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**ADDRESSING SOCIAL AND STRUCTURAL DETERMINANTS AFFECTING HIV  
MEDICAL CARE AMONG ADOLESCENTS AGED 13-24 IN GEORGIA, 2013**

BY

HETA S. PATEL

B.S. BIOLOGY, GEORGIA STATE UNIVERSITY

A THESIS SUBMITTED TO THE GRADUATE FACULTY OF GEORGIA STATE  
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DEGREE

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ADDRESSING SOCIAL AND STRUCTURAL DETERMINANTS AFFECTING HIV  
MEDICAL CARE AMONG ADOLESCENTS AGED 13-24 IN GEORGIA, 2013

BY

HETA S. PATEL

Approved:

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Committee Chair

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Committee Member

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Date

## **DEDICATION**

Every challenging work needs self-efforts as well as guidance of elders especially those who were very close to our heart. I dedicate my humble efforts to my sweet and loving parents whose devotion, encouragement, and prayers allow me to achieve such recognition and privilege.

## **ACKNOWLEDGEMENTS**

I wish to thank my committee members who were more than generous with their expertise and precious time. A special thanks to Dr. Richard Rothenberg and Jamila Ealey for their countless hours of reflecting, reading, encouraging, and most of all patience throughout the entire process. Thank you Dr. Monica Swahn for agreeing to serve on my committee.

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The author of this thesis is:

Heta Patel  
2949 Maple Walk Court  
Lawrenceville, GA 30044

The Chair of the committee for this thesis is:

Dr. Richard Rothenberg, MD, MPH  
School of Public Health  
Georgia State University  
140 Decatur St  
Atlanta, Georgia 30303

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## **ABSTRACT**

**BACKGROUND:** Adolescents aged 13-24 account for a substantial number of new HIV infections every year in the United States. Timely linkage to care and continuous engagement is very imperative for effective medical interventions and overall improved health outcomes for HIV positive young adults. This thesis addresses and evaluates the factors affecting linkage to and retention in care for the newly diagnosed HIV positive adolescents in Georgia in 2013 and potential solutions to address the disparities.

**METHODS:** The analysis assessed quantitative and qualitative data extracted from Georgia's HIV Surveillance-Electronic HIV/AIDS Reporting System (eHARS), Grady Infectious Disease Program (IDP), Ryan White CAREWare, and Georgia HIV Testing Data System. The data analysis was carried out using MS Excel and SAS 9.4. A univariate analysis was used by cross tabulating variables such as linked to care, any care, retention in care, and stratified by race/ethnicity, age, and risk factors. Inferential data was obtained from narrative reports of de-identified client-level from the Anti-Retroviral Treatment Access to Services (ARTAS) Intervention. Descriptive statistics analysis and logistic regression were performed using SAS version 9.4 with significance set at  $p < 0.05$ .

**RESULTS:** Of the total 2,555 newly diagnosed HIV infected persons in Georgia in 2013, 601 were adolescents aged 13-24 years old. In comparison to other age groups, adolescents had the second highest newly diagnosed rate. Of the HIV infected adolescents, only 58% were linked to care and 47% were retained in care. HIV infection was found prominently among Black MSM populations.

**CONCLUSION:** The results of this study indicated differences in factors and barriers that are associated with HIV positive adolescents and linkage to medical care and retention in medical care provide evidence for developing public health interventions. Public health intervention programs that address sex education, effect of IV drug use, and the importance of health insurance may help curb the prevalence of both HIV and sexually transmitted diseases in at-risk groups.

**KEY WORDS:** adolescents, youth, antiretroviral therapy (ART), HIV prevention, HIV counseling and testing (C&T), viral suppression, barriers, linkage to care, retention in care.



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# CHAPTER I

## INTRODUCTION

### 1.1 Background

Thirty-four years into the human immunodeficiency virus (HIV) epidemic in the United States, an estimated 50,000 persons become infected annually. Despite efforts to date, adolescents and young people aged 13-24 years old continue to be susceptible to HIV infection.<sup>8</sup> The Centers for Disease Control and Prevention (CDC) estimates that 26% of the approximately 50,000 new HIV infections diagnosed in 2010 were among the 13 to 24 years of age group. Over 100,000 adolescents aged 13-24 are currently infected with HIV.<sup>8</sup> Linkage to care for newly diagnosed HIV-positive adolescents is an important consideration as the United States HIV epidemic shifts toward younger individuals.

The number of people with undiagnosed HIV in Georgia is not known but the only way to know for sure if one is infected is to be tested. Timely entry into medical care is important for treatment of HIV and secondary medical illnesses. Linkage to care is the process of connecting a client from one service system to another, in this case from HIV testing to HIV care. Some persons never return for further HIV care after initial diagnosis and linkage. Retention in care reflects the recommended standard of care with at least two HIV care visits at least three months apart in a year.<sup>33</sup>

Viral load and CD4 count are closely monitored when beginning HIV treatment. These two counts express virus progression, therapy response, and help determine HIV treatment. A viral load of <200 copies/ml is crucial when preventing HIV progression to AIDS and to diminish viral transmission. Studies have shown that viral suppression

reduces transmission by 96%.<sup>39</sup> Overall, not being retained in care or having inconsistent medical visits is associated with higher mortality.

Adolescents are correlated with a low percentage of retention in care during the first two years following diagnosis and HIV-diagnosed persons younger than 35 years of age have more difficulty establishing and being retained in care.<sup>27</sup> Of the HIV-infected youths, approximately 41% of HIV-infected youth in the United States are aware of their diagnosis, while only 62% of those diagnosed engage medical care within 12 months of diagnosis.<sup>64</sup> Access to and uptake of HIV counseling and testing (C&T) by adolescents is significantly lower than for adults.

The Centers for Disease Control and Prevention advocates routine screening for HIV infection in clinical settings.<sup>15</sup> The implementation of this recommendation has been continuously remaining to a variety of concerns such as lack of awareness and misunderstandings related to HIV screening by physicians and patients, barriers at the facility and legislative levels, costs associated with testing, and conflicting recommendations concerning the value of routine screening. Eliminating these barriers is needed to increase the implementation of routine screening in clinical settings so that more people with unrecognized infection can be identified, linked to care, and provided treatment to improve their health and prevent new cases of HIV infection among adolescents in the United States.

## **1.2 Purpose of the study**

The purpose of this analysis is to examine the HIV Care Continuum methodology used to describe linkage to care and retention in care initiative for HIV-positive

adolescents aged 13-24 in Georgia in 2013 and discuss implications of low percentages of viral suppression for HIV prevention adolescents and possible barriers behind the outcomes. The analysis will be assessing data extracted from Georgia's HIV Surveillance-Electronic HIV/AIDS Reporting System (eHARS) and Georgia HIV Testing Data System in 2013 evaluating variables such as linked to care, retention in care, viral suppression, and stratified by race, ethnicity, age, and exploring other supporting risk factors.

Adolescents are developmentally at a challenging crossroad because of their need for independence and the reality their decision-making ability competes with their concrete thinking processes, risk-taking behaviors, and concern with self-image. This makes it perplexing to draw and sustain adolescents' attention on maintaining their health. Thus, every effort must be made to engage and maintain adolescents in care so they can improve and maintain their health for the long term.

### **1.3 Research Questions**

1. What social and structural disparities affect adolescents from engaging in HIV medical care?
2. How do these disparities among adolescents frame an outcome of the engagement in HIV medical care?
3. How do existing data collection systems support targeting and monitoring for those who need HIV services the most?

## **CHAPTER II**

### **REVIEW OF THE LITERATURE**

The literature review focuses on examining factors that have been found to be associated with increase susceptibility for lack of medical care. Studies that discuss the characteristics and distribution of HIV positive persons are also noted. Finally, the effect of different risk factors related to HIV and sexually transmitted diseases are discussed.

#### **2.1 HIV Testing Challenges Among Youth**

Most new HIV infections among youth occur among gay and bisexual males and accounted for a 22% increase in estimated new infections in this group from 2008 to 2010. Over 50% of youth with HIV in the United States do not know they have the infection.<sup>34</sup> Early detection of HIV infection facilitates people to start treatment sooner and leading to better health outcomes and longer lives. Studies show that people who know they contracted the illness are far less likely to have unprotected sex than those who do not.<sup>32</sup> HIV testing presents an essential opportunity to educate people on how they can protect themselves and others from HIV/AIDS and other sexually transmitted diseases (STDs).

With the increasing numbers of people with HIV/AIDS and missed opportunities for HIV testing, the Centers for Disease Control and Prevention recommends universal and routine HIV testing for all patients seen in healthcare settings. The epidemiologic data recommends that routine screening to be offered to all adolescents at least once by 16 to 18 years of age in healthcare settings where the prevalence of HIV in the patient population is more than 0.1%.<sup>18</sup> In areas of lower community HIV prevalence,

routine HIV testing is encouraged for all sexually active adolescents and those with other risk factors for HIV. This paper addresses any of the actual and perceived barriers that providers face in promoting routine HIV testing for their patients.

The CDC's national Youth Risk Behavior Survey (YRBS) is a school-based survey that monitors health risk behaviors among high school students. The survey provides data on the percentage of students in grades 9–12 who have been tested for HIV.<sup>72</sup> Since 1985, more than 6,600 cases of AIDS among youth aged 13–19 have been reported. By the end of 2006, Youth Risk Behavior Survey (YRBS) estimated 56,500 young people aged 13–24 years old were living with HIV infection or AIDS. Approximately 19,200 adolescents and young adults aged 13–29 were newly infected with HIV during 2006. This age group represented about 34% of all new HIV infections that year.<sup>72</sup> Certain subpopulations are disproportionately affected by HIV/AIDS, including young men who have sex with men (MSM), African Americans, and Hispanics.

According to the 2007 YRBS, 13% of 9th–12th grade students had ever been tested for HIV. Testing rates varied by sex (15% among female students and 11% among male students), race/ethnicity (22% among black students, 13% among Hispanic students, 11% among white students), and grade (9% among 9th graders, increasing to 19% among 12th graders). According to the 2013 national YRBS, 13% of 9th–12th grade students had ever been tested for HIV, which is the same from 2007's survey.<sup>21</sup>

HIV testing has additional public health benefits because it has shown to reduce sexual risk behaviors when implemented with client-centered prevention counseling. Much progress has been made in the area of HIV testing with the help of rapid and less

invasive diagnostic HIV tests that are available. The gold standard is an immunoassay, which tests for the antibodies that your body makes against HIV.<sup>68</sup> The immunoassay may be conducted in a lab or as a rapid test at the testing site. It may be performed on blood or oral fluid. Because the level of antibody in oral fluid is lower than it is in blood, blood tests tend to find infection sooner after exposure than do oral fluid tests. There are other types of HIV testing which are used once a person has been diagnosed with the virus, such as the CD4 test and the viral load test.<sup>34</sup>

Teens and young adults prefer rapid HIV testing that can deliver results in less than an hour but some still worry about whether their tests will be confidential, according to *Journal of Adolescent Health*.<sup>3</sup> A third of the teens from a Boston clinic for HIV testing surveyed preferred completely free HIV testing but many teens said they would be willing to contribute at least \$10 toward the cost of a future rapid HIV test. However, 39% said they had some concerns that their parents and health insurers would discover their results. The strong support for rapid HIV testing by adolescents was encouraging to fellow researchers at Children's Hospital Boston.<sup>3</sup> Few adolescents know where to undergo testing and those who get conventional tests rarely return for their results one to two weeks later.<sup>12</sup>

Most of the people who wanted free tests at the Boston clinic were women and the average age of the patients seeking HIV testing were 20 years old. Rebecca Swenson, Ph.D., an assistant professor of psychiatry and human behavior at Brown University who has studied other barriers to HIV testing among youth, said that "the context of a relationship" could also influence an adolescent's willingness to undergo testing.<sup>3</sup> Youth who use condoms inconsistently with a serious partner were nearly four

times more likely to accept testing than those reporting multiple sex partners. Sexually active teens that are not in relationships are less likely to accept testing despite potentially being at greater risk for HIV exposure. Some youth only test if it's free or if rapid testing is available. A Boston study suggests that health care clinicians might have to engage in some creative solutions to make teen HIV testing more routine, such as using alternate billing codes for the test to provide more confidentiality to the patients.<sup>13</sup>

Cathryn Samples, M.D., who heads the HIV adolescent program at Children's Hospital in Boston, believes providers should be more attentive when providing post-test counseling and medical follow-up, and approach unconventional options to routine testing because youths were less likely to be inclined to discuss test results with medical professionals.<sup>3</sup> Older youths were more likely to know about the different testing methods whereas younger patients were more quick to say they were scared of tests involving needles and knew less about the different testing choices available to them.<sup>41</sup>

## **2.2 HIV Transmission Among Youth**

Most young adults aged 13-24 years old acquire HIV through sexual risk behaviors. Many of them are recently infected and unaware of their HIV infection status. Thus, many are in an early stage of HIV infection, which makes them ideal candidates for early interventions, such as prevention counseling and linkage to and engagement in care. A cohort of youth aged 13-24 years old identified as HIV infected by adolescent HIV specialty clinics in 15 major metropolitan cities in the United States reported to have high-grade viremia. The mean HIV viral load for the cohort was 94,398 copies/ml and 30% of the 988 adolescents in the cohort study were not successfully linked to care.<sup>54</sup>



Another study among HIV infected adolescents and young adults in attendance for HIV care noted primary genotypic resistance mutations to antiretroviral medications in up to 18% of the evaluated sample of recently infected youth determined by the antibody testing assay within 180 days of testing. In addition to this study, considerable multiclass resistance was distinguished in the youth cohort.<sup>10</sup> This transmission dynamic reveals that a substantial proportion of youth's sexual partners are likely older and may be more antiretroviral therapy experienced. Also, this transmission dynamic puts a need for awareness on resistance testing among recently infected youth naive to antiretroviral therapy is crucial.<sup>55</sup>

Many adolescents engage in sexual intercourse with multiple partners and without condoms. Consequently, they engage in sexual behaviors that place them at risk of sexually transmitted diseases (STDs), including HIV. Among sexually active people, adolescents aged 15 to 19 years have some of the highest reported rates of STDs. In addition, particular groups of adolescents, such as males who have sex with males, injection drug users, and teens that participate in sex for drugs, engage in even greater risk-taking behavior. An estimated 25% of all people with HIV in the United States contracted HIV when they were young adults aged 13-24 years old.<sup>40</sup>

Globally, an estimated 11.8 million youth aged 15-24 was living with HIV by mid-2002. Almost 50% of all new HIV infections worldwide, or approximately 6,000 per day, occur among young adults.<sup>51</sup> Because many HIV-infected young adults have not been tested for HIV and their HIV status is not known due to the long latency period before development of clinical AIDS, many cases of HIV/AIDS that are identified among people

in their 20's or even early 30's may have been acquired during their teen years or in their early 20s.<sup>46</sup>

Despite the challenges of determining at what ages HIV infection occurs, the U.S. Office of National AIDS Policy has estimated that half of all new HIV infections occur in people under 25 and that half of these occur among young people between the ages of 13 and 24.<sup>40</sup> The risk for getting HIV is higher in communities where a higher percentage of people already have HIV because partners are more likely to be infected. African Americans have a greater burden of HIV than other racial or ethnic groups in the US so they are at higher risk.<sup>29</sup> Gay and bisexual men are forty times more likely to have HIV than other men. Studies indicate that young gay and bisexual males who have sex with older partners are at a greater risk for HIV infection.<sup>45</sup> This is because an older partner is more likely to have had more sexual partners or other risks, and is more likely to be infected with HIV.

Among new cases of HIV infection reported among 13 to 24 year old men in the United States in 2001, 48% were among men who have sex with men, 3% were among men who injected drugs, 3% were among men who both had sex with men and injected drugs, and only 6% were among men who were exposed through heterosexual contact.<sup>72</sup> Among new cases of HIV reported among young women aged 13-24 years, 33% of the exposure category was heterosexual contact.<sup>41</sup>

Simply providing facts about HIV transmission and prevention or promoting abstinence is not enough for adolescents. Both substance use and emotional unpreparedness of sexual intimacy impairs judgment in risky situations and putting

youth at increased risk for unplanned pregnancy and infection with HIV and other STDs. Youth frequently receive incorrect information from their peers which may give them the false sense that they are invulnerable or already protected. The risk for HIV for most adolescents begins when they start having sex or injecting drugs.<sup>71</sup> For both males and females, having sex under the influence of drugs or alcohol can increase risky behaviors that could lead to becoming infected with HIV.

According to a national survey conducted by the American School Health Association, approximately 25% of 8<sup>th</sup> grade students and nearly 40% of 10<sup>th</sup> grade students report having five or more alcoholic drinks on one occasion during a two-week period. In addition to these statistics, one out of every 15 adolescents has tried cocaine.<sup>12</sup> Even when drug use does not involve needles, alcohol and other drug consumptions impairs judgment, which may lead to unprotected sexual activity. As with alcohol and other drug use, many young people do not consider the consequences of unprotected sexual intercourse.<sup>29</sup>

For most adolescents, the decision to have intercourse is spontaneous where only 17% of young women and 25% of young men report planning their first act of intercourse.<sup>12</sup> Unprotected sexual intercourse causes serious consequences for youth. Approximately one in every five adolescent contracts an STD every year. A 1992 CDC study shows people with a history of STDs and the resulting open sores can facilitate the transmission of HIV and have a higher rate of HIV infection than those with no history.<sup>15</sup>

Although most high school students know the major modes of HIV transmission, misconceptions about the risk of contracting HIV from toilets, donating blood, and insect bites still remain. Also, the misconception of the efficacy of oral contraceptive use in preventing the transmission of HIV and the ability to identify those who are HIV positive by looking at them persist.<sup>71</sup> These misconceptions mislead adolescents about the proper precautions to take to prevent HIV infection and instead put them at a greater risk of infection.

Despite studies that have determined the majority of adolescents have much of the information they need about the dangers of alcohol, drug use, and unplanned unprotected sexual intercourse, risky behaviors among young adults are still resistant to change. In a CDC study, 49.4% of sexually active males and 40% of sexually active females in high school reported they used a condom during their last act of sexual intercourse. Less than half, 44% of gay and bisexual males in high school used condoms the last time they had sexual intercourse.<sup>1</sup> This is evident information alone is not sufficient for teenagers to feel personally at risk and these statistics suggest targeting adolescents' perceptions of vulnerability is necessary to motivate behavior change.

### **2.3 Perceived Barriers to Medical Care for Adolescents**

HIV infection among adolescents is also most likely to be under-reported because adolescents commonly lack access to medical care for HIV diagnosis and treatment.<sup>14</sup> Barriers to care have individual and structural roots. Several interventions for linkage to care are focused on the individual with varying levels of success.<sup>14</sup> Less

attention, however, has been given to “structural barriers” and factors impeding HIV-related care that originate in the social, economic and political disparities that shape and constrain individual health behaviors.<sup>29</sup> Structural barriers include HIV-related stigma and poverty, housing availability and homelessness, unemployment or job instability, insurance policy/eligibility, and public transportation options.<sup>64</sup>

Structural barriers are particularly relevant for HIV-positive adolescents who often have difficulty navigating fragmented care systems.<sup>15</sup> This structural fragmentation can occur when HIV testing sites fail to plan for long term care, when adolescents must negotiate transitions across multiple care systems, when legal or regulatory issues require disclosure to parents, and when providers are unprepared to care for HIV-positive adolescents.<sup>49</sup>

Research has found that youth might forgo reproductive health services if parental consent is required. Laws concerning consent and confidentiality for HIV care and treatment vary among states; thus, physicians need to familiarize themselves with local laws.<sup>50</sup> Public health statutes and legal precedents allow for medical evaluation and treatment of minors with certain illnesses, especially STDs, without parental knowledge or consent. Consent and confidentiality laws, even for the treatment of STDs, may have special provisions in some states for teenagers in foster care. Minors can now consent to HIV testing in all states, although the age of consent varies, pediatricians need to know and abide by the laws in effect in their jurisdiction.<sup>60</sup>

Adolescents maybe particularly likely to receive HIV testing in community-based rather than clinic-based venues, and given the fragmentation between diagnosis and

care, rates of successful linkage to care are lower in community-based settings compared to clinic-based settings.<sup>2</sup> Relatively few HIV-related health services are specifically designed for adolescents, even though adolescents differ from adults in their ongoing dependence on families for resources, health insurance, transportation, and access to clinics and pharmacies.

A study highlights macro, meso, and micro-levels of structural barriers to linkage to care for HIV positive adolescents. Macro-level barriers include navigating health insurance policies, transportation to appointments, and ease of collecting and sharing client-level contact information between testing agencies, local health departments, and clinic. Adolescents and young adults, especially poor and minority, are over-represented in the approximately 10% of American children and adolescents without healthcare insurance of any kind.<sup>6</sup> Lack of insurance also limits subsequent care engagement of newly diagnosed youth, especially if alternative means of payment are unavailable.<sup>48</sup>

Findings from other research show that transportation is uniformly cited as macro-level barrier to care, especially in areas with fragmented and limited public transportation systems.<sup>54</sup> Reduced cost or free transportation services for HIV-positive patients have been shown to improve HIV-related health outcomes.<sup>28</sup> However, our data demonstrate the difficulty of provision of transportation, particularly in a resource-limited time, that is associated with HIV-related care.

Meso-level barriers included lack of youth friendliness within clinic space and staff, and duplication of linkage services. This level of barrier also is affecting linkage to care focused on physical space and the attitudes and behaviors of clinic personnel.

Other studies have shown that staff attitudes often communicate larger social values of homophobia and HIV-related stigma.<sup>50</sup> The concept of adolescent friendliness reflects the importance of creating spaces where HIV-positive adolescents feel secure and not judged.<sup>61</sup> However, few studies aside from results stemming from this program have directly assessed what constitutes adolescent friendly qualities of clinics providing HIV-related care.<sup>62</sup>

Micro-level barriers included adolescents' readiness for care and adolescent developmental capacity. Micro-level level factors, such as individual readiness for care, have the potential to directly affect linkage to care. These data showed that linkage to care often required flexibility and persistence in maintaining contact with adolescents not yet ready to engage in HIV care. Though often seen as a structural issue, the stigma that results from an HIV diagnosis, the fear of rejection by family, peers, and community has individual implications.<sup>48</sup> Development of self- and social-identities during middle and late adolescence additionally affect the acceptance of the HIV diagnosis, which is associated with higher rates of depression, anxiety, social isolation, and stigma among HIV-positive adolescents.<sup>64</sup>

Adolescents are less likely to have health insurance than those of any other age group. In addition, people living with HIV are more likely to experience poverty and lack health insurance when compared with their uninfected counterparts. Studies and data show both behaviorally and perinatally infected youth, as well as pediatric and adolescent HIV care providers, find insurance issues to be a significant barrier to the transition process into medical care.<sup>5</sup> In one study, perinatally infected youth expressed concerns about access to quality providers caused by parental insurance changes,

whereas in another study of behaviorally infected youth, 20% of the participants specifically reported delays in accessing an adult provider because of difficulty navigating an insurance referral system.<sup>61</sup>

Gaps in health insurance coverage and other economic or transportation barriers may lead to missed appointments during transition, which in turn has been associated with rebound in viral load and clinically significant resistance. In addition, some behaviorally infected youth may also experience a “functional” loss of coverage if they are hesitant to access care because of not wanting to disclose their status to a parent or guardian who may be the primary beneficiary of the plan.<sup>61</sup>

Many adolescents living with HIV experience rejection, violence, discrimination, or other poor treatment as a result of disclosing their HIV diagnosis. Concerns about stigma and disclosure may be particularly prominent for young adults living with HIV during health care transition.<sup>14</sup> Several studies have specifically documented 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. This discrimination is to be related to the stigma that is prevalent and directed toward people who acquired HIV through risk behaviors including sexual activity or intravenous drug use.<sup>11</sup>

Similar apprehensions about stigma and fear of consequences of disclosure of diagnosis have been documented in the literature among different populations of behaviorally infected HIV positive adolescents including intravenous drug users and men who have sex with men.<sup>11</sup> Status disclosure is also a distress in this transitional



process. Behaviorally infected youth and their adolescent providers have reported they fear their status will be accidentally disclosed by forcing them to get their health care in facilities labeled as “infectious disease” clinics.<sup>18</sup> Their pediatric or adolescent HIV care is more likely to afford them a higher degree of anonymity and confidentiality.

#### **2.4 Constituents Shaping Adolescents in Medical Care**

There is an increasing trend toward earlier initiation of ART. However, even with the trend to treat all HIV infected individuals, significant barriers for successful ART treatment remain. Foremost, adolescents with HIV must be aware of their status and engage in care. Their physicians must be willing to accept potential barriers such as erratic lifestyle, substance abuse, unstable housing, and nondisclosure prior to initiating youth on life-long ART. Once in care, patients must remain in care and maintain a high degree of adherence to ART.

Despite this, patients may experience baseline viral resistance or could develop resistance due to poor adherence, drug–drug interactions, medication side effects, malabsorption of the medication, or any other factor that can cause delayed low serum blood levels of ART. A large national U.S. study found 14% of the 856 adolescents and young adults aged 13–29 years had transmitted resistance compared to 15% for the entire cohort. Another multisite study of 130 HIV-infected young adults aged 18–24 found 9.2% carried transmitted HIV resistance mutations.<sup>50</sup> Even with universal ART treatment, a significant portion of those who initiate therapy may not respond to typical first-line regimens.

Although recent studies with newer ART regimens have suggested high levels of viral suppression in adults, adolescents and young adults do not appear to achieve this goal. Recent first-line viral suppression rates after Highly Active Antiretroviral Therapy (HAART) initiation for adolescents in clinical trials report suppression rates as high as 86%.<sup>53</sup> However, observational studies report lower suppression rates ranging from 46% to 59%. Comparatively, adult first-line ART regimens report viral suppression rates between 79% in observational studies and 85–98% in clinical trials. By combining recent studies of potent ART regimens in adolescents and young adults, we estimate that only 51% achieve viral suppression to less than 400 copies/ml.<sup>52</sup>

During adolescence, youth with chronic illness commonly go through periods of poor adherence to medical regimens. Several studies have found poor viral suppression rates or poor adherence among HIV-infected adolescents. Among HIV-infected adolescents, barriers to adherence include medical, psychological, and logistical reasons.<sup>61</sup> Medical barriers shown to affect adherence in youth include an AIDS diagnosis, a difficult ART regimen, absence of symptoms, side effects of medication, and dissatisfaction with the health team/system.<sup>54</sup> Logistical barriers such as forgetting medication doses, travel, and inconvenience/inconsistent routine, commonly affect adherence in youth. Psychological barriers including depression/anxiety, perceived stigma, lack of support, behavioral and conduct problems are present in more than 50% of HIV-infected youth.

In order to sustain viral suppression while receiving antiretroviral therapy, it is essential to remain engaged in regular medical care. The ARTAS study found young adults aged 18 to 24 were significantly less likely (52%) to be retained in care than

adults (59%) at one year of treatment ( $p=0.02$ ). Another study found age was significantly associated with lack of retention in care in which 41% of those younger than age 25 were retained compared to 75% of those over 25 years old. A study from South Carolina found that only 31% of those aged 18–24 years were retained in care over 3 years.<sup>61</sup> Others have also found low retention rates in young adults. Combining published data on adolescents and young adults, we estimate that 43% are retained in care over 1–3 years.<sup>63</sup>

Improvement in antiretroviral therapy has changed perinatal HIV infection from a terminal disease into a chronic, manageable infection requiring medication adherence. This presents an additional challenge for many perinatally infected and younger behaviorally infected adolescents cared for in pediatric or adolescent facilities that must transition to adult care in their late teens or early twenties. Although HIV infected youth are more likely to have cognitive impairment and mental health problems, they are less likely to receive coordinated care in adult-oriented facilities. In addition, transition to adult services has been associated with lapses in adherence and worse clinical outcomes for adolescents with chronic illnesses. Changing of care providers, lack of youth-friendly services, rigid scheduling, increasing responsibilities, and decreasing involvement of adult caregivers all contribute to the challenges of transition care for adolescents and young adults.

## **2.5 HIV Care Continuum**

The HIV Care Continuum has become a fundamental in the public health world for the care of patients with HIV/AIDS. This paper addresses the phases that make up

the care continuum as linked to care, retained in care, and viral suppression. The term “linked to care” refers to process of assisting HIV-diagnosed clients into medical care within 3 months of diagnosis between January 1, 2013 and December 31, 2013. The term “retained in care” refers to having at least two CD4 or VL at least 3 months apart in 2013. Viral suppression refers to having a VL of less than 200 copies/ml in the most recent VL in 2013. Each stage in the continuum is independent of those preceding it and all percentages are of the total number of persons (N) diagnosed with HIV in each category.

Despite differing descriptions for the HIV care continuum, the outcomes carry similar trends. The continuum focuses on several steps of HIV medical service delivery, including diagnosis, linkage to care, retention in care, ART, and viral load suppression. The HIV Care Continuum provides a framework to better understand HIV care and treatment in the United States. Data suggest that without significant improvements at each stage of the HIV Care Continuum, more than 1.23 million new HIV infections could occur in the United States over the next 20 years.<sup>67</sup> The obvious decline between linkage to care and retention in care shows that these are serious intervention points for scaling up ART coverage and capitalize on public health and clinical benefits.

## **2.6 Anti-Retroviral Treatment and Access to Services (ARTAS)**

ARTAS or Anti-Retroviral Treatment and Access to Services is a Linkage Case Management System. ARTAS is an individual-level, multi-session intervention for people who are recently diagnosed with HIV or have fallen out of medical care. ARTAS Linkage Case Management is time and session limited with up to five sessions over a

90 day period. ARTAS can provide practical assistance to the client, including providing transportation to a clinic, making contact with the clinic, notifying a partner, getting housing, and identifying other barriers to following through with medical care.<sup>2</sup>

Sometimes ARTAS is completed within one session.

The goal of Grady Infectious Disease Program ARTAS Program is to assist people eligible for care in the program in enrolling in HIV medical care and related services for the first time or reenrolling those who have fallen out of care, often due to significant barriers.<sup>2</sup> The ARTAS Linkage Program considers this goal important because people who remain in care and on antiretroviral medications have better health outcomes than those who do not. Consistent medical care and treatment also reduces transmission of HIV to other people.

Some identified barriers include housing, transportation, employment, family support, substance abuse, mental health, nutrition, literacy, unknown resources, and the lack of perceived need for care. The Linkage to Care Resource Care Coordinator is responsible for screening recently diagnosed patients for eligibility to participate, conducting active case management, implementing a marketing plan, and creating materials to educate potential community partners.

## CHAPTER III

### METHODS AND PROCEDURES

#### **3.1 Data Source**

All health care providers diagnosing or providing care to a patient with HIV must by law report HIV infection using the HIV/AIDS Case Report Form (O.C.G.A. §31-12-2(b)). Case report forms must be completed within seven days of diagnosing a patient with HIV or AIDS or within seven days of assuming care of an HIV positive person who is new to the provider, regardless of whether the patient has previously received care elsewhere.<sup>57</sup>

Name-based reporting of HIV began in Georgia in 2004. Georgia law mandates that laboratory facilities licensed in Georgia report all HIV-related laboratory tests including undetectable viral loads and that all health care providers submit HIV case report forms to the Georgia Department of Public Health HIV/AIDS Epidemiology Section. Data from laboratory tests and case report forms are entered into the eHARS (electronic HIV/AIDS Reporting System) database.

Sex, race/ethnicity, age, status of linkage, status of engagement, status of retention, stage of diagnosis, and transmission category was stratified in the data. The risk factors presented on a HIV case report form include sex with male, sex with female, injection of non-prescription drugs, and heterosexual relations with a person with HIV.<sup>33</sup>

#### **3.2 Variables**

*Linkage to care.* Timely entry into medical care is important for treatment of HIV and other medical conditions. Linkage is the process of assisting HIV-diagnosed clients

into medical care with an HIV primary care provider authorized to prescribe HAART medications following the receipt of a HIV diagnosis. Linkage to medical care requires follow-up and documentation.

*Retention in care.* Retention in care more closely reflects the recommended standard of care with at least 2 HIV care visits at least 3 months apart in a year.

*Viral suppression.* A viral load <200 copies/ml is the important to prevent progression to AIDS and to eliminate viral transmission. Studies have shown that viral suppression reduces transmission by 96%.

*Stage of Diagnosis.* Based on the CD4 count (cells/ml), HIV infection is classified as stage 1 (CD4 count > 500), stage 2 (200-499) and stage 3, AIDS (<200). In Stage 3 disease, or AIDS, the individual is susceptible to infections and tumors.

*Transmission Category.* MSM = Male to male sexual contact. IDU = Injection drug use. MSM/IDU = Male to male sexual contact and injection drug use. HET = Heterosexual contact with a person known to have, or to be at high risk for, HIV infection. Other = hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified.<sup>33</sup>

### **3.3 Inclusions and Exclusions**

This analysis includes newly diagnosed adolescents aged 13-24 males and females with a current residence in Georgia. In addition, all age groups of newly diagnosed HIV infection were included in the study. The adolescents aged 13-24 in the analysis were diagnosed by January 1, 2013 and living as of December 31, 2013,

including those missing race. Data were extracted from eHARS using SAS and Microsoft Excel. A supplementary analysis was then performed by evaluating variables such as linked to care, retained in care, viral suppression (VS), stage of diagnosis by CD4 count, and stratified by race/ethnicity, transmission category, and age.

### **3.4 Statistical Procedure**

Statistical Analysis System (SAS) 9.4 was used to prepare data as well as analyze data and run statistical tests. Descriptive statistics were derived from the demographic variables using SAS. Prevalence of HIV positive individuals was derived from the data. Univariate logistic regression analyses were performed on HIV infected persons to determine their association with risk factors, which included race, gender, sex with male, sex with female, ever used injection non-prescription drugs, and heterosexual relations with person with HIV or at risk for HIV infection. A forward stepwise logistic regression analysis was performed on each dependent variable to determine which risk factors were the strongest predictors for each disease.

### **3.5 Anti-Retroviral Treatment Access to Services (ARTAS) Intervention**

Inferential data was obtained from narrative reports of de-identified client-level from the Anti-Retroviral Treatment Access to Services (ARTAS) Intervention at Grady IDP. Narrative Progress Reports were summarized toward contract deliverables including testing performed, percent of goals reached, and populations tested positive and linked to care from 2013-2015. Success and accomplishments during the period were recorded in the ARTAS Linkage to Care Program. Plans for corrections and improvement were noted if ARTAS fell below the target or behind schedule.



## CHAPTER IV RESULTS

### 4.1 Georgia Care Continuum, 2013

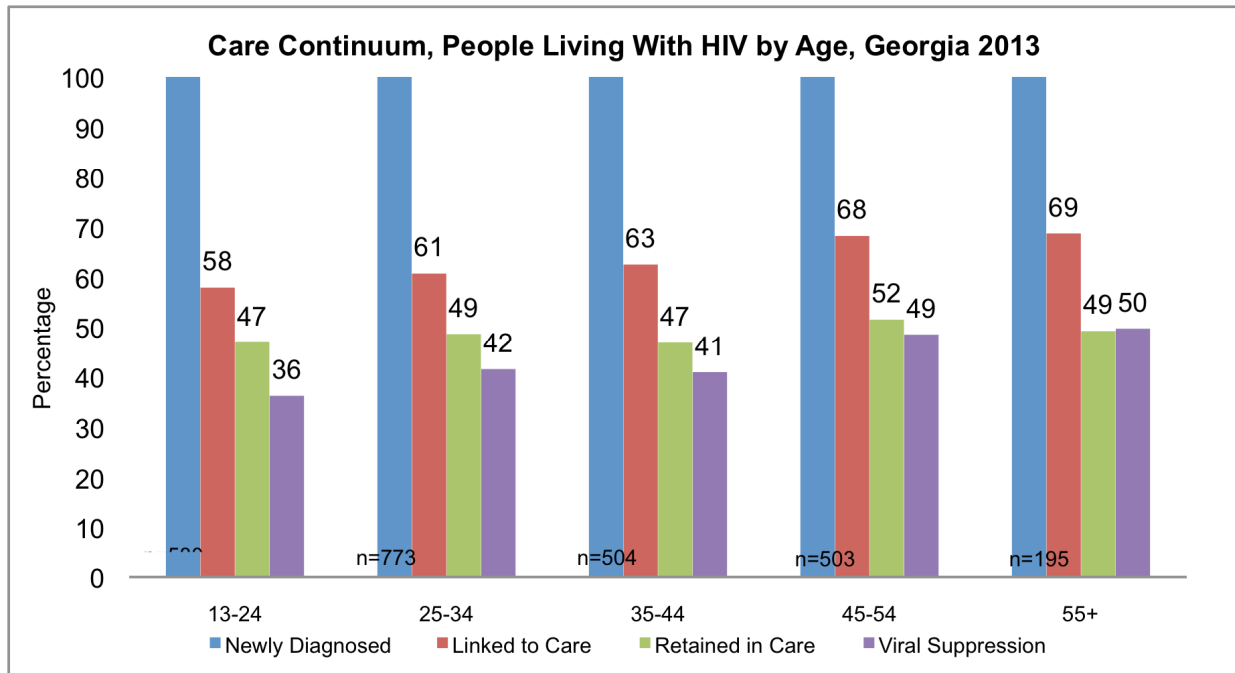


Figure 1 shows the HIV care continuum stratified by different age groups in Georgia in 2013. Adolescents aged 13-24 reports the second highest number of newly diagnosed HIV infection among the other age groups. Although these numbers may not seem significantly different, adolescents have the lowest linkage to care, retention in care, and viral suppression percentages in comparison to counter age groups.

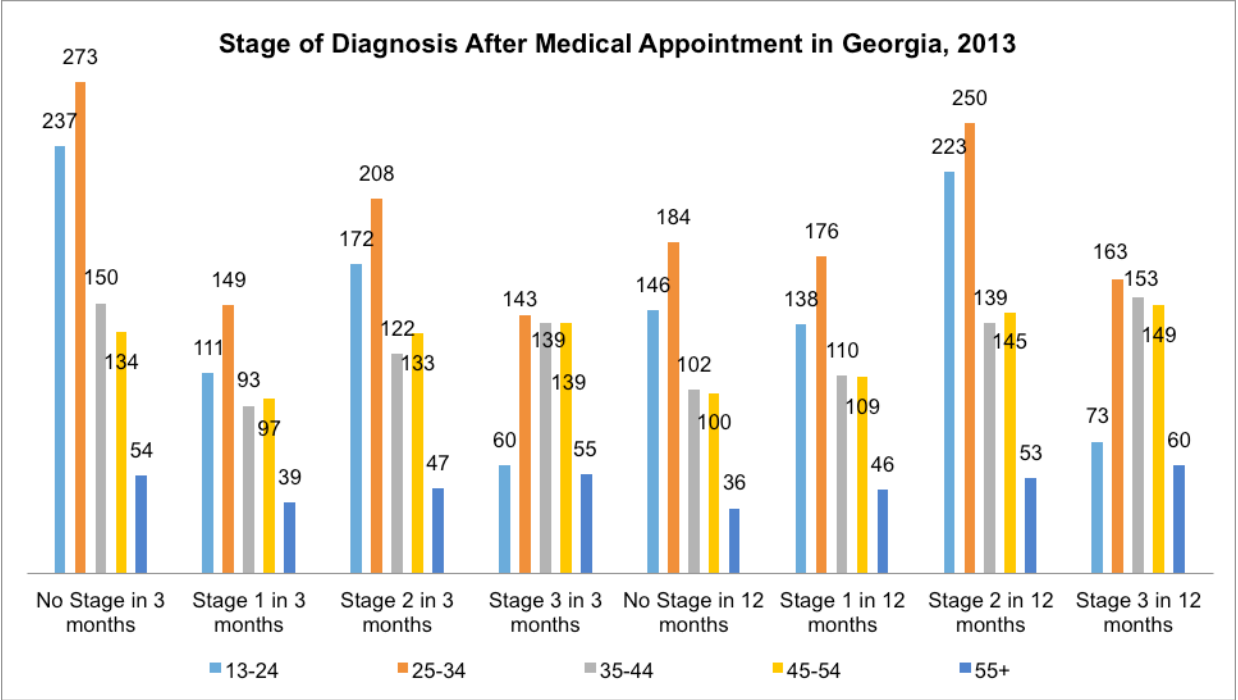


Figure 2 looks at the number reported for each stage of diagnosis by age group after attending HIV medical care appointment in 2013. The data indicates adolescents aged 13-24 years old have the second highest reported rate of acute infection after 3 months and 12 months when attending their HIV medical appointment. It is also important to notice adolescents aged 13-24 have the second highest rate of diagnosis for stage 1 and stage 2 in 3 months and 12 months after medical appointments. These numbers show compliancy with HIV medical care appointments lead to viral suppression.

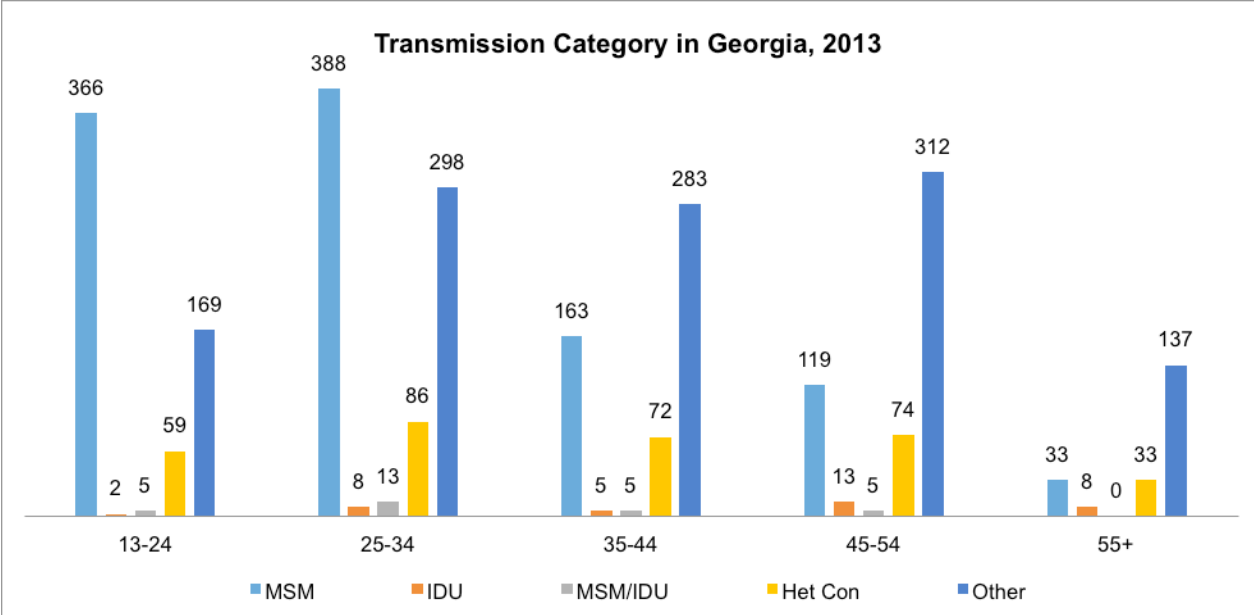


Figure 3 shows a breakdown of the transmission category by different age groups. MSM was the highest transmission category among adolescents aged 13-24 years old and adults aged 24-34 years old. Injection drug use and MSM/injection drug use were the lowest transmission categories reported among all age groups. The prominence of MSM transmission noted in 13-24 year olds and 25-34 year olds can be further evaluated when discussing social and structural barriers among this transmission group, which numbers alone cannot explain.

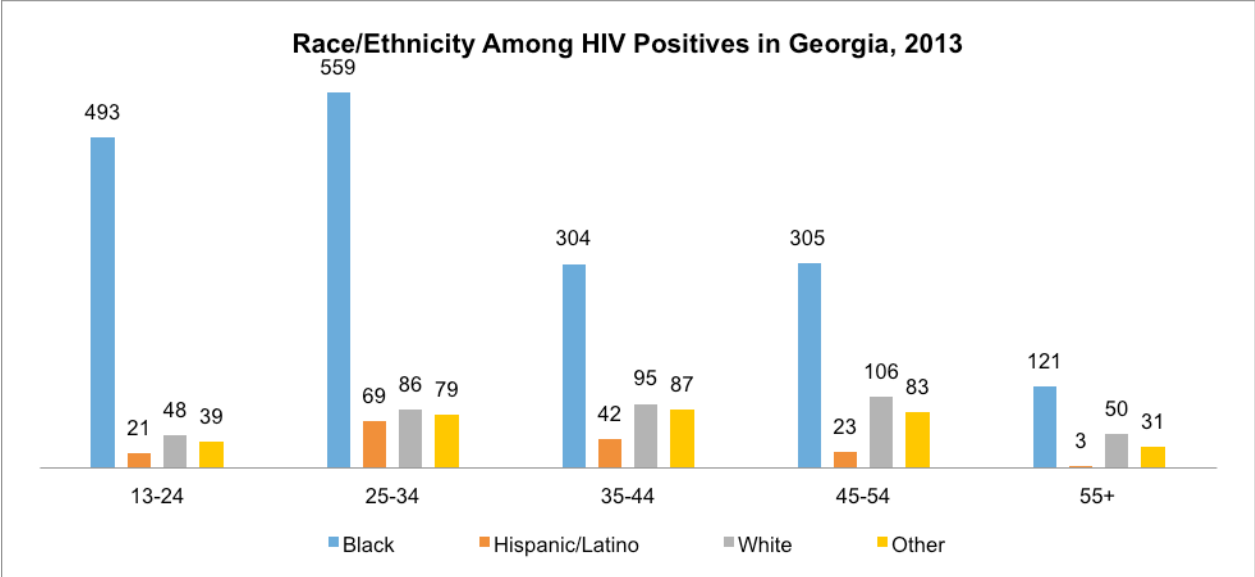


Figure 4 shows the number of newly HIV positive diagnosed in Georgia in 2013 categorized by race/ethnicity. The data found HIV positive rates were high among Black/African Americans and Whites. Transmission categories, particularly MSM, influence the high infection seen in Blacks and Whites. Hispanic/Latinos showed the lowest rate of HIV infection among the other race/ethnicities.

<b>OR (95% CI)</b>	<b>Linkage to Care</b>	<b>Retention in Care</b>	<b>Viral Suppression</b>
<b>Age</b>	*0.87 (0.82, 0.94)	0.94 (0.88, 1.01)	*0.90 (0.84, 0.96)
<b>Sex</b>	*0.78 (0.62, 0.97)	*0.77 (0.62, 0.95)	0.94 (0.77, 1.14)
<b>Race</b>	0.99 (0.91,1.07)	0.94 (0.87, 1.01)	*0.89 (0.83, 0.95)
<b>Transmission Category</b>	1.04 (0.99, 1.10)	*1.11 (1.06, 1.17)	1.05 (1.00, 1.10)

\*indicates significant association

Table 1 shows the measures of association of linkage to care, retention in care, and viral suppression by age, sex, race, and transmission category. The referent groups in each variable were assigned as: 13-24 age group, male sex, Blacks race, and MSM transmission category. This data indicates 13-24 year olds are less likely to be linked to care and virally suppressed than the other age groups. Males are less likely than women to be linked to care and retained to care. Blacks are less likely to be virally suppressed. MSM are less likely to be retained in care.

## **4.2 Anti-Retroviral Treatment Access to Services (ARTAS) Intervention**

The ARTAS Linkage to Care Program supported by Georgia Department of Public Health through Grady IDP was able to successfully link clients to medical care while assisting them in removing the barriers to their medical care. Some of those barriers included: substance abuse treatment, housing, and identification for registration to healthcare, linkage to medical case management, nutrition assistance and transportation. A few stories in particular were pulled out to compare and contrast the barriers found among various age groups.

### **Age 13-24:**

- ❖ Client One: A 25-year-old male recently moved to Atlanta, GA area and was previously diagnosed with HIV in 2009. He was actively in care in another state but become homeless as he moved to Atlanta, GA. He was hospitalized for 3 weeks in Grady's inpatient unit and was connected with the Linkage Coordinator from ARTAS and was assisted with enrollment and housing. In addition to housing, he was able to secure employment with aid in him remaining actively engaged in medical care. He is actively engaged in medical care and successfully completed the ARTAS intervention. His barriers included: homelessness and lack of income.
- ❖ Client Two: A 19-year-old male (along with his father) is homeless and newly diagnosed with HIV. He was assisted with enrollment into medical care at Grady IDP and referred to an agency for emergency lodging. Since he has been lodged, he has made his next two medical appointments and his father secured stable employment.

He is currently actively enrolled in medical care and successfully completed the ARTAS intervention.

- ❖ Client Three: An 18 year-old newly diagnosed African-American MSM came to Grady IDP the day after his initial HIV diagnosis at another facility. Someone else at this facility told him about Grady IDP. Before he came, he expressed he was nervous and anxious about what's next. He is being seen at a Pediatric/Adolescent Clinic and mother accompanies him to some appointment. He started medication on Wednesday, April 20, 2014.

**Age 25 and over:**

- ❖ Client Four: A 48-year-old transgender female was enrolled on ARTAS while he was a patient at the hospital. She was facing homelessness, which was a major barrier to medical care. The client was assisted with enrollment into medical care. She was also referred to an agency to assist with rental assistance. Her barriers included: homelessness and lack of perceived need. She has completed ARTAS intervention and is now committed to maintaining compliance with her healthcare.
- ❖ Client Five: ARTAS Staff encountered a 34-year-old male who came in as a walk in client at the Grady IDP Clinic. The client said he was referred to the clinic by a friend but did not present documents to prove that he qualified for services at the clinic. Client also stated that he was currently homeless, which was a major barrier to care. Client was referred to an agency to assist with his emergency housing needs and was also referred to the health department to obtain needed documentation to enroll in the clinic. Clinic never returned with the required documents necessary to enroll

into medical care nor followed up with emergency housing agency. Client was given contact information for the Linkage Coordinator and will hopefully follow up when he is ready.

- ❖ Client Six: A 65 year-old previously diagnosed African American heterosexual male was enrolled as a client on ARTAS program while a patient at Grady Hospital. The client was not in outpatient HIV medical care at all. The client had a “lack of perceived need” for medical care. After sessions with ARTAS, client became excited about healthcare and is now making all medical appointments. He started ARV’s on April 24, 2014.

The ARTAS Linkage to Care Program was able to successfully link clients to medical care while assisting them in removing the barriers to their medical care. Some of the major barriers found included substance abuse treatment, housing, identification for registration to healthcare, linkage to medical case management, nutrition assistance, and transportation. Clients were assisted with ways to address barriers so that medical care continues. While the number of LGBT and youth-friendly service centers are increasing, major barriers to connecting HIV-positive youth to care still exist. Most interventions to address the continuum have been developed for adults. These are not particularly generalizable to youth struggling with identity formation, economic hardships, and unstable housing.



## CHAPTER V

### DISCUSSION AND CONCLUSION

#### **5.1. Discussion and Conclusion**

Based on the data available from 2013, youths represent 6.7% of persons living with HIV in the United States and account for 25.7% of new HIV infections. Of new HIV infections among youths, 45.9% were among black males, the majority of which were attributed to male-to-male sexual contact. Nationwide, the percentage of youths who had ever been tested for HIV was low compared with other age. The higher HIV prevalence among blacks overall, which is nearly three times higher than among Hispanics/Latinos and nearly eight times higher than among whites. MSM are almost forty times higher more than other me contributes to the disproportionate number of new HIV infections among black youths and young MSM.

Because of this disparity, black youths are at higher risk for infection even with similar levels of risk behaviors. Other research has found that among young MSM, other factors such as stigma, discrimination, less condom use, more alcohol and drug use, and having sex with older partners contribute to even higher risk for HIV acquisition. This study also found that young MSM were significantly less likely to use condoms during last sexual intercourse, more likely to drink alcohol or use drugs before last sexual intercourse, and more likely to have four or more partners during their lifetime compared with young men who had sexual intercourse only with females. These behaviors are associated with substantial risk for infection. Moreover, the risk for HIV infection doubled for MSM with a sex partner five years older and quadrupled with a sex

partner ten years older. Although the number of new HIV infections is highest among males, fewer males have been tested for HIV than females.

Monitoring and evaluation activities allow public health authorities and their partners to assess the extent to which HIV Linkage programs are being implemented and are achieving the intended objectives. Regardless of similarities, monitoring and evaluation fluctuate in the extent to which findings at each level of service delivery can be attributed to a specific intervention or program.

Monitoring aggregates information across sites and time and optimally serves as a tool to highlight for program managers which program components may need to be strengthened or modified to reach specific goals for preventing HIV. Monitoring frequently counts the number of HIV positive people receiving HIV medical services, such as the number of people receiving pretest counseling. Evaluation assesses the worth or value of a program or collaboration between multiple programs over time through more detailed analysis of their outcomes and their impact on the HIV population.

Evaluation can potentially link observed outcomes and impacts and the program process. This is especially true when multiple public health agencies and programs are working together and measuring the impact of efforts by individual partners is difficult. Tracking trends over time through routine HIV monitoring and evaluation efforts will help program managers and decision makers in evaluating how successful programs are in meeting HIV linkage goals. Most indicators are not designed to explain why a situation has or has not changed but to simply measure trends over time. A plan for collecting

and analyzing data should therefore be developed and focus on linking indicators that are collected at the various levels of the health care system.

To address these needs, HIV/AIDS care and support data collection systems have the objectives of ensuring equitable access to diagnosis, health care, pharmaceuticals and comprehensive supportive services to reducing morbidity and mortality from HIV/AIDS and related complications. These data collection systems also are promoting opportunities for preventing HIV transmission within the delivery of care and support services. Ultimately, data collection systems improve the quality of life of both adults and children living with HIV/AIDS and their families.

## **5.2 Recommendations for Future**

Along the HIV Care Continuum, adolescents and young adults appear to have larger declines than older adults in all steps, resulting in estimated viral suppression of less than 6% of those infected. The most striking difference between young adults and older adults is in the number of undiagnosed youth. Approximately 80% of HIV-infected adults are aware of their status, compared to only 40% of adolescents and young adults. Sexual onset, particularly in young adults, may place youth at increased risk despite the low risk perception. This contradiction likely contributes to low voluntary HIV testing among youth with early new infections.

Targeted HIV testing in this population is urgently needed to bridge this disparity. The American Academy of Pediatrics and U.S. CDC recommend routine HIV testing for all individuals aged 13–64. Campaigns using social marketing to promote and normalize HIV testing among youth have shown success at increasing HIV testing. In addition,

venue-based testing promoting HIV testing in social venues where high-risk youth congregate are effective in identifying high proportions of previously undiagnosed youth. Increasing promotion, convenience, and availability of HIV testing demonstrates high uptake rates among youth. HIV testing needs to be integrated and expanded in areas where youth interact with the health system, particularly in sexual and reproductive health clinics, primary care clinics, and in emergency and urgent care facilities. These, in addition to venue-based testing, promoting recurrent testing among high-risk youth, and normalizing HIV testing, could reduce the number of undiagnosed HIV youth.

In addition to testing, linkage to care and retention in care account for a considerable drop off in the cascade of HIV-infected adolescents and young adults. Approximately 30% of the diagnosed youth are linked to care and retained for one year. Brief intensive case management and patient navigator systems have worked well with adults and are being used in adolescent networks. Peer or clinic-based system navigators form personal and professional relationships that break down some of the barriers to initiating care. The Adolescent Trials Network is focusing on improving relationships between testing sites and clinical sites, including multicultural, LGBT, and adolescent-friendly services to improve adolescent linkage to care. However, major barriers to linkage and retention in care exist, which include stigma, consent, payment, housing instability or homelessness, transportation, and mental health/substance use.

HIV-infected adolescents may fall out of care when cared for in or transitioning to adult care facilities, which are more focused on the adult environment. Early multidisciplinary and developmentally appropriate transition preparation can assist in transitioning youth to adult services. This transition planning ideally would address

issues inherent in adolescent health including mental health, medication adherence, sexuality, reproductive health, gender identity, socioeconomic and health insurance status, stigma, disclosure, and disrupted relationships.

In addition, poor adherence among youth contributes to low viral suppression in those accessing treatment. There is no simple solution to improve adherence among youth. Successful adherence interventions are typically multifaceted and address specific adherence barriers. Simplifying treatment regimens, using directly observed therapy and cell phone reminders have shown promise in improving adherence among HIV-infected youth. In adults, treatment of underlying depression and offering cognitive behavioral therapy has shown to increase adherence. Research needs to explore new areas and tailor existing interventions for HIV-infected youth, particularly those with depression.

Although there have been significant developments in HIV prevention with pre-exposure prophylaxis (PrEP) and treatment as prevention for adults, these interventions have not been sufficiently investigated, tailored, or scaled for youth. This cascade highlights that current efforts for treating already-infected adolescents and young adults remain a challenge. Most interventions to address the cascade have been developed for adults. These are not particularly generalized to youth struggling with identity formation, economic hardships, and unstable housing. Youth-focused interventions are necessary to improve the HIV cascade for adolescents and young adults.

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