The care continuum for people living with HIV in Georgia: How can we raise the bar?

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ABSTRACT

Background: Viral suppression (VS) improves quality of life and longevity for people living with HIV (PLWH) and reduces viral transmission, but is achieved by only a minority of PLWH in Georgia.

Methods: By use of the Georgia HIV/AIDS surveillance database, the HIV Care Continuum was stratified by age.

Results: Retention in care and VS generally increased with increasing age, with the exception of adolescents (aged 13-18 years), who had the highest retention and VS. Differences by sex, race and transmission category persisted across age groups. Among persons retained in care, the proportion achieving VS also generally increased with age. Linkage to care within 3 months of HIV diagnosis was lower among young adults (aged 19-24 years) (54%); young Black, non-Hispanic (NH) males (49%); and young Black NH men who have sex with men (MSM) (49%) as compared to those among adolescents (66%, 58%, and 57%).

Conclusions: Retention in care and VS decreases with the transition from adolescence to young adulthood, possibly reflecting loss of support systems and competing priorities. At the other end of the age spectrum, health care and social support systems will be confronted with increasing numbers of older PLWH in Georgia. Challenges in HIV treatment and prevention include (a) the need for integrated medical care for aging PLWH with co-morbid conditions, and (b) the changing social environment of young PLWH.

Key Words: HIV, viral suppression, retention in care, care continuum, age

INTRODUCTION

According to data from the Centers for Disease Control and Prevention (CDC), Georgia ranked fifth in the nation for total number of adults and adolescents living with diagnosed HIV infection in 2012 (CDC, 2013). As life expectancy for people living with HIV (PLWH) improves, the numbers of older PLWH continue to increase both in Georgia and nationally. New infections, however, occur primarily among younger age groups.

CDC reported that, in 2010, youth (aged 13-24 years) made up 17% of the population but accounted for 26% (12,000) for all new HIV infections (47,500) in the United States (CDC, 2013). Similarly, in Georgia, youth (aged 13-24 years) made up 21% of its general population but accounted for 23% (601) of all new HIV diagnoses (2,652) in 2013 (Georgia Department of Public Health, Office of Health Indicators and Planning, 2013). The term ‘new HIV diagnoses’ is not the same as ‘new HIV infections’ (incidence). New diagnoses reflect the year of a confirmatory HIV test, but do not indicate when the person was infected. It is possible for a PLWH to be unaware of his or her infection for years before diagnosis. In Georgia, the number of new HIV diagnoses among youth (ages 13-24 years) steadily increased from 391 in 2005 to 601 in 2009, then remained near that level until 2013 (Figure 1). About three-fourths of these new HIV diagnoses were seen among males, accounting for 88% of cases in 2013. During 2013, 73% of new diagnoses in this age group were among Black males, 9% among Black females, and 7% among White males. Almost all (93%) of the new HIV diagnoses in the young Black males in Georgia during 2013 were attributed to men who have sex with men (MSM).
Sustained viral suppression (VS) improves the quality of life and longevity for people living with HIV (PLWH) and reduces viral transmission and new infections. Considering that HIV treatment is an essential component of HIV prevention, it is necessary to understand the gaps in care and treatment among PLWH and new diagnoses of HIV in Georgia.

In January 2013, the Centers for Disease Control and Prevention released HIV Surveillance Supplemental Report Volume 18, Number 2 Monitoring Selected National HIV Prevention and Care Objectives by Using HIV Surveillance Data – United States and 6 U.S. Dependent Areas - 2010. The report provides data by selected jurisdictions on stage of disease at diagnosis of HIV infection, and on the HIV Care Continuum (previously called the HIV Care Cascade), i.e., linkage to and retention in HIV care and VS. These data can be used to monitor progress toward the achievement of objectives outlined in the National HIV/AIDS Strategy for the United States (NHAS), released by the White House in July 2010. While there is no consensus or “gold standard” for measures of linkage and retention in care, several measures for retention correlate with primary or secondary outcomes: e.g., ≥2 HIV medical care appointments at least 60 days apart within 12 months correlates positively with CD4 >500, and missing ≥25% of appointments correlates with CD4 ≤500, progression to AIDS, emergency department visits, and hospitalizations (Yehia et al., 2012). Selection of appropriate measures should take into consideration availability and accuracy of data collection systems, as well as potential uses of the data. When data on missed appointments are unavailable, CDC and state HIV surveillance programs have used HIV-specific laboratory data as a proxy for HIV clinical care visits (CDC, GDPH).

Name-based AIDS reporting began in the early 1980s, and name-based HIV reporting began in Georgia in 2004. Since January 1, 2004, the Georgia Department of Public Health (DPH) has had a dual reporting system that legally requires HIV/AIDS reporting by both health care providers and laboratories (O.C.G.A. §31-12-2(b)). All laboratories certified and licensed by the State of Georgia are required to report laboratory test results indicative of HIV infection, such as positive Western blot results, all detectable and undetectable viral loads, and all CD4 counts, to the DPH HIV/AIDS Epidemiology Program.

Electronic laboratory reporting (ELR) was implemented in 2011. Recent improvements in the ELR system have facilitated use of laboratory-based measures to estimate linkage, retention in care, and VS. Although other measures, such as missed appointments, health care visit consistency, and gaps in care may be assessed at individual health care facilities, it is difficult to gather data on these measures on a statewide basis. For these reasons, measures in this analysis rely on laboratory data-driven definitions for which laboratory tests provide a proxy measure for care visits.

The purpose of this report is two-fold: 1) to examine the HIV care continuum in Georgia by age groups and 2) to present age-specific challenges related to increasing retention and VS in younger PLWH and delivery of HIV care and maintenance of quality of life for an increasingly older population of Georgians living with HIV.

METHODS

Care continuum
HIV case and laboratory surveillance data were extracted from the enhanced HIV/AIDS Reporting System (eHARS) of the Georgia DPH. HIV-related laboratory measures were used as a proxy for clinical care visits. With SAS version 9.2, these data were analyzed to create an HIV care continuum stratified by age, race, sex, and transmission category. Care continuum measures were defined by use of CDC best practices and estimated among persons living with diagnosed HIV and new HIV diagnoses by age group (in years). For the prevalent care continuum, inclusion
criteria were adults and adolescents age 13 and older, diagnosed by 09/30/11, living as of 12/31/12, and with a current address in Georgia. For new cases, inclusion criteria were diagnosis between 01/01/11 - 12/31/11, alive at least 15 months after diagnosis, and residence at diagnosis and a current address within Georgia.

Age groups were initially stratified as 13-24, 25-34, 35-44, 45-54 and 55 years and older. The 13-24 years age group was further stratified into adolescents aged 13-18 years and young adults aged 19-24 years. The HIV care continuum criteria were defined as follows:
- Linked to care within 3 months was measured only for the new HIV diagnoses made in 2011 and defined by a CD4 or viral load (VL) measurement within 90 days of diagnosis, excluding the day of diagnosis, as this was viewed as insufficient evidence for linkage. This differs from the CDC national measure, which includes CD4 and VL measurements determined on the same day as the diagnostic HIV test as a proxy for linkage.
- Any HIV care was defined as having had at least one CD4 or VL measurement in 2012.
- Retained in care was defined as having had at least two CD4 or VL measurements at least three months apart in 2012.
- VS was defined as a VL of <200 copies/ml or undetectable in the most recent VL measurement during 2012.

All percentages related to the total number of persons diagnosed with HIV in Georgia. Cases with missing race/ethnicity, sex, and transmission category were also included in the analyses.

Transmission Category
HIV transmission categories were determined from risk behavior noted on case report forms or obtained through a match with other databases (such as CAREWare from the Ryan White program or non-HIV sources, such as the Georgia DPH Tuberculosis and Sexually Transmitted Diseases Program data). The transmission category assignments were hierarchical as per CDC methodology (CDC, 2012) and defined as follows:
- MSM was defined as male-to-male sexual contact.
- IDU was defined as injection drug use.
- The MSM/IDU transmission category included those persons who reported both male sexual contact and injection drug use.
- HET was defined as heterosexual contact with a person known to have, or to be at high risk for, HIV infection.
- ‘Other’ includes the transmission categories of hemophilia, blood transfusion, perinatal exposure, and risk factor not reported or not identified. Most cases in the ‘Other’ category are ‘no risk reported (NRR)’ or ‘no risk identified (NIR).’

Because many persons with diagnosed HIV infection are reported to the Georgia DPH without an identified risk factor, multiple imputation methods developed by the CDC (Harrison 2008) were used to assign transmission categories to those whose diagnoses were reported without a risk factor.

RESULTS
Figure 2 depicts the overall HIV care continuum for Georgia. Among new diagnoses in 2011, 62% were linked to care within 3 months of their first visit. Among all persons living with HIV in 2012, 59% had at least one CD4 or VL laboratory test in 2012 (“Any Care”), 43% were retained in care, and 42% achieved VS.
VS increased with age from 28% among males aged 13-24 years to 43% among males aged 45-54, then decreased to 39% for those aged 55 years and older (Figure 3). The greatest gap between ‘any care’ and VS was among the youngest age group, with 57% any care but only 28% achieving VS. Among females living with HIV in Georgia in 2012, VS increased with age from 28% among those aged 25-34 years to 43% among those aged 55 years and older (not shown). Although women aged 13-24 years had higher VS than males aged 13-24 years, the greatest gap between any care (61%) and VS (35%) in women was again among the youngest age group.

Among adults and adolescents males, VS among those retained in care in 2012 increased with age from 57% (aged 13-24 years) to 87% (aged 55 years and older) (not shown). Among females, VS among those retained in care increased from 62% (aged 13-24 years) to 83% (aged 55 years and older). Among Black MSM retained in care, VS was lowest at 51% for the youngest age group, increasing to 84% for Black MSM aged 55 and older. Among White MSM retained in care, VS was higher than Black MSM in all age groups. VS was lowest at 68% for the youngest age group retained in care, increasing to 92% for White MSM aged 55 years and older.

In contrast to Black and White MSM, among Hispanic/Latino MSM retained in care, the youngest age group of 13-24 years had a higher proportion of viral VS (79%) than those aged 25-34 years (71%) and 35-44 years (76%), but a lower proportion than those aged 55 and older (91%) (Figure 4).

**Figure 3. Adults and adolescent males living with diagnosed HIV by current age (years), Georgia, 2012**

![Graph showing VS among adults and adolescent males by age group.](image)

**Figure 4. VS among adult and adolescent MSM retained in care, by age and race/ethnicity, Georgia 2012**

![Graph showing VS among MSM by age group and race/ethnicity.](image)
Overall, a higher percentage of persons aged 13-19 years were linked to care within 3 months (66%), retained in care (68%), and VS (55%) than persons aged 19-24 years (54%, 34% and 26%, respectively), a consistent finding among all race/ethnicity and transmission categories. Males and females aged 19-24 years had lower proportions of VS at (25% and 32%, respectively) relative to males (56%) and females (54%) aged 13-19 years (Figure 5).

Figure 5. HIV Care Continuum for persons living with diagnosed HIV among adolescents (13-18 years) and young adults (19-24 years) by sex, Georgia, 2012

The young adult Black/Non-Hispanics and Other/Unknown racial categories had the lowest proportion of VS (26% and 24% respectively) (Figure 6).

Figure 6. VS among persons living with diagnosed HIV among adolescents (13-18 years) and young adults (19-24 years) by race/ethnicity, Georgia, 2012
Among those newly diagnosed with HIV in 2012, retention in care was higher relative to all PLWH aged 19-24 overall (40% compared to 34%), Black (40%, 34%), White (65%, 43%), and Hispanic/Latino (54%, 36%) young adults, as well as among those in the transmission categories MSM (40%, 33%), MSM/IDU (46%, 23%), and HET (50%, 35%).

**DISCUSSION**

In Georgia, age is a predictor of retention in HIV care and VS independent of sex, race, transmission category and stage of disease (Edison, 2014). In that analysis, young adults, the group with the lowest retention in care, were more likely to be retained in care if recently diagnosed. Further, the age-related differences in VS persisted among persons who were retained in care, demonstrating that the disparity in VS is not simply a function of decreased access to or utilization of care. Lack of VS may reflect lack of prescription of antiretroviral therapy (ART), lack of adherence to ART, or inappropriate medication choice, which could not be distinguished in this analysis. The fact that the disparities by age and race persist even among those retained in care reveals an inadequacy within the health care system. It is not sufficient to link and retain PLWH in care; the goal of VS relates to individual health and to public health by reducing potential HIV transmission. Both Public Health offices and medical providers should improve communication about the benefits of VS and facilitate support for ART adherence.

As HIV infected adolescents grow into young adulthood, many are lost to follow up during the transition to adult care services, which require more responsibility by patients. Continuity of care considerations may differ for young adults who had been perinatally-infected relative to those infected through high-risk sexual and IDU behaviors as adolescents. Multidisciplinary team care including medical, psychosocial and mental health services, is recommended for coordinated care for all age groups [New York State Department of Health AIDS Institute: www.hivguidelines.org]. Various agencies have produced guidelines for transition planning for adolescents moving to adult HIV healthcare setting (NASTAD, 2012).

For older adults with HIV (the group with the highest levels of retention and VS), there are additional challenges to consider. As life expectancy for PLWH increases, the numbers of older PLWH will increase. In 2012, 34% of PLWH in Georgia were aged 50 years and older, with another 35% aged 40-49 years (Georgia DPH, 2014). Comorbid conditions associated with aging (diabetes, cardiovascular disease, cancer, hypertension, and dementia) complicate HIV care in older adults. Concerns are (a) how well the health care system in Georgia is prepared for an increase in geriatric HIV patients, with increased demands for complex medical care and social services and (b) how well are HIV providers are prepared to treat other chronic diseases, to care for the aging HIV population, and/or work with primary care providers in a team care approach.

Geriatricians and infectious disease clinicians specializing in HIV care are in short supply. Of the 352 geriatrics fellowship positions open in 2015, fewer than half (155/352 or 44%) were filled (National Residency Match Program, 2015). From 2011-2015, the percent of Infectious Disease (ID) fellowship positions filled decreased from 85% (267/312) to 70% (228/327). Not all physicians caring for PLWH are ID-board certified and not all ID physicians treat HIV. The demand for geriatricians and ID specialists in HIV care will increase as the prevalence of an older, more medically-complicated HIV population grows. Primary care clinicians will be more involved in coordinating care among multiple providers.

**Limitations**

Limitations to this study include the use of CD4 or viral load as a proxy measure for linkage, engagement and retention in care. Missing laboratory data could result in an under- or over-estimation of care and VS. Further, if laboratory tests are obtained prior to an HIV care appointment which is not kept, retention in care may be overestimated; conversely, a person may be seen for HIV care without laboratory data marking the visit, resulting in an underestimation of retention in care. Incomplete reporting on race, sex, and risk behavior (which is used in defining transmission category) represents another limitation. Whether these transmission category adjustments using multiple imputations introduce systematic bias in under- or over-estimation of percentages of HIV infection attributed to specific categories is unknown. Populations for which data are missing may be different from other groups for which race, sex, and transmission category are known. Data analyzed here are only for males, females, Black NH, White NH and Hispanic/Latinos. Less than 0.5% of the prevalent population with HIV in Georgia is transgender, American Indian/Alaska Native, Asian, or Native Hawaiian/Other Pacific Islander, and these gender identity and race/ethnicity groups were not analyzed separately. Data on HIV infection in Georgia are also included in the CDC HIV Surveillance Report Volume 23, Diagnoses of HIV Infection in the United States and Dependent Areas, 2011 (CDC 2013). Data included in the national report differ from the Georgia report in that CDC does not include cases reported in Georgia which that are missing data on race or sex, whereas these cases are included in the Georgia surveillance reports.

**Implications for Public Health**

Advances in HIV treatment have reduced HIV-related deaths and prolonged the lives of people infected with HIV and have also reduced their risk of transmitting HIV to others. To retain more persons diagnosed with HIV in care and to reduce new infection and decrease mortality, it is necessary to identify and reduce disparities in access to HIV care and treatment.

Better understanding is needed of the predictors of ART adherence among youth an of the impact of perceived stigma and discrimination in their experience with the health care system. Retention in HIV care and VS decreases with the transition from adolescence to young adulthood,
possibly reflecting changing family/social support systems, housing transition, loss of insurance coverage, new levels of independence/responsibility, substance abuse movement from pediatric to adult health care, and/or competing priorities.

The public health implications of these decreases in retention and VS point to the existence of systematic deficiencies. Young adults have a shift in their lifestyle with new-found emotional, behavioral, cognitive, and financial autonomy and are held responsible for their decisions, actions, and consequences. They may be more likely to neglect healthcare, for they lack the guidance and structure that adolescents receive when living with family. Health care systems should respond with additional supportive services (e.g., appointment reminders, case managers, peer navigators), address competing priorities (e.g., housing, and food insecurity), be sensitive to psychosocial needs (e.g., same-day appointments and flexible evening and weekend hours), create an environment of trust (e.g., youth-friendly clinic setting, age- and culturally appropriate waiting area posters, magazines and health education literature), deliver comprehensive mental health and substance abuse services to this high risk population, use technology (e.g., appropriate use of text messaging, and apps), and solicit patient feedback on their barriers to retention in care and VS.

The public health implications of increasing numbers of older PLWH include the need to coordinate with medical fellowship programs and health care systems to ensure training for health care providers; to provide systems for specialty consultation via teledmedicine; and to support integrated care that combines social services, mental health, geriatrics, HIV, and primary care. As older PLWH become increasingly frail, assisted living and skilled nursing facilities must be prepared to serve their special medical and biosocial needs. Discrimination by HIV status is illegal, but older PLWH may nevertheless experience difficulty finding appropriate long-term care facilities that will accept them. The involvement of public health personnel in reducing stigma and increasing awareness of HIV as a chronic disease with negligible transmission risk outside of blood and sexual contact is essential because, as noted by Lambda Legal in 2010, “Federal disability discrimination statutes include an exception that allows a long-term care facility to exclude someone if the facility can show that the person would present a direct threat to the health or safety of others.” (Lambda Legal, 2010).

Systems barriers to continuous, comprehensive HIV care such as a complex multi-payer system, pharmacy services unfamiliar with the AIDS Drug Assistance Program, complicated enrollment procedures for Ryan White services, and fragmentation of medical care for HIV and non-HIV needs affect all PLWH but may have an especially great impact for the elderly.

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