HRSA (https://www.hrsa.gov/ending-hiv-epidemic)

HRSA: Ryan White Program

HRSA (2020a) reported that, "on August 18, 1990, by wide bipartisan margins, both houses of Congress passed the groundbreaking Ryan White Comprehensive AIDS

Resources Emergency (CARE) Act, named for an Indiana teen who lost his life to AIDS. By the time the bill became law, more than 150,000 U.S. AIDS cases had been reported in the United States. More than 100,000 had died" (para. 1). The Ryan White HIV/AIDS Program provides a comprehensive system of care that includes primary medical care and essential support services for people living with HIV who are uninsured or underinsured. The program works with cities, states, and local community-based organizations to provide HIV care and treatment services to more than half a million people each year (HRSA, 2020a). The majority of Ryan White HIV/AIDS Program funds support primary medical care and essential support services. The program serves as an important source of ongoing access to HIV medication that can enable people living with HIV to live close to normal lifespans (HRSA, 2020a). The Ryan White HIV/AIDS Program is divided into five Parts, following from the authorizing legislation:

- Part A provides grant funding for medical and support services to Eligible Metropolitan Areas and Transitional Grant Areas. Each of these areas are population centers that are the most severely affected by the HIV/AIDS epidemic.
- Part B provides grant funding to states and territories to improve the quality, availability, and organization of HIV health care and support services. Grant recipients include all 50 states, the District of Columbia, Puerto Rico, Guam, the U.S. Virgin Islands, and the 5 U.S. Pacific Territories. In addition, Part B also includes grants for the AIDS Drug Assistance Program.

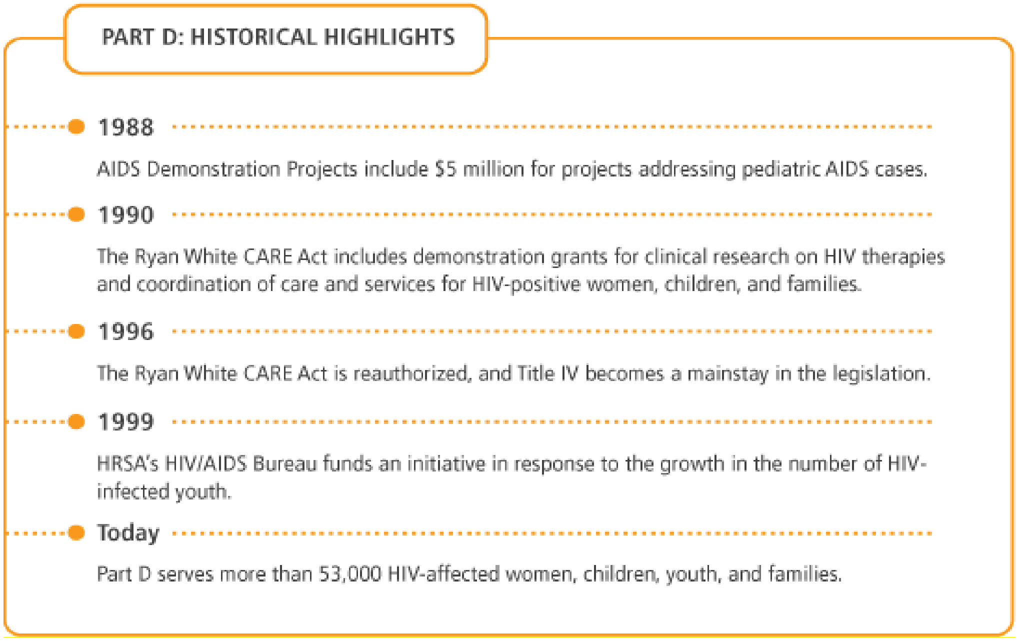
- Part C provides grant funding to local community-based organizations to support outpatient HIV early intervention services and ambulatory care. Part C also funds planning grants, which help organizations more effectively deliver HIV care and services.
- Part D provides grant funding to support family-centered, comprehensive care to women, infants, children, and youth living with HIV.
- Part F provides grant funding that supports several research, technical assistance, and access-to-care programs. These programs include:
- The Special Projects of National Significance Program, supporting the demonstration and evaluation of innovative models of care delivery for hard-to-reach populations;
- The AIDS Education and Training Centers Program, supporting the education and training of health care providers treating people living with HIV through a network of eight regional centers and three national centers;
- The Dental Programs, providing additional funding for oral health care for people with HIV through the HIV/AIDS Dental Reimbursement Program and the Community-Based Dental Partnership Program; and
- The Minority AIDS Initiative, providing funding to evaluate and address the impact of HIV/AIDS on disproportionately affected minority populations (HRSA, 2020a).

Origins of Ryan White Part D Clinics

Part D of the Ryan White HIV/AIDS Program has played a key role in the development and provision of the health care and support services at institutions that focus on women, infants, children, and youth living with and affected by HIV (see Figure 8). The program has evolved over time to keep pace with the progression of the epidemic and with the decline in pediatric AIDS cases in the United States.

Figure 8.

Ryan White Part D: Historical Highlights.



PART D: HISTORICAL HIGHLIGHTS

1988

AIDS Demonstration Projects include $5 million for projects addressing pediatric AIDS cases.

1990

The Ryan White CARE Act includes demonstration grants for clinical research on HIV therapies and coordination of care and services for HIV-positive women, children, and families.

1996

The Ryan White CARE Act is reauthorized, and Title IV becomes a mainstay in the legislation.

1999

HRSA's HIV/AIDS Bureau funds an initiative in response to the growth in the number of HIV-infected youth.

Today

Part D serves more than 53,000 HIV-affected women, children, youth, and families.

Note: "From "Ryan White Part D: Historical highlights," by HRSA (https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program)

HRSA (2020a) reported that, "greatly concerned with the increase in the number of pediatric AIDS cases, Congress first acted to address pediatric cases in 1987 by providing $5 million for the Pediatric AIDS Demonstration Projects in the FY 1988 budget. At the end of 1987, 737 pediatric AIDS cases had been reported to the Centers for Disease Control and Prevention, up from 410 cases at the end of 1986" (para. 8). The goal of the demonstration project, which originally supported 13 programs, was to develop care and treatment models for children with AIDS and HIV-infected pregnant women and their families as well as to enhance the participation of women and children in HIV-related clinical trials. Part D programs consider the entire family their client, helping all family members weave together a network of medical care and support services to address their health and social needs (HRSA, 2020b).

From the outset, the Part D program was designed to address the unique needs of women living with HIV/AIDS and their children and families. Parents living with HIV must manage their own care while caring for their children. Coordinating childcare, transportation, and medical and social service appointments can present major challenges, especially for single parents or if a child or partner is also infected. Children living with HIV/AIDS also face a range of special issues, including delayed growth and development, mental health needs, and the unique side effects of HIV medications on children, among others (HRSA, 2020b).

The Need for Transition to Adult Care

The AAP (2011) defined the achievement of optimal health as the time at which every person, regardless of age, receives medically and developmentally appropriate care (p. 182). A national survey (AAP, 2009) revealed that a majority of pediatric clinicians either delay transition planning late into adolescence or do not offer the critical transition support services that have been proven effective in the smooth transition to adult health care. AAP further stated that, “the goal of a planned health care transition is to maximize lifelong functioning and well-being for all youth, including those who have special health care needs and those who do not” (p. 182).

McManus et al. (2013) found that most youths with special health care needs are not receiving the essential groundwork for a successful transition to adult care from their pediatric provider. Hepburn et al. (2015) stated that, “the complexity of pediatric-to-adult transitions demand system-level solutions that address the alignment of providers in multiple settings, collaboration across various sectors, facilitated communication (including record sharing) and capacity building, all of which commonly demand new, flexible funding arrangements” (p. 1).

The AAP (2011) described transition planning as an essential standard in the provision of care for all youth and young adults and underscored the importance of every patient having a plan for transition to adult care regardless of their specific health needs. Hepburn et al. (2015) stated that, “given the sensitivity of this critical period, it is imperative that youth with chronic medical conditions are provided seamless transition care” (p. 1). Transition must be a meaningful and strategic process for the young person, but also their guardian, parent, or support system as well as their team of medical providers. Maturo et al. (2011) reported that, “appropriate transitioning support does not occur automatically, and because young people infected with HIV are now living longer as the result of medical advancements, transitioning is a particularly important issue” (p. 18). Ross et al. (2010) stated that, “adolescents with chronic health conditions are often followed in pediatric/ adolescent clinics through young adulthood” (p. 5).

Intellectual/Developmental Disability (IDD)

Blum et al. (2005) reported that, “a generation ago, most young people with chronic or disabling conditions died before they reached adulthood. (p. 1). Prokup et al., (2017) stated that, “developmental disabilities are severe, chronic conditions that impair cognitive and/or physical functioning, are manifest before the age of 22 years, result in functional limitations in at least 3 major activities of daily living, and require assistance throughout the lifespan” (p. 471). Over the last several decades, advances in technology, treatment and preventative interventions for the young person living with a disability or a chronic health condition have seen great progress, resulting in the ability to lead longer and healthier lives (Rhode Island Department of Health, 2014). Blum et al. further reported that, “today, more than 90 percent will survive into adulthood” (p. 3).

Recognizing the crucial role health care plays in the lives of individuals with disabilities and chronic health conditions, a smooth and seamless plan for transition from one provider to another needs to be present in order to prevent the young person from experiencing a gap in health care (Rhode Island Department of Health, 2014). Blum et al. (2005) stated that, “unfortunately, many young people with disabilities have had fewer opportunities to develop social skills. Coupled with the effects of stigma, time demands, and constraints imposed by their conditions, young adults with disabilities are often socially isolated, and social isolation is the foundation of depression” (p. 3). Kim et al. (2017) stated that, “these young adults are simultaneously leaving the protections of the education and pediatric health systems while expected to make health care decisions independently” (p. 1). Blum et al., (2005) argued that that” social isolation further impedes the important informal supports that arise from friends, coworkers, and others who can help youth manage the transition to adulthood" (p. 3). Prokup et al. (2017) stated that, "as a result, many of these young adults will remain in pediatric care well into adulthood" (p. 471).

Significant gaps in policy and services available to assist youth with disabilities and chronic health conditions transition from pediatric to adult health care were identified in the late 1980s. "In 1989, the United States Surgeon General issued a report titled Growing Up and Getting Medical Care: Youth with Special Health Care Needs, which addressed the needs of youth, families, and health care providers with respect to health care transitioning (Rhode Island Department of Health, 2014, p. 2). Throughout the decade to follow, health care transition was researched, and policy statements were issued regarding the need for and challenges to transition planning (Reiss & Gibson, 2002). The Rhode Island Department of Health went on to report that, "goals focused on system development and youth empowerment were later developed by the Healthy and Ready to Work Initiative, designed to research and address health, education and employment transition issues facing young persons with disabilities and chronic health conditions. These goals were incorporated into Healthy People 2010 – a plan that defined health goals for the country over the following decade" (p. 2).

"For the 15% of adolescents who have intellectual/developmental disabilities (IDD), transitioning to adulthood can present unique challenges to accessing necessary health care" (Kim et al., 2017, p. 1). Many primary care pediatricians have not yet adopted health care transition planning into their practices (Rhode Island Department of

Public Health, 2014). The Rhode Island Department of Health (2014) reported that "data from the 2000-2001 national Survey of Children with Special Health Care Needs, conducted by the National Center for Health Statistics, indicate that not much progress was made in the adoption of health care transition planning" (p. 3). Several key barriers to health care transition planning include the following important issues:

- When it comes time to make their own health-related decisions, youth with disabilities may not receive necessary decision-making support.
- Adult Medicaid plans are not as comprehensive or widely accepted as children's Medicaid plans.
- When coverage is available, identifying adult providers can be difficult.
- Limited services in adult setting may prevent young adults with IDD from receiving necessary tests or treatments.
- Most states have decades-long waitlists for community-based, long-term care services that many young adults with IDD need once they leave high school. (Kim et al., 2017)

Prokup et al. (2017) explored the health care differences across the lifespan comparing people with developmental disabilities to people without developmental disabilities highlighted the need to educate health care clinicians on the care of patients with disabilities of all ages. This research found that "81% of medical students reported having had no clinical training in disabilities, and 58% of medical school deans reported that curriculum for patients with disabilities was not a high priority" (Prokup et al., 2017, p. 474). Although previous research highlighted the difficulty in transitioning from pediatric to adult care for young adults with disabilities, the Ohio study did not find that the young adults had unique health care needs and therefore underscores the importance of disability competency for clinicians (Prokup et al., 2017, pp. 473-474).

HIV/AIDS

As science has progressed over the course of the domestic epidemic, we have learned a great deal about the optimal clinical standards of HIV care, proper disease management, and have reached a moment of transformation at which ongoing and consistent access to antiretroviral therapy has greatly improved the prognosis of an individual with HIV infection (Schackman et al., 2006). Disease management for this population has largely remained in the hands of caregivers and HIV clinicians who have had difficulty letting go. Gipson and Garcia (2009) stated that, “in this reactionary environment, there has been minimal effort to provide practitioners with a baseline understanding of perinatally infected HIV positive youth that is sensitive to the population’s variances in status, identities, and programmatic needs” (p. 3).

Prevalence among young persons born with HIV now approaching adulthood continues to multiply, highlighting the increased need for further analysis of this transition from pediatric to adult health care. Ross et al. (2010) reported that, “many perinatally infected children have survived into their second or third decade of life because of the advent of combination anti-retroviral therapy and effective viral suppression with immunologic reconstitution” 2010, p. 3). The majority of research published regarding HIV focuses on progression and treatment in adults (Greifinger, 2012). Historically, organizations and institutions have had the role of managing long-term client expectations and preparing youth for short-term prognosis of death and disease, youth serving agencies must now prepare HIV positive young people for living a self-sufficient life with HIV as a long-term chronic illness. Leaving the nurturing confines of youth-centered care and support settings can be an unsettling and traumatic event for young clients with good reason. Long-term who are survivors transitioning out of youth-centered medical care into adult care often find there are far fewer supports for HIV positive clients in adult care than what youth experienced in an adolescent-centered clinical setting.

Research supporting the HIV clinicians' unique viewpoints and perceived challenges of health care transition for this population would provide further support for the planning and implementation of transition programs that successfully retain young clients in care and treatment, which can be crucial to their long-term prognosis, to slow the disease progression, and assist HIV positive clients in their secondary prevention efforts through viral load management. The small degree of research exploring existing models of health care transition among perinatally infected HIV positive young persons is narrowly focused on the experiences of the young person, rather than their providers or caregivers. There is a growing need to better understand the attitudes and beliefs of HIV clinicians with patient populations of young persons born with HIV and the distinctive barriers to transition before age 21.

Obstacles to Transition

Pediatric HIV clinics have struggled to keep pace with adapting service modalities along with the increased lifespan of their patients. HIV positive young persons must now be presented with the necessary life skills, opportunities to manage their own care and treatment, and pro-active transition plans to ensure successful adherence and retention, an unexpected phenomenon earlier in the epidemic when these young persons were not anticipated to live long enough to see adulthood. Adult primary care is not designed to be as coddling and supportive as pediatric care, thus, this period of transition for a young person can be overwhelming. Often, clinicians lose young clients for periods of time in systems of care during this period of transition, regardless of their HIV status. Therefore, early conversations and planning between the clinician, parent and young person are vital to their successful transition. Transition within the context of this research is defined as "the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child/adolescent-centered to adult-oriented health care systems" (Fair et al., 2011, p. 966).

Hepburn et al. (2015) stated that, "despite the well-documented risks and costs associated with a poor transition from pediatric to adult care, little policy attention has been paid to this issue" (p. 1). With a growing level of concern surrounding the need for successful models for care transition by the health community, there is an equal need for government to focus on this complex health system issue. The importance of transition planning has been underscored in recent years by its recognition as an essential health home service (Patient Protection and Affordable Care Act, 2010, pp. 310-318), as well as a newly incorporated public health goal in Healthy People 2020 (Healthy People 2020 Summary of Objectives, 2012). Hepburn et al. further stated that, "while policy frameworks are not sufficient for change, they are an important first step in improving transition from pediatric to adult care" (p. 5).

McManus et al. (2013) indicated that often parents do not prioritize transition until late in their child's adolescence and, therefore, may hamper transition preparation. McManus et al. also demonstrated that the providers of youth with special health care needs are more likely to encourage an increased level of responsibility for health care management, than on discussions that place emphasis on the importance of transfer to an adult health care provider and health insurance continuity. McManus et al. reported that, "expanded efforts are needed to educate parents and other caregivers about the significance of transition along with practical steps they can take to support their youth in self-care management and to partner with health care providers in identifying adult medical home and specialty providers" (p. 1094).

Ross et al. (2010) reported that, "HIV infected adolescents represent a challenging population with unique and diverse needs for optimal health" (p. 6). Successful transition to adult primary care for young persons born with HIV infection will require significant changes in the management of HIV care, family dynamic, and patient-physician relationship. Ross et al. further stated that, "challenges facing these young people include developing self-care skills to become the primary manager of their illness as they leave pediatric care models that often include multidisciplinary, family-oriented care; lack of social support because of the stigmatization of HIV; and they have to address the impact of their infection on their sexuality and reproductive health" (p. 6).

Transition is a period of numerous obstacles to navigate, where the young person, their caregiver, and the clinician – who is often considered a trusted member of the family – must effectively communicate and work together through the significant changes in the experiences of the young persons' continuum of care. Many perinatally infected youth describe leaving their pediatric providers as similar to the loss of a family member because many of them have known these providers their entire lives. Therefore, communication between the patient and clinician surrounding the timeline and expectation for transition out of pediatric care is critical. Patients, caregivers, and clinicians recommend early discussion of health care transition as a means for reducing barriers.

Wiener et al. (2011) reported that, "youth identified the need for increased continuity of care, assistance with logistics, improved communication with providers and caregiver, and individualized management of their transition process" (p. 141). Universal challenges exist in the transition of care for perinatally infected youth living with HIV. Cognitive development, mental health, medication adherence, sexual health, stigma, and disclosure are among many considerations when developing models of transition that are sensitive to the unique experiences of a young person living with HIV. Dowshen and D'Angelo (2011) stated that, "although the need for evidence-based HIV-specific health care transition models is clear, future research will need to examine quantitative clinical outcomes such as disease progression and medication adherence as well as qualitative outcomes including patient satisfaction after transition" (p. 769). Effective health care transition and understanding the unique challenges perceived by HIV clinicians during this period will be a critical factor for ensuring healthy and fruitful futures of these young people.

Theoretical Framework

Smith and Larimer (2013) described program theory as an assumption that the very existence of a policy represents a theory in the sense of a causal claim linking inputs to outputs (p. 144). By definition, if the purpose of a policy is to seek to achieve a specific goal or objective, then logically a policy represents some expectation that the prescribed activities will cause those objectives to be achieved (Smith & Larimer, 2013). Mohr (1995) described that, "program theory always states that the program's activities will have certain specified results, perhaps through the medium of some intermediate events or accomplishments that are also specified" (p. 2). Program theory can be a useful way of bringing together evidence about a program or policy, understanding how that program or policy works, and identifying where there are gaps in the evidence.

According to Funnell and Rogers (2011), a program theory ideally has two components: (a) a theory of change, and (b) a theory of action. The theory of change is about the central processes of drivers by which change comes about for individuals, groups or communities and a theory of action explains how programs or interventions are constructed to activate these theories of change (p.11). Program theory can produce many benefits including:

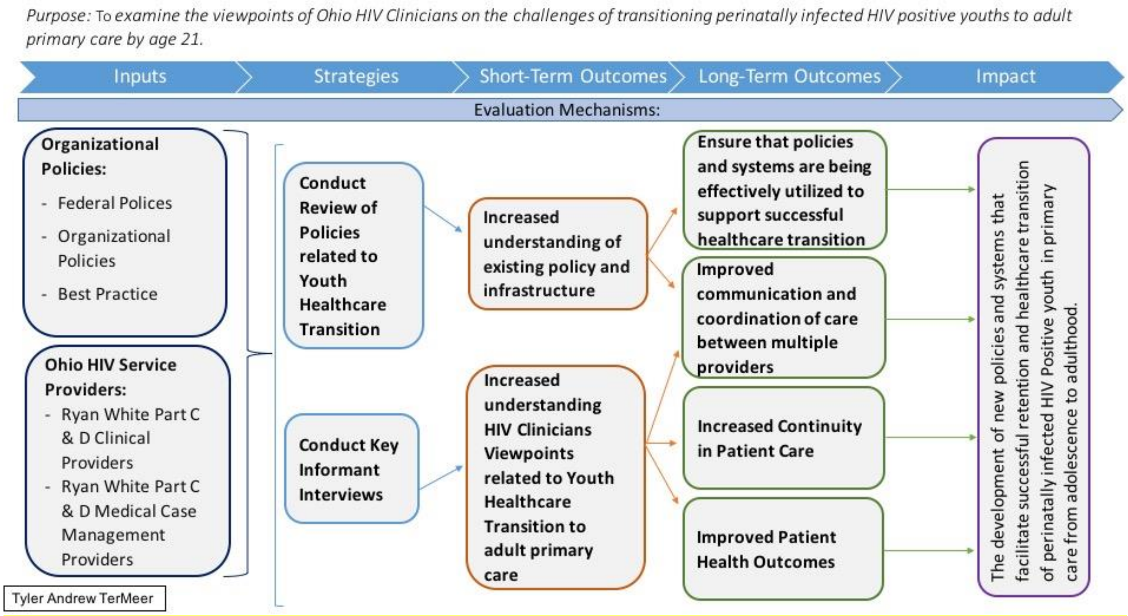
1. It can develop agreement among diverse stakeholders about what they are trying to do and how or identify where there are legitimately different perspectives.

2. It can help to improve plans by highlighting gaps and opportunities for collaboration with partners.
3. It can help to set realistic objectives.
4. It can support the development of meaningful performance indicators to track progress and report achievements.
5. It can be used to identify where and why unsuccessful programs work, and how they might be reproduced or adapted elsewhere.
6. It can provide a framework to bring together information from many sites, many projects, or many evaluations so that it is possible to learn from the past to improve the future. (Funnel & Rogers, 2011, pp. 11-12)

The creation of an outcome line is a relatively standard approach to program theory. In its plainest form, an outcome line starts from the right and works leftward through the outcomes. “The outcome line makes explicit the causal beliefs that link the policy to its desired objectives” (Smith & Larimer, 2013, p. 145). According to Mohr (1995, p. 19) a well-constructed outcome line provides a ready method to identify the outcome of interest. Figure 9 represents the hypothesized outcome line for my study.

Figure 9.

Outcome Line: Health care transition among perinatally acquired HIV Positive youth



The outcome of interest is where:

1. All outcomes to its right are considered immaterial (we do not care what those outcomes are, or even if they occurred).
2. We are willing to assume that all outcomes to the right will happen if this outcome is achieved.

Smith and Larimer (2013) stated that, "the immediate advantages of an outcome line are that it can help identify the outcome of interest and can alert a researcher to the activities and outcomes that may lie between the policy and its outcomes of interest (p. 145).

The qualitative research questions addressed in this dissertation explore the viewpoints of Ohio HIV clinicians regarding the challenges of transitioning perinatally infected HIV positive youths to the adult primary care by age 21. For more than 3 decades, Ryan White funded clinics, the medical community, mental health providers, people living with or affected by the disease, community-based organizations, and many levels of government have been engaged in critical discussions about the continuum of care for individuals living with HIV. Ryan White Part C and D clinics were established specifically to provide increased access and improved health outcomes for women and youth living with HIV. As the disease has progressed, so has the need to examine the impact of these clinics. Throughout the development of research questions, literature review, and study design for this dissertation, the beliefs and actions of Ohio-based HIV clinicians working in these clinics was examined.

Barriers to Transition in HIV Care

Cognitive Development and Mental Health

Children born with HIV early on in the epidemic and now entering young adulthood face both the challenges commonly associated with adolescence as well as a unique set of stressors that have a direct correlation to medical adherence and the ability to sustain optimal health outcomes. Ross et al. (2010) described “adolescence as a developmental stage characterized by immature concrete reasoning often manifested by denial of diagnosis, a sense of invulnerability reflected by risk-taking, and behaviors that are strongly influenced by peer norms” (p. 5). As perinatally infected HIV positive youth continue to age with their disease, more studies are needed to better understand the unique cognitive development and mental health challenges of this population.

> Scharko (2006) stated that, “adolescents and young adults living with HIV, both behaviorally and perinatally infected, have higher rates of cognitive impairment and mental health problems such as anxiety, depression, attention-deficit/ hyperactivity disorder, and posttraumatic stress disorder when compared to their HIV negative counterparts.” (p. 442)

Advancements in HIV care and treatment over the past three decades have highlighted the increased need for the perinatally infected HIV positive young person and his or her caregiver to transition to models that emphasize life-skills and disease management of HIV as a long-term chronic illness. Ross et al. (2010) stated that, “young adults born with HIV have lived with multiple stressors, which include having a socially stigmatized illness, the loss of one or both parents or siblings, and being raised by relatives, adoptive families, or within the foster care system” (p. 5). Coordinated systems of care are not as accessible as young persons transition to adult care, therefore addressing these barriers within a culturally sensitive, youth-centered environment and approach to treatment will be critical in the continuum of care. (Gibson & Walker (2005) reported that, “in the pediatric care setting, young people living with HIV, as with many other chronic diseases, are accustomed to an inter-disciplinary approach to care or a ‘1-stop shopping’ model in which a patient’s medical and psychosocial needs are addressed simultaneously” (p. 115). Remien and Mellins (2007) stated that, “both youth living with HIV and their pediatric providers have expressed concerns about the fact that adult care models often fragment medical and psychosocial services, which makes it difficult for patients to access appropriate mental health providers” (p. S57).

Medication Adherence

Medication adherence for individuals living with chronic illness is an obvious challenge, however, for those individuals living with HIV, there is potential for higher consequences associated with nonadherence than for that of a patient living with other chronic illness. The CDC (2014) reported that, “a continuum of services including HIV testing, HIV medical care, and antiretroviral therapy (ART) can lead to viral suppression, improved health and survival of persons infected with HIV, and prevention of HIV transmission” (para. 1). HRSA (2011) stated that, “adherence to ART among PLWHA is critical for treatment success and is highly associated with beneficial health outcomes, including reduced mortality” (para. 1). However, data released by the CDC further underscores that “of persons living with HIV in the United States in 2011, only 30% achieved viral suppression” (para. 17). The CDC highlighted necessary improvements across the HIV care continuum to effectively protect the health of persons living with HIV, reduce HIV transmission, and reach prevention and care goals laid out by the NHAS (CDC, 2014).

Unsurprisingly, viral suppression among HIV infected young persons remains relatively poor (CDC, 2014). Lack of consistent medication adherence can be attributed to a wide spectrum of challenges ranging from inconsistencies in health literacy, daily routine and fear of side effect or disclosure (Dowshen & D’Angelo, 2011) Ross et al. (2010) stated that, “this population experiences many contributors to poor adherence, including mental health issues and substance abuse, caregiver fatigue and stress, HIV stigma and disclosure, peer relations, and immature concrete reasoning” (p. 4).

Sexual Health

Communication regarding the unique sexual, reproductive, and gender health of perinatally infected HIV positive young persons is critically important as they enter adolescence, specifically because their illness is sexually transmitted. Dowshen and D'Angelo (2011) stated that, "for all youth living with special health care needs, issues related to sexual orientation, reproductive health, and gender identity should be addressed while they are adolescents and throughout the health care transition process" (p. 766). The consequences of not practicing safer sex, including heightened risk of sexually transmitted co-infection or HIV reinfection with a potential drug-resistant HIV strain all impact health care outcomes (Gipson & Garcia, 2009). Vijayan et al. (2009) reported that, "in a study of perinatally infected youth, pediatric providers expressed concerns about the lack of resources in the pediatric setting for appropriate sexual and reproductive health care" (p. 1225). With advancement of treatment options over the last three decades, there has also been an increased need for supporting a shift in paradigm surrounding the importance of sexual risk reduction and secondary prevention strategies among young persons with HIV infection.

Stigma and Disclosure

The World Health Organization (WHO) cited fear of stigma and discrimination as the primary reluctance for people living with HIV to disclose their status and take anti-retroviral drugs (WHO, 2011). The White House (2012) reported that, "despite progress in understanding and treating HIV, stigma and discrimination continue to be serious issues for people living with HIV/AIDS across the globe" (para. 1). Stigma and disclosure may pose an even greater concern for the young person living with HIV as they transition from pediatric to adult health care. Santamaria et al. (2011) stated that, “similar to youth with other stigmatized illness (e.g., epilepsy, psychiatric disorders), youth whose HIV status becomes public may experience or perceive discrimination and rejection from others, and subsequently withdraw” (p. 258). This experienced stigma could negatively impact the young person’s physical and mental health (Santamaria et al., 2011). On the other hand, as the young person gains increased awareness and comfort surrounding their HIV status, HIV-related stigma and rejection could still occur and make them less likely to be open about their status (Santamaria et al., 2011).

Gilliam et al. (2011) reported that, “perinatally infected youth and their pediatric care providers are concerned about transition to the adult health care environment because they may experience discrimination from providers or other patients” (p. 286). Further, as observed in other chronic illnesses, most pediatric HIV providers admit to experiencing difficulty in letting go of patients in which they have been long-term providers and recognized that their institution may no longer be the best provider for the complexities of their patients’ adult health care needs (Vijayan et al., 2009). The perinatally infected young person often has known their pediatric provider for their entire life and will describe the transition away from this provider and into an adult health care setting as being comparable to the loss of a family member (Wiener et al., 2011). For many patients, the care team in a pediatric setting represents a member of the “family”, which could create additional barriers to transition for both the patient as well as the providers (Wiener et al., 2011).

Children born with HIV are often not told about their status until late in their adolescence. However, the AAP (1999) released guidelines several decades ago regarding the disclosure of HIV serostatus to children and adolescents that strongly recommended that “older school-age children and adolescents living with HIV be informed of their HIV diagnosis” (para. 5). Santamaria et al. (2011) reported that, “the AAP argued that adolescents fully informed of their status can tackle illness and issues of dying and immediate future, consider the consequences of their sexual behavior, and participate in their own medical treatment” (p. 257). Decisions about appropriate timing and the conversation subject matter surrounding disclosure of status with children that were born with HIV and are now entering adolescence have continued to be a challenge for medical providers and caregivers (Santamaria et al., 2011).

Despite these recommendations, not all children are informed of their diagnosis before adolescence. Santamaria, et al. further also reported that, “even youth who have not told others about their HIV status may experience internalized stigma in the form of shame, self-blame, and stress related to hiding a potentially damaging ‘secret’ from others as they engage with the negative evaluations of what it means to be HIV+ found within their immediate and broader social context” (p. 258).

Summary

In this chapter, I presented my literature review regarding the history, public health importance, and obstacles related to the transition of perinatally infected HIV positive young persons from pediatric to adult health care. With foresight and proper planning, providers can help minimize the negative impacts of transition and increase the probabilities that HIV positive clients are retained in care and treatment. However, the political framework that has been established as the guiding blueprint for the nation’s response to HIV fails to provide policy recommendations that address the health care transition of young persons born with HIV.

In Chapter 3 I describe the research design, methodology, sample, and data analysis plan used to explore the HIV clinicians’ viewpoints on the challenges of transitioning perinatally infected HIV positive youths, to the adult primary care by age 21. Chapter 4 is a presentation of the results analyzed from the data collected. In Chapter 5, there will be further discussion of these findings and the results as compared to both the existing literature as well as the connection to the theoretical framework.

Chapter 3: Research Method

In this phenomenological study, I explored the perspectives of Ohio HIV clinicians regarding the challenges of transitioning perinatally infected HIV-positive youths to adult primary care by age 21. Additionally, I designed this study to examine factors that led to successful medical adherence and retention in medical care when pro-active transition planning that includes life skills development and opportunities for the young person to manage their own care and treatment exist. This qualitative study was also conducted to gain a better understanding of the motivation and decision-making processes of clinicians when developing policies and protocols that support the unique health care needs of the young person born with HIV entering early adulthood. In Chapter 3, I describe the qualitative research method and design that was used to address the primary research question. I also discuss the role of the researcher and issues of trustworthiness as well as provide a detailed presentation of methodology that includes the processes for sample selection; instrumentation; and data collection, storage, and analysis.

Research Design and Rationale

RQ

The RQ that guided this study was: How will understanding the lived experiences of Ohio HIV clinicians inform why many perinatally infected HIV-positive youths are remaining in pediatric care beyond the age of 21?

Research Methodology

Denzin and Lincoln (2005) described qualitative research as involving "… an interpretive naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret phenomena in terms of the meanings people bring to them" (p. 3). The fundamental phenomenon of this qualitative study was the coming of age of perinatally infected HIV-positive adolescents and the unique viewpoints and challenges perceived by HIV clinicians in transitioning these youths from pediatric to adult care. The majority of research published regarding HIV focuses on progression and treatment in adults (Greifinger, 2012). In the literature review of this study, I highlighted the minimal amount of research that focuses specifically on the thoughts and beliefs of HIV clinicians related to patient populations of young persons born with HIV and the distinctive barriers they face in transition to adult care.

Heuristic Phenomenological Approach

The qualitative investigator has multiple inquiry approaches to choose from as they conduct their research. Phenomenological research, as originated by Husserl (1913), is research meant to study how people describe things and experience them through their senses. The phenomenological approach was designed to help gain a stronger understanding of the nature or meaning of people's everyday lived experiences and requires the researcher to carefully and thoroughly capture how people experience a phenomenon. Moustakas (1990) described heuristics, a form of phenomenological inquiry, as a process of internal search through which an individual discovers the nature and meaning of experience and develops methods and procedures for further investigation and analysis. Moustakas went on to say that

> The power of heuristic inquiry lies in its potential for disclosing truth. Through exhaustive self-search, dialogues with others, and creative depictions of experience, a comprehensive knowledge is generated, beginning as a series of subjective and developing into a systematic and definitive exposition. (p. 40)

Moustakas described the heuristic approach as a combination of personal experience and intensity that yields an understanding of the essence of the phenomenon.

Moustakas' (2001) basic philosophy was that "in every learner, in every person, there are creative sources of energy and meaning that are often tacit, hidden, or denied" (p. 265). The core processes of heuristic inquiry, as described by Moustakas (1990) are:

- Identify with the focus of the inquiry: Getting inside the research question, becoming one with it, living it.
- Self-dialogue: The critical beginning, a researcher allowing the phenomenon to speak directly to their own experience.
- Tacit knowing: Underlies and precedes intuition and can guide the researcher into untapped directions and sources of meaning.
- Intuition: The bridge between explicitly and tacit knowledge.
- Indewelling: The conscious and deliberate process of turning inward to seek a deeper more extended comprehension of a quality or theme of human experience.

- Focusing: Inner attention, a staying with, a sustained process of systematically contacting the central meaning of an experience.
- Internal frame of reference: The understanding that the outcome of the heuristic process in terms of knowledge and experience must be placed in the context of the experiencer’s own internal frame of reference and not some external frame. (pp. 15-27)

Additionally, there are seven basic phases of heuristic inquiry identified by Moustakas (1990):

- Initial engagement: The act of discovering an intense interest; a passionate concern that calls out to the researcher, one that holds important social meanings and personal, compelling implications.
- Immersion: This ensures that the research question is lived in walking, sleeping, and even dream states.
- Incubation: A retreat from the intense concentrated focus, allowing the expansion of knowledge to take place at a more subtle level, enabling the inner tacit dimension and intuition to clarify and extend understanding.
- Illumination: A breakthrough, a process of awakening that occurs naturally when the researcher is open and receptive to tacit knowledge and intuition.
- Explication: A full examination of what has been awakened in consciousness.
- Creative synthesis: The process of the researcher placing the component and core themes into a narrative account.

- Validation of heuristic inquiry: Returning again and again to the data to check whether they embrace the necessary and sufficient meanings. (pp. 15-27)

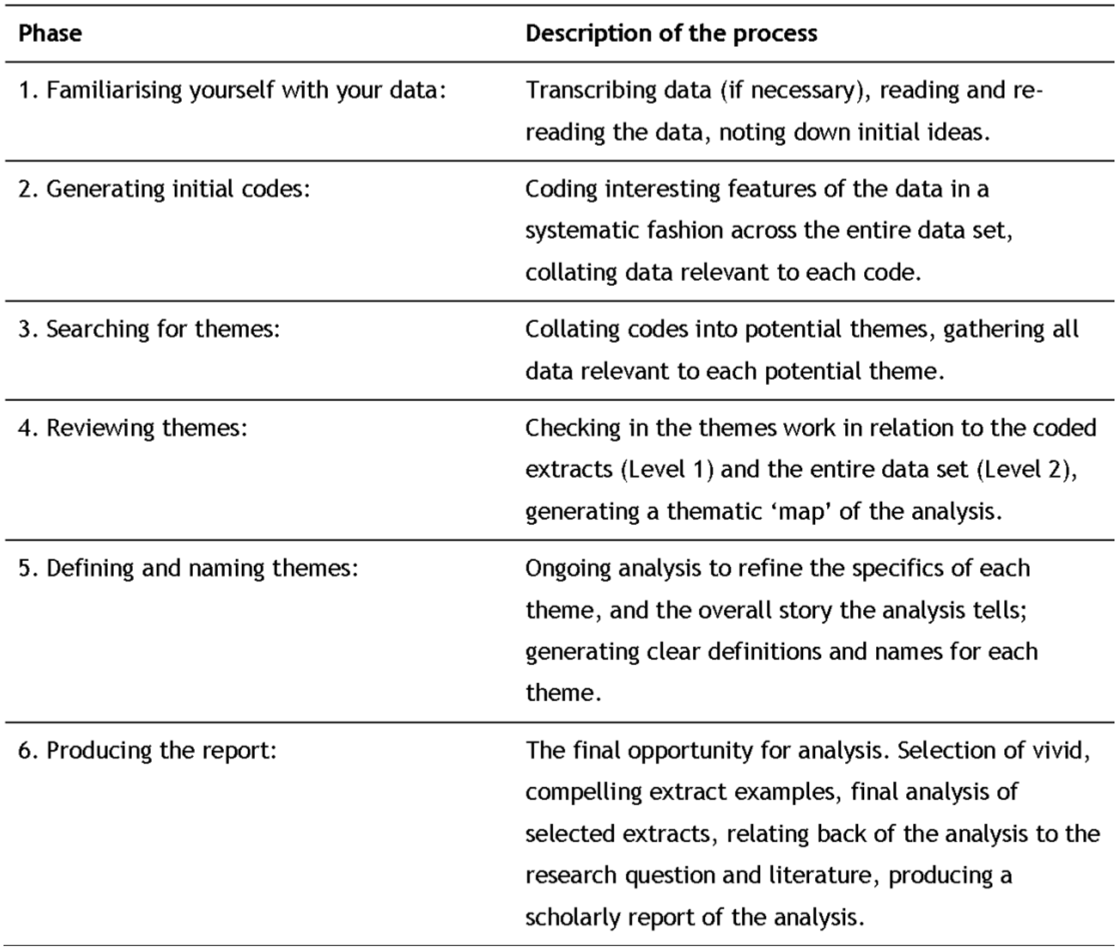
Thematic Analysis

Guest et al. (2012) stated that “Thematic analysis is one of the most common forms of analysis in qualitative research” (p. 11). The method highlights the identification, examination, and recording of patterns or themes within the data (Guest et al., 2012). Braun and Clarke (2006) defined a theme by saying that “A theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set” (p. 10). Braun and Clarke argued that “it is the first qualitative method of analysis that researchers should learn, as it provides core skills that will be useful for conducting many other forms of qualitative analysis” (p. 5).

A thematic analysis provided an accessible and flexible approach for searching across data sets within this study – be that a number of key stakeholder interviews or range of policies across health systems – to find repeated patterns of meaning. Braun and Clarke (2006) provided an outline (see Figure 10) to guide the researcher through conducting the six phases of thematic analysis.

Figure 10.

Six Phases of Thematic Analysis



Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Note: "From "Using thematic analysis in psychology," by V. Braun and V. Clarke. Used with permission (see Appendix A)

In this phenomenological study, I explored the views of multiple Ohio HIV clinicians concerning their experience with perinatally infected HIV-positive youths in transition from pediatric to adult primary care through the lens of Braun and Clarke's (2006) six phases of thematic analysis as described in Figure 10. The study design included in-depth key informant interviews of HIV clinicians in Ohio and a planned examination of existing policies and procedures within the health systems the clinicians worked in; however, I found that either no topic-related, clinic-based policies and procedures existed or that these clinics were unwilling to electronically transmit policy documents (see Chapter 4).

Role of the Researcher

Considered to be the founder of phenomenological research, Moustakas (1994) theorized that research should focus on the wholeness of the lived experience and that experience and behavior have an integrated and inseparable connection. Within this phenomenological study, I served as the interviewer and document interpreter as well as analyzer of the data to draw together general themes that highlighted the shared viewpoints of multiple clinicians. It is the role of the qualitative researcher to interpret what is heard and observed regardless of their personal background as well as previous knowledge and understanding. One of the more complex challenges of qualitative research is the separation of personal experience and biases from data collection. Maxwell (2013) discussed the importance of understanding how the inquirer influences what the informant says and how this affects the validity of the inferences that they can draw from the study.

The role of the researcher can be of particular importance when the study is focused on addressing the individual perception of challenges that may exist in policy or practice that could be impacting successful health care transition, particularly when the interview sample consists of clinicians that have been passionate about and dedicated to their patients’ continuum of care. My biases as the researcher included a genuine interest in the health outcomes of persons living with HIV and a particular interest in identifying the perceived barriers and obstacles to successful health care transition of young persons born with HIV as they approach adulthood. This interest stemmed from more than 17 years working in HIV and sexual health related fields and 16 years living with my own HIV diagnosis. I am currently the CEO of an AIDS service organization that supports and empowers all people with or affected by HIV; works to reduce stigma; and to provide the lesbian, gay, bisexual, transgender, and queer community with compassionate health care. As the researcher, I made my professional background known to the research participants in order to help ease any apprehension but took a more neutral role while conducting interviews with clinicians. I remained self-aware of these biases and specifically was mindful in the development of open-ended interview questions, note-taking, and data interpretation to ensure that my own professional background did not introduce any biases into the interviews or data collected. In order to eliminate bias, qualitative data were not collected from organizations where I am currently or have been previously employed.

Methodology

The targeted population for this qualitative study was Ohio HIV clinicians working with HIV-positive youth with perinatal acquisition. I first intended to examine existing policy and procedure documents related to patient transition from pediatric to adult health care settings for the eight HRSA-funded Ryan White Part C and two Part D clinics or health systems throughout Ohio; however, I found that either no topic-related, clinic-based policies and procedures existed or that these clinics were unwilling to electronically transmit policy documents (see Chapter 4). Part C of the Ryan White HIV/AIDS Program, as described by HRSA (2017), is grant funding to local, community-based organizations that support comprehensive primary outpatient health care for people living with HIV through early intervention services, core medical services, support services, clinical quality management, and administrative cost. Part D of the Ryan White Program, as described by HRSA, provides outpatient ambulatory, family-centered primary, and specialty medical care and support services for women, infants, children, and youth living with HIV. These policy documents would have provided the written procedures for health care transition to support the process and to authenticate or counter information collected during conducted key informant interviews. The sample was to be determined from the number of clinics or health systems that volunteered to submit their policy and procedure documents until a quota of at least eight clinics was reached. To ensure the participation of these Ryan White Part C and D funded clinics, I engaged the Ohio Department of Health HIV/AIDS Bureau to support participation. In the circumstance that a clinic was unwilling to provide data, policy documents for these government-funded entities would be requested through a Freedom of Information Act request.

Patton (2002) defined the criterion sampling strategy as a review and study of all cases that meet some predetermined criterion of importance (p. 238). The population of stakeholders for interviews was HIV clinicians within Ryan White Part C and D funded clinics in Ohio. From a list of qualifying stakeholders, I purposefully selected clinicians (physicians, nurses, medical case managers, and social workers) who were actively seeing patient populations of perinatally infected HIV positive youth for either primary care or infectious disease. These clinicians had active patients on their caseload that were 21 years of age or older and still enrolled in pediatric care. Additional priority was placed on stakeholders from within this group who held responsibility over policy development as well as those who determine or influence impact on patient eligibility, clinical experience and protocol, and how to appropriately implement these policies into practice within their day-to-day health care practice. This criterion sample of qualifying stakeholders was selected to best highlight different perspectives on the issue. This sampling strategy allowed me to conduct interviews with multiple stakeholders.

Instrumentation

Content Expert Validation

For the purpose of this qualitative phenomenological research, a content expert approach was conducted with two clinicians in a Ryan White-funded clinical setting supporting perinatally infected HIV-positive young persons in Arizona. Clinicians were presented with the opportunity to review and offer feedback of the proposed interview questions as a tool for validation. An email communication was sent to the director of the Arizona-based Clinic asking for the ability to pass along this volunteer opportunity among their colleagues. Two clinicians within the clinic were selected for participation based on a first-come-first serve volunteer basis. The content expert approach presents the opportunity to test the interview script for its clarity, logic and flow. Participating clinicians received a $10 gift card or choice of making a donation either in their name or anonymously to a nonprofit organization of their choice for their time following their review.

Documentation Rubric

The first instrument to be used was a review protocol (see Appendix B) developed in a comparison rubric for examining the policies and procedures of health systems related to health care transition for young people born with HIV infection. This protocol represents one of two instruments that was to be used throughout the study. The inclusion of this comparison rubric within the process was intended to add additional credibility to the research. Key themes among cases would have been documented and coded for qualitative data review within NVivo 12 Mac. Clinic-based policies and procedures related to health care transition for these young people either did not exist or these clinics were unwilling to electronically transmit policy documents. As such, this study aspect was eliminated (See Chapter 4).

Interview Protocol

For the purposes of this qualitative data collection and research, a developed interview protocol (see Appendix C) was used to guide the interview process. The interview protocol was developed based on current literature examining the health of young persons born with HIV infection and the policies and stakeholders that inform their transition from pediatric to adult care. The interview protocol drew from key themes related to the systemic barriers and opportunities for successful health care transition by age 21, found in current literature. This protocol also facilitated a process for capturing common themes across cases, based on viewpoints, experiences, and policy interpretation by participating stakeholders.

The interview protocol included a combination of strategies that included an interview guide and a standardized open-ended interview format. Patton (2002, p. 347) described a common combination strategy in which the interviewer uses the guide approach with a standardized format by specifying certain key questions exactly as they must be asked while leaving other items as topics to be explored at the interviewer's discretion. The interview protocol was developed with an established set of questions to be asked of all stakeholders. The interview process closed with a series of open-ended questions that allowed interview participants the opportunity to provide policy recommendations and perceived viewpoints as they relate to the transition of perinatally infected HIV-positive youth from pediatric to adult health care-based systems.

Responses to interview questions were captured through use of an electronic interview recording device, upon receiving permission of the interview participant. A transcription service was paid to assist in my ability to efficiently and effectively convert the audio recorded interviews into a written form for closer study. For the purposes of confidentiality, the transcription service signed a confidentiality agreement. The combination of these approaches ensured consistency, accuracy and added validity to the study. Themes were drawn from the collected responses through use of the NVivo software.

I developed data collection instruments to ensure standardization and a focused research design. These instruments were designed to address the overarching research question presented by highlighting the viewpoints of HIV clinicians related to the transition to adult health care for the young person living with HIV since birth. Questions were developed based in a foundation of current literature to ensure the validity of content.

Procedures for Recruitment, Participation, and Data Collection

Interviews

Study data were collected through a series of interviews with HIV clinicians based in HRSA funded Ryan White Part C and D clinics that are currently serving a patient population of perinatally infected HIV-positive youths throughout Ohio. As the primary researcher in the study, I was the person collecting information from stakeholders and will interview at least 10 HIV clinicians throughout Ohio's Ryan White Part C and D clinics.

Study participation was voluntary and began with email outreach to the Ohio Department of Health HIV/AIDS Care Services (ODH-HCS), the Midwest AIDS Education and Training Center (AETC) and their network of Ryan White Part C and D funded clinical providers throughout the state of Ohio. Participants were consenting as a confidential participant in which their name was protected through use of a randomly generated pseudonym. An email communication that details the purpose and intent of the study was sent to each perspective clinical provider through the ODH-HCS and Ohio AETC distribution lists along with my contact information and a request for participation in the study. A follow-up phone call was conducted with each interested party. Based on the level of response, additional participants may need to be recruited under the same recruitment criteria to achieve the desired sample size. Should additional participants be needed, then targeted emails were sent to providers that are publicly listed on the HRSA website as Ryan White Part C and D funded clinics that are known to be currently serving perinatally HIV-infected young persons.

Interviews were electronically recorded, with the permission of the participant, using a mobile recording device and were anticipated to last 1 hour or less. If a participant declines to be electronically recorded, the participant would need to be notified and acknowledge their understanding that notes would be taken during the interview session. Interviews were to be conducted in-person, at the local public library or community space, throughout Ohio over a 2 week period in cities with known Ryan White Part C and D clinics (Canfield, Cincinnati, Cleveland, Columbus, Dayton, Portsmouth and Toledo). While awaiting additional prospective participants and preparing to travel to Ohio for scheduled interviews, the COVID-19 pandemic began to rapidly impact the United States and limited the possibility of safely conducting in-person participant interviews. After internal review board (IRB) approval for a change in procedure in February of 2020, all participants scheduled were converted to audio recorded interviews through the use of SKYPE video internet protocol. Data were collected from at least 10 participants. If there were not enough expressed interest in the interview process, additional recruitment and incentive-based strategies were to be implemented. Due to the anticipated nature of their schedules, interviews were conducted at mutually agreed upon time, via SKYPE.

Participants successfully completing the interview process received a $10 gift card to a local coffee shop, big box retailer, or the participant could choose to have a donation of equal value made to the organization of their choice either in their name or in recognition of an anonymous donor. A participant's employer refusing the acceptance of incentives did not prohibit participation.

Data Analysis Plan

Throughout my research process there were two forms of data to be collected. Data were to be generated through document review as well as through conducted interviews that will be detailed in the comparison rubric (see Appendix B). Collectively, these two data sources were anticipated to address my posed research question particularly in the area of thematic triangulation. Clinic-based policies and procedures either did not exist or these clinics were unwilling to electronically transmit policy documents; therefore, this aspect of data collection did not occur (See Chapter 4).

The stakeholder interviews provided the viewpoints of HIV clinicians based in Ohio Ryan White Part C and D clinics who are focused in their day-to-day processes on translating policy into practice, whereas the document review details the expected policies and procedures of the health system. Transcripts from each interview were uploaded into NVivo. Initial codes, known as Level 1 coding, were generated systematically across the data set and then further divided into subcategories in the software known as nodes. This study was driven by a thematic analysis (see Figure 10), where related excerpts or common themes across documents are grouped and defined for further analysis.

The NVivo 12 Mac program was the primary tool for data analyses. Patton (2015) noted the value of working with collected information beyond data entry into a computer program.

Issues of Trustworthiness

Credibility

Patton (2002) described credibility within qualitative research as being dependent on rigorous methods, the credibility of the researcher, and the philosophical belief in the value of qualitative inquiry. To ensure credibility, interview transcript triangulation was used as a method of comparison and verification. Patton (2002) stated that, “triangulation strengthens a study by combining methods or data sources to develop a comprehensive understanding of the phenomena” (p. 246).

Transferability

Guba and Lincoln (1985) proposed four criteria for judging the soundness of qualitative research, one of which is transferability or the ability to generalize or transfer to other context or settings within a qualitative methodology. My study had a high likelihood of transferability because what was learned through the interview process from HIV clinicians across the state of Ohio about the barriers to successful transition of perinatally infected HIV-positive youth from pediatric to adult care by the age of 21 could be applied to other Ryan White Part C and D clinics throughout the country.

Additionally, my study could act as a solid foundation for additional research in another state or comparison of findings across multiple states or regions. HRSA funds Ryan White clinics throughout the nation, the establishment of this research as a foundation builds the support for additional resources to support population specific health care transition as well as establishes a pathway for federal policy change.

Dependability

To ensure dependability within my study, triangulation using available literature, researcher notes, audio recorded interviews, and a review of the transcribed interviews by the participant before these data were coded and entered into NVivo 12 Mac for analysis. Patton (2015) highlighted that, “researchers and evaluators can learn a great deal about the accuracy, completeness, fairness, and perceived validity of their data analysis by having the people described in that analysis reach to what is described and concluded” (p. 668). Initially, it was never anticipated that young people born with HIV infection would live to see adulthood, therefore standards for successful health care transition from pediatric to adult care are left in the hands of the individual HIV clinician (Ross et al., 2010, p. 5). Understanding the accurate viewpoints of these clinicians provides the ability to improve systems and policies both within the clinics where they currently work and beyond.

Confirmability

Confirmability is a criterion of authenticity and trustworthiness that a qualitative researcher must establish in order to provide a level of confidence that the research study’s findings are based on the participants’ narratives and words rather than the potential researchers’ own voice and perspective (Patton, 2015). There are a variety of techniques used to establish confirmability, for the context of this study I highlighted a technique commonly used in phenomenological research known as reflexivity. Patton

(2015, p. 63) defined reflexivity as efforts by the qualitative analyst to ensure authenticity and trustworthiness. Patton went on to state that, “reflexivity reminds the qualitative inquirer to be attentive to and conscious of the cultural, political, social, linguistic, and ideological origins in one’s own perspective and voice as well as the perspective and voices of those one interviews and those to whom one reports” (p. 65).

Maxwell (2013) stated that, “what is important is to understand how you are influencing what the informant says, and how this affects validity of the inferences you can draw from the interview” (p. 125). Working professionally in the nonprofit sector to support and empower all people with or affected by HIV, I anticipated that colleagues would be eager to ask questions regarding the data, other interviewees, and any themes emerging early on in the collection process. As the qualitative researcher, I allowed the research to tell this story on its own but also needed to explore why these questions may be asked.

Ethical Procedures

Documentation necessary to ensure ethical procedures were upheld were submitted along with my application for approval (10-23-19-0156151) through the Walden University IRB. Data are stored on a password-protected drive. All data will be kept for 5 years and then destroyed through the reformatting of the drive.

Summary

This phenomenological study served the purpose of illustrating the unique viewpoints of HIV clinicians within Ryan White Part C and D clinics throughout Ohio and the perceived challenges of health care transition for perinatally infected HIV-positive youths. My research approach initially anticipated the use of two forms of data – documentation of policies and procedures related to health care transition for young people born with HIV infection, which were either nonexistent or not available for electronic transmission and conducted interviews. Data from conducted interviews via audio recording and researcher notes were coded and thematically analyzed through the use of NVivo software. Study participants were selected from the four Ryan White Part C and D clinics throughout Ohio. Interview protocols were fully disclosed, and confidentiality held in the highest regard. In Chapter 4 I present and analyze the data collected via the above methods.

Chapter 4: Results

The purpose of this qualitative phenomenological study was to fill a gap in existing literature in relation to successful transition of perinatally infected HIV-positive youth from pediatric to adult primary care by age 21 by examining the viewpoints and challenges perceived by HIV clinicians caring for this population in Ohio. The following RQ guided this study:

> RQ: How will understanding the lived experiences of Ohio HIV clinicians inform why many perinatally infected HIV-positive youths are remaining in pediatric care beyond the age of 21?

In this chapter, I discuss the settings, participants' demographics, data collection, data analysis, evidence of trustworthiness, and study results. I conclude with an overall summary of the chapter.

Setting

I conducted the interviews for this study via SKYPE video over the internet; the interviews were audio recorded. All participants consented in accordance with Walden University IRB policies using the presented informed consent document. Each participant voluntarily agreed to involvement and to being audio recorded. Interviews were scheduled around the availability of participants, each who lived in a time zone with a 3-hour differential from my own. No personal or organizational conditions appeared to influence the participants that could have affected the interpretation of the study results.

Demographics

All participants met the inclusion criteria of being an HIV clinician within an Ohio-based, Ryan White Part C and D funded clinic with active patients on their caseload who were 21 years of age or older, living with perinatal HIV acquisition, and still enrolled within pediatric care. For the purposes of this study, a HIV clinician was inclusive of physicians, nurses, medical case managers, and other social workers. Participants were each working within a clinic that was embedded in a large hospital system or at a community-based, social service nonprofit serving people living with HIV. Of the HIV clinicians participating, 8% were physicians, 25% were nurses, and 67% were medical case managers or social workers.

Data Collection

I recruited 12 participants with whom I conducted SKYPE-based, audio recorded interviews in March of 2020. Following being granted initial IRB approval from Walden University, the recruitment process began in November 2019. I emailed the study invitation to the ODH-HCS and the Midwest AETC who had both approved and agreed to forward my communication to their network of Ryan White funded clinical providers throughout the state of Ohio. I had no direct involvement in the recruitment of participants. The email communication I sent contained the study invitation and a copy of the IRB-approved consent form. Within a few weeks, I had not received any initial email interest back from potential participants. Upon a follow-up communication with both ODH-HCS and the AETC, I confirmed that both institutions had not yet had the opportunity to forward the study invitation on to their networks; however, each agreed to do so in the business days ahead. By mid-January 2020, I started receiving emails from interested participants and began initial efforts to schedule interviews.

The initial IRB-approved protocol called for in-person, audio recorded interviews. My intent was to travel to Ohio to conduct scheduled face-to-face interviews in March 2020. While awaiting additional prospective participants and preparing to travel to Ohio for scheduled interviews, the COVID-19 pandemic began to rapidly impact the United States and limited the possibility of safely conducting in-person participant interviews. After receiving IRB approval for a change in procedure in February of 2020, I converted all participant interviews scheduled to audio recorded interviews through the use of SKYPE video internet protocol.

The data collection process commenced on March 2, 2020. Participants were sent a confirmation email the day before their scheduled interview. On the day of their interview, I contacted each participant via SKYPE. At the start of each video call, I introduced myself to the participant and before proceeding, confirmed that they had voluntarily consented to participate in the study as a confidential participant in which their name would be protected through use of a randomly generated pseudonym. All participants were reminded that their interview would be audio recorded. They confirmed that they had consented voluntarily and were ready to proceed with the interview. SKYPE interview sessions lasted 45 to 60 minutes and were recorded with an audio recorder. Following the completion of each session, I uploaded the audio file to NVivo for transcription under a bounded confidentiality agreement. Full transcripts from each session were received within 24 hours. The last interview was conducted on March 20, 2020.

No unusual circumstances occurred during data collection related to the interview process. Throughout interview sessions, there were several instances where participants provided robust answers and unknowingly answered a question that I was intending on asking as a separate question later in the interview process. In these circumstances, I remained nimble in the moment and did not repeat a question if the participant had already previously answered it. I also chose not to redirect peripheral responses throughout the interviews because the information being shared by the participant was still valuable to the body of research.

The original IRB-approved protocol also called for the use of a comparison rubric for examining the policies and procedures of health systems related to health care transition for young people born with HIV infection (see Appendix B). I sent requests to the eight HRSA-funded Ryan White Part C and two Part D clinics or health systems throughout Ohio. Responses to these requests were limited, and many provided no response at all; however, those that did respond indicated that their clinic either did not have a formal written policy or that they were unwilling to electronically transmit policy documents to me. As a result, the proposed comparisons of policies and procedures were unable to be fulfilled.

Data Analysis

Throughout the interview process, I kept a research log in the form of a notebook. Each interview had a unique tabbed section where I would record the Ohio-based city in which the participant was located; their randomly generated pseudonym; their professional role; and the date, time, and overall length of the SKYPE interview. Following the completion of each interview, I would playback the recorded audio and capture my initial considerations in the margin of the page. Once I received and reviewed each transcribed interview document, I began drawing similarities between the participants' lived experiences by noting key words and/or phrases in the document for further analysis.

Once all interviews were completed, I formatted each of the transcribed interview files to prepare them for import into NVivo. Next, I looked to confirm any significant themes in the lived experiences shared by the study participants by running a query. I began sorting each coded section under a specific category based on likenesses to other responses. Each of the coded categories were reviewed to confirm that these sections were addressing similar concepts and that participant responses were comparable. Names chosen for these categories were a result of commonality in concept and shared language across interviews. Overarching groupings or themes were developed after naming each of the various categories.

Three main themes emerged from my analysis: lack of awareness or absence of formal policies, barriers created by the hand-holding nature of the pediatric system, and the relationship dynamics between the young person and their HIV care team.

Theme 1: Lack of Awareness or Absence of Formal Policies

The first theme emerged from Interview Questions 1 and 4. This theme describes participants acknowledgement that there are no official or formal policies in place to guide the transition process within their Ryan White clinical setting. Participants' responses related to their knowledge of existing policies were brief with short phrases, such as "I don't believe we have an official policy," "I am the policy," "currently there are none," "we kind of just wing it," "does it have to be an official policy?" and "right now there really are no policies, but we have a transition group that is meeting about once a month trying to create policies and procedures for this period of transition."

The majority of participants reported informal practices or indicators that may underscore the readiness of a young person with perinatal HIV acquisition to begin their transition from pediatric to adult care. For instance, Alexa stated, "typically if they're acting like an adult, we're going to begin to move them into the adult world." Doris replied, "it's very fluid on when we transition from a pediatric provider to an adult provider, it could be between the ages of 18 to 21, 22, possibly even older than that." Brie added, "if a client identifies that they want to move, we do a case conference and sort of do a transition in that way." What was universally identified was that there was no "one size fits all" approach to this period of transition. Jade shared her perspective by stating,

> I don't think you can do it an any certain age. I think it has to be tailored. In that case, the policy is that it's up to us to do what we know how to do as nurses and social workers to provide the information. Kids need to become functional adults.

Claire shared in this perspective by adding,

> It would be nice to have a policy, but I don't know if that be helpful. Part of me feels it could be better if there was a policy and that transition happened the same

> for everybody, but then part of me feels like we should just kind of be going with what the patient needs, when the need it and how they need it.

Other participants like Doris, expressed confusion about the lack of current policy:

> There are several other clinics that see pediatrics into adulthood here at our hospital and a few of them are already navigating transition, they have a successful transition plan. So, we have to figure out how to work with them to bring their ideas into life. What do they do that we could carry over into our clinic?

Fern added,

> The lack of buy in from providers to have a standardized transition policy kind of sets our kids up for failure. For example, if a parent says no, then we can’t tell them by law. But also, when we do start transition, where we lack a standard process, we also fail to teach them what they need to know, how to get their medications, how to call for their prescriptions. They don’t know because that’s stuff mom and dad take care of. So, it’s both accountability and teaching how to start to navigate the systems that you have to go through.

Theme 2: The Hand-Holding Nature of the Pediatric System

The second theme encompasses two categories that emerged from Interview Questions 3, 4, and 5. In this theme, participants described a culture of hand-holding in the pediatric health care system and a lack of general life skills education and health care management skills for patients in the transition process. Alexa described the differences between pediatric and adult systems:

> We often describe the role of the physician as different when you're a pediatrician versus an adult physician. With a pediatrician it's much more of a maternal or paternal role. The provider is telling you what to do. Whereas in the adult world, adult medicine is in your hands, you're partners with the provider. It's your responsibility to do this and you have to act like an adult. It's having more of a shared decision-making and shared conversation, which sometimes works and sometimes doesn't. But the approach to health care, as in who it's coming from and who's in charge of the conversation, is different when you look at the pediatric approach versus the adult.

Category 1: Unique Differences Between Pediatrics and Adult Care Settings

In this category, participants described a common practice of hand-holding by HIV clinicians, many of which have been following their pediatric patients through their continuum of care since birth. For instance, Doris stated, "I wouldn't say this to our doctors, but some of the nurses who have been here for a long time and certain pharmacy staff do a lot of hand-holding." Brie added, "I think that the adult system is very different, there is a lot less hand-holding." Doris also stated, "we hold hands quite a bit with some of our patients and have a hard time letting them figure things out completely on their own, we should be letting them fail a little bit so they can learn."

Several participants mentioned the need to teach patients how to be more independent in their health care. Lane stated,

> I think as children, especially if we have children that have a chronic disease, regardless of what it is, we tend to as parents and caretakers, hold their hands and

> take care of them not necessarily allowing them to be a part of the process of aging and aging out of services. Moving into adulthood and taking more responsibility for their own care is an important part of that process. I think we need to become more proactive in that regard and have our clients just be more able to take control of their own care.

Inger further supports this perspective when she stated,

> So, I think we try to support them through the transition by accompanying them if they want that support to the adult care facility for one or more appointments. I personally do a lot of follow up with them on and this transition period while there’s still staff helping them understand how insurance works and helping them understand how to access their medication and making them aware of who to call if they’re having an issue, getting their medication filled or getting an appointment or any of those sorts of things. I think a lot of them struggle with switching over to being the one ultimately responsible for doing that stuff if their parents have been doing it for them. I feel like in pediatrics we do a great job of supporting kids, but I feel like we struggle with seeing them as adults if we’ve been treating them since they were small children. So, we may unintentionally hinder their growth a little bit by continuing to do everything for them until the point that they're in adult care.

Category 2: Life Sills and Health Care Management

In this category, participants underscore a lack of necessary life skills, health care literacy and knowledge for many young patients to navigate the transition into adulthood.

The majority of participants listed a number of obstacles in the process of transition for young people related to the management of their own care. Participants generally noted that youth born with HIV have a different set of challenges that go along with the way they acquired the disease. Responses included “I didn’t do this to myself,” “I didn’t do anything wrong to get this infection,” “many experience challenges with medication adherence, pill swallowing or pill fatigue,” and “there is often burden on their emotional capacity and mental health.”

Grace stated:

> I think a lot of the barrier has to do with the responsibility of being diagnosed with a chronic illness in childhood. If you're perinatally infected, navigating the different systems that we ask folks to navigate and then having the expectation that when you turn 18, that you're going to be making your own doctor’s appointments does not always happen. Or when you're 18, that you're going to know how to navigate the department of Job and Family Services to keep your Medicaid when that's not always realistic if parents or providers have not provided that guidance in making sure people understand those processes - because these are big processes. Additionally, being responsible for taking the medicine every day, if your mom or your dad is giving you your pills every day and then you now are expected to dispense your own medication, that's a transition. That is a challenge. So, I guess I would like to see our programming be able to ease our adolescent patients who are perinatally infected into these new habits, these new lifestyle changes.

Inger supported this statement when she stated:

> I think there are definitely a lot more supports built into the children's system. For instance, if there is an issue with their insurance or an issue is getting medication, they are able to fill it without worrying about whether or not they are going to be able to pay. Like we'll get them their meds and we'll figure it out later and that's not the mentality in the adult system. So, that is something that they tend to struggle with when they switch over. Like, I don't understand, why can't they just give me my meds and then we'll figure this out, so that is something that I think we have to work through when they transition. A built-in thing that really works well at children's facility, but then they're left without it post transition.

Lane further supports this perspective by stating:

> Learning what insurance is, learning how much their medication costs, learning what they need to do, to learn that responsibility and be able to take that responsibility out of the hands of the parents and put it into the hands of the young person. I don’t think anytime is too early to start that conversation. I think if you take the approach of social workers, we start graduating a client the day we do the initial intake. I’m preparing them early and I think about if we’re going to be working with the children and their families, that same approach needs to be taken. We start teaching them in the very beginning because this is a lifelong disease and they’re going to need to learn how to take care of themselves after they graduate high school, after they get out of college. As a society we don’t do

> very good at teaching beyond adolescence - the basic skills that you need to survive.

Inger also stated:

> There needs to be more of a focus on how all of those systems work and handing over more responsibility in little baby steps to the client so they can start having some autonomy over their own care. They need to start to be able to do it and have a chance to have missteps where we can address it in a more supportive environment.

Theme 3: Relationship Dynamics Between Young Person and Their HIV Care Team

The third theme encompasses two categories that also emerged from Interview Questions 3, 4, and 5. In this theme, participants described the relationship dynamics between the patient, parent or caregiver, and their HIV care team.

Category 1: Patients and Their HIV Care Team

In this category, participants describe the complexity of the relationship between youth with perinatal HIV acquisition and their care team. In approaching this relationship, Alexa noted:

> I think it’s important to keep in mind that they are still kids, and one of the things that we see particularly in adolescence is that their brain isn’t finished developing until they are in their mid-twenties. As a clinical provider, recognizing that there may be moments, even within an office visit where the patient is really acting and needs to be treated as a kid. Other times where they’re acting or want to be treated as an adult. Their growth isn’t linear, so being ready for that fluidity in their care.

Grace added:

> I think it’s helpful that the kids we work with, some of them have known our staff since they were born. Being able to continue on with the staff they feel comfortable with, that knows your needs, that knows your family. That can specifically provide wraparound services that are going to be beneficial to you. Just the fact that you don’t have to explain yourself again to another provider.

Alexa provided support to this perspective:

> I think the real benefit of team-based care is that the social worker who works with perinatally infected youth stay with them through the transition. It’s useful to have a consistent face that can help navigate some of the scary features of changing doctors or physically changing the clinic without having to have everybody in the process be different. I think it’s really important for kids to have an anchor, someone they see that’s not changing. With the transition, while their doctor may change, as a nurse may change, they’ve got at least somebody on the team that stays the same. That person may also move between the adult and pediatric world. While it’s probably not policy, I think its best practice to have identified providers that are comfortable and familiar with perinatally infected children in care of those youth, just like we have providers who are extra trained or extra familiar with hormonal transgender affirming health.

Participants also described challenges in balancing the relationship between the care team and young person as it related to their health care transition. Martin reinforced this notion when he stated, “are we setting this client up for stability or are we just kind of adding more fuel to the fire by not allowing this client to learn how to take care of themselves medically?"

Grace added:

> Our clinic is ensuring that we are providing appropriate transition resources because otherwise it is seen as kind of handholding behavior, being able to provide that guidance and still assess if you need help. We're not going to say no or that we are not going to help you. But there's a difference between being able to provide the resources and guide somebody through something versus doing that something for them. We just want to be able to empower all of our patients to be able to know when to ask for help and also to be able to get stuff done for themselves too.

Inger further spoke to this dynamic when she stated:

> One of the barriers is that the social workers at are much more involved in pediatrics. If someone struggles with adherence or transportation or any variety of issues, they are both addressed by a social work team. It's really intensive social work support. When there are barriers, they will call them and text them and email them and go pick them up and make sure they have transportation for things and work out any of those issues for them. I do not think that really happens at all outside of our system. Once they switch to adult care, they do have a social worker, but that person is working with every person. We're talking about a 23 or 24-year-old and we are still doing everything for you. And you you're creeping on the age where you actually no longer are allowed to be in service at a children's

> facility. So sometimes that leads to an abrupt transition that didn't have to be. I think they want to hang on to these young people as long as possible and keep them in a more supportive environment. But I think that's something that they're definitely in need of working on transitioning at a more appropriate age.

Doris also added:

> I think certainly as social workers, we can help with advocating for the patients and stressing the importance of being able to successfully transition and be independent in health care due to the barriers that we often see with lapse of insurance and housing, transportation, mental health services and also both helping the other staff that may not have a social work lens understand those barriers better and how we prepare our patients for a successful transition. It would be a lot easier not only on staff, but patients too, in seeing that they can manage their health care independently and be able to successfully do that. I think that we play a strong role in that by advocating for the patients and the policies to be implemented in our clinic. We also do that by supporting the patients and the staff in the transition and preparing for that process.

Category 2: Patients and their Parents

In this category, participants describe the relationship dynamics between youth with perinatal HIV acquisition and their parent or caregiver. Participant responses often pointed to communication in this bond as one of the greatest barriers to successful transition. Claire stated:

> I think one of the biggest challenges is usually the dynamic between the child and the parents. If the parents are still living. I would say that the perinatally infected youth that probably have done the best are the ones that were adopted or don't live with their bio family. Which is probably bad to say, but it's such a challenging relationship between the child and their parent. The guilt one feels and an innocence that maybe the other one feels. Some families won't even talk about it, which is a problem. It's a fight to event tell the kid.

Lane further supported guilt as an obstacle when she added:

> Looking at it through the parent's eyes, there's guilt that the parent feels because these kids probably got this invitro. So, the parent already feels guilt for that, and they've taken care of them all their lives and they don't necessarily want to let go. I think we need to start educating, working with families, more with the parents, more with the caregivers. Whoever it is so that we can teach how to let go and allow the children to grow up and become adults and become responsible for their illness.

Hope stated:

> Helping the parents and the patients or the guardian and the patient handover that responsibility to the patient and allowing them to take an initiative in doing that, but also still being there in support. I think that one of the barriers is family communication. If we're not having open conversations with our own kids about what is going on and we expect them to take care of something that we're not being honest about, it is just unreasonable. Unfortunately, many young people

> who are born with HIV have seen their moms get sick and die and they know they have the same thing. It's not a matter of the pill is too big to swallow. I cannot remember to take it. I do not like the doctor. Those are simple things. It is really deep psychological things that people struggle with that makes it hard to take care of themselves.

Participants also highlighted the overall importance of the child being aware of their HIV status at an early age as a significant step in the transition process. Doris stated:

> I think the topic should be discussed with the parent before the patient just to prepare the parent as well. That is a huge thing for the parent. Letting them know and helping them let go at whatever age we feel that it is developmentally appropriate for their child. Some parents have had a hard time even just talking about or saying HIV in front of their child. However, you could start that conversation with the parent early and then and just let them know that we will work with them and their child to transition in the health care setting and in transition to an adult provider to prepare them, because that's a big step for the parent, too.

Fern supported this approach when she stated, “I think one thing that works well when they transition is those kids whose parents told them early on and helped them through the process.”

Evidence of Trustworthiness

Credibility

To ensure credibility and to provide an authentic opportunity for participants to share their lived experience during the interview process, they were each reminded at the start of their interview that, as stated in the consent process, participants hold the right to decline participation or to withdraw from the interview at any given time without any explanation. Throughout the entirety of the study, I placed a high priority on the development of relationships of respect with the participants. I did so by ensuring that they were well informed throughout their participation, that the process was clear and transparent and by placing emphasis on making sure that participants were as comfortable as possible. This foundational work provided an atmosphere for participants to more openly share in depth information regarding their lived experiences with the phenomenon. To ensure credibility, triangulation was be used as a method of comparison and verification.

Transferability

My study results have a high likelihood of transferability because the qualitative data gathered through the interview process related to the barriers to successful transition of HIV-positive youth with perinatal acquisition from pediatric to adult care can be applied to other Ryan White clinical settings throughout the country. To ensure transferability, I provided both a review of existing literature related to the identified phenomenon, demographic information pertaining to the interview participants, the specific parameters pertaining to how the study was conducted, and an overall detailed report on the research findings.

Dependability

To ensure the dependability, triangulation using available literature, researcher notes, audio recorded interviews, and a review of transcribed interviews was conducted before these data were coded and entered into NVivo 12 Mac for analysis. The study provides a detailed account of methodology to ensure that similar studies could easily be replicable by other scientists in the future. Specifically, all audio recorded interviews and transcripts, as well as research journal notes have been maintained so other researchers could easily replicate and build on this body of research.

Confirmability

Confirmability is a criterion of authenticity and trustworthiness that a qualitative researcher must establish in order to provide a level of confidence that the study's findings are based on the narratives provided by a participants account of their lived experience rather than having been influenced by the researchers own voice and/own perspective (Patton, 2015). Confirmability was maintained by providing the research findings directly from collected data and not from my own interpretations. There are a variety of techniques used to establish confirmability, for my study's context I used a technique commonly used in phenomenological research known as reflexivity. As a result, I provided direct quotations from research participants without adding my personal analysis of the phenomena.

Results

Throughout my research, I sought to answer one primary research question. Based on the conducted analysis, three themes were established from various interview questions to answer the above research question. Themes 1, 2, and 3 respectively answered the RQ.

Theme 1: Lack of Awareness or Absence of Formal Policies

Participants shared their lived experiences working in Ohio-based Ryan White clinical settings and their role in supporting the health care transition of young persons with perinatal HIV acquisition. All of them consider themselves to be a part of a care team, that encompasses a variety of HIV clinicians including physicians, nurses, medical case managers, and other social work staff. None of the participants worked within a setting in which they were aware of formal policies that address the health care transition of perinatally acquired HIV positive youth from pediatric to adult care settings. Brie stated:

> I don't know if we have any formal policy, but we have an informal protocol to try and bridge it. I will say that the biggest barrier when bridging care is that a lot of these young people that are transitioning have a lot going on in their lives and their health care may not be their top priority.

An absence of policies was further supported by Doris who reported:

> There currently aren't any policies. We kind of just wing it by continuing their care here in pediatrics. It's very fluid on when they transition from pediatric provider to adult provider between the ages of 18 to 21, 22 possibly even older

> than that. If we see they’re not quite ready to transition, there are steps that they kind of work through to show their readiness for transition to adult care.

Hope added:

> In terms of things written down, I don’t know that there is a lot, but there are more informal policies. I feel like we have a pediatric infectious disease physician who sees kids and when they get to be around age 15 or 16 years old, it seems that they’re transitioning them to adult clinic. But it’s more of a soft transition where the person is getting care from a physician who specializes in working with youth and young adults.

Jade stated:

> Written policies are great, but of course they do not take into account the variance of families and ages and such. We are, however, currently working on a more formalized plan for transition. I think when people are coming in with my background, it is a little bit easier, but I do not think it is as easy for some people to just step into the work and feel comfortable when they need a process, a policy to be able to plan ahead for the children whose care they are going to be responsible for. Some of us have been in the program 30 years, so we have been doing work a long time, even before that with the children as inpatients. So, I think that having a formalized policy and process is an important step to helping people be able to then know what we do and then plan for that particular family or child. Not that it is black and white because it's a lot of gray in between based on this population.

Additionally, several participants described that their patients were ill prepared or unaware of their options to transition from a pediatric to adult provider. To that effect Martin stated:

> I have had clients who are beginning to age out of the pediatric system, and they do not even know that another system is an option. They just know what they have known for so long and they do not even know that another hospital network is available or maybe not even a network, but that there is just a more independent kind of adult health care environment available. So, it can take a long time for that transfer to occur. Even then, I usually do not start that conversation unless that client has given me some sort of reason to initiate.

Theme 2: Barriers Created by the Hand-Holding Nature of the Pediatric System

As more context was provided on the health care transition process for HIV positive youth with perinatal acquisition, the majority of participants began highlighting a common practice of coddling and hand-holding of this population. In many cases, participants not only considered themselves as a part of the patients care team, but part of their “family.” Inger stated:

> I think it’s coming from a good place, but at times, I think they want to hang on to these young people as long as possible and keep them in a more supportive environment. I think that’s something that they’re definitely in need of working on - transitioning at a more appropriate age.

Brie shared:

> I think that the adult system is very different. There is a lot less hand-holding. I’m not sure how many of these young people would be able to navigate the adult health care system if they didn’t have the support of somebody who already knew how to navigate these systems, especially if they were used to people always doing it for them.

Further underscoring this phenomenon, Elaine shared:

> As we approach transitioning the youth to the adult care, we would let the youth know that they are at the age that they need to be transferred to adult care. Then we would give them the option of either staying within our group program or they could choose someone out in the community. Most of them chose to stay. I am not trying to brag on the nurses, but patients don't really want to lose their nursing case management. So, I guess that is one thing that they are concerned about when they get ready to go transfer to the adult clinic, that their leaving and not will not have the same nurses anymore. We also want to have the parent know that we are doing this so that they are also onboard and can help and let them know that what we are' doing is going to help them. So, they don't have, or I should say, feel like the that the patient is a burden on them. I think that in the past we have kind of enabled our patients because we have always done a lot for them. We are trying to get them into a routine so that they know exactly what steps they need to take to be successful on their own.

A more positive framing of this hand-holding was described by Elaine when she added:

> We approach the transition to adult clinic in a soft hand-holding way. We're doing it by transitioning to a clinic that works in both the pediatric and adult specialty clinic, and if not with one of the other clinical providers who have a softer, youth friendly touch. So, I think the transition timeline is earlier rather than later. I think if we had to do a written procedure policy, it would be to transition folks earlier and to make sure they're with a user-friendly provider because for not all of our providers is that the case.

Theme 3: Relationship Dynamics Between the Young Person and Their HIV Care Team

Beyond the concept of hand-holding, participants commonly raised concerns about the preparedness of their patients to navigate both the life skills necessary in transition to adulthood and the tools necessary to manage their own health care. To that effect, Doris provided her perspective on the supportive role of the care team when she stated:

> The social worker plays a big role in helping them transition and meeting those goals, showing readiness for transition, health, education, understanding their diagnosis, their medication, being able to independently name their medications and being able to call the pharmacy as well as request a refill and request an appointment. Talking to the providers a lot of the times, with what I have noticed, the parents are still in the room and they do a lot of the talking. So, having the actual patient doing the talking. The one who is transitioning, leading more the conversation with their providers is an important step. I feel like we see we see a

> lot of patients in their 20s who don't know what questions to ask or how to manage their own care. They just don’t know how. They don’t have the education. They’ve never been provided that education. So that’s part of our transition. It’s social work providing the health care educations and the things they need to stay engaged in care. It’s our role to provide them with those skills and prepare them with that education and that information to show them that they can independently do that without their parents. I would say, in our clinic we have very few young adults who show those skills. But the ones who have are independently managing their own health care.

Hope provided further context on this supportive relationship between patient and care team when she shared:

> I think that our current strategy has been really successful. We have created a hybrid model that combines our support groups and an evening clinic with our adult providers that is just for youth. So really nobody else is around during that time. There's something about the co-location where it’s just really easy to walk next door when it's with someone that they trust. In many cases this a nurse or social worker who has been working with a lot of these kids since they were 3, 4 or 5 years old and now they are teenagers. It's the same person that has been working with them the whole time. I think that continuity is really, really important. The whole clinic being willing to do things a little differently. For instance, it is not usually how you would run a group, people coming in and out of the room. But we found that it works really well and that we were just trying to be

> really flexible with people. We also have to find ways to help parents support their kids during that transition. But a lot of times they do not have good support and so we have to be like surrogates to coach people and teach them. It's basic kind of health literacy and taking care of someone that I think like nobody knows when they are 16, 18 years old. It’s something we all have to learn.

Additionally, several participants spoke about the often-challenging relationship between patient and parent as a potential barrier to successful transition. In many circumstances, it is a challenge for the parent to let go and stop managing the care of their child. Martin stated:

> I have had overbearing parents and needed to remind them that a lot of the work is stuff that that parent cannot really even touch. For example, a lot of issues their kids need to work through, they are going to come to terms with when they are ready and on their own terms. Our role is pushing parents to just to ask questions in a way that makes sense for that patient or coaching parents on how to give their children some space.

Inger stated:

> In terms of we are going to start talking to this client about transition, usually a lot of them are still attending with their parents and for the ones that are not, it is really because their parents are not involved anymore. The conversation happens together, or the parents are no longer coming to the appointments, because they’re 23 years old and still engaged in pediatric care. I think they do a good job of letting them know what the options are. I think there is maybe a strong push, but

> maybe the strongest option offered to remain with a provider that exists in the same clinical operations but moving to the adult facility. We do a good job of supporting them through that and trying to answer questions, alleviate fears, doing a warm handoff.

Doris underscored this complexity when she stated:

> It is kind of tricky because you're not changing a provider, you are just changing the perspective of the health care. Essentially, you are still going to see the same doctor, but you are switching from pediatric to adult care. It may be difficult for a patient and a parent to understand because you are still seeing the same person. But now they are in adult care.

Summary

The purpose of this phenomenological study was to fill a gap in existing literature by examining the viewpoints and challenges perceived by HIV clinicians in the successful transition of perinatally infected HIV-positive youth from pediatric to adult primary care by age 21. Twelve participants voluntarily took part using a series of audio recorded SKYPE interviews that followed a predetermined interview protocol. Once transcribed, these data were analyzed using NVivo 12 software where the coding process allowed for categories and later themes to surface. The following themes emerged from the analysis: lack of awareness or absence of formal policies, barriers created by the hand-holding nature of the pediatric system and the relationship dynamics between the young person and their HIV care team.

These three themes facilitated the ability to answer the central research question. Overall, most participants reported informal processes to assist in the successful health care transition of young persons with perinatal HIV acquisition from pediatric to adult health care by age 21. None of the participants had formal written policy guiding their Ryan White clinical practice for this period of health care transition. They described their lived experiences as members of an HIV care team that provided a system of both clinical and social support to their patients from birth, through adolescence, and to adulthood. Support of these care teams, often provided in a very hand-holding manner, range from life skills development to the creation of tools and strategies for health care management.

Finally, they described the complexity of the relationships between patient, parent or caregiver, and the HIV care team. Many participants believe that there is not really another population that deals with the same guilt and shame. In fact, in addition to navigating the already difficult transition from adolescence to adulthood for any young person, youth living with perinatal HIV acquisition have to do so while managing a lifelong chronic illness that was transmitted to them at birth. Furthermore, many are not provided with knowledge of their diagnosis until their teenage years, adding even more complexity to state of their emotional and mental health. The viewpoints of these HIV clinicians underscore a lack of structured policy to guide this process of health care transition and an overly protective environment facilitated by parents and the HIV care team that can result in a delay of health care transition or an abrupt shift in the continuum of care.

In Chapter 5 I summarize the findings of my study and offer theoretical interpretations based on thematic conclusions. In this chapter I will also discuss the identified study limitations, recommendations for future research, implications for positive social change, as well as an overall study conclusion.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this phenomenological study was to fill an existing gap in the literature by examining the viewpoints of and challenges perceived by HIV clinicians in the successful transition of perinatally infected HIV-positive youth from pediatric to adult primary care by age 21. After reviewing and analyzing the collected data, three themes emerged: (a) lack of awareness or absence of formal policies, (b) barriers created by the hand-holding nature of the pediatric system, and (c) the relationship dynamics between the young person and their HIV care team. I used these individual themes to answer the research question.

Overall, most participants described a lack of formalized clinical policies to guide their patients from pediatric to adult systems of care. In the absence of formalized policies or timelines for transition, many participants described a clinical setting with complex relationship dynamics between the patient and their HIV care team that often fosters the nurturing and hand-holding of patients. This phenomenon further creates unintended barriers in the young person's ability to successfully manage their own health care and, ultimately, may impact their continuum of care. To that effect, Martin stated, "I often times think social service agencies don't look at matters seriously, like are we setting this client up for stability or are we just kind of adding more fuel to the fire." In this chapter, I address and interpret the key findings of the study as well as discuss the study limitations, recommendations, and implications for social change before ending the study with an overall conclusion.

Interpretation of the Findings

In this section, I discuss the main findings of this study and how these findings confirm, disconfirm, or extend knowledge in the HIV/AIDS field. The following topics are also discussed: (a) how the obstacles to successful health care transition for HIV-positive young persons with perinatal acquisition identified in this study compare with similar factors in relevant, peer-reviewed literature; (b) how the absence of policy and processes in Ryan White clinics related to the health care transition for HIV-positive young persons with perinatal acquisition identified in this study compare with similar findings discussed in relevant, peer-reviewed literature; and (c) how the findings of this study relate to the theoretical foundation of the study.

Obstacles to Successful Health Care Transition Identified

There were three main themes that emerged from the data analysis: (a) lack of awareness or absence of formal policies, (b) barriers created by the hand-holding nature of the pediatric system, and (c) the relationship dynamics between the young person and their HIV care team. In addition to these barriers, much of the existing literature illustrated that cognitive development, mental health, medication adherence, sexual health, stigma, and disclosure are among many considerations when developing models of transition that are sensitive to the unique experiences of a young person living with HIV. These findings were further highlighted by the responses of the study participants.

Cognitive Development and Mental Health

Several participants discussed cognitive development and mental health as one of the primary barriers to health care transition. Alexa stated,

> Our perinatally infected youth have a different set of challenges that tend to go along with the way they were infected. There is a certain perception. There is a feeling of "I didn't do this to myself" or "I didn't do anything wrong to get this infection." And that, I think, offers a lot of burden on their mental health and their emotional capacity.

These observations confirm findings by Scharko (2006) that showed that adolescents and young adults living with HIV, both behaviorally and perinatally infected, have higher rates of cognitive impairment and mental health problems, such as anxiety, depression, attention-deficit/hyperactivity disorder, and posttraumatic stress disorder, when compared to their HIV-negative counterparts.

Medication Adherence

Participants highlighted struggling with medication adherence as another significant barrier to successful health care transition. Lack of consistency in medication adherence contributed to a wide variety of factors. Alexa stated,

> Getting to a point where they're on a stable regimen and they're taking that regimen can be a challenge. There may be more pill fatigue. Having been taking pills for their entire life, it's not uncommon. That is, they're in their teens, late teen years or early 20s and think – "All right. Nobody is making me do this. I can stop now."

These experiences confirm the findings of Ross et al. (2010) that indicated that this population experiences many contributors to poor adherence, including mental health issues and substance abuse, caregiver fatigue and stress, HIV stigma and disclosure, peer relations, and immature concrete reasoning.

Sexual Health

A few participants discussed the lack of sexual health resources to support HIV-positive young persons with perinatal acquisition. Furthermore, participants reported the delayed disclosure of disease status to these young people until a period of heightened sexual awareness as a barrier. Hope stated, “Disclosure concerns come up a lot. Sexual health concerns. Negotiation skills. We have a lot of comorbid sexually transmitted infections. So, we to find way to talk about testing and things like condoms and PrEP for their partners.” These concerns confirm findings of Vijayan et al. (2009) in which pediatric providers expressed concerns about the lack of resources in the pediatric setting for appropriate sexual and reproductive health care.

Stigma and Disclosure

Participants indicated that stigma and disclosure may pose an even greater concern for the young person living with HIV as they transition from pediatric to adult health care. Fern stated,

> There are a lot of struggles with disclosure. I think the more that we normalize it, the easier it will be when they transition into adulthood. We’ve had kids who haven’t known their status until it was time to transition into adult care. Often these young people are still scared to tell people. They are scared to even get in a relationship, a healthy relationship. Even though they know their taking their medicine. They know they are undetectable. There’s not a chance to transmit.

> They are still afraid. And so that can cause other issues such as depression from the isolation. You see them become anxious because they think somebody is going to find out. All of that impacts into their social and mental health.

These experiences confirm findings by Santamaria et al. (2011) that showed that similar to youth with other stigmatized illness (e.g., epilepsy, psychiatric disorders), youth whose HIV status becomes public may experience or perceive discrimination and rejection from others and subsequently withdraw. This experienced stigma could negatively impact the young person’s physical and mental health.

Absence of Formalized Policies Identified

Participants shared their experiences working within Ryan White clinical settings that have an absence of formalized policies related to the health care transition from pediatric to adult care. These experiences confirm the findings of Hepburn et al. (2015) that showed that despite the well-documented risks and costs associated with a poor transition from pediatric to adult care, little policy attention has been paid to this issue. Lane stated,

> I think we try to protect them and end up putting up our own barriers. We don’t teach these kids how to do enough because we give them so many things. That’s just the way we have evolved. What we end up doing is creating what we think are good barriers, but they do not always end up being good barriers because when we protect too much, then they become dependent.

Furthermore, these experiences confirmed findings by McManus et al. (2013) that indicated most youths with special health care needs are not receiving the essential groundwork for a successful transition to adult care from their pediatric provider. Jade described,

> I think I’m in a unique situation coming from one of the best hospitals in the nation for children. I have been in the program for 30 years, so I’ve been doing this work a long time, even before that with the children as inpatients. We don’t currently have written policies, but many of us in the clinic have been doing this for so long that we just know what to do. So, I think having a formalized policy and processes is an important step to helping new people, new members of the HIV care team, understand what we do and how to plan for a particular family or child. With that being said, written policies are great, but they don’t take into consideration the variances of family dynamics, developmental ages, and such. It’s not black and white, it’s a lot of gray in between based on the patient.

While the majority of study participants indicated that they worked within clinical settings that had informal processes, they expressed a desire for increased coordination and more strategic planning for this period of health care transition. These experiences confirmed the findings of AAP (2011) that underscored transition planning as an essential standard in the provision of care and the importance of every patient having a plan for transition to adult care regardless of their specific health needs. These experiences further confirmed findings of Hepburn et al. (2015) that pediatric-to-adult transitions demand system-level solutions that address the alignment of providers in multiple settings, collaboration across various sectors, and facilitated communication (including record sharing) and capacity building, all of which commonly demand new, flexible funding arrangements.

How Findings of This Study Relate to the Theoretical Foundation

In this study, I used Mohr’s (1995) program theory as a guiding theoretical framework. In program theory, Mohr highlighted that a program’s activities will have certain specified results, perhaps through the medium of some intermediate events or accomplishments that are also specified. Moreover, program theory can be a useful way of bringing together evidence about a program or policy, understanding how that program or policy works, and identifying where there are gaps in the evidence. The findings of this study aligned to this theoretical framework because they show a link between the peer-reviewed literature while also examining the multitude of factors that influence HIV health care transition for perinatally infected HIV-positive youth and a variety of stakeholders. Additionally, the current study findings align with multiple previously noted benefits of program theory, including helping to develop agreement among diverse stakeholders about what they are trying to do and how to identify where there are legitimately different perspectives as well as helping to improve plans by highlighting gaps and opportunities for collaboration with partners.

As outlined in Chapter 2, the creation of an outcome line is a relatively standard approach to program theory. According to Mohr (1995), a well-constructed outcome line provides a ready method to identify the outcome of interest (p. 19). The hypothesized outcome line, found in Chapter 2, Figure 9, visually displays the inputs, strategies, short- and long-term outcomes, as well as the impact or results. For the purpose of examining the viewpoints of Ohio HIV clinicians regarding their lived experiences in working with children born with HIV, two input categories were anticipated.

The first input category was organizational policies and best practices. As previously noted, I planned to conduct a review of policies and procedures in Ohio-based Ryan White Part C and D clinical settings; however, I found that none existed at the clinic level or that participating clinics were unwilling to electronically transmit policy documents. The short-term outcome, or what Mohr would have referred to as an intermediate event, was to gain an increased understanding of existing policy and infrastructure to achieve the long-term outcomes of ensuring that policies and systems are being effectively utilized to support successful health care transition as well as improved communication and coordination of care between multiple providers.

The second input category was centered around Ohio-based HIV service providers working in funded Ryan White Part C and D clinics. HIV clinicians were defined as providers, registered nurses, medical case managers, or social workers that were actively working with the target population of the study. I conducted key informant interviews via internet video calls with these clinicians. The intermediate outcome was to gain an increased understanding of HIV clinicians’ viewpoints related to youth health care transition to adult primary care and, ultimately, to achieve improved communication and coordination, increased continuity in patient care, and improved patient health outcomes. The impact of this outcome line, as supported by my research findings, is a study that lays the foundation for additional research that may assist decision-makers in the development of new policies and systems that facilitate the successful retention and health care transition of HIV-positive youth with perinatal acquisition in primary care from adolescent to adulthood.

Limitations of the Study

This study contained three limitations. The first limitation was that the 10 HRSA funded Ryan White Part C and D clinics were located throughout the state of Ohio in a combination of rural, suburban, and urban communities. In a more rural community, the HIV clinician may be one of the only providers of infectious disease health care in the region, whereas in an urban center the patient may have many options in their transition from pediatric to adult care. This limitation may have impacted the HIV clinician's availability to participate.

Another limitation was that clinics either existed as a standalone practice or within a larger health system or FQHC. I planned to conduct a review of policies and procedures and found none existed at the clinic level or that these clinics were unwilling to electronically transmit policy documents. Key stakeholder interviews also needed to be focused only within these Ryan White clinics and not within the larger health systems. Viewpoints of individual HIV clinicians may not reflect that of the larger health system.

As a person living with and working in the field of HIV over the last 17 years, my own personal and professional experience bring potential bias. This potential bias was acknowledged to participants in the informed consent process. In order to eliminate this bias, qualitative data are not collected from any organization where I was currently or have previously been employed.

Recommendations

My study’s literature review highlights that most academic research related to the health care transition of HIV positive individuals with perinatal acquisition from a pediatric setting to adult primary care setting is centered around the experiences of the young person. There is a lack of academic research that explores the various perspectives and lived experiences of the caregivers, guardians, and HIV clinicians that often compose the care team of those young persons. Researchers are encouraged to continue to address this literature gap in the area of health care transition for HIV positive young persons with perinatal acquisition. In the absence of further research and understanding of multiple viewpoints, public policy practitioners will continue to face challenges in designing policy that supports this period of transition and retains these young persons in their continuum of care. Based on my findings, further studies, described below, could be conducted to uncover additional knowledge that could benefit the creation of public health guidelines or policy that will support this populations successful transition from pediatric to adult care.

I recommend that interested researchers undertake a similar qualitative study exploring the experiences of the parent or guardian of HIV-positive young persons with perinatal HIV acquisition. A review of the literature highlights that children born with HIV were not expected to live until adulthood and therefore the parent or guardian often presents as very coddling having managed all aspects of the child’s life, including their HIV care. In some cases, as noted by participants, the child’s health status is kept from them well into adolescence creating additional obstacles in their care management. I recommend that future research on this population be conducted with their parent or guardians which would allow policymakers to assess trends in health care transition and make informed decisions about policies or guidelines that support both the young person as well as their parent or guardian in being more prepared to navigate through this transition.

A comparative study assessing differences in relationship dynamics between members of the HIV care team (provider, RN, medical case manager, and social worker) and the HIV-positive young person with perinatal acquisition is also recommended for researchers that may be interested in building on my study’s findings. A review of literature illustrated the unique, almost familial relationship, between members of the HIV care team and these young persons throughout their health care journey. My findings highlighted a hand-holding phenomenon and dissonance on the timing and level of involvement the HIV care team as a potential barrier to a successful health care transition.

Many of these clinical providers have been members of the HIV care team for these young persons since birth and are challenged by the experience of letting go. This phenomenon is especially true for those young persons that were born with HIV and may have lost one or both parents to HIV-related complications over time. I recommend that future research on this population be conducted that compares the relationship dynamic between various members of the HIV care team and their differing viewpoints on the timing and approach to health care transition for these young persons. Such data would allow policymakers to establish policy or guidelines that support both the young person as well as their care team in being more prepared to navigate this transition.

A quantitative study assessing the relationship between timing of health care transition and HIV viral suppression is also recommended to help inform the development of policy and guidelines that support the successful continuum of care of HIV positive young persons with perinatal acquisition. A review of the literature highlights that health care transition in this population is often delayed out of fear that the young person may fall out of care and treatment and therefore experience negative impacts on their health outcomes. The creation of more formal policy or guidelines around this period of health care transition, as highlighted in the findings of my research, would be greatly supported by data that draws a correlation between health care transition and health outcomes.

Implications

Through this research, I hoped to fill an information gap by examining the viewpoints and challenges perceived by HIV clinicians in the successful transition of perinatally infected HIV-positive youth from pediatric to adult primary care by age 21. Focusing on HIV clinicians based in Ohio Ryan White funded clinics and using Mohr’s (1995) program theory as a theoretical foundation, I found that several factors have an impact on this population’s continuum of care during their health care transition – namely a lack of awareness or absence of formal policies, barriers created by the hand-holding nature of the pediatric system, and the relationship dynamics between the young person and their HIV care team. Furthermore, I contributed new information and an in-depth understanding on the perspectives of HIV clinicians and their lived experiences in assisting young persons born with HIV in their transition from pediatrics to adult primary care.

This new information and clinical perspective on the health care transition of young persons with perinatal HIV acquisition has the potential for deep impact on social change. My research has a high likelihood of transferability because what was learned through the interview process from HIV clinicians across the state of Ohio could act as a solid foundation for additional research in another state or comparison of findings across multiple states or regions. Understanding the lived experiences of these clinicians provides the ability to improve systems and policies both within the clinics where they currently work and beyond. HRSA funds Ryan White clinics throughout the nation, the establishment of this research as a foundation builds the support for additional resources to support population specific health care transition as well as establishes a pathway for federal policy change.

My study findings have specific implications for public policy practitioners focused on establishing new policy that further supports the continuum of care for people living with HIV and brings us closer to meeting the goals of the NHAS. My research was able to gain a better understanding of the viewpoints and challenges perceived by HIV clinicians. Through the use of these reported data, other researchers could frame additional research questions for future studies that would expand the current body of literature, potentially help improve the continuum of care of this patient population, and create effective social change.

Conclusion

I conducted this research to fill an existing information gap by examining the viewpoints and challenges perceived by HIV clinicians in the successful transition of perinatally infected HIV-positive youth from pediatric to adult primary care by age 21. To gather data, I conducted recorded video conference interviews via SKYPE with 12 participants, which were later transcribed, prior to analyzing the data using NVivo 12 software. From these analyses, three themes emerged that provided a more detailed understanding of the lived experiences of Ohio HIV clinicians as they navigate the health care transition of HIV-positive young persons with perinatal acquisition. By and large, participants described an absence of formalized policies to guide this period of health care transition and support the continuum of care of their patients. Additionally, the majority described the complexity of relationship dynamics between the HIV care team, and the young person. It was commonly noted that a clinical atmosphere that fosters hand-holding and the nurturing of patients may be creating additional barriers for the patient population as they navigate a transition from adolescence to adulthood.

It is recommended that additional research be conducted to ensure that this population is not lost in their continuum of care. Lessons learned can be drawn from existing informal practices within clinical settings that will support the creation of a more formalized policy framework for the health care transition of HIV-positive young persons with perinatal acquisition. On the contrary, the development of any policy must take into account that health care transition is not a one size fits all model.

References

Advocates for Youth. (2010). *Statement by James Wagoner on the release of the national HIV strategy*. https://www.advocatesforyouth.org/category/press-releases/

Advocates for Youth. (2015). *On World AIDS Day we recommit to prioritizing young people.* http://www.advocatesforyouth.org/blogs-main/advocates-blog/2551-on-world-aids-day-we-recommit-to-prioritizing-young-people

American Academy of Pediatrics, Committee on Pediatric AIDS. (2014). Disclosure of illness status to children and adolescents with HIV infection. *Pediatrics*, 103(1), 164- 166. http://pediatrics.aappublications.org/content/103/1/164.full

American Academy of Pediatrics. (2011). Clinical report – Supporting the healthcare transition from adolescence to adulthood in the medical home. *Pediatrics*, 128(1), 182-200. http://pediatrics.org/cgi/doi/10.1542/peds.2011-0969

Blum, R., Haydock White, P., & Gallay, L. (2005). Moving into adulthood for youth with disabilities and serious health conditions. *Research Network on Transitions to Adulthood, 12(9), 785-788.* https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2532874/

Braun, V., & Clarke, C. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. https://www.tandfonline.com/doi/abs/10.1191/1478088706qp063oa

Bradley, H., Hall, I., Wolitski R., Van Handel, M., Stone, A., LaFlam, M., & Valleroy, L. A. (2014). HIV diagnosis, care, and treatment among persons living with HIV – United States, 2011. *Centers for Disease Control and Prevention: Vital Signs*., *63*(47), 1113-1117. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6347a5.htm

Centers for Disease Control and Prevention. (2014). *Achievements in public health: Reduction in perinatal transmission of HIV infection.* http://www.cdc.gov/mmwr/

Centers for Disease Control and Prevention. (2018). Diagnoses of HIV infection among adolescents and young adults in the United States and 6 U.S. dependent areas, 2006–2009. *HIV Surveillance Supplemental Report 2011-2016*, *23(3)*, 1-45. https://www.cdc.gov/hiv/pdf/library/reports/surveillance/cdc-hiv-surveillance-supplemental-report-vol-23-3.pdf

Center for Disease Control and Prevention. (CDC; 2019). *HIV and pregnant women, infants and children.* https://www.cdc.gov/hiv/group/gender/pregnantwomen/index.html

Centers for Disease Control and Prevention. (2020). *HIV and youth.* https://www.cdc.gov/hiv/pdf/group/age/youth/cdc-hiv-youth.pdf

Cervia, J. S. (2013). Easing the transition of HIV-infected adolescents to adult care. *AIDS Patient Care STDs*, *27(12)*, 692-696. https://doi.org/10.1089/apc.2013.0253

Cheever, L. (2015). Engaging HIV-infected patients in care: their lives depend on it. *Oxford Journals*, *44(11)*, 1500-1502. https://doi.org/10.1086/517534

Chu, P. Y., Maslow, G. R., von Isenburg, M., & Chung, R. J. (2015). Systemic review of the impact of transition interventions for adolescents with chronic illness on transfer from pediatric to adult healthcare. *Journal of Pediatric Nursing*, *30*(5), E19-E27. https://doi.org/10.1016/j.pedn.2015.05.022

Crowley, R., Wolfe, I., Lock, K., & McKee, M. (2011). Improving the transition between pediatric and adult healthcare: A systematic review. *Archives of Disease in Childhood, 96(6),* 548-553. https://doi.org/10.1136/adc.2010.202473

Dowshen, N., & D'Angelo, L. (2011). Healthcare transition for youth living with HIV/AIDS. *Pediatrics, 128(4),* 762-772. https://doi.org/10.1542/peds.2011-0068

Fair, C. D., Sullivan, K., & Gatto, A. (2011). Indicators of transition success for youth living with HIV: Perspectives of pediatric and adult infectious disease care providers. *AIDS Care*, *23(8)*, 965-970. https://doi.org/10.1080/09540121.2010.542449

Funnell, S. C., & Rogers, P. J. (2011). *Purposeful program theory: Effective use of theories of change and logic models.* John Wiley & Sons.

Gardner, E., McLees, M., Steiner, J., del Rio, C., & Burman, W. (2011). The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clinical Infectious Diseases, 52(6),* 793-800. https://doi.org/10.1093/cid/ciq243

Gilliam, P. P., Ellen, J. M., Leonard, L., Kinsman, S., Jevitt, C. M., & Straub, D. M. (2010). Transition of adolescents with HIV to adult care: Characteristics and current practices of the Adolescent Trials Network for HIV/AIDS Interventions. *Journal of the Association of Nurses in AIDS Care, 22(4)*, 283-294. https://doi.org/10.1016/j.jana.2010.04.003

Gipson, M., & Garcia, G. (2009). *Transitioning HIV positive youth into adult care.* Faithwalk Enterprises, LLC. http://www.ohioaidscoalition.org/documents/ClientOutreachAttachment4.pdf

Greifinger, R. (2012). *Moving on positively: A guide for youth, care givers and providers.* Massachusetts Community AIDS Resource Enhancement.

Guest, G., MacQueen, K., & Namey, E. (2012). *Introduction to thematic analysis.* Sage.

Health Resources and Services Administration. (2011). *HIV/AIDS care & treatment in health centers* [Program letter 2011-06]. http://bphc.hrsa.gov/policiesregulations/policies/pal201106.html

Health Resources and Services Administration. (2016). *HIV care continuum.* https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum

Health Resources and Services Administration. (2019). *Ending the epidemic: A plan for America. https://www.hrsa.gov/ending-hiv-epidemic*

Health Resources and Services Administration. (2020a). *About the Ryan White HIV program.* https://hab.hrsa.gov/about-ryan-white-hivaids-program/about-ryan-white-hivaids-program

Health Resources and Services Administration. (2020b). *Clinical care guidelines and resources*. https://hab.hrsa.gov/clinical-quality-management/clinical-care-guidelines-and-resources

Health Resources and Services Administration. (2020c). *Federally qualified health centers*. https://www.hrsa.gov/opa/eligibility-and-registration/health-centers/fqhc/index.html

Health Resources and Services Administration. (2020d). *HRSA accreditation and patient-centered medical home recognition initiative.* https://bphc.hrsa.gov/qualityimprovement/clinicalquality/accreditation-pcmh/index.html

Hepburn, C. M., Cohen, E., Bhawra, J., Weiser, N., Hayeems, R. Z., & Guttmann, A. (2015). Health system strategies supporting transition to adult care. *Archives of Diseases in Childhood, 100(6).* 1-6. https://doi.org/10.1136/archdischild-2014-307320

Hussen, S. A., Chahroudi, A., Camacho-Gonzalez, A. F., Hackett, S., & Chakraborty, R. (2015). Transition of youth living with HIV from pediatric to adult-oriented health care: A review. *Future Virology*, *9(10)*. 921-929. https://doi.org/10.2217/fvl.14.73

Kim, R., Steinway, C., Gable, J., & Jan, S. (2017). *Transitioning to adulthood: Unique health care challenges for youth with intellectual/developmental disabilities.* Children's Hospital of Philadelphia Policy Lab. https://policylab.chop.edu/sites/default/files/pdf/publications/Transitioning_To_Adulthood_IDD_0.pdf

Krefting, L. (1991). Rigor in qualitative research: The assessment of trustworthiness. *American Journal of Occupational Therapy*, *45(71)*, 219. https://doi.org/10.5014/ajot.2017.71S1-PO2161

Maturo, D., Powell, A., Major-Wilson, H., Sanchez, K., De Santis, J. P., & Friedman, L. B. (2011). Development of a protocol for transitioning adolescents with HIV infection to adult care. *Journal of Pediatric Health Care*, *25(1)*, 16-23. https://doi.org/10.1016/j.pedhc.2009.12.005

Maxwell, J. A. (2013). *Qualitative research design: An interactive approach*. Sage Publications, Inc.

Mohr, L. (1995). *Impact analysis for program evaluation*. Sage Publications, Inc.

Moustakas, C. (1990). *Heuristic research: Design, methodology and applications.* Sage Publications, Inc.

Moustakas, C. (1994). *Phenomenological research methods.* Sage Publications, Inc.

Moustakas, C. (2001). *Statement.* http://unioninstitute.edu/Faculty/FacultyGrad.Moustakas.html

Peter, N. G., Forke, C. M., Ginsburg, K. R., & Schwarz, D. F. (2009). Transition from pediatric to adult care: Internists' perspectives. *Pediatrics, 123(2),* 417-423. https://doi.org/10.1542/peds.2008-0740

Prokup, J., Andridge, R., Havercamp, S., & Yang, E. (2017). Healthcare disparities of Ohioans with developmental disabilities across the lifespan. *Annals of Family Medicine*, *15(5)*, 471-474. https://doi.org/10.1370/afm.2108

Reiss, J., & Gibson, R., (2002). Health care transition: Destinations unknown. *Pediatrics, 110(3)*, 1307-1314. http://pediatrics.aappublications.org/content/110/Supplement_3/1307.long

Reiss, J., Gibson, R., & Walker, L. (2005). Health care transition: Youth family and provider perspectives. *Pediatrics*, *115(1)*, 112-120. https://doi.org/10.1542/peds.2004-1321

Remien, R., & Mellins, C. (2007). Long-term psychosocial challenges for people living with HIV: Let's not forget the individual in our global response to the pandemic. *AIDS*, *21*, S55-S63. https://doi.org/10.1097/01.aids. 0000298104.02356.b3

Rhode Island Department of Health (2014). *Healthcare transition for youth with disabilities and chronic health conditions: A Rhode Island policy brief.* http://health.ri.gov/publications/policybriefs/HealthcareTransitionForYouthWithdisabilitiesAndChronicHealthConditions.pdf

Ross, A., Camacho-Gonzalez, A., Henderson, S., Abanyie, F., & Chakraborty, R. (2010). The HIV-infected adolescent. *Clinical Infectious Diseases*, *12(1)*, 63-70. https://doi.org/10.1007/s11908-009-0077-4

Santamaria, E., Dolezal, C., Marhefka, S., Hoffman, S., Ahmed, Y., Elkington, K., & Mellins, C. (2011). Psychosocial implications of HIV serostatus disclosure to youth with perinatally acquired HIV. *AIDS Patient Care STDS, 25(4)*, 257-264. https://doi.org/10.1089/apc.2010.0161

Schackman, B. R., Gebo, K. A., Walensky, R. P., Losina, E., Muccio, T., Sax, P. E., & Freedberg, K. A. (2006). The lifetime cost of current human immunodeficiency virus care in the United States. *Medical Care, 44(4),* 990-996. https://doi.org/10.1086/522546

Scharko, A. (2006). DSM psychiatric disorders in the context of pediatric HIV/AIDS. *AIDS Care*, *18(5)*, 441-445. https://doi.org/10.1080/09540120500213487

Schulzinger, R. (2000). *Key transition issues for youth with disabilities and chronic health conditions: Healthy and ready to work* (Policy brief). https://trove.nla.gov.au/work/156248080?q&versionId=170322476

Smith, K. B., & Larimer, C. W. (2013). *The public policy theory primer.* Westview Press.

Tanner, A. E., Philbin, M. M, Duval, A., Ellen, J., Kapofiannis, B., Fortenberry, D., & The Adolescent Trials Network for HIV/AIDS Interventions. (2016). Transitioning adolescents with HIV to adult care: Lessons learned from twelve adolescent medicine clinics. *Journal of Pediatric Nursing, 31(5),* 537-543. https://doi.org/10.1016/j.pedn.2016.04.002

The White House, Office of the Press Secretary. (2012, July 21). *Fact sheet: HIV/AIDS-related stigma and discrimination* [Press release]. http://www.whitehouse.gov/the-press-office/2012/07/21/fact-sheet-hivaids-related-stigma-and-discrimination

The White House, Office of National AIDS Policy. (2010). *The National HIV/AIDS Strategy*. http://www.whitehouse.gov/administration/eop/onap/nhas

The World Health Organization. (2011). *Global HIV/AIDS response: Epidemic update and health sector progress towards universal access.* Progress Report 2011. http://whqlibdoc.who.int/publications/2011/9789241502986_eng.pdf?ua=1

U.S. Department of Health and Human Services. (2020a). *HIV continuum of care.* https://www.hiv.gov/federal-response/policies-issues/hiv-aids-care-continuum

U.S. Department of Health and Human Services. (2020b). *HIV medication adherence.* https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21/54/hiv-medication-adherence

U.S. Department of Health and Human Services. (2020c). *Viral suppression.* https://aidsinfo.nih.gov/understanding-hiv-aids/glossary/1650/viral-suppression

Vijayan, T., Benin, A., Wagner, K., Romano, S., & Andiman, W. (2009). We never thought this would happen: Transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care, 21(10),* 1222-1229. https://doi.org/10.1080/09540120902730054

Watson, A. R. (2012). Continuity in transition from pediatric to adult healthcare. *Journal of College Physicians Edinburg*, *42*, 3-4. https://doi.org/10.4997/JRCPE.2012.101

Wiener, L. S., Kohrt, B., Battles, H. B., & Pao, M. (2011). The HIV experience: Youth identified barriers for transitioning from pediatric to adult care. *Journal of Pediatric Psychology, 36(2)*, 141-154. https://doi.org/10.1093/jpepsy/jsp129

Zaboni, B., & Mayer, K. (2014). The adolescent and young adult HIV cascade of care in the United States: Exaggerated health disparities. *AIDS Patient Care STDs*, *28(3)*, 128-135. https://doi.org/10.1089/apc.2013.0345

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Appendix B: Policy & Procedure Comparison Rubric

Ohio Ryan White Part C & D Clinics: Youth Health Care Transition Planning Comparison Rubric				
Health Resources and Services Administration HIV/AIDS Bureau Performance Measures	Describe how the policy reflects elements that are considered in a transition plan for youth	Describe how the policy provides guidance on when to start the discussion about health care transition	Describe how the policy discusses the involvement of parents or guardians	Describe how the policy discusses who will conduct the discussion about health care transition planning
Clinic 1				
Clinic 2				
Clinic 3				
Clinic 4				
Clinic 5				
Clinic 6				
Clinic 7				
Clinic 8				

Appendix C: Interview Protocol

Interview Protocol Topic: Challenges to Successful Health Care Transition Among HIV Positive Youth with Perinatal Acquisition

Time of the Interview:

Date:

Place:

Interviewer:

Interviewee / Position of the Interviewee:

1. The interview session will begin with greetings, a brief personal introduction, and review of the research topic.

2. Appreciation to the participant will occur for volunteering and taking the time to permit the interview.

3. A brief review of the consent form will occur to ensure complete understanding and if any final clarifying questions are needed. Participant will then be asked to sign the consent form. A copy will be provided for them to keep.

4. The participant will be informed an electronic audio recorder is being turned on and I will note the date, time, and location.

5. The coding identification (where applicable) of the interview will be indicated verbally and written on the actual consent form.

6. The interview will begin.

7. The interview will take approximately 60-minutes for exhaustive responses to the questions.

8. The researcher will use the questions in sequence.

9. The researcher will pause after each question is asked to ensure the participants understand the question. If they do not want to answer any particular question, they may do so for any reason or no reason at all.

10. At the end of the interview, the researcher will thank the interviewee again for taking the time to participate in the study.

Interview Questions:

1. What policies currently exist within your Ryan White Part C or Part D funded HIV clinic that help to support the successful health care transition of youth born with HIV infection from pediatric to adult primary care before the age of 21?

2. In your role as a clinician, what do you perceive to be working well or as success experienced by youth born with HIV infection in their health care transition to adult primary care?

3. In your role as a clinician, what do you perceive are the greatest barriers or challenges experienced by youth born with HIV infection in their health care transition to adult primary care?

4. What policies, if any, currently exist within your Ryan White Part C or Part D funded HIV clinic that you believe may be creating unintentional barriers or challenges to the successful health care transition of youth born with HIV infection from pediatric to adult primary care before the age of 21?

5. In your role as a clinician, how do you personally approach the topic and timeline of health care transition with your perinatally infected HIV Positive youth patients and their parent or guardian?

6. In your role as a clinician, what opportunities do you believe exist for system-level policy change that would support the successful transition of perinatally infected HIV-positive youths into adult primary care by age 21?