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Mapping Patient–Identified Barriers and Facilitators to Retention in HIV Care and Antiretroviral Therapy Adherence to Andersen's Behavioral Model

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Abstract

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Andersen's Behavioral Model (ABM) provides a framework for understanding how patient and environmental factors impact health behaviors and outcomes. We compared patient-identified barriers/facilitators to retention in care and antiretroviral therapy (ART) adherence, and evaluated how they mapped to ABM. Qualitative semi-structured interviews with 51 HIV-infected adults at HIV clinics in Philadelphia, PA in 2013 were used to explore patients' experiences with HIV care and treatment. Interview data were analyzed for themes using a grounded theory approach. Among those interviewed, 53% were male and 88% were non-white; 49% were retained in care, 96% were on ART, and 57% were virally suppressed. Patients discussed 18 barriers/facilitators to retention in care and ART adherence: 11 common to both behaviors (stigma, mental illness, substance abuse, social support, reminder strategies, housing, insurance, symptoms, competing life activities, colocation of services, provider factors), 3 distinct to retention (transportation, clinic experiences, appointment scheduling), and 4 distinct to adherence (medication characteristics, pharmacy services, health literacy, health beliefs). Identified barriers/facilitators mapped to all ABM domains. These data support the use of ABM as a framework for classifying factors influencing HIV-specific health behaviors, and have the potential to inform the design of interventions to improve retention in care and ART adherence.

Keywords

Barriers; Retention in Care; Antiretroviral Therapy; Adherence; Andersen's Behavioral Model

Introduction

Advances in antiretroviral therapy (ART) have significantly changed the management of HIV infection by decreasing HIV-associated morbidity and mortality (Crum et al., 2006; Mocroft et al., 2003). However, many people living with HIV (PLWH) do not fully benefit from ART due to poor retention in care (henceforth referred to as retention) and/or treatment adherence (henceforth referred to as adherence) (Arici et al., 2002; Cooke, Lee, & Xing, 2014; Fleishman et al., 2012; Yehia, Fleishman, Metlay, Korthuis, et al., 2012). In the United States (U.S.), less than half of all PLWH are linked to and retained in care; and of these, only 68% achieve viral suppression (Centers for Disease Control [CDC], 2012; Hall et al., 2012). Improving retention and adherence is critical to meeting the three goals of the U.S. *National HIV/AIDS Strategy* (NHAS) – reducing new infections, improving health outcomes, and reducing health disparities – as these behaviors increase survival and decrease HIV transmission (Cohen et al., 2011; Granich, Gilks, Dye, De Cock, & Williams, 2009; Metsch et al., 2008; Mugavero et al., 2009; Thompson et al., 2012; Ulett et al., 2009; Yehia & Frank, 2011; Yehia, Fleishman, Metlay, Moore, & Gebo, 2012; Yehia et al., 2014).

To better develop interventions for improving retention and adherence, a deeper understanding of patient perceived barriers to HIV care and treatment is needed. Anderson's Behavioral Model of Health Service Use (ABM) provides a theoretical framework for understanding how patient and environmental factors impact health behaviors and outcomes (Andersen, 1995) (Figure 1a). These factors can be grouped into 7 domains: patient factors (predisposing, enabling, perceived need), health care environment factors (system, clinic, provider), and external environment factors. ABM has been used to examine health care and

treatment utilization among PLWH (Andersen et al., 2000; Kilbourne et al., 2002; Saint-Jean et al., 2011; Smith & Kirking, 1999). Unlike other models, such as the Health Belief Model and the Transtheoretical Model, ABM considers both patient-related and environmental determinants of health behaviors (Glanz, Rimer, & Viswanath, 2008). Therefore, the model can be an effective framework for building retention and treatment interventions.

Prior qualitative studies examining barriers and facilitators to retention and adherence have been limited in that the majority focused on specific populations (e.g. women, low income individuals) (Boehme et al., 2014; Kempf et al., 2010; Moneyham et al., 2010; Sevelius, Patouhas, Keatley, & Johnson, 2014) or evaluated these health behaviors separately and not jointly (Boehme et al., 2014; Coleman et al., 2007; Kempf et al., 2010; Moneyham et al., 2010; Murphy, Roberts, Martin, Marelich, & Hoffman, 2000; Proctor, Tesfa, & Tompkins, 1999; Rajabiun et al., 2007; Remien et al., 2003; Roberts, 2002; Sevelius et al., 2014). Although retention and adherence are distinct behaviors, they are interrelated and may share similar barriers and facilitators. We aimed to identify and compare and contrast patient reported barriers and facilitators to retention and adherence separately, and evaluate how these barriers and facilitators map to ABM. By structuring our findings to ABM, we aimed to provide an informative tool for developing interventions that can improve retention and treatment adherence.

Methods

Study Design, Sample, and Recruitment Strategy

We recruited HIV-infected adults (> 18 years) from three urban, Ryan White Program funded clinics in Philadelphia: Hospital of the University of Pennsylvania MacGregor Infectious Diseases Clinic, Temple University Comprehensive HIV Program, and the Jonathan Lax Treatment Center at Philadelphia FIGHT. Two clinics were university affiliated, and one was community-based. Using purposive sampling (Daniel, 2012), a nonprobability sampling technique whereby subjects are selected because of specific characteristics, patients with differing retention and viral suppression patterns (retained and suppressed, not retained and suppressed, retained and not suppressed, not retained and not suppressed) were invited by phone or approached while in the clinic waiting room to participate in the study. Persons were eligible for participation if they had been enrolled in the clinic for at least 12 months. Participants were compensated \$25 for their time. Recruitment concluded when we reached thematic saturation in our sample (see “Data Analysis”). The study was approved by the institutional review boards of the University of Pennsylvania, Temple University, and Philadelphia FIGHT.

Data Collection

For each patient, sociodemographic (age, race/ethnicity, HIV transmission risk factor, health insurance coverage) and clinical data (CD4 cell counts, ART regimen) at the time closest to the interview date were abstracted from the medical record. Retention was defined as completing 2 or more primary HIV care visits separated by < 90 days in the 12-month period prior to the interview date, per NHAS guidelines (The White House Office of

National AIDS Policy, 2010). Primary HIV care visits refer only to medical care appointments and did not include nursing, pharmacy, laboratory, social services, or other types of visits. HIV viral suppression (HIV-1 RNA < 400 copies/mL) was based on the median value in the 12-month period before the interview date.

We developed a semi-structured interview guide designed to elicit patients' perspectives on managing their HIV infection. Interview questions were based on a literature review of barriers and facilitators to HIV care and treatment, and discussions with experts involved in the care of PLWH. Each interview lasted 20-30 minutes, and was conducted by a trained interviewer familiar with the study goals and skilled in qualitative interview techniques. Interviews began with open-ended questions exploring patients' experiences with HIV medical care and treatment. Then, patients were asked to reflect on barriers and facilitators to retention and adherence, relationships with their providers and clinic/pharmacy staff, and experiences navigating the healthcare system. Following this, patients were asked to comment on their health beliefs, support networks, and ability to address problems that may compromise clinic attendance and medication adherence. Finally, patients had the opportunity to share any concerns and thoughts regarding managing their HIV infection.

After piloting the interview guide with 6 patients, all of whom were included in the final analysis, the research team, including experts in HIV care, health behavior science, and qualitative research methods, met to review early transcripts and adjust the interview guide to better capture patients' perspectives. In-person interviews were conducted between March 2013 to November 2013.

Data Analysis

All interviews were audio recorded, professionally transcribed, and imported into NVivo10 software for analysis (QSR International, Melbourne, Australia). Interview 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 (Bernard, 2006; Tashakkori & Teddlie, 2003). The process develops themes and sub-themes that emerge "from the ground" based on responses to the questions. 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, a subset of the research team applied the final coding scheme to all transcripts.

After all transcripts were coded, we synthesized the data in summary tables. After reviewing the ABM domains and associated definitions, the research team mapped themes and sub-themes to Anderson's model. Because of the applicability of the ABM, themes mapped easily to each domain. The frequency for each identified barrier/facilitator was categorized into tertiles (high, medium, low). Barriers/facilitators to retention and adherence were compared and assessed for differences. Barriers and facilitators were grouped together as "barriers/facilitators" because participants' narratives about retention and adherence behaviors often included both their challenges and successes.

Results

A total of 51 HIV-infected patients were interviewed (Table 1). Median age was 45 years (range 24-65); 27 patients (53%) were male. Most participants were of minority race/ethnicity (87%), reported heterosexual transmission as their HIV risk factor (69%), and were on Medicaid or uninsured (73%). All but two patients (98%) were on ART. Over half of the sample (69%) had a CD4 cell count ≥ 350 cells/mm³. Twenty-five patients (49%) were retained in care and 29 (57%) were virologically suppressed.

Patients discussed 18 main types of barriers/facilitators to retention and adherence: 11 common to both behaviors (stigma, mental illness, substance abuse, social support, reminder strategies, housing, insurance, symptoms, competing life activities, colocation of services, provider factors), 3 distinct to retention (transportation, clinic experiences, appointment scheduling), and 4 distinct to adherence (medication characteristics, pharmacy services, health literacy, health beliefs) (**Appendix Table 1**). Barriers/facilitators mapped to all 7 domains of ABM (Figure 1b). Tables 2 and 3 categorize barriers/facilitators according to ABM patient (predisposing, enabling, and perceived need) and environment (health system, clinic, provider, external) domains, respectively; display selected quotes; and show the relative frequency (high, medium, low) that each theme was discussed in relation to both behaviors and for each individual behavior. A more detailed analysis and description of barriers/facilitators, grouped by ABM domain, are presented below and in Appendix Table 2.

Patient Factors

Predisposing factors—Predisposing factors are characteristics intrinsic to the patient. Patients in this study identified four of these types of factors: stigma, substance abuse, mental illness, and health literacy. Of these, stigma was most commonly endorsed as a barrier to retention. Many patients did not disclose their HIV status to family or friends due to fear of being ostracized or shamed. Consequently, patients took great measures to maintain confidentiality and evade others they may know, such as skipping appointments, avoiding laboratory tests, and using pharmacies outside their community. Some patients wore obscure clothing or chose not to enter a building if they saw someone they knew. In addition, they hid their medications or skipped doses to avoid suspicion regarding their HIV status.

Patients mentioned that during periods of substance abuse and active mental illness (depression, schizophrenia, post-traumatic stress disorder, bipolar disorder), they often became apathetic about their health care. This led to missed appointments and poor medication adherence. Misconceptions about mixing HIV medications and illicit drugs and alcohol also compromised ART adherence.

Some patients reported being confused about their medication regimen and did not know at what time of day to take them and whether they should be taken with food. Patients were more likely to adhere to medications when they reported that their providers spent time talking to them about their medication regimens.

Enabling factors—Enabling factors are resources or tools that encourage health care usage. Patients in this study identified 6 of these types of factors: social support, reminder strategies, medication characteristics, transportation, insurance, and housing. Transportation was more frequently identified as a barrier/facilitator to retention, whereas medication characteristics, reminder strategies, and housing were more commonly linked to adherence.

Supportive family members, friends, and neighbors were considered instrumental in helping patients maintain appointments and adhere to therapy. These individuals would remind patients of their appointments, offer transportation, and on occasion accompany them to medical visits. Furthermore, support people motivated participants to take their medications, with some inquiring daily about their adherence. Many patients with limited social support said that they actively concealed their HIV infection out of fear of stigma and discrimination. Some patients reported that their family members avoided discussion of HIV-related topics and discouraged their use of ART because they did not believe it to be effective.

Simply forgetting was a reason many patients gave for missing appointments and medication doses. Reminder strategies such as using alarms, calendars, and pillboxes; writing notes; keeping medications visually present; and following a daily routine helped patients remember appointments and adhere to therapy.

High pill burdens and difficulty swallowing pills made it challenging for patients to consistently take their medications. Some patients stopped ART when they experienced adverse effects that impacted their daily activities. In addition, several patients commented that they didn't want to be reminded of their HIV status, and therefore, had difficulty taking their medications consistently.

Securing reliable and affordable transportation to appointments was difficult for many patients. In addition, bad traffic and inclement weather deterred patients from keeping appointments. Despite the availability of free transportation programs, patients encountered challenges with their scheduling system and commented that they were often unreliable and inconsistent. Maintaining appointments and taking medications became less important when patients had inconsistent housing. Housing instability resulted in a lack of privacy, which compromised medication adherence due to fear of stigma, and made medications more susceptible to theft and loss. In addition, without a stable address, some patients were unable to complete the necessary paperwork required to maintain their health insurance.

Attending appointments and filling prescriptions were cost prohibitive for those patients with no health insurance or health insurance with high co-pays. Patients found the insurance enrollment process complicated, which resulted in delayed insurance coverage and compromised retention.

Perceived need—Perceived need relates to a patient's own health care beliefs and value system that affect a subjective acknowledgement of need. Patients in our study reported that they would only take their medications when they felt sick, as opposed to regular, daily consumption. Others would not take ART during periods of illness. A subset of participants

commented that they were motivated to take their medications daily because they believed it was keeping them alive.

Health Care Environment

System factors—System factors include ancillary services that comprise the overall health care environment for the patient. In our study, patients described pharmacy services as important to adherence. Unprofessional staff, refills not ready as promised, and limited hours made it difficult for patients to get their medications and remain adherent to therapy. Pharmacies that offered medication blister-packing, home delivery services, automatic refills, and reminder calls facilitated adherence by improving convenience. Patients stated that co-location of multiple services, such as medical care, pharmacy, social work, case management, and mental health care, were convenient and made it easier to keep appointments.

Clinic factors—Appointment scheduling and clinic experiences were identified as barriers/facilitators to retention. Complicated automated phone systems, trouble getting referrals, and limited appointment availability made it difficult to schedule appointments. In addition, long wait times and discourteous clinic staff deterred patients from keeping appointments. In contrast, supportive clinic staff that expressed genuine concern for patients promoted engagement in care.

Provider factors—Patients endorsed four provider-level factors impacting health behaviors: trust, compassion, delivery of individualized care, and responsiveness. Providers demonstrated these characteristics when they treated patients as equals, considered their unique situations when formulating a care plan, gave them the opportunity to talk about their personal lives, followed-up with them outside the office visit, and returned their phone calls. These qualities and actions created a relationship of trust, enabling patients to follow through with their providers' advice and recommendations. Many felt that their providers cared about them as individuals when they took time to listen to their problems. Patients admitted that poor relationships with providers deterred them from attending appointments, while positive relationships supported adherence to treatment plans.

External Environment

The external environment includes physical, political, and economic factors unrelated to the health care environment. In our study, patients mentioned that competing life activities such as jobs, schooling, caregiving responsibilities for children and the elderly, and legal issues made it difficult to keep appointments and to adhere to medications. Often, these responsibilities took precedence over the patients' own health. Some patients reported that they were so busy taking care of their sick relatives and accompanying them to their appointments that they forgot about their own. Many also did not have jobs or sympathetic bosses that allowed them to leave work to attend appointments. Lastly, court dates took precedence over clinic appointments, with some patients also requiring clearance from their parole officer to attend medical visits.

Discussion

This study extends prior research on Andersen's Behavioral Model, demonstrating that some barriers/facilitators to retention and adherence overlap and others differ for PLWH. Overall, the majority of barriers/facilitators related to both retention and adherence. However, the relative frequency that each was discussed varied by health behavior. Identified barriers/facilitators mapped to all 7 domains of ABM. These data support the use of ABM as a framework for classifying factors influencing HIV-specific health behaviors, and have the potential to inform the design of interventions to improve both retention and adherence.

Multiple studies, across a wide range of diseases and health settings, have used ABM to characterize factors associated with health services utilization (Babitsch, Gohl, & von Lengerke, 2012). In 2009, Ullet and colleagues adapted ABM for PLWH using data from prior research and expert opinion, identifying 27 factors that may impact linkage to care, retention in care, and ART receipt and adherence (Ulett et al., 2009). The current study builds on this work by describing 5 new themes impacting HIV-specific health behaviors that have not been mapped to ABM: health literacy, medication characteristics, reminder strategies, competing life activities, and pharmacy services. Most of these themes relate to ART adherence, reflecting the finding that the majority of prior studies using ABM as a framework focused on linkage to care and retention in care (Anthony et al., 2007; Saint-Jean et al., 2011; Ulett et al., 2009).

Patients referenced certain themes more frequently when discussing retention (i.e. stigma) versus adherence (i.e. reminder strategies, housing, insurance, mental illness). Moreover, medication characteristics, pharmacy services, health beliefs, and health literacy were barriers/facilitators unique to adherence; while transportation, clinic experiences, and appointment scheduling were unique to retention. These differences may reflect the actions, settings, and tools required to perform each individual health behavior. For example, retention requires quarterly to biannual execution and involves interacting with multiple individuals (e.g. front desk staff, other patients in the waiting room, health providers), while medication adherence requires daily execution and involves fewer social interactions. Therefore, experiencing HIV stigma, which is often amplified in public settings, may represent a greater barrier to retention as compared to adherence (Kempf et al., 2010; Sevelius et al., 2014). Conversely, adopting personal reminder strategies may be more central to taking daily medications as opposed to completing 2-4 primary HIV outpatient visits annually.

Our findings may be useful in the design of future interventions to improve retention and adherence. By mapping barriers and facilitators to ABM, we identified patient, clinic, and health system-level targets for intervention. On the patient level, interventions to treat co-occurring conditions (mental illness, substance abuse); reduce housing, transportation, and insurance barriers; and provide social support may improve retention and adherence. On the clinic and health system-levels, streamlining the appointment scheduling process, expanding clinic visit time to allow providers to meaningfully converse with patients, and working with pharmacies to provide medication blister-packing and free delivery may be helpful techniques to achieve better medication adherence and clinic attendance. In addition, by

identifying common and unique barriers/facilitators to retention and adherence, interventions can be designed to address both health behaviors. For example, connecting and encouraging participation in peer groups and networks may provide patients with social supports to promote adherence to visit and treatment recommendations. However, evaluating the impact of these interventions may be challenging as standardized measures for both retention and adherence are lacking (Mugavero, Davila, Nevin, & Giordano, 2010; Thompson et al., 2012). Additional research comparing existing indicators and identifying new measures with the goal of standardization is warranted.

There are several limitations to our study. First, we specifically recruited patients who at some point enrolled in primary HIV care. Future studies should explore patient-identified barriers/facilitators to accessing and linking to care, which may represent a different set of patient experiences. Second, our sample primarily consisted of heterosexual racial/ethnic minorities residing in an urban setting. Racial and ethnic minorities are often subjected to discrimination, and those residing in urban settings to poverty and violence. These unique challenges can play an important role in the types of barriers identified. Therefore, our results may not generalize to other populations and locales, specifically white men who have sex with men, marginalized groups (e.g. transgender, sex workers), and rural settings. Third, we were unable to identify differences across the various sites, which were either university-based or clinic-based, due to the small number of patients in each category. Further research in this area would help identify barriers/facilitators specific to these settings. Fourth, patients' responses may have been influenced by social desirability bias. Ensuring confidentiality of results from participants' primary care providers and having interviewers avoid any judgmental reactions may have helped minimize this risk.

Despite these limitations, our findings provide new insights into barriers and facilitators to retention and adherence. These data can inform future interventions aimed at the patient, clinic, or health-system, such as treatment of patient co-occurring conditions, provision of social support, and collaboration with pharmacies that provide medication adherence tools. Hopefully, this can improve retention and adherence, and ultimately, health outcomes for PLWH.

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Appendix

Appendix Table 1

Barriers/facilitators affecting retention and adherence

Retention Alone	Retention and Adherence	Adherence Alone
Transportation	Stigma	Medication characteristics
Clinic experiences	Mental Illness	Pharmacy services
Appointment scheduling	Substance abuse	Health literacy
	Social Support	Health beliefs
	Reminder Strategies	
	Housing	
	Insurance	
	Symptoms	
	Competing life activities	
	Colocation of Services	
	Provider factors	

Appendix Table 2

Patient-identified barriers/facilitators to retention and adherence, categorized by ABM domains

	Barriers	Facilitators
Patient Characteristics		
Predisposing factors	<ul style="list-style-type: none"> • Stigma • Mental illness • Substance abuse • Difficulty taking or understanding medications 	<ul style="list-style-type: none"> • Lack of mental illness • Having HIV knowledge
Enabling factors	<ul style="list-style-type: none"> • Family or friends unsupportive • Forgetfulness with appointment dates and medications • Intolerable medication adverse effects • High medication burden • Transportation/challenges getting to provider • Inconsistent housing • No or inadequate insurance • High cost of medications 	<ul style="list-style-type: none"> • Presence of social support with appointments and medications • Use of reminder strategies to help with appointments and medications • Minimal medication adverse effects • Low medication burden • Availability of transportation assistance • Having insurance & medical assistance • Ability to afford medications
Perceived need	<ul style="list-style-type: none"> • Not feeling well 	<ul style="list-style-type: none"> • Feeling physically healthy • Belief in treatment efficacy and success
Health care environment		
System factors	<ul style="list-style-type: none"> • Long pharmacy wait times and discourteous staff 	<ul style="list-style-type: none"> • Availability of special pharmacy services (e.g. blister-packing, delivery) • Good pharmacy location and hours • Colocation of multiple services
Clinic factors	<ul style="list-style-type: none"> • Difficult clinic experiences • Difficulty with scheduling appointments 	<ul style="list-style-type: none"> • Lack of discrimination at clinic • Ease of scheduling appointments • Availability of reminder phone call for appointment
Provider factors	<ul style="list-style-type: none"> • Negative relationship with providers 	<ul style="list-style-type: none"> • Positive relationship with provider
External Environment		

	Barriers	Facilitators
External factors	<ul style="list-style-type: none"> • Competing life activities 	<ul style="list-style-type: none"> • Not having a busy schedule • Not having to go to work or school

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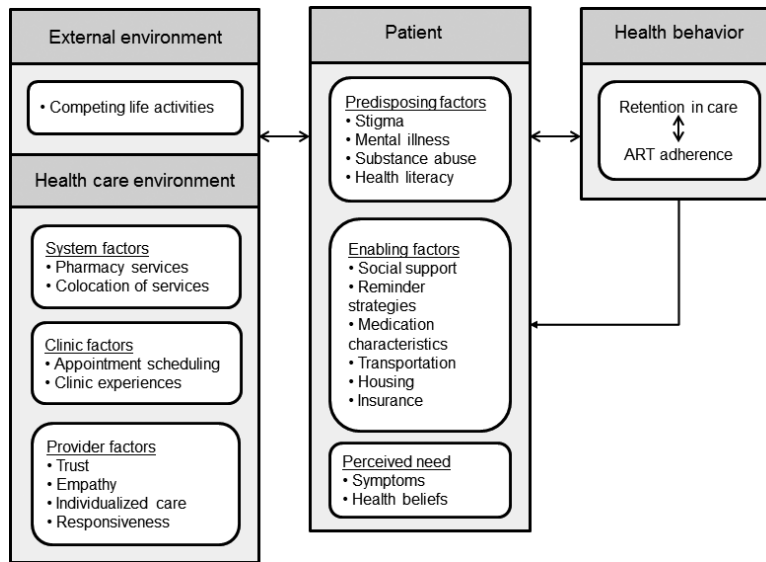


Figure 1(a).
The Andersen Model of Health Care Utilization (adapted) (Andersen, 1995)

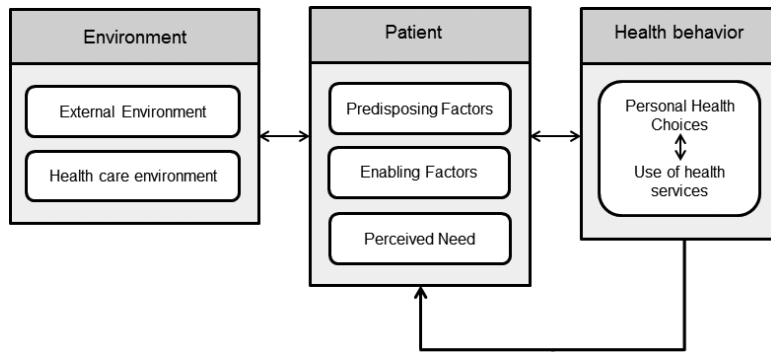


Figure 1(b).
Map of 18 identified barriers/facilitators to retention and adherence

Table 1

Sample sociodemographic and clinical characteristics

Characteristic ^a	Total (N=51)
Age (years)^b	
18-29	4 (8%)
30-39	11 (22%)
40-49	18 (35%)
50	18 (35%)
Sex	
Male	27 (53%)
Female	24 (47%)
Race/Ethnicity^c	
White	6 (12%)
Black	41 (80%)
Hispanic	3 (6%)
Other	1 (2%)
HIV Risk Factor^d	
MSM	13 (25%)
Heterosexual	35 (69%)
IDU	3 (6%)
Insurance^e	
Private	4 (8%)
Medicaid	34 (67%)
Medicare	10 (20%)
Uninsured	3 (6%)
ART Regimen^f	
PI	29 (57%)
NNRTI	15 (29%)
Integrase	5 (10%)
Not on ART	2 (4%)
CD4 Cell Count (cell/mm³)^g	
200	8 (16%)
201-350	8 (16%)
351-500	8 (16%)
> 500	27 (53%)
Viral Suppression^h	

Characteristic ^a	Total (N=51)
Suppressed	29 (57%)
Not Suppressed	22 (43%)
Retention ⁱ	
Retained	25 (49%)
Not retained	26 (51%)

Abbreviations: MSM=men who have sex with men; IDU=injection drug use; PI=protease inhibitor; NNRT=non-nucleoside reverse transcriptase inhibitor

^a Characteristics and values within the 12-month period prior to interview date.

^b Age was divided into four groups: 18-29, 30-39, 40-49, and over 50 years old.

^c Race/ethnicity was categorized as non-Hispanic White, non-Hispanic Black, Hispanic, and other.

^d HIV transmission risk factor was grouped into men who had sex with men (MSM), heterosexual transmission, and injection drug use (IDU). Patients who had IDU in combination with another risk factor (e.g. MSM, heterosexual transmission) were classified as IDU.

^e Insurance coverage was categorized as private, Medicaid, Medicare (including dual eligibles), and uninsured.

^f 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 patient was prescribed closest to the interview date was grouped using the following hierarchy: (1) protease inhibitor (PI)-based; (2) non-nucleoside reverse transcriptase inhibitor (NNRTI)-based; and (3) integrase inhibitor-based.

^g CD4 count closest to the interview date was grouped as < 200, 201-350, 351-500, and > 500 cells/mm³

^h 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.

ⁱ Retained individuals defined as completing 2 or more primary HIV care visits separated by ≥ 90 days in the 12-month period prior to the interview date.

Table 2

Patient-level barriers/facilitators to retention and adherence

ABM domain	Barrier/facilitator	Selected patient quotes	T	R	A
Enabling factors	Transportation	<p>"What makes it hard sometimes if you don't have money to get here." –M, NR, S</p> <p>"The bus pass/token thing, they tell you to order yourself a week in advance. I done ordered mine two weeks in advance and it still didn't come on time." –F, NR, NS</p>	H	H	–
	Reminder strategies	<p>"I keep my medicines] right beside where my nightstand is. I have this little wall...I put a note there. Did you take your medication today? ...I keep it right there so I can see it." –F, NR, NS</p> <p>"[The clinic]...usually calls me the day before or a couple days before [my appointment] and I usually put it in my phone on my calendar." –M, NR, S</p>	H	M	H
	Social support	<p>"[My mom would say]...if you have to do this for the rest of your life, then that's death. You're prisoned to medication. You're a prisoner to facilities. You have no life...That just makes me, like, okay, I can't share this with my mom." –F, NR, NS</p> <p>"It helps to have supportive family and friends, a network of people that you can unload and that you can express and that you can go to in times of need because often people that are HIV positive and have AIDS feel alone." –M, R, NS</p>	H	H	H
	Medication characteristics	<p>"I take so many medicines that they make me real sick and I can't function so I opt to either decrease it or don't take any at all." –M, R, NS</p> <p>"Since I'm on one medication, it's not hard. It's easy." –M, R, S</p>	H	–	H
	Housing	<p>"I'm going through a situation right now with my living conditions. I haven't [taken] my medications in about three weeks now...I'm living right now in a warehouse with my cousin...so I'm going through a lot of stress with that." –M, R, S</p> <p>"And then not having a place to properly store your medication...people don't want you to come in their place and take...medicine." –M, R, NS</p>	H	M	H
	Insurance	<p>"The job I had, they had health insurance, but the health insurance did not cover the medicine." –F, NR, NS</p> <p>"Things they [insurance] used to cover they don't cover no more...and having this disease, we need a lot of things done. They don't send out no letter...just saying you can't have this done no more or it's going to be an extra charge." –M, R, S</p>	M	L	M
Predisposing factors	Stigma	<p>"Seeing [others]...or just being out [in the waiting room]...and nobody know what you here for and just waiting out there. I be wanting to hurry up and get back here...I hate the waiting room." –M, R, S</p> <p>"How [are] you going to walk around with like five, six, seven, eight pills?...the world is getting a little bit smaller every day and you want to keep your anonymity at this present time...It's your business." –M, R, NS</p>	H	H	M
	Mental Illness	<p>"Just anxiety, depression...not really wanting to be a part of the world at that time, not wanting to deal with public transportation and just people in general. So I would just call and reschedule [the appointment] or I guess blank out and forget." –M, R, S</p> <p>"When I'm down, I'm down. And mentally, sometimes I feel like I just want to give up. Don't take none of the medications, whether I go crazy, the HIV tum to AIDS, whatever, sometimes I get mentally tired and I just want to throw up my hands." –F, NR, NS</p>	M	L	M
	Substance abuse	<p>"I forgot a lot of appointments. I was on drugs and...I wouldn't come in for like months, six months, to a year." –F, R, S</p> <p>"We addicts we don't want to hear [what providers have to say]...We just want to [ignore]...the medication and go for the crack and the weed." –F, NR, NS</p>	L	L	L
	Health literacy	<p>"It was like 2:30 [am] and...I usually take them at 9 or 10, so I won't bother...I didn't know...Because I thought it was only two hours after that you could take it, so I didn't do it." –M, R, S</p> <p>"If I drink, I will take my medicine the next day, only because I don't know the side effects that's going to occur if I intake a lot of alcohol and then take my medicine." –F, NR, NS</p>	L	–	L
Perceived need	Symptoms	<p>"Maybe because it was cold or it was raining and I was sick and I didn't feel like coming...I couldn't even have the strength to get up to come to see the doctor." –F, R, S</p> <p>"Sometimes because I didn't feel good, I'd have an upset stomach or something, and I just didn't want to take all these strong medications... and I'd give myself a day or two holiday." –M, R, S</p>	H	M	M

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ABM domain	Barrier/facilitator	Selected patient quotes	T	R	A
	Health beliefs	"But since they put me on [medications]...I felt good. I say okay, I'll go for it. And when I went for it, it works...I know it's important that I have to take this medicine, because it's gonna keep me alive for a long time." -M, R, S	L	--	L

Abbreviations: ABM=Andersen's Behavioral Model; F=female; M=male; R=retained; NS=not retained; NR=not suppressed (virologically); S=suppressed (virologically); T=total; R=retention; A=adherence; H=high (most commonly identified barrier/facilitator to the specific health behavior); M=medium (less commonly identified barrier/facilitator to the specific health behavior); L=low (least commonly identified barrier/facilitator to the specific health behavior)

Table 3

Environmental barriers/facilitators to retention and adherence

ABM domain	Barrier/facilitator	Selected patient quotes	T	R	A
System factors	Pharmacy services	<p>"The machine automatically calling me, telling me my medicine...you can come pick your refills up this day and time. Then I get there and they [say]...we out of stock of this, come back in two days." -F, NR, NS</p> <p>"Everything's good with the pharmacy. Yeah, he sends it [medications] right out. He makes sure it comes. When I had to stay at my mom's afterwards. He would send it up there because he knew I was up there...the pharmacy is great." -F, NR, S</p>	H	--	H
Clinic factors	Co-location of services	"I get everything done [here]...blood work, pharmacy, come see my doctor, everything is here. So all I got to do is get on the elevator, go to the first floor, go to the second floor or walk across the bridge...very convenient." -M, R, S	L	L	L
	Appointment scheduling	<p>"Well, what about this day [clinic staff]? I'm like no, I've got to work today. What about that day? No, we're not taking appointments then. Like that's the game that I have to play when I schedule an appointment." -F, NR, NS</p> <p>"I can be scheduled another appointment. And that's what I like about her [clinic staff] though, because she tries to make it convenient for you...like I want to give you soonest available appointment we got. But if you don't have what you need, I will find a way to squeeze you in before that." -F, NR, NS</p>	H	H	--
Provider factors	Clinic experiences	<p>"You shouldn't be sitting out there for 2 to 3 hours, even though there is a lot of people. I understand that, but it doesn't seem...fair. And then come to see you and tell this and that. Don't do this. Don't do that...No." -F, R, S</p> <p>"The clinic staff is very involved. They're really sincere about helping you getting yourself together...I haven't had no complaints." -M, R, S</p>	M	M	--
	Provider factors	<p>F: "She doesn't talk at you, she talks to you. And she'll call you on your stuff too....she'll reach out to you...she doesn't have to take time out to call you." -F, NR, S</p> <p>B: "She walks around like well what do you want? You've got a virus in your body. That was her approach to me. I'm like I need a little more sympathy than this. I'm just new to this." -M, NR, S</p>	H	H	H
External environment	Competing life activities	"Mother of four. Work 40-hour full-time job, come home to a full-time job, single mom...it's just sheer exhaustion...before I know it, I'm asleep somewhere and I'm sleeping so long, it's the next day. But when I get up, I will take it [medications]. It's far and few between, but it happens." -F, NR, NS <p>"I try to schedule where I don't have nothing to do that week. When nothing else is coming up and if I have an appointment, it will just be my appointment that I have to go to that week without anything else bothering me." -F, R, S</p>	H	M	M

Abbreviations: ABM=Andersen's Behavioral Model; F=female; M=male; R=retained; S=suppressed (virologically); NR=not retained; NS=not suppressed (virologically); T=total; R=retention; A=adherence; H=high (most commonly identified barrier/facilitator to the specific health behavior); M=medium (less commonly identified barrier/facilitator to the specific health behavior); L=low (least commonly identified barrier/facilitator to the specific health behavior)