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PPACA and Low-Income People Living with HIV: 2014 Qualified Health Plan Enrollment in a Medicaid Nonexpansion State

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Abstract

People living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) often are uninsured or underinsured, and they may benefit from the Patient Protection and Affordable Care Act (PL 111-148) and its improved access to medical care. Safety net programs, such as AIDS Drug-Assistance Programs (ADAPs) funded through the Ryan White HIV/AIDS Program, which serve low-income people living with HIV, are incorporating Patient Protection and Affordable Care Act Marketplace-qualified health plans (QHPs) and helping to fund patients' participation. This changing landscape differs from state to state, and one main element contributing to the differing situations is whether a state elected to expand Medicaid. This review examines QHP enrollment of ADAP clients in Virginia, a Medicaid nonexpansion state, and explores some issues that affect people living with HIV in other Medicaid nonexpansion states. Virginia is a leader in the shift of ADAP healthcare delivery from direct medication provision to purchasing QHPs. Virginia ADAP clients accounted for approximately 2% of ADAP clients nationally, but they represent 17% of ADAP clients enrolled in QHPs nationwide. Ensuring good HIV care of the ADAP population is important to each patient's personal longevity, the public health, and the efficient use of healthcare dollars. As healthcare delivery models shift, the effects on patients and health outcomes achieved should be monitored, particularly for chronic diseases such as HIV.

Keywords

human immunodeficiency virus; Patient Protection and Affordable Care Act; Medicaid; health services research; healthcare delivery

The Patient Protection and Affordable Care Act (PPACA, PL 111-148) aims to enroll people who were uninsured or underinsured by offering financial subsidies based on income to purchase qualified health plan (QHP) coverage or through inclusion in an expanded Medicaid program. Many people living with human immunodeficiency virus (HIV) or

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acquired immunodeficiency syndrome (AIDS) are uninsured or underinsured.¹⁻⁴ The chronic disease burden in the United States is increasing and these illnesses disproportionately affect minority and low-income populations.⁵ People living with HIV and those with chronic medical conditions may benefit from the PPACA through improved access to medical care. Safety-net organizations and free clinics may be able to learn from the healthcare delivery shift that is occurring in HIV care. Safety nets that served low-income people living with HIV, such as AIDS Drug Assistance Programs (ADAPs) that are funded through the Ryan White HIV/AIDS Treatment Extension Act of 2009 (PL 111-87)^A, are now incorporating QHPs, and many ADAPs, including that of the state of Virginia, are helping to fund patients' participation. This changing landscape differs by state, especially because it is related to a state's decision about whether to expand Medicaid.

Our review examines QHP enrollment of ADAP clients in Virginia, a Medicaid nonexpansion state, and explores some issues that affect people living with HIV in other Medicaid nonexpansion states across the United States. Virginia is an important state to study given that although Virginia ADAP clients accounted for approximately 2% of all ADAP clients nationwide, they represented 17% of ADAP clients enrolled in QHPs in 2014. More impressive, they accounted for 58% of ADAP clients enrolled in QHPs in southern states.⁶

ADAPs

The Ryan White Comprehensive AIDS Resources Emergency Act of 1990 (PL 101-381) created ADAPs.^{6a} Before the PPACA was implemented, state ADAPs were the main resource responsible for providing key medications, including antiretroviral therapy and opportunistic infection prophylaxis, to uninsured or underinsured people living with HIV. ADAPs provided an estimated one-third of medications to people living with HIV in 2013 in the United States.⁷ ADAP is funded through annual federal allocations and discretionary state support; federal funding has declined in the last few years.⁸ Although many ADAP clients in Medicaid expansion states are being shifted to public insurance, in Medicaid nonexpansion states the need for continued strong ADAP funding persists because ADAPs fund direct provision of medications or support patients' enrollment in QHPs. In addition, consideration should be given to redirecting ADAP funds that have been spent on medications to provide support for services not currently covered by insurance programs such as case management, adherence support, and housing assistance that have improved HIV outcomes.

After the PPACA passed but before the Supreme Court upheld it in *National Federation of Independent Business v Sebelius* (2012), researchers interviewed the ADAP directors of 22 states and found that directors anticipated that they would help patients navigate the QHP enrollment process and likely pay for insurance in the PPACA Marketplaces.^{9,10} Directors expressed concern about the difficulty of demonstrating that buying insurance for patients was an appropriate use of funds.¹⁰ The Ryan White Comprehensive AIDS Resources Emergency Act of 1990^{6a} federal legislation allows state ADAPs to purchase health

^AIs this PL what was intended or a different piece of legislation? Pls clarify.

insurance and pay insurance premiums, deductibles, and medication copayments for individuals who were eligible for ADAP as long as the insurance plan covers comparable formulary benefits to that of the state ADAP.

In February 2014, 44 state ADAPs reported using ADAP funds for purchasing insurance in fiscal year 2013; this resulted in insurance coverage for 52,568 ADAP clients.¹¹ This was estimated to cost \$397 million, which is a substantial increase from the estimate of \$227 million in fiscal year 2012, when ADAPs funded preexisting condition insurance plans for some ADAP clients.¹¹ Within the group of 44 states that reported using ADAP funds for purchasing insurance coverage, there was considerable variation in enrollment strategies and enrollment rates. In some states, ADAP case managers were trained as healthcare exchange navigators, whereas others referred clients to community-based organizations. Some programs managed QHP enrollment at the state level, but the majority relied on individual care sites. As a result, differential enrollment success was achieved based on geographic location and clinic characteristics. Best practices have not been identified and may vary in urban versus rural areas, in large versus small states, in individual clinics, and among states based on the level of popular and political support of the PPACA.

During the 2014 enrollment period there were technical and other difficulties with the healthcare.gov Web site, general unfamiliarity with the enrollment process, and difficulties meeting deadlines. In some states, this resulted in lower-than-desired enrollment for the ADAP client population. For example, Virginia ADAPs hoped to enroll approximately 3000 clients in QHPs, but the final tally was 2310—approximately 77% of that targeted.^{6,12} Some states faced additional challenges. For example, in Louisiana, insurance companies refused to accept ADAP premium payments to support the purchase of QHPs for people living with HIV.¹³ A court ruled that not accepting them was a form of discrimination and insurance companies were forced to accept ADAP funds.

Medicaid Expansion and Low-Income People Living with HIV

Medicaid provides the largest share of the care of people living with HIV. In 2012, Medicaid covered approximately half of the people living with HIV who were receiving regular HIV care.¹⁴ Before the PPACA, the two eligibility criteria for Medicaid coverage were being a member of an eligible population and having an income below the threshold for that population. The core population that had to be covered included children, pregnant women, parents, people who are blind, and people who are disabled. States have some flexibility in terms of including other populations, and previously they could lower the income threshold. The PPACA originally included Medicaid expansion to all people with incomes <138% of the federal poverty level, but the 2012 Supreme Court ruling made it an optional program for states. In states that did not expand Medicaid, childless people with HIV must be classified as disabled to qualify for Medicaid.

In March 2014, when 28 states decided to move forward with Medicaid expansion and increase the income threshold, an estimate suggested that 60,000 uninsured and low-income people living with HIV lived in states that were not expanding Medicaid.¹⁵ Medicaid expansion to all people with incomes <138% of the federal poverty level would have

resulted in coverage for approximately 70% of all US ADAP clients in 2014.¹⁶ It is important to note that HIV viral suppression achieved by people living with HIV who are receiving Medicaid has been reported to be in the range of 65% to 68%, which is lower than the viral suppression rate of approximately 72% of people living with HIV who receive care at Ryan White–funded clinics and the viral suppression rate of approximately 78% to 80% achieved by those with Medicare or private insurance.^{17,18} The viral suppression rate associated with QHP coverage is not yet known; however, it has been demonstrated that even when people living with HIV access free care through Ryan White clinics, being uninsured negatively affects retention in care and HIV viral suppression.¹⁷

The expansion of Medicaid may shift a larger portion of the care of the ADAP population from a state expense to a federal expense. With the PPACA Medicaid expansion, the federal government offered to cover 100% of the costs of those made newly eligible for Medicaid from 2014 to 2016. The federal contribution then phases down to 90% by 2020 and beyond.¹⁹ For fiscal year 2014, the federal government provided only 35% of state ADAP budgets.¹⁶

Case Study of Virginia ADAP and the Incorporation of the PPACA

ADAP eligibility is set at the state level. To be eligible for Virginia ADAPs, a person living with HIV must reside in Virginia and must have a household income <400% of the federal poverty level. That person also must provide documentation of a CD4 count and an HIV viral load from within the past 6 months. The person cannot receive or qualify for Medicaid. Before the PPACA, Virginia ADAP had four delivery mechanisms for service, which included the direct provision of medications through local health departments (Direct ADAP), premium and copayment assistance for those with Medicare Part D, copayment assistance for those eligible for ADAP with private insurance, and premium and copayment assistance for preexisting condition insurance plans.

2014 QHP Enrollment in Virginia

At the beginning of the 2014 enrollment period, approximately 80% of Virginia ADAP clients were eligible for ADAP-funded QHPs, meaning that they were US citizens who did not have Medicare, Medicaid, or private insurance.²⁰ Other states may have lower rates of eligibility for shifting ADAP clients to QHPs, depending on the percentage of their clients who are US citizens and who have no other insurance coverage. With this opportunity, Virginia ADAP started its Health Insurance Marketplace Assistance Program. ADAP encouraged clients to enroll in QHPs and paid insurance premiums, deductibles, and medication copayments.¹² Virginia ADAP can purchase QHPs for two clients for the same cost as one client served by pre-PPACA Direct ADAP.⁶ In 2014, Virginia ADAP estimated that they would pay an average of \$4585 per patient annually for QHP coverage, which is less than what it costs (\$10,224) to pay for medications for uninsured ADAP patients under Direct ADAP.⁶ (These numbers will need to be calculated annually.) In addition, each state will need to assess its own situation because, depending on its ADAP population's financial status, a state may benefit more or less than Virginia from the federal tax subsidies. Purchasing QHP plans allows Virginia ADAP to use federal and state funds to cover the

greatest number of clients. Because Virginia did not expand Medicaid alongside the PPACA implementation, efforts were made to enroll all eligible Virginia ADAP clients in QHPs. ADAP clients who did not enroll remained in the Direct ADAP program.

All new ADAP applicants during the 2014 QHP enrollment period were screened for QHP/Health Insurance Marketplace Assistance Program eligibility. All ADAP clients received letters about QHP enrollment and QHP enrollment flyers were included with their monthly medications. Some HIV clinics took active roles by making available certified application counselors onsite. Community-based organizations also helped enroll ADAP clients in QHPs. The Virginia Department of Health provided guidance throughout the PPACA enrollment period by posting almost weekly updates on its Web site, as well as holding weekly calls with certified application counselors.

Some difficulties were encountered with the 2014 PPACA enrollment period, as may be expected with the first attempt at a large nationwide policy change. Figure 1 depicts the enrollment timeline. Period 1 encompassed October 1, 2013–December 9, 2013; during this period, ADAP did not have plan and formulary information from local insurance companies.²¹ This period also was plagued by the aforementioned government enrollment Web site glitches. As such, despite enrollment beginning on October 1, 2013, Virginia ADAP was not able to endorse QHPs until December 9, 2013, which marked the beginning of period 2. This period spanned through January 15, 2014, when an extension for preexisting condition insurance plans was announced. At the end of period 2, when approximately 60% of enrollment had passed, only 370 ADAP clients had been enrolled.²² Period 3 began on January 15, 2014 and lasted through the end of enrollment on March 31, 2014. Period 4 began on the last day of enrollment, when the enrollment extension for complex issues was announced. During period 4, which was the enrollment extension period, an additional 635 clients completed QHP enrollment.^{23,24} This means that 27% of ADAP clients who enrolled did so after the official close of the enrollment period. Figure 2 depicts the timing of the Virginia ADAP client QHP enrollment. There were 2310 Virginia ADAP clients enrolled in QHPs during the 2014 PPACA enrollment period.²⁴ Approximately 1800 Virginia ADAP clients were eligible to be enrolled in ADAP-funded QHPs, but were not enrolled and remained in Direct ADAP.⁶

The reasons that these people living with HIV did not enroll is being studied and could include barriers such as education, mental health, or substance abuse; lack of access to clinics, insurance information, insurance plans, and the Internet; HIV stigma; or mistrust of the medical system, health insurance companies, federal government, state government, and the PPACA. It also may have been easier for people living with HIV who were initiating care to enroll in QHPs because they did not yet have a specific HIV provider. It is not known whether concerns about having to change HIV providers discouraged some people living with HIV from enrolling. In Virginia, financial barriers are not likely to have played a role because Virginia ADAP covered all of the costs of the QHP, including premiums, deductibles, and copayments for medications. Understanding the demographic- and system-level determinants of enrollment will help to ensure that future enrollment strategies target populations that are less likely to enroll.

Transition to QHPs Across the Nation

As patients, physicians, HIV clinics, and state ADAPs navigate the continuing transition to the PPACA, the factors affecting enrollment and the relation between HIV outcomes and PPACA insurance should be defined. The unenrolled population of low-income people living with HIV who remain in Direct ADAP at the end of each year will need outreach and education during PPACA enrollment periods. In a time of constrained budgets, outreach and education efforts should be focused on the populations that have been missed during previous PPACA enrollment periods.

Demographics affect most aspects of HIV care engagement and are likely to affect QHP enrollment. There have been many studies on the demographics associated with better engagement in HIV care.^{25,26} Studies have found that younger age, minority status, and being transgender are associated with poorer clinic appointment attendance or retention in care.^{25,26}

During the first PPACA enrollment period, healthcare delivery issues may have been as important as patients' demographic characteristics. Healthcare delivery factors that could be studied include county of residence, HIV primary care clinic, or licensed independent provider. For example, insurance plan availability in Virginia had geographic variability, and insurance plans had to be selected based on a person's place of residence.²⁷ Some Virginia counties had extremely limited or no insurance options.²⁸ Accordingly, there may be geographic areas in the United States that need more health insurance plan options, more outreach, or more HIV care delivery.

If there is geographic variability in QHP enrollment, then researchers and policy makers must seek the perspective of patients and providers in the areas with low enrollment rates. If low enrollment is associated with certain clinics, then assessments regarding their infrastructure (eg, size, design, maintenance, utilities) and human resources (eg, number of medical providers as well as provider's expected weekly workload, number of nurses, number of and caseload of case managers, clinic support staff, community resources) should be evaluated.

PPACA and HIV Outcomes

To achieve treatment goals, it is important that people living with HIV obtain and maintain access to insurance because this is a barrier to receiving appropriate care²⁹⁻³²; but even when people living with HIV were able to access care through federally supplemented Ryan White HIV clinics, being uninsured negatively affected their retention in care and HIV viral load suppression.¹⁷ Access to care and retention in care are of paramount importance for a patient's personal health, in addition to the larger benefits to public health. In terms of individual health, having access to care is associated with viral suppression and longevity,^{33,34} and retention in care is an essential step to achieving these goals. Looking at the public health implications, people living with HIV who are in care will have access to antiretroviral therapy, which decreases transmission rates and prevents new HIV infections.³⁵⁻³⁸

Although the goal of the PPACA is to achieve improved health outcomes, changes in insurance or in methods of accessing care and medications can result in unintended outcomes. Although it was not HIV specific, a 2005 study of economically vulnerable patients with chronic illness in Oregon who were receiving public insurance demonstrated that changes in healthcare insurance plans created interruptions in coverage that culminated in reduced quality of life and worsened disease outcomes.³⁹ It is important to achieve and maintain health coverage to adequately manage chronic conditions.

The National HIV/AIDS Strategy for the United States and the federal government's HIV Care Continuum Initiative established goals for the HIV epidemic.^{40,41} A study of HIV outcomes demonstrated that Ryan White clinics' outcomes are better than national estimates in terms of retention in HIV care and HIV viral suppression.¹⁷ Outcomes under the PPACA system also must be studied to assess whether QHPs are associated with optimal HIV outcomes in line with the goals set out in the National HIV/AIDS Strategy.

One of the goals of the PPACA is to “bend the cost curve” of health care to slow the growth in American healthcare spending. The Centers for Disease Control and Prevention projected new HIV infections in 2009 to cost the United States \$16.3 billion during the lifetime of newly infected people living with HIV.⁴² With the advent of “treatment as prevention,” per the Centers for Disease Control and Prevention, adequate access to care for people living with HIV has demonstrated public health benefits and may prove cost-effective in the long run.⁴³ Furthermore, with its focus on quality improvement and reducing costs, the PPACA may be an opportunity for state ADAPs to reduce costs and improve quality of care, as defined by HIV-associated health outcomes.

Future Directions

QHP enrollment determinants for people living with HIV and the effects of QHP coverage on HIV outcomes need to be studied. As policy changes are implemented, studies should evaluate whether policy changes have the intended beneficial effects on patients. This is essential for effective advocacy for people living with HIV. It is unknown whether the health outcomes are the same or better with the PPACA. In Virginia, ADAP has been transparent about its QHP funding calculations and its cost-effectiveness, and HIV medications and QHP costs are relatively similar across state lines, so we suspect that this information is relevant across state lines.⁶ Also, because insurance companies may change premium amounts, formularies, and medication copayments, this is likely something that will need to be studied over time to fully understand the costs to ADAP and patients.

Without appropriate management of the ADAP population, expensive medical care and hospitalizations will increase healthcare costs. Moreover, the care of the ADAP population is important for each patient's longevity and the public health interest because HIV viral suppression prevents transmission.³³⁻³⁸ Studies have shown that reductions in community viral load are associated with decreased HIV infections.⁴⁴ It is estimated that each newly infected person with HIV will incur average lifetime medical expenditures of between \$253,000 and \$402,000, depending on his or her CD4 count at diagnosis.⁴⁵

A study of safety net organizations providing insurance to a low-income population demonstrated that insurance was associated with improved chronic medical disease outcomes for diabetes mellitus and hypertension.⁴⁶ States, clinics, and providers should be assessing how their patients' health outcomes are changing with different healthcare delivery models under the PPACA. It is unclear how costs and outcomes differ among expanded Medicaid, continued Direct ADAP, and QHP coverage. With data, states, clinics, and providers can advocate for the optimal healthcare delivery for their patients. If QHP coverage results in cost-effective and better HIV outcomes, then more safety net organizations and state ADAPs will need to consider shifting their resources into purchasing or providing insurance for people living with HIV in Medicaid nonexpansion states and for Medicaid-ineligible people living with HIV in Medicaid expansion states.

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Key Points

- Approximately one-third of people living with human immunodeficiency virus (HIV) or acquired immunodeficiency syndrome (AIDS) in the United States rely on the safety net of state AIDS Drug Assistance Programs to obtain their key HIV medications; most of these AIDS Drug Assistance Programs are incorporating Patient Protection and Affordable Care Act–qualified health plans (QHPs) into their care delivery model.
- The 2014 QHP enrollment of eligible low-income people living with HIV in Virginia included a well-organized coordinated state plan, but difficulties in reaching targeted enrollment numbers were still experienced.
- Patient-level determinants and healthcare delivery factors of QHP enrollment need to be examined.
- Outcomes associated with healthcare delivery shifts to QHPs need to be analyzed in a timely manner to ensure that patients receive good care and maintain or achieve optimal disease outcomes.

Fig. 1.

The 2014 PPACA enrollment period spanned from October 1, 2013 to March 31, 2014. Period 1 encompassed October 1, 2013–December 9, 2013. During this time, Virginia ADAP did not have insurance plan and formulary information from local insurance companies that were offering PPACA-QHPs, and there were government enrollment Web site glitches. Period 2 began on December 9, 2013, when Virginia ADAP was able to endorse specific QHPs. At the end of period 2, when approximately 60% of enrollment had passed, only 370 ADAP clients were enrolled, which represents 16% of the total number of ADAP clients who enrolled for 2014. Period 3 began on January 15, 2014, when an extension for preexisting condition insurance plans was announced. Period 4 began on March 31, 2014, which was the last day of enrollment, but an enrollment extension for complex issues was announced. During period 4, an additional 635 clients completed QHP enrollment. A total of 27% of ADAP clients who enrolled did so after the official close of the enrollment period. ADAP, acquired immunodeficiency syndrome drug-assistance programs; PCIP, preexisting condition insurance plan; PPACA, Patient Protection and Affordable Care Act; QHPs, qualified health plans. Source: Virginia Department of Health public data.

Fig. 2.

The 2014 PPACA enrollment period spanned from October 1, 2013 to March 31, 2014. During this period, 1675 ADAP clients enrolled in QHPs. By April 25, 2014, 2310 Virginia ADAP clients were enrolled in QHPs. ADAP, acquired immunodeficiency syndrome drug-assistance programs; PPACA, Patient Protection and Affordable Care Act; QHPs, qualified health plans. Source: Virginia Department of Health public data.