

# Impact of the Outpatient Clinic Experience on Retention in Care: Perspectives of HIV-Infected Patients and Their Providers

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Dear Editor:

ONLY 25% OF HIV-INFECTED PERSONS in the United States are virally suppressed, in part due to the multiple challenges patients face in navigating the healthcare system.<sup>1</sup> Retention in care is critical to HIV treatment success and represents the step along the HIV care continuum (HIV testing, linkage to care, retention in care, initiation of anti-retroviral therapy (ART), and viral suppression) with the highest attrition rate.<sup>1</sup> Prior studies have mostly focused on patient-level barriers (e.g., HIV stigma, substance abuse, mental illness, food/housing insecurity), with few focusing on the clinic experience, despite the finding that patient satisfaction with their HIV clinic strongly correlates with HIV outcomes.<sup>2</sup> We aimed to elicit patient and provider perspectives on the outpatient HIV clinic experience to identify targets for future interventions.

We recruited HIV-infected adults ( $\geq 18$  years) from three Ryan White Program-funded clinics in Philadelphia between March and November 2013. Using purposive sampling, patients with varying retention in care (defined as completing  $\geq 2$  primary HIV care visits separated by  $\geq 90$  days in the 12-month period prior to interview) and viral suppression (defined as median HIV-1 RNA in the 12-month period prior to interview  $\leq 400$  copies/mL) patterns were invited by phone or in the clinic waiting room to participate in qualitative, semi-structured interviews. Patients were compensated \$25 for their time. HIV care providers at these clinics were invited electronically. Recruitment concluded when we reached thematic saturation. The institutional review board of each clinic approved the study.

Two interview guides (patient and provider) were developed to elicit perspectives on the outpatient HIV clinic experience. Interviews began with open-ended questions exploring interviewee perspectives on HIV care and treatment. Then, interviewees were asked to reflect on barriers and facilitators to engagement in care, relationships between

patient and provider/clinic staff, and navigating the healthcare system. Lastly, interviewees were asked to share any additional thoughts on the HIV care experience. In-person interviews lasted 20–30 min. After piloting the patient interview guide with 6 individuals, the research team met to review early transcripts and adjust the interview guide to better capture perspectives.

All interviews were audio recorded, professionally transcribed, and imported into NVivo10 software for analysis (QSR International, Melbourne, Australia). Data were analyzed for themes and patterns using a grounded theory approach, a methodology that involves iterative development of theories about what is occurring in the data as they are collected.<sup>3</sup> First, an initial set of transcripts was reviewed line-by-line to generate a working coding scheme. Then, using this scheme, we independently coded a second set of transcripts and revised the scheme until no new themes were identified. Lastly, after assessing inter-rater reliability, the final coding scheme was applied to all transcripts. Identified themes were compared to assess patient and provider perspectives on the outpatient HIV clinic experience.

A total of 51 HIV-infected patients were interviewed (Table 1). Median age was 45 years; 24 patients were female, and most were of minority ethnicity (87%). Over half of the patients (69%) had a CD4 count  $\geq 350$  cells/mm<sup>3</sup> at the time closest to interview, 25 (49%) were retained in care, and 29 (57%) were virologically suppressed. Among the 13 providers interviewed, 11 were physicians and 2 were nurse practitioners; 5 were female and 4 were of minority ethnicity.

Based on transcript analysis, interviewee responses about the outpatient HIV clinic experience were conceptualized into three stages: pre-appointment interactions (appointment and transportation scheduling, reminder phone calls), waiting room experiences (contact with staff and other patients, stigma, privacy, wait time length), and the patient-provider relationship (trust, mutual respect, communication). Patients

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TABLE 1. SAMPLE SOCIODEMOGRAPHIC AND CLINICAL CHARACTERISTICS

Characteristic <sup>a</sup>	Total (N = 51)
Age (years) <sup>b</sup>	
18–29	4 (8%)
30–39	11 (22%)
40–49	18 (35%)
≥ 50	18 (35%)
Sex	
Male	27 (53%)
Female	24 (47%)
Race/ethnicity	
White	6 (12%)
Black	41 (80%)
Hispanic	3 (6%)
Other	1 (2%)
HIV risk factor <sup>c</sup>	
MSM	13 (25%)
Heterosexual	35 (69%)
IDU	3 (6%)
Insurance <sup>d</sup>	
Private	4 (8%)
Medicaid	34 (67%)
Medicare	10 (20%)
Uninsured	3 (6%)
ART regimen <sup>e</sup>	
PI	29 (57%)
NNRTI	15 (29%)
Integrase	5 (10%)
Not on ART	2 (4%)
CD4 cell count (cell/mm <sup>3</sup> ) <sup>f</sup>	
≤ 200	8 (16%)
201–350	8 (16%)
351–500	8 (16%)
> 500	27 (53%)
Viral suppression <sup>g</sup>	
Suppressed	29 (57%)
Not suppressed	22 (43%)
Retention in care <sup>h</sup>	
Retained	25 (49%)
Not retained	26 (51%)

ART, antiretroviral therapy; IDU, injection drug use; MSM, men who have sex with men; NNRTI, non-nucleoside reverse transcriptase inhibitor; PI, protease inhibitor.

<sup>a</sup>Characteristics and values within the 12-month period prior to interview date.

<sup>b</sup>Age on the date of interview.

<sup>c</sup>Patients who had IDU in combination with another risk factor (e.g., MSM, HET) were classified as IDU.

<sup>d</sup>Patients with both Medicare and Medicaid were grouped as Medicare.

<sup>e</sup>Patients were considered to be on ART if they concomitantly received ≥ 3 antiretroviral drugs (excluding ritonavir) during the 12-month period prior to the interview date. ART regimen prescribed closest to the interview date was grouped using the following hierarchy: (1) PI-based, (2) NNRTI-based, and (3) integrase inhibitor-based.

<sup>f</sup>CD4 cell count closest to the date of interview.

<sup>g</sup>HIV viral suppression was categorized as suppressed (HIV-1 RNA ≤ 400 copies/mL) and not suppressed (HIV-1 RNA > 400 copies/mL) based on the median value in the 12-month period before the interview date.

<sup>h</sup>Retention in care was defined as completing two or more primary HIV care visits separated by ≥ 90 days in the 12-month period prior to the interview date.

described their personal experiences with each stage, while providers discussed each stage more generally (Table 2).

Most patients discussed minimal barriers to scheduling appointments, though non-retained patients were more likely to identify difficulties. Patients also described how reminder phone calls, particularly if received close to the appointment date, facilitated clinic attendance. Providers agreed with the utility of these reminders, but highlighted the difficulties with inaccurate phone numbers. These perspectives reflect recent data that show improved visit adherence with the use of mobile text messaging or phone call reminders, but also that 40–50% of HIV-infected persons are without a mobile phone, and up to 24% experience telephone service disconnection during a 1-year study period.<sup>4,5</sup> Though not a universal solution, HIV clinics should obtain detailed contact information and verify this at each visit so those patients with access to mobile phones can benefit from these reminders. Lastly, both patients and providers also discussed transportation-related challenges, such as availability, accessibility, and cost, related to clinic attendance. Services, such as public transportation tokens or assistance navigating medical transportation services, to address these barriers may improve visit attendance.<sup>6,7</sup>

The waiting room experience elicited mixed perspectives from patients and providers. The majority of patients expressed satisfaction with clinic wait times and described positive relationships with front desk staff and other patients. However, lack of privacy and anxiety about HIV-related stigma were significant issues for non-retained individuals. Similarly, half of providers expressed concerns about stigma and lack of privacy in the waiting room. Prior studies show that the waiting room provides a space for positive interactions with staff and other patients for some individuals, but represents a barrier for others due to concerns over privacy and stigma.<sup>7,8</sup> Waiting room experiences may be improved by reducing wait times, creating safe and welcoming physical spaces, and reducing the effects of HIV-related stigma by training clinic staff to be respectful, nonjudgmental, and confidential when interacting with patients.<sup>8–10</sup>

Lastly, the patient–provider relationship was discussed as one of the most critical components of the HIV clinic experience. Both patients and providers expressed that trust and mutual respect fostered improved appointment adherence; patients also explicitly discussed the importance of communication. Prior research demonstrates that the patient–provider relationship is one of the most significant drivers of patient satisfaction with the HIV clinic experience, more so than issues such as appointment scheduling, facility environment, and wait times.<sup>2,8</sup> Furthermore, high quality patient–provider relationships and communication are associated with improved retention in care, ART adherence, and viral suppression.<sup>9,11</sup>

Our study is limited by (1) a focus on patients enrolled in primary HIV care, (2) a sample predominately composed of urban-based racial and ethnic minorities, and (3) the potential influence of social desirability bias on patients' responses. Future studies should explore the perspectives of patients not linked to care and those lost to follow-up.

In conclusion, patients and providers had a similar perspective of the HIV clinic experience. Both groups identified good patient-provider relationships, reminder phone calls, waiting room communities, and helpful staff as positive aspects of the HIV clinic experience, while transportation

TABLE 2. HIV-INFECTED PATIENT AND PROVIDER PERSPECTIVES ON THE HIV CLINIC EXPERIENCE

Themes	Patient quotes	N = 51 (%) <sup>a</sup>	Provider quotes	N = 13 (%) <sup>a</sup>
<i>Pre-appointment interactions</i> Appointment and transportation scheduling	<p>“But then they ask you to push the button, and then – I mean they – it’s easy once you, once you know, you get in the routine of it, it’s easy, you just follow the phone.” –NR Female</p> <p>I: “What don’t you like about going to clinic?”</p> <p>R: “Traveling. Yeah, sometimes traveling. And then you call. And then if you – see, you can use the transportation system, but the thing with that is that you have to give them 72 hours notice. If you don’t give them 72 hours notice, you have to catch the bus.” –NR Female</p>	39 (77%)	<p>“We try to schedule them with a follow up appointment before they leave the office that day. But often that doesn’t happen, because people don’t know their schedules, etcetera.”</p> <p>“I talk to them while we’re in the exam room about when I’d like to see them again and why I’d like to see them again at that time. I don’t mark it down that way until they agree that they think that’s a good time.”</p>	12 (92%)
Reminder phone calls	<p>“It makes it simple because they do reminders, I love that, because if not, I wouldn’t make it to no appointments, because I forget, especially because I don’t write it anything down because of my kids.” –R Female</p>	9 (18%)	<p>“A high percentage of our patients often don’t have working cell phone numbers, so we call everybody before their appointments – or the receptionist calls everybody before their appointments, but often by that point, three months have passed since their last appointment and their cell phone number is different or they don’t have minutes or whatever.”</p>	5 (39%)
<i>Waiting room experiences</i> Contact with staff and other patients	<p>“We can start talking about anything out there. I’m just being serious. It depends on the crowd of people that is there. They can go start talking about like the benefits that you can get through this, you know, like it’s like certain things that you can make phone calls and you can get certain things because you’re HIV positive.” –NR Female</p> <p>“So this is kind of like – like a new type of family in that sense that – it’s been great coming here.” –NR Male</p>	38 (75%)	<p>“Most of my patients have said after their first visit, oh I feel very comfortable here. So that’s, I think been a positive thing for us. And we have things to do, we have the television on. A lot of times people hang out in the waiting room, so they’ll talk to each other.”</p> <p>“If you have a front desk that is smiling and trying to help the patient, and has a sense of humor, I think that helps.”</p>	6 (46%)
Stigma and privacy	<p>“You don’t want to see nobody you know and all that kind of stuff. I hate the waiting room, I wish I could put on my hood and walk right through there when I leave.” –R Male</p> <p>“Then again, early on, it’s like, oh man, I hope I don’t run into anybody that I know. I was like why would I worry about that for. They got the same thing or something different.” –NR Male</p>	18 (35%)	<p>“Then sometimes people are afraid that they’re gonna see someone they know and their health secret gets disclosed to a larger group. So that can be a considerable fear.”</p> <p>“It’s not unheard of for someone to say, I recognize someone out there, I’m very uncomfortable. That even extends to the people who work in the clinic, desk staff.”</p>	10 (77%)

(continued)

TABLE 2. (CONTINUED)

Themes	Patient quotes	N = 51 (%) <sup>a</sup>	Provider quotes	N = 13 (%) <sup>a</sup>
Wait time length	<p>“I know when it’s crowded, you might be a little wait. But I don’t worry about that, you know, because I’m waiting, they’re waiting. You know, you aint going to go nowhere, and come in and go right back out. So you’ve got to learn how to be patient and flexible.” –R Female</p>	35 (69%)	<p>“I mean I think the more they wait, the less likely they are to want to come back next time. And I can’t say I really blame them for that. But it’s kind of the nature of working in a place like this where you have to be kind of lenient because a lot of people have social issues, they have really terrible medical issues, and if you turn people away you start impacting harmfully on their care.”</p>	7 (54%)
<i>Patient-provider relationship</i>				
Trust	<p>“If I was having any kind of side effects or anything like that, I would talk to her about it, but I haven’t had any side effects. And I trust her 110 – completely to – you know, subscribe the correct medications for me.” –NR Female</p>	40 (78%)	<p>“Oh it’s fundamental. The patient has to trust you. You’re prescribing a very expensive medication with a lot of side effects, and the patient has to trust that you know what you’re doing. That you’re not just going through the mechanics.”</p>	6 (46%)
Mutual respect	<p>“I tell the doctor anything. If I drank, I tell the doctor. If I did a line of coke, which I haven’t done in 20 years, but if I did that I’d tell them. They’ll work with it. I mean, they’re not gonna judge you for it. It helps them work with what they’re doing, because the dosage is different and stuff.” –R Male</p>	25 (49%)	<p>“Again also, because people have to feel comfortable – I don’t think a good doctor or a good clinician, patient relationship, makes you take your meds more. But I think a good clinician patient relationship allows you to diagnose the problem with adherence once it occurs, much better.”</p>	7 (54%)
Communication	<p>“She gets a lot of info about what’s going on, about my status, she tells me, she explains everything down on the computer, telling me about my say like sugar level, blood pressure level, the hepatitis level, all kinds of stuff, the liver. It’s a whole lot, she break it down to me, make sure everything is normal and stuff. So that’s a good thing.” –R Male</p>	21 (41%)	<p>“When you explain everything to them and let them know that we really believe this is going to work for you and our experience in the past and how people have dealt with it. And if you tell people the side effects – patients the side effects to expect, that helps them to understand.”</p>	7 (54%)

NR, not retained; R, retained.

<sup>a</sup>Numbers and percentages reflect number of participants who discussed a particular topic from either a positive, neutral, or negative perspective.

issues, concerns over privacy, scheduling appointments, and clinic wait times were negatives. Interventions targeted at improving the overall HIV clinic experience may be an effective strategy for increasing retention in care, potentially reaching a larger group of patients in a more cost-effective manner than individually-oriented interventions.<sup>12</sup> This study provides new data on patient and provider perspectives on the outpatient HIV clinic experience that can inform the design of new interventions to improve retention in care.

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