

Patient Perspective of People with HIV Who Gained Medicaid Through Medicaid Expansion: A Cross-Sectional Qualitative Study

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Abstract

Given the large numbers of people with HIV (PWH) with Medicaid coverage, it is important to understand the patient experience with Medicaid. Understanding experiences with and attitudes around the program have important policy and clinical implications. The objective was to understand the patient perspective of PWH in Virginia, who transitioned to Medicaid in 2019 due to Medicaid expansion. English-speaking PWH who gained Medicaid due to Medicaid expansion in 2019 were recruited at one Virginia Ryan White HIV/AIDS Program clinic. The goal was to enroll >33% of those who newly were on Medicaid for 2019. Participants were surveyed about demographic characteristics, and semistructured interviews were performed. Descriptive analyses were performed for cohort characteristics. Using qualitative description and an open coding strategy, codebooks were generated for the interviews and themes were identified. The cohort ($n=28$) met our recruitment goal. Most participants had positive feelings about Medicaid before enrollment (general: 68%; good for general health: 75%, and good for HIV care: 67%) and after enrollment (general: 93% and good for HIV care: 93%). All participants expressed incomplete understanding about Medicaid before enrollment. Seventy-nine percent needed outside help to complete enrollment. Approximately 40% described overlaps of Medicaid with other insurance/payers or gaps in insurance coverage when transitioning from one insurance/payer (such as AIDS Drug Assistance Program [ADAP] medication provision and ADAP-subsidized insurance) to Medicaid. Participants suggested more access or easier access to information about Medicaid and more explanation of Medicaid benefits would be helpful. Our findings indicate participants had mostly positive perceptions of Medicaid before and after enrollment. Even with enrollment help, participants voiced that dealing with insurance is hard. Medicaid and other programs should prioritize more access to information, smoother processes, and less burdensome enrollment/re-enrollment.

Keywords: HIV, Medicaid, access to health care, health care reform, health insurance, Patient Protection and Affordable Care Act

Background

CURRENTLY, 38 STATES and the District of Columbia have expanded Medicaid through the Patient Protection and Affordable Care Act (ACA) in an effort to increase access to

health care for people with low incomes.¹ In 2018, almost half of people with HIV (PWH) in Medicaid expansion states were covered by Medicaid, and in Medicaid nonexpansion states, one-third of PWH had Medicaid.² Given the large numbers of PWH relying on Medicaid, it is important to

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understand the patient experience associated with Medicaid. Understanding experiences with and attitudes around the program have important policy and clinical implications.

Beginning in 2014, all PWH with low income, who were Virginia AIDS Drug Assistance Program (ADAP) clients, were offered individual private plans or Qualified Health Plans (QHPs) purchased on the ACA Marketplace and funded by the Virginia ADAP. This program resulted in a significant increase in viral suppression³ and was viewed favorably by patients in a three-clinic mixed-methods study.⁴ When Virginia expanded Medicaid in January 2019, many PWH transitioned from ADAP-purchased QHPs to Medicaid. In Virginia, PWH choose a plan from one of six Medicaid Managed Care Organizations (MCO) within the first 90 days of coverage. They are covered by fee-for-service Medicaid for ~2–6 weeks before the Medicaid MCO plans start.⁵

As more states expand Medicaid, more PWH will shift off ADAP-purchased QHPs to Medicaid.¹ In addition, employment changes brought on by the COVID-19 pandemic⁶ may result in more PWH transitioning from individual and/or employer-based private insurance to Medicaid. Our recent quantitative analysis demonstrated lower rates of viral suppression in 2019 for PWH who transitioned to Medicaid.⁷ Given this observation, it is critical to understand the patient experience of PWH who transition to Medicaid Expansion. Our goal was to understand the patient perspective and health care experience of PWH in Virginia, who transitioned to Medicaid in 2019 due to Medicaid expansion.

Methods

Study setting, participants, and enrollment

Participants were recruited and enrolled from a nonurban academic-affiliated RWHAP clinic at the University of Virginia (UVA). Clinic patients are eligible for RWHAP-supported services with an income below 500% of the federal poverty level (FPL). Approximately 98% of the clinic population received RWHAP-supported services (2018–2019). Among those who did not have Medicare in 2018, 151 RWHAP clients were newly eligible for Medicaid in 2019 due to Medicaid expansion. Of those eligible, 77 (51%) enrolled.⁷

This prospective study's goal for recruitment was to enroll at least one-third (≥ 26) of the RWHAP clients who newly enrolled in Medicaid in 2019 due to Medicaid expansion. The UVA Institutional Review Board approved this study. Participants recruited for the study were English-speaking PWH, had been seen at the studied RWHAP clinic at least once in both 2018 and 2019, did not have Medicaid as their primary insurance in 2018, and newly had Medicaid as their primary insurance in 2019. They were recruited over the phone or face-to-face before or after an HIV medical visit in a medical examination room to ensure privacy and confidentiality. Enrollment took place from February 2020 to June 2020. Participation in the study took approximately of min. Participants received compensation for their time. The study included a descriptive survey and an interview, both of which were administered verbally to minimize any barrier related to low literacy.

Cohort characteristics

Participants were surveyed with validated measurement tools, when possible. We collected age, self-reported gender,

race/ethnicity, financial status (annual income as a percentage of the FPL), highest level of education completed, housing stability,⁸ self-reported disability status, employment status, hours employed per week, transportation difficulties, travel time to HIV clinic, internet access, food security,⁹ use of the Supplemental Food Assistance Program (SNAP), health literacy,¹⁰ and mental health, including depressive symptoms,¹¹ problem drinking,¹² and illicit drug use.¹³ Due to the onset of the COVID-19 pandemic during enrollment, we modified the survey in April 2020 to capture COVID-19 pandemic-related unemployment. We also collected years since HIV diagnosis, self-reported viral suppression status over the past 12 months, and self-reported current viral suppression status. Characteristics were used to provide additional context to the qualitative interviews and were hypothesis generating in nature.

Participant interviews

Semistructured interviews were designed to elicit participants' experiences about switching to Medicaid. Participants were asked about their perceptions before enrollment, during the enrollment process, and after enrollment. Interviews were conducted by two members of the study team, after training in interview methods. Interviewers had no prior relationship with the participants or involvement in their medical care. The interviewers followed the interview guide to ask questions in the same order for each participant. They offered specific prompts if needed for clarity and asked follow-up questions. All interviews were audio-recorded and transcribed verbatim, and then imported into Dedoose (Socio-Cultural Research Consultants, LLC) for analysis.

Qualitative analysis

Our analysis was guided by qualitative description.¹⁴ A codebook was generated iteratively by the study team, using an open coding approach with constant comparison methodology to capture themes emerging from participants' experiences. During codebook development, interviews were coded independently by two reviewers and any discrepancy resolved by consensus. The codebook was refined until intercoder agreement of 0.74 was achieved, and thematic saturation was reached. The codebook was then applied to all interviews so code frequencies could be determined.

Themes were grouped within temporal categories to capture perceptions at time points of interest (before, during, and after enrollment). Additional categories included themes affecting participants at multiple time points and were cross-cutting in nature, such as social determinants of health. Participant-generated suggestions or recommendations for improvement in the Medicaid enrollment process were also classified and categorized. Participants' perceptions were rated as positive, neutral, or negative, when relevant. To maintain rigor, decisions regarding the analysis were made open to all members of the study team.¹⁵

Results

Participant characteristics

Twenty-eight participants met the enrollment goal (≥ 26 participants). The participation rate was 47%. Cohort characteristics are described in Table 1. Participants had a median

TABLE 1. COHORT CHARACTERISTICS

Characteristics	Total (n=28), n (%)
Age, years	
Median [IQR]	43 [32–53]
Sex	
Male	19 (68)
Female	9 (32)
Race/ethnicity	
Black	17 (61)
White	6 (21)
Hispanic	3 (11)
Other	2 (7)
Financial status	
<50% FPL	7 (25)
51%–100% FPL	8 (29)
101%–133% FPL	4 (14)
>134% FPL	4 (14)
Education	
Less than high school	4 (14)
High school or equivalent	12 (42)
Vocational	4 (14)
College degree	8 (29)
Housing stability ^a	
Unstable housing	3 (11)
Stable housing with future concern	7 (25)
Stable housing without future concern	18 (64)
Self-reported disability status	
Disabled	12 (43)
Not disabled	16 (57)
Employment status	
Unemployed	22 (79)
Employed	6 (21)
Hours worked/week, median [IQR]	35 [20–50]
Transportation access	
Difficulty	18 (64)
No difficulty	10 (36)
Travel time to HIV clinician (min)	
Median [IQR]	53 [28–120]
Internet access	
None	4 (14)
Smartphone only	7 (25)
Computer only	0 (0)
Computer and smartphone	17 (61)
Food security ^{bc}	
Food insecure	13 (46)
Marginal food security	6 (21)
Food secure	9 (32)
Use of SNAP services	
Yes	12 (43)
No	16 (57)
Health literacy level ^d	
Adequate	23 (82)
Marginal	3 (11)
Inadequate	2 (7)
Depressive symptoms ^e	
Yes	17 (61)
No	11 (39)

(continued)

TABLE 1. (CONTINUED)

Characteristics	Total (n=28), n (%)
Problem drinking ^f	
Yes	7 (25)
No	21 (75)
Drug use within the past year ^g	
Yes	7 (25)
No	21 (75)
Time since HIV diagnosis, years	
Median [IQR]	10.5 [5.7–18.5]
Viral suppression status, past 12-months	
Suppressed viral load	20 (71)
Detectable viral load	7 (25)
Unsure	1 (4)
Viral suppression status, current	
Suppressed viral load	28 (86)
Detectable viral load	4 (14)
Unsure	0 (0)

^aHousing stability assessed using methods from Montgomery *et al.*⁸^bFood Security assessed using the USDA Food Insecurity Measurement Guidelines, 2012.⁹^cTwo categories (Marginal Food Security, Low Food Security) were collapsed into one category, Marginal Food Security.^dHealth literacy level based on the Short Test of Functional Health Literacy in Adults (STOFHLA): inadequate health literacy (0–5 points), marginal health literacy (6–7 points), and adequate health literacy (≥8 points).¹⁰^eDepressive symptoms assessed using the 5-item MHI scale from Berwick *et al.*¹¹^fProblem drinking assessed using AUDIT-C questionnaire from Bush *et al.*¹²^gDrug use assessed using single-question screening test from Smith *et al.*¹³

FPL, federal poverty level; IQR, interquartile range; SNAP, Supplemental Food Assistance Program.

age of 43 [interquartile range (IQR) 32–53]. Sixty-one percent were black participants. Participants had been diagnosed with HIV for a median of 10.5 years (IQR 5.7–18.5). More than half (54%) had incomes at or under 100% FPL. Approximately one-third had unstable housing or stable housing concerns. About 40% reported being disabled. Six participants (21%) reported being employed with median hours of 35 (IQR 20–50) per week. Almost 80% of participants ($n=22$) were unemployed. Of those 22, 8 (36%) reported they were looking for work. Of the 12 who enrolled during the COVID-19 pandemic, all reported being unemployed, with 4 (33%) attributing their unemployment to the COVID-19 pandemic. More than half (64%) the participants reported difficulty with transportation to HIV clinic. Participants reported a median travel time of 53 min (IQR 28–120) to HIV clinic. Fourteen percent had no internet access, and 25% had internet access only on a smartphone. Sixty-one percent endorsed depressive symptoms, one-quarter reported problem drinking, and one-quarter reported illicit drug use in the last year. Less than one-third were food secure. Almost 20% had marginal or inadequate health literacy. About 70% reported durable viral suppression for the past year. Eighty-six percent reported having a suppressed viral load at the time of enrollment.

Participant interviews

Perceptions of Medicaid pre-enrollment. In general, 19 participants expressed positive feelings about Medicaid before their enrollment, 15 neutral, and 2 negative (Table 2-A). For all quotes, participants' self-identified race, gender, and age group are stated, except for themes or race-gender categories with only one participant to preserve privacy. Participants could express mixed feelings, as discussed further below. Most participants (75%) felt having Medicaid improved one's general health. One explained their impression was positive "because I could see my regular doctor and I can get all my prescriptions that I need" (black male, 36–45). Of those who addressed whether Medicaid would impact HIV care (15), 10 felt Medicaid's effect would be positive, 4 neutral, and 1 negative. The most commonly expressed themes were better affordability/lower cost of Medicaid and access to care with Medicaid. For example, one participant stated, "it will help out people with their basically their care and kind of like their plans where otherwise they could not get the care they need" (black male, 26–35).

All participants expressed a lack of awareness or incomplete understanding about Medicaid before enrollment. As one stated, "I'm like a lost babe in the woods...I really am uninformed about it to be honest" (white male, 56–64). Others lacked confidence in being able to understand insurance: "when it comes to stuff like that I've never been good at it" (white male, 56–64). Some had a vague impression of Medicaid, but little specific knowledge: "I only know that it was for people who needed help with medical assistance and things like that but like what they offered and stuff like that I didn't really know" (Hispanic male, 26–35). Pre-enrollment perceptions included potentially stigmatizing beliefs that Medicaid is for marginalized individuals, such as those with low income.

Regarding their switch to Medicaid (Table 2-B), most participants (78%) expressed positive feelings, such as "I felt good because it was better than going to the Health Department, find out where I get my, you know, my meds from, that I could go to the hospital" (Hispanic male, 46–55). Only one expressed a negative feeling: "It just made me a little worried about the providers."

For perceptions with positive, neutral, or negative ratings, some participants expressed more than one type in their interview (Table 3). For perceptions of Medicaid pre-enrollment, six participants expressed both positive and neutral feelings. One participant had positive impressions from others, "I had heard through the grapevine from other people that Medicaid was pretty good," but also negative impressions they had heard, "the problem with Medicaid that it doesn't help a lot like if you work, especially when a person is sick and they have a lot of health issues" (black female, 36–45). One participant expressed positive, neutral, and negative feelings, sharing a variety of stories they had heard before enrollment and seeing both pros and cons, for example, "It's just that some people say government programs are a little bit slow but besides that some people say they give you a health plan" (Hispanic male, 26–35).

Enrollment process. All participants reported having a formal source of information about Medicaid (e.g., at HIV clinic; Table 2-C). Many also used informal sources (54%) such as friends or family. Some also reported receiving

information from Medicaid in the mail (39%). Many participants (79%) needed outside help to complete the administrative process of enrollment, such as from a case manager or social worker (Table 2-D). Most found the information they received to be clear and understandable (71%). Some still expressed difficulty, even with outside help, in navigating the process (25%).

When receiving help with the enrollment process, many participants deferred any decision-making about their plan to the person who assisted them. For example, "I had a case manager that walked me through everything and signed me up for the program" (white female, 46–55). Others expressed self-efficacy in making decisions for themselves (54%). In particular, participants spoke about making choices regarding their plan, based on lowest co-pays or best medication coverage.

When transitioning from one insurance/payer (such as ADAP medication provision and ADAP-subsidized insurance) to Medicaid, some participants encountered difficulty with overlap of Medicaid with other insurance or the Virginia AIDS Drug Assistance Program (11%) and problems with gaps in insurance coverage (32%) either at the time of initial enrollment or re-enrollment. Overlap led to administrative difficulty and confusion. For example, "when they stopped paying for one the Health Department then...it made it complicated because they still had me in the system as active even though I was inactive" (black male, 36–45). Gaps in coverage had a negative impact on participants' access to care and medications: "I don't know if I got it and if I'm gonna be approved for it so right now not having anything is affecting me being able to be seen, you know, or get medicine, things that I need" (black female, 46–55).

For the enrollment process, 18 participants had only positive impressions of the clarity of information they received and 4 had negative only (Table 3). For two participants, both positive and negative statements were expressed. For example, one had a positive experience with initial enrollment, but then was switched from one Medicaid insurance provider to another without understanding why or realizing that would happen. The other encountered a similar problem. Although initially feeling well informed about the enrollment process, they had a subsequent change in Medicaid insurance provider without warning or adequate explanation, causing difficulty obtaining their HIV medications from the specialty pharmacy.

Changes after enrollment. Most participants had no change in providers after Medicaid enrollment (22, 79%; Table 2-E). Three reported a change in HIV care provider and four in other specialist providers. One participant had to change oncology providers and reported a negative impact on their patient-provider relationship: "You build a connection with your doctor, you know, cause he knows you and you know him and I've been dealing with him for so long with my cancer and everything and trying to find someone new and start all over is, you know, is awful" (black female, 36–45).

Most had no change in HIV medication (75%) or non-HIV medication (61%). For those who had changes, these included method of getting medications (e.g., switching from pharmacy pick-up to mail order) or change in coverage for medications. Some gained more reliable access to medications, with subsequent improvement in adherence: "I'm using the same medication and I'm just taking it as scheduled"

TABLE 2. THEME CATEGORIES FROM ANALYSIS OF SEMISTRUCTURED INTERVIEWS WITH PEOPLE WITH HIV IN VIRGINIA REGARDING TRANSITION TO VIRGINIA MEDICAID IN 2019 DUE TO MEDICAID EXPANSION WITH REPRESENTATIVE PARTICIPANT QUOTE EXAMPLES AND FREQUENCIES

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
A. Perceptions of Medicaid pre-enrollment		
General feelings: describes general feelings toward Medicaid pre-enrollment		27 (96)
Positive	INTERVIEWER: “So you just kind of had an idea that it, like, helped other people with their healthcare but didn’t know a ton about it?” INTERVIEWEE: “Yeah, cause certain medications are, like, very expensive, you know.” (black female, 18–25)	19 (68)
Neutral	“I would say somewhere neutral. I don’t think it would think it would be negative but then, you know, I thought about what I heard so to me I was a little neutral.” (black male, 36–45)	15 (54)
Negative	“[My friends and family] like Medicaid but the problem with Medicaid that it doesn’t help a lot like if you work, especially when a person is sick and they have a lot of health issues.” (black female, 36–45)	2 (7)
Perception that Medicaid improves your general health		25 (89)
Positive	“Financially I can’t afford to pay for teeth on my own but Medicaid’s helping me a lot with that and I appreciate that.” (black female, 36–45)	21 (75)
Neutral	“I thought about what I heard so to me I was a little neutral.” (black male, 36–45)	6 (21)
Perception that Medicaid improves your HIV care		15 (54)
Positive	“It’s positive because I get the care I need.” (white female, 46–55)	10 (67)
Neutral	INTERVIEWER: “Okay, and did you think that it would have a positive or negative effect on your HIV care?” INTERVIEWEE: “No, I really didn’t think about that part of it.” (Hispanic male, 26–35)	4 (27)
Negative	INTERVIEWER: “Did you think it would have a positive or negative effect on your HIV care?” INTERVIEWEE: “Negative... I don’t think it would affect it because it’s open for everybody, the coverage. You know, that’s when I found out, you know, they was giving it to a lot of people.”	1 (7)
Lack of awareness/understanding	“I hadn’t heard nothing about it” (black male, 56–65)	28 (100)
Access to care	“[T]hey pay for your medical expenses if you can’t afford them and they pay for prescriptions and doctor visits, and transportation.” (black male, 36–45)	18 (64)
Better affordability/lower cost	“[Medicaid] helps, it helps pay medical bills that I can’t afford because I don’t have the means to have medical insurance otherwise.”	14 (50)
Prior experience with Medicaid or other insurance		
Prior experience with Medicaid	“Oh I had Medicaid when I was very young.” (black female, 56–65)	9 (32)
Experience with other insurance (besides Medicaid)	“Oh, [private insurance] was pretty good, they pretty good. I mean, you know, they, everything’s good.” (black male, 56–65)	8 (29)
Perception that marginalized individuals use Medicaid		
Low income/stigma	“[Medicaid] is for people who can’t afford their medical coverage and it’s basically nothing.” (black female, 56–65)	9 (32)
Who is Medicaid for?: Perception of what groups use Medicaid	“[Medicaid is] a government program to help people with financial medical assistance.” (Hispanic male, 26–35)	6 (21)
B. Perception of switch to Medicaid		
General feelings toward switching to Medicaid		23 (82)
Positive	“I was surprised cause I didn’t know that I could be on Medicaid. I guess they changed that they broadened I guess the eligibility. That’s what I was told, so excited.” (black male, 46–55)	18 (78)
Neutral	“To me it didn’t really matter any one way cause I know it would just be another, you have to have to navigate smoothly no matter what, okay, and I just figured there would just be some bumps in the road with it and there are a few little hiccups where you have to call, make some calls and get it straightened out, and they’d straighten it out and that was that.” (white male, 46–55)	4 (17)
Negative	“I was okay with it. I was fine, yeah. It just made me a little worried about the providers.”	1 (4)

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
No problems with switch/indifference	“I haven’t seen any difference or anything like that...I haven’t had any real problems.” (white male, 56–64)	3 (11)
C. Sources of information		
Formal sources	“I let my case manager...sign me up for Medicaid...it was through my caretakers down there [UVA] and my case manager.” (white male, 56–64)	28 (100)
Informal sources	“[I discovered eligibility] through a friend. They told me to go ahead and sign up.” (black male, 36–45)	15 (54)
Mail from Medicaid	“I think I’ve probably got like two or three advertisements from [Medicaid].” (Hispanic male, 46–55)	11 (39)
D. Enrollment process		
Reason for choosing plan	“I think it was dependent on the co-pay.” (black male, 26–35)	24 (86)
Enrollment burden: describes participants’ duration of enrollment, difficulty with administrative information/tasks, and experience with clarity of information		
Duration of enrollment	“I don’t think it was [complicated]...I don’t think it was that long.” (white male, 56–64)	23 (82)
Difficulty with administrative information/tasks	“I always find it difficult to... try to find papers and gather stuff together.” (white male, 56–64)	7 (25)
Outside help needed/obtained?: describes interviewee’s experience with self-efficacy in Medicaid enrollment decision making or having someone break down the enrollment process for them		
Having someone break down process	“I let them make a lot of the decisions...any kind of paperwork I’ve always had a problem dealing with.” (white male, 56–64)	22 (79)
Self-efficacy in decision making	INTERVIEWER: “And how did you choose between these companies?” INTERVIEWEE: “Which one did the most.” (black female, 56–65)	15 (54)
Clarity of information: describes participants’ experience with information clarity during their enrollment process		
Positive	INTERVIEWER: “And did you find that the information was easy to understand through your social worker?” INTERVIEWEE: “Yes, she was pretty straightforward and very informative about Medicaid and that’s how we can go about that.” (Hispanic male, 26–35)	20 (71)
Negative	“Honestly I have never fully understood any insurance, you know, whether it’s Medicaid, Medicare, or private insurance, you know. It just goes over my head.” (white male, 56–64)	4 (14)
Insurance overlaps vs. gaps		
Gaps in insurance coverage: describes difficulty with gaps in coverage or trouble with re-enrollment that contributed to a lack of access	INTERVIEWER: “Have any other aspects of your care changed with Medicaid? Is there anything else that’s different?” INTERVIEWEE: “No. I mean, not that I’m aware of right now. I just been back on it recently cause I was away...I was in prison for a while.”	9 (32)
Overlap of Medicaid with other insurance/ADAP	“They didn’t have me in the one system, they had me in the other system and I had to go to the Health Department to get my medicine for a month.” (Hispanic male, 46–55)	3 (11)
E. Changes after enrollment		
General feelings: describes general feelings toward changes after participant enrollment		
Positive	“Yeah I do have a generally positive opinion of Medicaid post-enrollment.” (white male, 56–64)	14 (50)
Neutral	INTERVIEWER: “Has your opinion about Medicaid changed since enrolling?” INTERVIEWEE: “I don’t have none (black male, 36–45)	3 (11)
Negative	INTERVIEWER: “Has your experience with getting your medications changed other than what we discussed earlier?” INTERVIEWEE: “It’s hard sometimes, it’s hard for me, you know, but I have to get it.” (black male, 56–65)	3 (11)
Ryan White: describes effect on Use of Ryan White services	Ryan White post-enrollment “Other than case management I don’t really use [Ryan White services] yet. There’s a process you have to go through to get to the Ryan White but you got the case management there and they help me work out with the bill I was getting.” (black female, 36–45)	27 (96)

(continued)

TABLE 2. (CONTINUED)

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
No change to Ryan White services	“No, the services are pretty much the same.” (black male, 56–65)	16 (57)
Changes to Ryan White services	“Has [Ryan White support] changed at all since your Medicaid enrollment?” INTERVIEWEE: “No. Actually, it’s better...I went to the dentist and whatever my dentist doesn’t get paid for then the Ryan White picks up. I mean whatever my prescription, so that’s a good thing and some of the doctors use Medicaid cards too to help with dental so yeah.” (black male, 36–45)	11 (39)
Provider: describes switching HIV provider, switching specialist provider without changing HIV provider, or not changing HIV providers post-enrollment		
No major change in provider	“I’m still getting the service. I haven’t seen any difference or anything like that.” (white male, 56–64)	22 (79)
Non-HIV specialist provider change	“I feel overwhelmed with appointments cause I have appointments and my kids have appointments and I forget about me sometimes and I miss appointments and the doctors just told me because I missed they’re gonna have to let me go, but I’m still at the same company but just a different doctor.” (black female, 36–45)	4 (25)
Switching HIV provider	“I switched [HIV providers] because I moved at the same time.” (white male, 56–65)	3 (11)
Medication: describes changes or lack of changes to non-HIV and HIV medication and medication accessibility post-enrollment		
No major change in HIV medication	“As far as right now I think everything’s the same because I’ve been getting my prescription as scheduled so I’m taking everything the same as usual.” (black male, 56–65)	21 (75)
HIV medication access	“When I first started [Medicaid] I was getting it from the Health Center and then after a few months they started mailing it to me.” (black male, 26–35)	17 (61)
No major change in non-HIV medication	“Everything’s still the same. I just turn in my card to my pharmacy, and they accept it and UVA at the doctor’s office do too. I just present my card and they accept it, so everything’s okay.” (black male, 46–55)	17 (61)
Non-HIV medication access	“I can’t afford it and they don’t pay for it...Medicaid won’t pay [for Viagra].” (white male, 56–64)	7 (25)
Care/services: describes post-enrollment changes or lack of changes to care and access to services		
No major change in care (in general)	“It’s all pretty much the same. Good doctors, so I went from good doctors to good doctors and no bad experiences or anything.” (white male, 18–25)	19 (68)
Changes in access to services	“I’ve needed more care and I’ve gotten more care [since enrolling]. I’ve needed more services and I’ve gotten more services as I’ve needed.” (white female, 46–55)	17 (61)
Changes in health: describes no major change in, improvement in, or worsening of health post-enrollment		
Improvement in health post-enrollment	“I think it’s better and I think it’s helped with me getting the things that I need with HIV and stuff like that, so yeah.” (black male, 46–55)	17 (61)
No major change in health	“Everything’s kind of still the same.” (black male, 26–35)	8 (29)
Worsening of health post-enrollment	INTERVIEWER: “Did your health improve since you transitioned to Medicaid?” INTERVIEWEE: “Nope, it probably got worse.”	1 (4)
Changes to the cost of medications/services	“See it went up, you know. I mean, you know, I thought it was supposed to be decreased but it went up....I’m thinking my co-pays, but I thought everything I get is supposed to be free and my medicine’s supposed to be free so that’s why I’m mad now cause I have to pay for some medicines and some I shouldn’t have to pay for.” (black male, 56–65)	7 (25)
Dental care	“Mainly it’s just dental insurance and I’d like to get my teeth care. I think that’s very important.” (Hispanic male, 26–35)	5 (18)
F. Perceptions of Medicaid post-enrollment		
General feelings: describes participant’s general feelings toward Medicaid post-enrollment		
Positive	Medicaid has been very good for me. I haven’t had any issues with Medicaid at all.” (black female, 36–45)	26 (93)
Neutral	“Yeah, I mean I already have medicine, yeah. It’s the same.” (black male, 26–35)	6 (21)
Negative	“If I had a choice I would not have Medicaid if that’s what you want to know.”	1 (4)
Good care for HIV: describes participant’s post-enrollment perception that Medicaid provides good care for HIV		28 (100)

(continued)

TABLE 2. (CONTINUED)

Theme	Representative quote	n (%)
Positive	"I think they do a pretty good job to make sure that we get our medicine and stuff like that and it's not a struggle to get there. I'm pretty sure the way they look at it here and I guess look at it is it's guaranteed for us to be able to have that medication, have that medication to be able to get it on time." (black male, 46–55)	26 (93)
Neutral	INTERVIEWER: "... Do you think that Medicaid provides good care for people living with HIV?" INTERVIEWEE: "I don't know that either." (black male, 36–45)	2 (7)
Negative	INTERVIEWER: "Do you think that Medicaid provides good care for people living with HIV?" INTERVIEWEE: "Oh, they could do better." (black female, 56–65)	2 (7)
Uncertainty/lack of awareness post-enrollment	"I don't really know about much information about that." (Hispanic male, 26–35)	2 (7)

For all quotes, participants' self-identified race, gender, and age group are stated, except for themes or race-gender categories with only one participant to preserve privacy.

ADAP, AIDS Drug Assistance Program; UVA, University of Virginia.

(black male, 56–65). Others encountered unexpected negative changes: "I thought everything I get is supposed to be free and my medicine's supposed to be free so that's why I'm mad now cause I have to pay for some medicines and some I shouldn't have to pay for" (black female, 46–55).

Almost all participants reported use of Ryan White services (96%). Some reported less utilization of Ryan White support after Medicaid enrollment, because of increased access to services now covered by Medicaid. However, even with Medicaid, Ryan White assistance was still needed to fill coverage gaps: "whatever my dentist doesn't get paid for then the Ryan White picks up" (black male, 36–45).

Although most participants reported no change to their medical care in general (68%), some experienced a change in access to services. Many of these changes were positive with increased access to care or gaining benefits they did not previously have, such as dental coverage. However, some experienced an increase in cost of care and difficulty with co-pays. As one stated, "Some appointments I don't go to because I don't have it, like things that I need to go to I can't go to like cause I don't know if they're gonna charge me and I can't afford to be garnished out of my check...so if I know it's not gonna cover it I'm not gonna go if it ain't life and death" (black female, 46–55).

Overall, most participants reported an improvement in their health after Medicaid enrollment (61%). Positive changes included improvement in management of HIV and other chronic conditions: "I think it's better and I think it's helped with me getting the things that I need with HIV" (black male, 46–55). Only one participant reported a worsening of health post-enrollment. This participant also experienced gaps in coverage due to difficulties with re-enrollment and reluctance to access medical care due to cost concerns.

People could express multiple perceptions toward Medicaid (totals >100%). Most perceptions of Medicaid post-enrollment were generally positive (Table 2-F). Twenty-six (93%) participants made positive statements about their post-enrollment feelings, such as "Medicaid has been very good for me" (black female, 36–45). Six expressed neutral feelings, mostly due to lack of change in care attributable to Medicaid: "nothing's changed so I guess it's fine" (black male, 36–45). One had negative feelings post-enrollment: "If I had a choice I

would not have Medicaid." Most felt Medicaid provided good care for PWH (93%), although two expressed room for improvement: "they could do better" (black female, 56–65).

Regarding their post-enrollment perceptions of whether Medicaid provides good care for PWH, 24 participants expressed positive feelings only, 2 neutral only, and 2 both positive and negative (Table 3). One with mixed feelings reported being satisfied with their coverage from Medicaid, but was encountering difficulties with their transportation assistance. The other was satisfied with the experience, but was concerned about a friend who had difficulty with HIV medication access on Medicaid.

Themes across time points. Themes across multiple time points included medication adherence, trust in providers, and social determinants of health (Table 4). Medication adherence was discussed by four participants. Some were able to improve adherence, due to more reliable access to medications with Medicaid. However, interruption in medication access due to insurance problems had a negative impact on adherence for others. Trust in medical providers and their care team was discussed by five participants. Confidence that the care team had their best interests in mind helped some participants through the enrollment process: "I just go wherever my case manager and my doctors and all thought are best" (white male, 56–64). Some who had a change in providers due to insurance coverage had difficulty re-establishing trust, especially when "meeting a whole new group of people and talk about like very sensitive information and stuff" (black male, 26–35). Of the social determinants of health, participants most frequently discussed transportation (79%). Assistance with transportation was generally considered a positive aspect of Medicaid; however, the process of arranging transportation did not always go smoothly, including unreliable rides causing participants to miss medical appointments. In addition, the logistics were difficult to navigate: "I had to request transportation five days ahead to get it paid for and then fax and do all this and I just think that that's stupid" (black male, 36–45). Many participants continued to use Ryan White services for transportation. Other challenges included food access/security, housing, mental health, and incarceration.

TABLE 3. CROSS-QUERY ANALYSIS TO ASSESS MIXED FEELINGS AT DIFFERENT TIME POINTS OF PEOPLE WITH HIV IN VIRGINIA REGARDING TRANSITION TO VIRGINIA MEDICAID IN 2019 DUE TO MEDICAID EXPANSION

<i>Perception of Medicaid pre-enrollment</i>		
General feelings ($N=27$): Category, n (%)		
Positive 11 (41)	Neutral 8 (30)	Negative 0 (0)
Positive and neutral 6 (22)		Positive and negative 1 (4)
Positive, neutral, and negative 1 (4)		
Medicaid will improve your general health? ($N=25$): Category, n (%)		
Positive 19 (76)	Neutral 4 (16)	Negative 0 (0)
Positive and neutral 2 (8)		Positive and negative 0 (0)
<i>Enrollment process</i>		
Clarity of information ($N=22$): Category, n (%)		
Positive 18 (82)	Neutral 0 (0)	Negative 4 (18)
Positive and neutral 0 (0)		Positive and negative 2 (9)
<i>Changes after enrollment</i>		
General feelings ($N=14$): Category, n (%)		
Positive 8 (57)	Neutral 3 (21)	Negative 3 (21)
Positive and neutral 0 (0)		Positive and negative 2 (14)
<i>Perceptions of Medicaid post-enrollment</i>		
General feelings ($N=26$): Category, n (%)		
Positive 19 (73)	Neutral 0 (0)	Negative 0 (0)
Positive and neutral 6 (23)		Positive and negative 1 (4)
Good care for HIV ($N=28$): Category, n (%)		
Positive 24 (86)	Neutral 2 (7)	Negative 0 (0)
Positive and neutral 0 (0)		Positive and negative 2 (7)

Participants' suggestions/recommendations. The most frequent category of suggestions from participants was related to information access (Table 5). Fourteen participants desired more access or easier access to information about Medicaid and 12 wanted more explanation of Medicaid benefits. Some felt better online access to information would be helpful, although not all would be able to take advantage. In particular, some participants expressed a need for more information about re-enrollment, to avoid gaps in coverage, and more warning about any change to their plans with explanation of the implications of any change. Other suggestions from participants included having more assistance with enrollment, improvements in the enrollment and re-enrollment processes, better coverage and lower cost to patients, improvements in the transportation assistance, and ensuring uninterrupted timely access to medications.

Discussion

Participants had mostly positive perceptions of Medicaid both before and after enrollment. Most felt that their own health improved after Medicaid enrollment and that Medicaid allowed PWH to have good care. Even with enrollment help, participants voiced that dealing with insurance is hard. This might have important consequences and may be why a quarter of participants self-reported a detectable viral load in the first year on Medicaid. Some suggestions from our participants to improve Medicaid enrollment included more access to information, smoother processes, and less burdensome re-enrollment. These suggestions can be used by any program/insurance that anticipates new PWH to enroll/re-enroll and may be helpful for the RWHAP and RWHAP case management/insurance assistance programs.

Positive aspects of Medicaid discussed by participants included the following: affordability of care, access to HIV care and other medical and dental care, access to HIV and non-HIV medications, and transportation assistance. From the perspective of patients, expansion of Medicaid seems generally needed to facilitate access to care.

However, some negative experiences were also reported. More than 40% raised the issue of either overlaps of Medicaid and other insurance/ADAP or gaps in insurance coverage when transitioning from one insurance/payer (such as ADAP medication provision and ADAP-subsidized insurance) to Medicaid. While an overlap might not seem like as big of an issue as a gap, we have heard from insurance assisters that both overlaps and gaps can result in lack of access to medications, including HIV medications.¹⁶ We hypothesize that these overlap and gap issues described by this cohort may be the reason for the lower viral suppression among PWH who transitioned to Medicaid in 2019, which was observed in our clinic's quantitative study.⁷ Overlaps/gaps may have only been an issue during the transition year (2019). Future studies will need to see if the overlap/gap issue and lower viral suppression persist for this population.

All participants reported difficulty understanding insurance-related information. Half suggested both more explanation of Medicaid benefits or more/easier access to information in general. Our team's previous research demonstrated PWH who learned about the ACA from websites were more likely to have accurate knowledge about HIV-related aspects of the ACA.¹⁷ Websites may be an avenue to increase information dissemination about aspects of Medicaid that are important for PWH.

Similar to what we have found with previous health care transitions for PWH in Virginia,⁴ most participants had assistance in the enrollment process from people such as case managers or social workers. Previous work has demonstrated assisters tailor their approaches to HIV-specific and person-specific concerns by navigating challenges related to affordability, formularies, and provider networks.¹⁶ Almost a quarter stressed the importance of having assistance by including it in their suggestions for Medicaid. The insurance enrollment process can be challenging, especially for patients with limited education or low health literacy. This suggestion highlights the key role of case managers and social workers, who are supported by RWHAP funds or federal navigator funds, as sources of accurate and timely knowledge about the health care delivery system. Recently, there were cuts to the federal

TABLE 4. THEMES ACROSS TIME POINTS FROM ANALYSIS OF SEMISTRUCTURED INTERVIEWS WITH PEOPLE WITH HIV IN VIRGINIA REGARDING TRANSITION TO VIRGINIA MEDICAID IN 2019 DUE TO MEDICAID EXPANSION WITH REPRESENTATIVE PARTICIPANT QUOTE EXAMPLES AND FREQUENCIES

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
Social determinants of health: describes underlying social determinants of health throughout interviews, including challenges of transportation, housing security, food access/security, incarceration, mental health, and outside social support.		
Transportation	“Medicaid is just for me to, I guess, you know, give me rides back and forth to doctors’ appointments and pay for some medications.” (black male, 56–65)	22 (79)
Food access/security	“I was smaller [before enrolling] but then when I got to a weight where they wanted me and it’s holding up well. I’m not going up and down. It’s the same.” (black male, 56–65)	8 (29)
Housing	INTERVIEWER: “Yeah, what can Medicaid do better for you?” INTERVIEWEE: “Just better housing...” (black male, 36–45)	2 (7)
Mental health	“That’s one thing I think a lot of us HIV people have to deal with is the swings, the different swings in your mood. You’re up one day and down the next and sort of the normal life I would say. You need a good support. That’s why I was saying I think I might try to go to this men’s thing in a couple weeks. Support group, I don’t know.” (white male, 56–64)	2 (7)
Incarceration	“My family, when I got arrested said, ‘I need to bring her medication to the jail,’ you know, ‘She’s gonna need her medication,’ ... but they wouldn’t ... so that made me not be able to get the medication for like almost two to three weeks.” (white female, 46–55)	2 (7)
Trust: describes sentiments of trust displayed in clinicians, social workers, or case managers throughout Medicaid enrollment	“I mean, one way or the other something will be in place. I know even with all these changes there’s always gonna be one by the wayside that you’d have something to fill in and continue on with it so that was kind of like a reassuring thing to me, talking to the people where you are.” (white male, 46–55)	5 (18)
HIV medication adherence	“I was taking [HIV medications] but I was having problems getting them because I didn’t have Medicaid.” (black female, 56–65)	4 (14)

For all quotes, participants’ self-identified race, gender, and age group are stated, except for themes or race-gender categories with only one participant to preserve privacy.

insurance navigator funds,¹⁸ but in April 2021, the U.S. Health and Human Services announced \$80 million or an eightfold increase in funding for navigators to assist people for the 2022 Open Enrollment period.¹⁹ Assistants’ roles will continue to be crucial, especially given the various, complex, and often-changing resources and funding for medical care for PWH. PWH view HIV clinicians as a more trustworthy source of information than their health insurance company,¹⁷ so having clinicians and clinic staff help with insurance transitions could be a facilitator to successful insurance enrollment.

Despite assistance, participants still complained about challenges with the enrollment and re-enrollment process. Other negative experiences highlighted included the following: interruptions in access to care and medications due to re-enrollment problems or changes in insurance providers, unexpected increases in costs for medications or services not sufficiently covered, and missed appointments due to cost concerns and unreliable transportation. Some cost concerns may reflect participants’ uncertainty about whether they would be charged cost-sharing or co-pays. Even if their actual costs would have been minimal, their perception of risking a cost could still create a barrier to care with potential negative impact on viral suppression. More transparency around medication and visit costs could help address misperceptions.

Having Medicaid was valuable, but not sufficient to achieving medication adherence, engagement in care, and viral suppression. Difficulties with Medicaid had a negative

impact on care for some participants. Others faced difficulties beyond Medicaid itself, including needs related to social determinants of health not fully addressed by insurance coverage. Notably, while this group of PWH has access to RWHAP resources, almost a third had unstable housing, and less than one-third were food secure. Housing and food are two social determinants of health where insurance companies could help bolster resources, in addition to the RWHAP resources. Insurance companies, including Medicaid, should consider ways to address barriers to care, including needs related to social determinants of health.

This study has several limitations. All participants in this study were successfully enrolled in Medicaid in 2019. The benefits and challenges with Medicaid identified by this group may not be generalizable. There could be selection bias with people who opted to participate having more positive experiences with Medicaid. This study recruited from one academic medical center within a single state, so results may not be transferable to other care environments or states that expanded Medicaid in 2014. Future studies in other states would be helpful to determine if this study’s findings are unique characteristics to Virginia or are more broadly applicable to the Medicaid for PWH in other states. Other questions to explore further in future work include additional investigation of experiences with overlap/gaps in coverage and the potential role of politicization of health policy in shaping participants’ views of Medicaid. In addition, this study was cross-sectional in nature. There is a gap in understanding the

TABLE 5. SUGGESTIONS FOR IMPROVEMENT FROM ANALYSIS OF SEMISTRUCTURED INTERVIEWS WITH PEOPLE WITH HIV IN VIRGINIA REGARDING TRANSITION TO VIRGINIA MEDICAID IN 2019 DUE TO MEDICAID EXPANSION WITH REPRESENTATIVE PARTICIPANT QUOTE EXAMPLES AND FREQUENCIES

<i>Theme</i>	<i>Representative quote</i>	<i>n (%)</i>
Information-related suggestions: describes information-related suggestions for more explanation of Medicaid benefits or more/easier access to information in general		
More/easier access to information (in general)	“Just get more education to the ones that are applying and let them know what the options are and what the benefits, you know, the pros and cons are.” (black female, 46–55)	14 (50)
More explanation of Medicaid benefits	“Like [Medicaid] should have like a seminar or something about different things that Medicaid offers and how Medicaid would assist.” (black male, 36–45)	12 (43)
Better coverage/lower cost to consumers	“The only issue that I had with it, is pregnant women don’t get Medicaid sooner or longer than, you know, longer as they need it.” (white female, 46–55)	8 (29)
No suggestion stated	INTERVIEWER: “Okay, so do you think there are any things that Medicaid could do to better improve your healthcare?” INTERVIEWEE: “No, I’m pretty much offered everything that I need.” (white female, 46–55)	7 (25)
Having someone assist with the Medicaid enrollment process	“I like how [clinic], you know, and the Ryan White program help the patients get, make sure that they have everything filled out and do it for the next year and so on and so forth. A lot of people just don’t have that type of patience to want to fool with it.”	6 (21)
Improvement to enrollment/re-enrollment	“Just that if the [enrollment] process was shorter probably and I didn’t have to do it that often, you know.” (black female, 46–55)	3 (11)
Other suggestions not directly related to Medicaid	“I think there should be better housing as far as like, for HIV clients and families that can’t afford like to pay for the rent like I’m paying. Like just a better housing situation.” (black male, 36–45)	3 (11)
Suggestions related to clinicians	“I don’t have no problem with the Medicaid, it’s just if I have to get a specialist or just a doctor that’s not related to my HIV I will not be able to find a carrier at all, like I have a name on my card and I called for and tried to make appointments and she says, “I’m not working with Medicaid,” so I get confused.” (white female, 36–45)	3 (11)
Timeliness of medication	“[Getting HIV medications] started getting easier once they worked all the kinks out because they still had me active with the Marketplace and then I had to call and get inactive and then I still had to wait some, like a month or so, but I mean they was able to find me medicine.” (black male, 36–45)	2 (7)

For all quotes, participants’ self-identified race, gender, and age group are stated, except for themes or race-gender categories with only one participant to preserve privacy.

longitudinal perspective related to care changes and how participants navigate those changes in real time. This gap highlights the need for future longitudinal perspectives.

Given the recent economic disruption caused by COVID-19²⁰ and the co-location of HIV and COVID-19 in areas with greater poverty and unemployment,^{21–24} Medicaid likely played an important role in 2020 and beyond as a safety net in states with Medicaid Expansion.²⁵ Our own clinic found rapid unemployment with the start of COVID-19.⁶ In a recent national survey, 40% of RWHAP clinicians reported changes in their patients’ insurance status/coverage, which they described as an increase in clients who were uninsured, followed by private coverage losses, and then increases in clients with Medicaid.²⁶ State Medicaid programs may be able to learn from our participants’ perspective and suggestions. State ADAPs and RWHAP clinics may also find this information valuable, as they are often helping to navigate insurance status/coverage changes for PWH.

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