

Facilitators and Barriers: Clients' Perspective on the Virginia AIDS Drug Assistance Program's Affordable Care Act Implementation

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Abstract

Many AIDS drug assistance programs (ADAPs) purchased Affordable Care Act (ACA) qualified health plans (QHPs) for low-income people living with HIV. To date, little has been written about this from the client perspective. The study's objective was to gain information about the experience of Virginia ADAP-funded QHP enrollment and the impact of this change. English-speaking clients who were eligible for ADAP-funded QHPs were recruited at three HIV clinics in Virginia. The goal was to enroll $\geq 5\%$ of those who were eligible for ADAP-funded QHPs in two Virginia Department of Health planning districts. Participants were surveyed about demographic characteristics, and semi-structured interviews were performed. Descriptive analyses were performed for cohort characteristics. Using an open coding strategy, codebooks were generated for the interviews and themes were identified. The cohort ($n=53$) met our recruitment goal. Two-thirds gained their ACA knowledge at HIV clinics from case managers and social workers. Many barriers to enrollment were identified, including internet access/literacy. Almost 9 out of 10 participants had concerns about privacy, which centered on QHP's mandated use of mail-order pharmacies. Except for medication concerns, most participants had positive perceptions of the impact of QHP enrollment on their health care. HIV clinic case managers and social workers are often the primary source of knowledge for patients about insurance options and their assistance is crucial for QHP enrollment. Our findings indicate that reducing identified barriers and addressing privacy concerns by allowing people to opt out of mail order pharmacies may encourage QHP enrollment.

Keywords: HIV, AIDS drug assistance programs, access to health care, patient protection and Affordable Care Act, health care reform, health insurance

Introduction

MANY STATE AIDS DRUG assistance programs (ADAPs) purchased Affordable Care Act (ACA) qualified health plans (QHPs) for low-income people living with HIV (PLWH).¹ In Virginia, a Medicaid non-expansion state from 2014 to 2018, the state ADAP decided to offer Direct ADAP clients who previously were receiving medications from their local health department the opportunity to shift to an ADAP-funded QHP. Virginia ADAP paid the insurance premiums,

deductibles, and medication copayments.² The clients who shifted to ADAP-funded QHPs achieved higher rates of viral suppression than ADAP clients who were engaged in care and remained on Direct ADAP for the first 2 years of the shift in the HIV health care delivery system.^{3,4} This has been shown in Nebraska as well.⁵ In addition, within the Health Resources and Services Administration's Ryan White HIV/AIDS Program (RWHAP), PLWH with private insurance have demonstrated higher rates of viral suppression compared with PLWH who are uninsured.^{6,7}

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The goal of this study was to gain insights regarding the process of decision making about and the experience of enrolling in health insurance for Virginia ADAP clients who were eligible for ADAP-funded QHPs. To date, little has been written about this from the client perspective. Kaiser Family Foundation (KFF) has conducted two focus groups with PLWH in urban settings who have had differing experiences with the ACA related to eligibility for Medicaid expansion, remaining uninsured, and enrolling or attempting to enroll in ACA QHPs.^{8,9} This study adds to the literature by focusing on a rural population of PLWH who had many of the financial barriers to QHP enrollment removed. Studying PLWH in rural settings is important since the United States HIV epidemic has shifted from urban centers to rural and suburban areas.¹⁰ Facilitators and barriers to insurance enrollment in rural/suburban areas may differ from urban areas.

The rural area studied in this work, the Virginia Department of Health's Northwest and Southwest planning regions, is representative of Western Virginia, which includes Appalachian Virginia, since the two planning districts encompass almost the entire west half of the state. Approximately 16% PLWH in Virginia live in the studied area.¹¹ This area encompasses many medically underserved areas, and due to many factors including the opioid epidemic, the area is at risk for rapid dissemination of HIV among people who inject drugs.^{12,13}

Methods

Study enrollment

The recruitment goal of this prospective study was to enroll $\geq 5\%$ of those who were eligible for ADAP-funded QHPs in two Virginia Department of Health planning regions (Northwest and Southwest). The study was approved by the University of Virginia Institutional Review Board (IRB) for Social and Behavioral Sciences and the Centra Health IRB. English-speaking PLWH, ages 18–64, who were eligible for a Virginia ADAP-funded QHP were recruited face-to-face in a medical exam room to ensure privacy and confidentiality of the participants' HIV diagnosis. This was a convenient sample, and it was stratified by the Virginia Department of Health planning region to ensure that the recruitment goal was met in both planning regions. Recruitment occurred either before or after an HIV medical care visit. Recruitment took place at three RWHAP clinics during two periods, December 2015 to May 2016 and January 2017 to February 2017. The participants did not have a relationship with the interviewer before the study, and they were aware of the goals of the research study. Participation in the study took ~ 45 min, and the participants were compensated for their time.

Cohort characteristics

Demographics, socioeconomic status, and HIV-related information were collected through surveys that were administered verbally to participants to reduce issues related to literacy. Demographic characteristics of participants collected included age, self-reported gender, and race/ethnicity. Socioeconomic information assessed included: income, education, housing stability (using a validated instrument to assess imminent risk of homelessness¹⁴), mental health (using

the Mental Health five-item scale¹⁵), substance use (using the Alcohol Use Disorders Identification Test-Concise [AUDIT-C]¹⁶ and a single-question screening test for drug use¹⁷), transportation barriers, Internet access, and HIV stigma (using the HIV Stigma Scale¹⁸). In terms of HIV care, the information collected included: time since HIV diagnosis, current antiretroviral prescription status, and current viral suppression status. When available, participants were surveyed by using validated measurements as cited. For cohort characteristics, descriptive statistics were performed.

Qualitative analysis of participant interviews

The semi-structured interview guide was developed with the Health Belief Model as the framework for questions.^{19,20} This theoretical framework was chosen as it is often used in exploring health-seeking behaviors related to HIV.^{21–25} Semi-structured interviews were performed face-to-face with participants. The interviewer asked the same questions in the same order for each interview. The interviewer had suggested prompts to use if respondents needed additional guidance. They could ask clarifying questions of their own if needed, when a response was unclear, or more detail would be helpful. Participants could answer the questions however they wanted, and they could introduce topics that were not covered by the interview. Audio recordings were collected and then converted into verbatim transcripts for analysis. Participant interviews were imported into NVivo software for qualitative data analysis (QSR International Pty Ltd.; Version 11, 2012).

The Health Belief Model framework, which was the basis for the interview questions, also informed the analysis. We had *a priori* expectations of coding for barriers to enrollment, beliefs about the ACA, and impact of the ACA on care. When interviews were coded, barriers were also recorded if the participant described a resource that was critical for them to overcome the given barrier. The sub-codes were determined based on the concepts emerging from the interviews, using an open coding strategy that allowed the themes to emerge from the data. For example, sub-codes within the category of “barriers to enrollment” were based on concerns mentioned by participants in their interviews, such as time, difficulty understanding information, or insufficient assistance.

The initial codebook was generated by a single reviewer. The codebook was then evaluated by a second reviewer and applied to a subset of the interviews by both reviewers to assess reliability. Any discrepancies in coding were resolved by consensus of the study team, which included expertise in HIV clinical care, health care policy, and qualitative research methods. Any codes or definitions that were not applied consistently were revised. Data saturation was achieved before applying the codebook to the entire dataset. This process was iterated until excellent reliability was achieved, with a kappa statistic of 0.85. Then, the codebook was applied to the entire set of interviews so that frequencies of themes could be assessed.

Codes were refined to capture the concepts as accurately as possible. For example, the barrier sub-code of “lack of internet access” was changed during codebook iteration to “computer and internet access and literacy,” because the original code was too narrow to address the scope of technological barriers experienced by participants. The

sub-code of “risk of disclosure” was changed to “privacy” to include the range to privacy risks expressed by participants, related to enrollment and medication mail delivery.

The codebook was then applied to the entire set of interviews so that frequencies of occurrence for each theme could be assessed. For themes related to the impact of enrollment on access to medications or providers, coders classified themes as positive, neutral, or negative, depending on the participants’ expressed attitude toward the change that they experienced or anticipated. These categorizations were not mutually exclusive, as participants could express mixed feelings. A cross-query analysis was performed to assess mixed feelings.

Results

The cohort of 53 participants met the study recruitment goal. All participants enrolled in an ADAP-funded QHP in the first year (2014) or second year (2015) that the option was offered. Descriptive statistics of cohort characteristics are in Table 1.

Qualitative results

Table 2 shows each theme category identified from the interviews, with a representative participant quote and the frequency of occurrence. There are three categories of themes: belief systems, barriers to ADAP-funded QHP enrollment, and ADAP-funded QHP’s impact on care.

Belief systems. Three themes related to belief systems emerged: the value of health insurance and the availability of alternatives, the role of government in health care, and investigating how patient beliefs about the ACA were formed. Almost all of the participants felt that health insurance is a necessity and/or beneficial. Reported benefits included lower medical bills, prescription medication benefits, the ability to see physicians for a range of issues including non-HIV-related medical problems, improved well-being, and lower stress. One shared, “Bills, oh my god, bills will drive you crazy, especially if you can’t afford them. Healthcare, bills are the highest bills” (black woman, age 56). Many reported that it was extremely dangerous not to have health insurance.

Alternatives to health insurance were identified by 69.8% of participants, such as RWHP-funded clinics, free clinics, and financial aid assistance through safety-net hospitals that would allow them to continue to receive health care. Participants reported that support from RWHP and Virginia ADAP was a critical part of their lives, even with insurance, but that without insurance, it would be an important resource for continued HIV care. One participant summarized the complexity and intertwining of the different aspects of the HIV health care delivery system as well as the value of these systems for PLWH by saying, “Without insurance and without Ryan White and without Virginia ADAP, I don’t know where I would be” (white man, age 33).

About a third of the participants reported dissatisfaction with health insurance, saying that it was unnecessary or that it had a limited impact. High costs and perceived or actual limited coverage of emergency room visits and surgery were specifically identified as problematic. One participant described their concerns with this statement, “...just feel[s] like well he’s got HIV, he’s got cancer, so what’s the point of

TABLE 1. COHORT CHARACTERISTICS

<i>Cohort characteristics</i>	<i>Total (n=53) n (%)</i>
Age (years; mean ± SD)	40.9 (±11.4)
Gender	
Male	35 (66.0)
Female	17 (32.1)
Transgender	1 (1.9)
Race/Ethnicity	
Black	30 (56.6)
White	19 (35.8)
Hispanic	2 (3.8)
Asian	1 (1.9)
Other	1 (1.9)
Annual income (mean ± SD)	18,523 (±22,872)
Federal poverty level (FPL)	
<50% FPL	16 (30.2)
51%–100% FPL	16 (30.2)
101%–133% FPL	5 (9.4)
134%–200% FPL	7 (13.2)
>201% FPL	9 (17.0)
Education level	
Less than high school	5 (9.4)
High school or equivalent	30 (56.6)
Vocational school	5 (9.4)
College degree	11 (20.8)
More than college	2 (3.8)
Housing ^a	
Current unstable housing	3 (5.7)
Stable housing concerns	10 (18.9)
Stable housing	40 (75.5)
Transportation difficulties	
Yes	15 (28.3)
No	38 (71.7)
Internet access	
Yes	44 (83)
No	9 (17)
Depressive symptoms ^b	
Yes	35 (66.0)
No	18 (34)
Problem drinking ^c	
Yes	13 (24.5)
No	40 (75.5)
Drug use ^d	
Yes	12 (22.6)
No	41 (77.4)
Berger stigma scale ^e (mean ± SD)	103.3 (20.2)
Factor 1—Personalized stigma	43.7 (12.1)
Factor 2—Disclosure concerns	29.9 (5.1)
Factor 3—Negative self image	30.4 (7.7)
Factor 4—Concern with public attitudes with HIV	52.1 (11.4)
Time since HIV diagnosis (years; mean ± SD)	12.1 (±9.5)
Currently on antiretroviral therapy	49 (92.5)
Current viral suppression status	
Virally suppressed	41 (77.3)
Not virally suppressed	6 (11.5)
I don’t know	5 (9.6)

Descriptive statistics regarding demographics, socioeconomic status, and HIV-related information are shown for the cohort of Virginia AIDS Drug Assistance Program clients who were surveyed and interviewed.

^aHousing status was categorized by using the Homelessness Screening Clinical Reminder.¹⁰

^bDepressive symptoms were assessed by using the Mental Health Inventory-5.¹¹

^cProblem drinking was assessed with the Alcohol Use Disorders Identification Test.¹²

^dDrug use was assessed by using a drug use screen.¹³

^eStigma was assessed by using the Berger HIV Stigma Scale.¹⁴ SD, standard deviation

TABLE 2. THEME CATEGORIES FROM ANALYSIS OF SEMI-STRUCTURED INTERVIEWS WITH VIRGINIA AIDS DRUG ASSISTANCE PROGRAM CLIENTS REGARDING AFFORDABLE CARE ACT QUALIFIED HEALTH PLAN ENROLLMENT/RE-ENROLLMENT WITH REPRESENTATIVE PARTICIPANT QUOTE EXAMPLES AND FREQUENCIES

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
A. Belief systems		
Value of insurance: Describes beliefs of value of health insurance		
Necessary/beneficial: Describes value of health insurance. Often describes benefits such as lower hospital bills, medication coverage, ability to see physicians, increased general well-being, less stress	“Bills—oh my god, bills will drive you crazy, especially if you can’t afford them. Health care, bills are the highest bills.”	51 (96.2)
Available alternatives: Describes that health insurance is unnecessary due to availability of alternatives	“I’m not too sure. I know because the clinic here is Ryan White Program. If you qualify for that, they pay for that. As far as medical insurance, it’s used outside the [HIV] clinic.”	37 (69.8)
Unnecessary/limited impact: Describes that health insurance is unnecessary or that it will not have an impact on health, costs, or coverage	“They didn’t cover anything. I had to pay a lot of out of pocket stuff. I mean, they would only cover just a little bit and most of it was out of pocket costs. So they really didn’t cover nothing.”	20 (37.7)
Role of government: Describes beliefs of what government should/should not provide to citizens, or mandate that they do	“[I] knew they were talking that you were going to need to have to have insurance or you were going to have a penalty, but I really wasn’t too keen on all that.”	15 (28.2)
Understanding of ACA: Describes sources of information that led to understanding of ACA and/or enrollment		
HIV Clinic: Describes how clinic/health department/case manager impacted participant understanding; can also report that someone in one of these settings handled all forms/completely guided process for enrollment	“Case managers, medical case managers, um explained stuff to me, um I even received a booklet that, from the health insurance and so that helped me along.”	36 (67.9)
Personal research: Describes how participant individually researched the legislation, marketplace, insurance options, etc., and may include describing resources, such as the newspaper or the internet	“I had so much access to much more information. People who maybe have read up on it and people writing things, not just like the format of forms or papers, but people’s opinions and views on it. Maybe it’s worded a little differently that made it easier for me to understand. A whole lot more information having the Internet.”	26 (49.1)
Social relationships: Describes how participant contacts (such as family/friends) impacted participant understanding	“I think they get turned off because it’s difficult and they’re not good with computers and you have to go online a lot. So unless they get someone to help them, they don’t understand it.”	20 (37.7)

(continued)

TABLE 2. (CONTINUED)

Theme	B. Barriers to enrollment and/or re-enrollment	Representative quote	n (%)
Privacy: Describes concerns that enrollment or mailed medications will result in loss of privacy or disclosure of HIV positive status	“Somebody took it [mailed medications] and spread it all through my neighborhood...yeah. It was devastating.”	45 (84.9)	
Computer and internet access and literacy: Describes lack of experience or challenges with computer and/or internet access, which then impacted ability to enroll and/or knowledge of ACA	“People who don’t understand computers as well or, whatever not computer savvy they would have a hard time with dealing with websites in general but have a hard time signing up and they would need someone to help them.”	36 (67.9)	
Insufficient assistance: Describes a challenging experience with clinic/case manager on getting assistance to enroll; can also describe poor relationships with clinic/provider/case manager (participant does not need to describe that poor relationship with clinic/provider/case manager directly impacted enrollment likelihood/experience, only that the relationship is poor)	“I think a lot of times if you are left to your own devices, it can sometimes be overwhelming or just, you know, a little intimidating, so it was a lot easier and a much better experience having someone that knew what was going on and the best thing to offer as far as coverage was concerned.”	33 (62.3)	
Difficulty understanding information: Challenges with understanding information; can describe that the process is complicated or that they aren’t able to understand the information given	“By me not having the full education, and I have a reading disorder. I don’t understand a lot. When I read something, I don’t understand it. Yeah, it was pretty rough.”	33 (62.3)	
Mental health: Describes difficulties with enrollment due to mental health problems	“I mean if you can’t get out of bed because you’re so depressed, you’re not going to go and get health insurance.”	33 (62.3)	
Substance misuse: Describes challenges with enrollment due to substance misuse	“I guess, if you’re drunk all the time. You can’t get your mind together to get the stuff.”	31 (58.5)	
Physical barriers: Describes difficulties with physically getting to clinic or health department (e.g., transportation or living in a rural area)	“Not as many outlets and places to go, especially of transportation is an issue or if Internet is an issue. Also, living in a very rural area—whether or not maybe you can’t access or it’s a far drive or it’s hard to get to a place to sign up. It just adds another factor.”	29 (54.7)	
Other priorities: Describes challenges with enrollment due to other concerns in their life, such as problems with substances or housing	“You’re not going if you’re a drug addict. You’re going to have a hard time prioritizing whether you need to take care of your HIV or even get health insurance.”	24 (45.3)	
Costs: Describes costs of enrollment/continued enrollment in health insurance, added costs, unexpected costs	“Just some of the insurance you just have to watch what you’re getting because after the fees and stuff you know, you just have to be careful.”	23 (43.4)	
Ineligibility: Describes a participant’s perceived or actual ineligibility to enroll and can include concerns about ineligibility, such as drug use or no stable housing (no address)	“Because drugs man...it says on the application ‘do you do drugs?’”	22 (41.5)	
Challenging process: Challenges with overall process; describes in a broader sense that the participant can understand information, but the entire process is difficult	“In trying to fill it out for my son, the Obamacare, it’s been really, really complicated. And I’ve tried three or four times and still haven’t gotten it complete.”	16 (30.1)	

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
B. Barriers to enrollment and/or re-enrollment		
Form of enrollment: Describes challenges with the form of enrollment (paper enrollment, online enrollment, unsure but recalls that it was challenging); can include challenges with internet/webpage	“It was complicated. I guess that was when they were having all the issues with the site and stuff, so kept messing up, or it wouldn’t process through. We had to keep redoing stuff.”	13 (24.5)
Concerns about medications being mailed: Describes concerns about medications not being delivered in time, being stolen, or being of poor quality	“I was doing good and then I started getting sick and the medicine tasted funny or tasted different and I was asking if I could go somewhere to get it analyzed and I thought well I’m not getting the right medication because I feel like it’s a government controlled thing that they...would have my guarantee that I’m getting what I’m supposed to be getting. I questioned it and so now that made me sick so I’m still questioning the safety of it.”	13 (24.5)
Alternate source for insurance: Describes that person did not have need to enroll because they were able to get insurance through other means	“I guess my friends have jobs so they have insurance through their jobs.”	12 (22.6)
Time: Describes that the process took a long time (note: can overlap “form of enrollment” in event that with challenge internet was slow)	“It was on the computer. It took two hours. It was a very long process.”	8 (15.1)
Taxes: Describes challenges with filing taxes, after enrolling	“When you go to fill out your taxes, you have to prove that you have Obama insurance, and then they have to look up if you’re golden or if you’re bronze or anything like that.”	7 (13.2)
Inability/difficulty in gathering applicant information: Describes difficulties collecting information to enroll (e.g., previous taxes, bank statements)	“Proving my income was complicated because I haven’t filed tax returns in a while. And they wanted to see a bunch of bank account statements and then a bunch of invoices from customers and stuff. So that was the only way I could prove it and they rejected me the first time. So I basically had to give them much more information, which is fine. I get it. It just was not clear exactly what I needed to show them”	5 (9.4)
Lack of knowledge: Describes lack of knowledge of enrollment options	In response to “Why didn’t you enroll in 2014?”: “I didn’t know nobody that done it. Nobody told me about it.”	5 (9.4)
Political barriers: Describes that political beliefs resulted in decreased interest or in complete disinterest in enrolling	“But because of their prejudice—and it’s not just toward Obamacare, just because Obama was black—for where I live, that’s all it takes...If I say Obamacare, all of a sudden it’s a color thing. And they haven’t even looked in it, know anything about it.”	3 (5.7)

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
B. Barriers to enrollment and/or re-enrollment		
Lack of impact: Describes belief that insurance won't actually impact the participant's life, such as	"It's like the low income for example always—it's like this is somebody that's helping you. Okay, we're going to help you do this. But we're only going to give you this much."	2 (3.8)
Lack of health problems: Describes belief that insurance is not necessary due to lack of chronic illnesses	"I don't want that. I'm a healthy person. I don't get sick. You got those people. I've got a good immune system."	2 (3.8)
C. Impact to care after enrollment and/or re-enrollment		
Medication access: Describes impact in delivery of medications		
Positive: Describes improved delivery or easy transition to new system	"The change is good because it is coming to your house. If you don't want anybody to know anybody about you, you don't have to run into anybody. It's coming directly to you. You don't have to go through the health department and see Michael, Jody, or Susie there; and wondering if they know which are coming for. It's more personal when it comes to your house."	41 (77.4)
Neutral: Describes being neither satisfied nor dissatisfied with altered medication delivery; can also report no change in medication delivery		31 (48.5)
Negative: Describes frustration or challenging experience, distrust, concerns, or dislike of altered medication delivery	"One time I did when we had that bad snow storm. I had a little problem getting it because they couldn't get through because the roads were so bad. It took three weeks before I could get it."	27 (50.9)
Provider access: Describes change or addition of providers in HIV care and/or other medical care		
Positive: Describes benefits of added providers and/or care; can also include continued ability to see a provider, if dependent on insurance	"Having insurance has changed my non-HIV medical care due to the fact that I'm more on top of that due to the fact that it could lead to other things if I'm not on top of it."	38 (71.7)
Neutral: Describes being neither satisfied nor dissatisfied with providers/care; can report no change to provider choice, availability, frequency of seeing providers, etc.	"No, I'm seeing them about the same."	36 (67.9)
Negative: Describes frustration or challenging experience, distrust, concerns, or dislike of providers/care	"Actually, I was going less because they cover nothing."	1 (1.9)

Themes were assessed using an open coding strategy which is further described in methods. The themes were categorized into (A) belief systems, (B) barriers to ACA QHP enrollment and/or reenrollment, and (C) impact to care after Affordable Care Act (ACA) Qualified Health Plan (QHP) enrollment and/or re-enrollment. For each theme, a representative participant quote is included. For frequencies, participants contributed multiple statements. Totals can be >100%.

spending this money on him?" (white man, age 56). Some believed that insurance would not actually impact health outcomes as one participant reported, "My health is still going to be the same. It helps with the cost and the doctors and the blood and all that stuff but my health ain't going to change" (white man, age 30).

Regarding the government's role in health care, 28.3% of participants shared some belief that QHP enrollment felt compulsory and that the government should not be mandating the purchasing of insurance. One participant conveyed this with the statement, "Basically, I had to do it. So I didn't have a choice. If I had a choice, no. I would choose not to because I don't agree with it philosophically" (white man, age 42). Some felt specifically as though the government could not be trusted with the information or to handle health care.

The interviews explored how participants developed their understanding of the ACA and insurance options. Overall, 67.9% participants reported that their knowledge was formed at their clinic, specifically through working with case managers and social workers. One participant shared, "Yeah they basically broke [it down], showed me what plans were available and basically the plan that I chose was based on my needs" (white woman, age 39). Several participants reported they did not research their options, but they had confidence in HIV clinic staff to make decisions on their behalf. For example, one participant reported, "I didn't really have any questions. Honestly, I kind of trusted the people here and they seemed to think it was just an A, B, C process and just go through the steps and you'll be fine, and it was" (white man, age 42).

Half of the participants reported that personal research impacted knowledge on available options and on the ACA. The Internet was the most commonly cited resource, but television and newspapers were also used. Social relationships contributed to personal knowledge among 37.7% of participants. One participant described using several resources after being in an environment that was particularly against the passing of the ACA: "I was a student at [X], great conservative, and all of the uproar about the Affordable Care Act and how it was not great and everything, so I did a lot of research on my own. I had a lot of questions. I spoke to my dad. I spoke to my social worker. I Googled a bunch of things" (white man, age 26). The ability to combine resources and improve knowledge on insurance was often valued by participants.

Barriers to ADAP-funded QHP enrollment. Although all of the participants were enrolled in ADAP-funded QHPs by 2015, they reported perceived barriers or actual barriers that they overcame to complete the enrollment process. The most common experienced and perceived barriers were concerns about privacy (84.9%), computer and internet access/literacy (67.9%), insufficient assistance (62.3%), difficulty understanding information (62.3%), mental health problems (62.3%), substance misuse (58.5%), and physical barriers (54.7%). See Table 2 for additional barriers mentioned less frequently. In terms of privacy, participants voiced concerns about medications being mailed, disclosure concerns during the enrollment process, and concerns about living in a rural area, where their confidentiality might be more at risk. For example, one participant voiced, "I would be scared that they were going to break my confidentiality because there's a lot of

that in [town]... if they hear something in the street, they're going to run away with it" (black woman, age 52). Many reported concerns that neighbors would steal or open their mailed medications and reveal their HIV status. One participant did experience this: "Somebody took it [mailed medication] and spread it all through my neighborhood...yeah, it was devastating" (black woman, age 39). In addition, many participants reported that although they did not experience this type of issue, it was a fear, particularly when they started receiving HIV medications through the mail.

Computer and internet accessibility and literacy were also reported barriers. Many participants felt as though having internet access was a crucial part of their enrollment process. One person shared that they could see how lack of internet access would restrict their understanding of insurance options and then reduce enrollment interest: "If you don't [have internet] that would obviously be a problem, but the website works. It's if you know how to use a website or not. I mean it can get sophisticated at points because they're asking all this information and if you make a mistake, it's like, what do I do? So I can understand how people might get frustrated" (white man, age 42). Another reported that poor computer literacy would be a likely barrier for their family, who might have otherwise utilized ACA insurance options. Many of the participants reported that they were not familiar with computers and/or the website and that it would have been especially challenging without readily available assistance from HIV clinic staff and certified application counselors.

Assistance was often crucial to knowledge of insurance options and ultimately, enrollment in insurance. Many participants reported that the process was easier or more successful because they had help. One participant shared, "Yes, it was very, very complicated. At first I tried to do it myself by calling marketplace and that didn't work. So then I had—I called [X] here [at the clinic] and he made an appointment [to meet with me] and he helped me through it" (white man, age 53). Many participants also shared that a case manager, social worker, or certified application counselor completed much of the enrollment paperwork for them.

Difficulty understanding information was one of the other most commonly cited barriers that participants reported. As one participant stated, "You need a college degree to figure this thing out" (white man, age 46). Another respondent said, "It's pretty complex. It's not something that I would just advise anyone and everyone to think that they can go in and do it themselves. It was difficult for me, and I'm pretty smart. I can see where people can get very confused with it" (black man, age 29). One person reported that the process was especially challenging due to a reading disorder. The health care system was identified as difficult to comprehend, with unfamiliar vocabulary, and a large amount of details, and the insurance enrollment process was characterized as a challenging process.

Of note, some RWHAP-funded clinics had case managers and social workers become certified application counselors. Many participants reported that they only had to provide signatures and to answer particular questions on the application. One participant shared, "My case manager did it. The first time we did it all I had to do [was] pen [my] name and you know, build up an email to them; and then my case manager got on the phone and called and basically we did it over the phone. It was real quick" (black woman, age 39).

Others felt that they might have been able to enroll themselves but were more comfortable with assistance and less worried about making a critical error. For example, one participant reported, “I just felt more comfortable talking to someone who was more experienced with the ins and outs of it because it’s not intentionally tricky but if you don’t know what you’re doing, if you’re not paying attention to all the details, you could get screwed” (white man, age 42). Participants were often very grateful for the assistance they received and readily credited the help as crucial to successful enrollment.

Problems with mental health and substance misuse were reported as potential barriers. Many people voiced that mental health problems could result in an inability to comprehend information or engage in the enrollment process. A participant described this by saying, “I mean if you can’t get out of bed because you’re so depressed, you’re not going to go and get health insurance. You’re going to have a hard time prioritizing whether you need to take care of your HIV or even get health insurance. So that’s going to be an issue” (white man, age 42). Another participant said that mental health issues could be a challenge, because “you get too depressed to sign the paperwork or go down and get it” (white man, age 53). Substance misuse was believed to present similar challenges. Participants reported that intravenous drug use would likely be more debilitating than other drugs, but that many drugs, including alcohol or marijuana, could be problematic. One participant shared, “That you’re addicted to and you’re using it to black out the world, yeah. You’re not going to be functioning. You’re not going to be thinking about. I mean the only time I’ve ever missed a dose [of my HIV medication] was when I was drinking heavily and forgot because I was so hung over. I mean it’s been years but that’s happened before” (white man, age 42). Participants reported that drugs could impact one’s ability to gather application information, decision making, and interest in enrolling.

More than half of the participants reported physical barriers such as difficulties getting to their HIV clinic or health department. Most of the comments centered on the difficulty caused by lack of sufficient public transportation, especially in a rural area. For example, one participant shared, “Not as many outlets and places to go, especially of transportation is an issue or if internet is an issue. Also, living in a very rural area—whether or not maybe you can’t access or it’s a far drive or it’s hard to get to a place to sign up. It just adds another factor” (white man, age 25). In addition, some participants felt guilty asking others for help, especially if the person giving them a ride had to take off from work.

ADAP-funded QHP’s impact on care. Impact on care was sorted into two themes: changes in medication access and changes in provider access. Statements about changes to medication access focused on the change from picking medications up through health departments while receiving medications from Virginia ADAP’s direct ADAP program to having medications mailed to their homes through insurance-mandated specialty pharmacies. Participants identified changes in medication access as positive (77.4%), neutral (58.5%), or negative (50.9). Many had mixed feelings, expressing two or all three categories (Table 3). Those with positive feelings reported improved medication coverage or

TABLE 3. CROSS-QUERY ANALYSIS TO ASSESS MIXED FEELINGS ABOUT MEDICATION AND PROVIDER CHANGES AFTER AFFORDABLE CARE ACT QUALIFIED HEALTH PLAN ENROLLMENT AND/OR RE-ENROLLMENT

<i>Impact to care after enrollment and/or re-enrollment</i>		
<i>Medication access: category n (%)</i>		
<i>Positive</i>	<i>Neutral</i>	<i>Negative</i>
41 (77.4)	31 (58.5)	27 (50.9)
<i>Positive and neutral</i>		<i>Neutral and negative</i>
24 (45.3)		13 (24.5)
<i>Positive, neutral, and negative</i>		
10 (18.9)		
<hr/>		
<i>Provider access: category n (%)</i>		
<i>Positive</i>	<i>Neutral</i>	<i>Negative</i>
38 (71.7)	36 (67.9)	1 (1.9)
<i>Positive and neutral</i>		<i>Neutral and negative</i>
25 (47.2)		1 (1.9)
<i>Positive, neutral, and negative</i>		
0		

Cross-query analysis comparing statements from each participant with their other statements regarding impact to care after Affordable Care Act Qualified Health Plan enrollment/re-enrollment on medications and providers.

preferred the convenience and privacy of receiving medications by mail. One reported, “The change is good because [it] is coming to your house. If you don’t want anybody to know anybody about you, you don’t have to run into anybody. It’s coming directly to you. You don’t have to go through the health department and see Michael, Jody, or Susie there, and wondering if they know which [you] are coming for. It’s more personal when it comes to your house” (black woman, age 56). However, others identified concerns about medications not arriving on time or potentially being stolen. One participant reported, “One time I [had a medication refill issue] when we had that bad snow storm. I had a little problem getting it because they couldn’t get through because the roads were so bad. It took three weeks before I could get it” (white woman, age 54). Participants also described difficulties coordinating between using mail order for HIV medications and an in-person pharmacy for non-HIV medications: “They do deliver the HIV medications to my house, but all the rest I have to come here [to the pharmacy]” (white man, age 45). Negative impacts also included concerns such as inadequate prescription drug benefits and challenges with coordinating with insurance on mailed medications to obtain timely refills.

In terms of ADAP-funded QHP’s impact on provider access, 71.7% reported positive changes and 67.9% reported neutral feelings. Only 1 person described negative feelings. A cross-query analysis identified that almost half of the participants had both positive and neutral feelings on provider changes, 1 participant had neutral and negative feelings, and there were no participants who overlapped in all three categories (Table 3). Positive changes described benefits of added providers or included continued ability to see their provider. Several participants reported that they were able to or felt able to access a primary care provider. They often felt that they had excellent HIV care already through

Health Resources and Service Administration's RWHAP-funded clinics, but they had improved non-HIV medical care. One participant shared, "Having insurance has changed my non-HIV medical care due to the fact that I'm more on top of that" (white man, age 33). Participants with neutral feelings reported that they had not experienced changes in how often they see medical providers or who they are seeing. For the participant who reported a negative impact on their provider care, this was due to poor coverage: "Actually, I am going less [to my doctor] because they [insurance company] cover nothing" (white woman, age 53).

Discussion

Almost all participants reported that insurance was necessary and/or beneficial, citing the benefit of coverage of health care bills, decreased stress, and improved access to medical care. Participants credited their HIV clinic case managers and social workers as key sources of knowledge about their insurance options under the ACA and critical assistants for enrollment. Many participants described conversations with staff at their HIV clinic about the value of insurance to themselves and how it impacted their care. This demonstrates the key role of case managers and social workers, who are supported by RWHAP funds, as sources of accurate and timely knowledge about the health care delivery system. Their crucial role and importance will only grow as patients need to navigate the changing United States health care delivery system, especially given the different resources and funding for medical care for PLWH.

Two systems-level barriers were concerns regarding difficulty understanding information or difficulty with the process. This was also expressed by PLWH in KFF's 2016 focus groups.⁹ Best practices in how to communicate with patients about the ACA need to be developed and disseminated. In addition, when possible, processes need to be streamlined.

Although most QHP costs were covered by Virginia ADAP funds and many financial barriers were removed, participants identified numerous individual-level and systems-level barriers to QHP enrollment. The participants in this study were able to overcome any perceived or identified barriers and were enrolled by the end of the second ACA open enrollment period. This is due, in part, to the support of the HIV clinic staff as cited by the participants themselves.

In terms of individual-level barriers to enrollment, mental health issues and substance misuse were cited by more than half of the participants. These concerns echo findings from KFF's focus groups.⁸ Mental health and substance misuse are concerns that are cutting across many issues in health care given the shortage of mental health providers and the opioid epidemic.²⁶⁻²⁸ Many HIV clinics use RWHAP funds to include mental health specialists and substance use counselors on staff to provide wrap-around services that insurance plans may not cover in an effort to improve engagement in care and HIV viral suppression. A collateral benefit of having these resources in HIV clinics could be reducing barriers to QHP enrollment.

Two barriers, including lack of transportation and lack of computer/internet access, are issues that affect people at the individual level, but geographic location as well as, specifically, rurality factor into these social determinants of health. Most of the participants lived in rural areas where public

transportation is limited, and therefore, being able to use RWHAP funds to support their transportation to the HIV clinic is essential. Lack of computers and internet access and/or limited technology literacy at home also complicate access to QHP enrollment. Disparities in access to technology, such as broadband internet, due to geographic availability and cost, may exacerbate health disparities for certain groups.^{29,30} Efforts to expand internet access and skills-building to address these issues must still be a priority.

Privacy was a huge concern with participants. This is a theme that did not emerge in the KFF focus group results, perhaps because of increased HIV stigma in rural areas.³¹ There were some participants who felt that the anonymity of mail order pharmacies protected their privacy, but others felt that their privacy was better protected when they picked up their medications in person. When designing or optimizing health care delivery systems, whether insurance benefit plans or state ADAPs, it remains important to plan for and allow some flexibility for PLWH to opt in or out of certain components to improve their comfort with the system and to protect their privacy. Recent lawsuits that have been filed against insurance companies that require PLWH to obtain HIV medications through mail order pharmacies, including one filed in 2018, highlight this point.³²⁻³⁴

This study has several limitations. Notably, all participants in this study were successfully enrolled in a QHP during either the 2014 or 2015 ACA open enrollment period. The barriers to enrollment identified by this group may not be generalizable. Interviews with those who have not been successfully enrolled in ADAP-funded QHPs despite eligibility may reveal new or additional barriers. Future work should prioritize understanding the experience of that group. Another limitation is the changing political climate and potential instability of the ACA. Interviews occurred both before and after the 2016 presidential election. Media and results of the election may have had an impact on views of the stability of the ACA, eligibility and sustainability of insurance, and value of insurance through a QHP. Changes in these factors were not studied.

Given the previously published benefit of private insurance and specifically ADAP-funded QHPs for PLWH, the reasons that PLWH did or did not enroll in ADAP-funded QHPs should continue to be investigated. Case managers and social workers are often the primary source of knowledge for patients about insurance options, and ensuring that case managers and social workers are available and well informed is crucial for enrollment. Knowledge about and mitigation of barriers can improve enrollment and, thus, contribute to better health and well-being of PLWH. Our findings indicate that addressing privacy concerns may encourage enrollment. Virginia will be expanding Medicaid at the start of 2019, and with this shift in health care delivery, Virginia ADAP clients who are eligible will face another health care delivery shift. Ensuring that their voices are heard and understood will be essential for successful transition.

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