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# Linking and Retaining HIV Patients in Care: The Importance of Provider Attitudes and Behaviors

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## Abstract

Retention in HIV treatment may reduce morbidity and mortality, as well as slow the epidemic. Myriad barriers to retention include stigma, homophobia, structural barriers, transportation, and insurance. The purpose of this study was to evaluate patient perceptions of provider attitudes among HIV-infected persons within a state-wide public hospital system in Louisiana. A convenience sample of patients attending HIV clinics throughout the state participated in an anonymous interview. Factors associated with negative perceptions of care were evaluated in conjunction with a validated stigma measure. Factors associated with having a delayed entry into or break in care were evaluated in conjunction with perceived stigma. Between 2/1/09 and 7/31/11, 479 participants were interviewed and had sufficient data available, of whom 53.4% were male, 79.3% were African American, and 29.4% reported a break or delayed entry into HIV care of >1 year. A break in care was associated with perceiving that the doctor or health professionals do not listen carefully most or all of the time ( $p < 0.01$ ), having an elevated stigma score ( $p < 0.05$ ), and indicating that providers dislike caring for HIV-infected people ( $p < 0.01$ ). Women were more likely to have an elevated stigma score than men ( $p < 0.01$ ), as were participants over 30 ( $p < 0.01$ ); those with a gay/bisexual orientation ( $p < 0.05$ ) were less likely to have an elevated stigma score. Those with a break in care were less likely to have Medicaid ( $p < 0.05$ ). Providers play a key role in the retention of HIV-infected persons in care and are critical to improving outcomes and slowing the epidemic. Development of novel approaches to reduce stigma are imperative in improving retention.

## Introduction

**I**N RECENT YEARS, RESEARCH has demonstrated substantial progress in diagnosis and treatment of HIV, with potential for impact not only on the individual level, but the population level as well.<sup>1-5</sup> Adequate engagement in specialty treatment for HIV may result in reductions in morbidity and mortality, as well as a slowing of the epidemic overall.<sup>1-7</sup> Recent data from the randomized controlled trial HPTN 052<sup>1,4</sup> reveal that antiretroviral treatment of the HIV-infected partner in a discordant dyad reduced the risk of the uninfected partner acquiring HIV by 96%, corroborating the findings of previous ecological, modeling, and epidemiologic studies, which suggested the potential impact of viral suppression in preventing HIV transmission at the individual and population levels.<sup>2,3,6,7</sup> Unfortunately, despite a robust understanding of the importance of retention in care for HIV infected persons, challenges still remain: Gardner et al.<sup>6</sup> estimate that, in the

United States, only 79% of HIV-infected persons are aware of their HIV status. Of those, 50% are inadequately engaged in care, putting them at increased risk of complications of HIV, as well as increased risk of transmitting the virus to sexual and needle sharing partners.<sup>6</sup> In concert, these have heightened the urgency of health care system initiatives to promote widespread HIV testing and to better understand means of promoting lasting retention in care for HIV-infected persons.

Myriad barriers to retention in HIV care have been previously suggested in the literature, including those on the individual level, such as stigma, homophobia, lack of awareness of importance of care, substance abuse, untreated mental illness, and lack of trust in the medical system often confounded by conspiracy beliefs, as well as structural barriers, such as location, access to transportation, and healthcare insurance.<sup>8-15</sup> Nurse and physician provider reactions to HIV-infected persons, as well as patient perceptions of their reactions, have been shown to play an important role in whether patients return to

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care and under which circumstances.<sup>16,17</sup> One challenge in exploring the role of providers in retention in care is the bias that it necessarily introduces into its measurement. Measuring perceptions among those patients not attending HIV clinics presents significant challenges: these patients do not interface with medical or social service providers, and contact information may be outdated or incomplete, thwarting all attempts to reach out and communicate with the patients. On the other hand, measuring perceptions of those in a clinic may be biased, since they may represent only patients who experience positive provider interactions or those who experience severe enough symptoms that they decide to seek care in spite of discomfort or negative perceptions.

The purpose of this study was to evaluate patient perceptions of provider attitudes and practices among HIV-infected persons at multiple clinics within a state-wide public health clinic system in Louisiana, comparing those who had experienced a break of one or more years or delay in entering care of one or more years after initial HIV diagnosis with those who had not. Results from this study may be able to inform physicians and nurses of the importance of interpersonal interactions and targeted practices to improve linkage, as well as provide a foundation for future intervention development to enhance retention in care.

## Methods

### *Data collection*

This study was conducted as a part of a comprehensive evaluation of Louisiana Public Health Information Exchange (LaPHIE), a public health/health care delivery information exchange program implemented to provide clinical decision support to physicians and nurses on patients who required follow up for HIV.<sup>18,19</sup> One facet of the evaluation was intended to characterize trends regarding acceptance of health information technology among patients affected by LaPHIE, as a part of a multi-site evaluation coordinated by a centralized evaluation and support center located at the University of California, San Francisco (UCSF)/Center for AIDS Prevention Studies (CAPS). Within the Louisiana State University Health System, seven hospitals and their related primary care and specialty clinics, and emergency departments participated in LaPHIE; patients attending six of the HIV clinics were eligible to participate in an interview that collected detailed demographic, clinical, and perception data. Participants in this part of the evaluation were not necessarily those who were identified by the LaPHIE system as having been out of care, although they could have been in the past had they experienced delays or break in care. This system includes both urban and rural clinic settings, allowing a wider perspective on the research questions. The survey tool was developed by UCSF/CAPS and included a variety of domains including Internalized Stigma,<sup>16</sup> Kinsler measures,<sup>17</sup> and other measures of barriers to healthcare access. Sayles et al.<sup>16</sup> developed the 28-item Internalized Stigma Scale to assess stigma related to HIV/AIDS treatment and disease (Cronbach's coefficient  $\alpha=0.93^{17}$ ). The Kinsler measures were adapted from the HIV Cost and Services Utilization Study (HCSUS) instrument<sup>17</sup> and included four items to (Cronbach's coefficient  $\alpha=0.90^{17}$ ), with one or more indicating perception of stigma by care providers. Every 6 months during the study period, a convenience sample of 100 patients

attending HIV clinics throughout the system was invited to participate in an anonymous interview. The interview was developed by UCSF/CAPS to be computer assisted, but based on participant preference, the vast majority of interviews were conducted face-to-face by a trained interviewer logging patient responses into a laptop. Following the informed consent process, participants were asked to self-report whether they had experienced a delay in entering care of >1 year or a break in care of >1 year, then proceeded to complete the survey/interview. Participants received a \$10 gift card as recognition for participation.

### *Primary variables of interest*

In addition to demographic, utilization, and clinical data, the questionnaire gathered information on perceptions of stigma (using the Internalized Stigma Scale,<sup>16</sup> perception of being stigmatized by healthcare providers,<sup>17</sup> and satisfaction with care, providing additional insight into the potential barriers to and facilitators of care experienced by people receiving HIV care. For the stigma score, a subset of 14 measures was included in the survey extracted from the core 28 measures.<sup>16</sup> In our sample, we found that scores were not normally distributed and could not be normalized, thus we dichotomized based on the median score for our sample to indicate "high" or "low" stigma. For component variables where the response set was comprised of always, usually, sometimes, and never, based on the distributions that were largely positive, variables were recoded as "always" or "not always". For the Kinsler scale, as has shown to be effective,<sup>17</sup> it was characterized as having any one of the four component variables responded to as "yes" to a negative experience with the provider.<sup>17</sup> The primary dependent variable of interest was whether participants had experienced a delayed entry into care of >1 year or a break in care of >1 year.

### *Statistical methods*

Following a univariate description of frequencies and distributions of variables of interest, chi-square tests were used to compare unadjusted distributions of demographic and clinical variables between persons with and without a break in care and between persons with and without an internalized stigma score higher than the median. Kruskal-Wallis tests were used to compare continuous variables such as stigma score that were not normally distributed. For the first model, a multivariable model exploring demographic and clinical characteristics (including diagnosis of AIDS) associated with having an elevated stigma score was developed using a two-step procedure: demographic and clinical variables found to be significant in bivariate analysis were tested for inclusion in the models and remained if they were statistically significant or if addition or removal resulted in a change of  $\pm 10\%$  in the estimates. This model was then adjusted for variables that met this criterion with the addition of known confounders. For the second model, we focused on the healthcare provider stigma-related questions, adjusting for race, gender, and age in order to identify the relationship between stigma and reporting a break in care of >1 year. Given that half of the participants had Medicaid, we compared Medicaid to all other forms of insurance, to ensure that there was no system-wide barrier to care introduced by this insurance source. All models were clustered on location of clinic to adjust for the effect of

differential sample size and rural versus urban status at the clinics, and similarities between patient populations at each, and tested for fit using a Goodness-of-Fit test of  $p > 0.25$ . Analyses were conducted in Stata Version 10.0/SE (College Station, TX). All data collection methods and procedures were approved by the LSU, Department of Health and Hospitals of the State of Louisiana, and George Washington University Institutional Review Boards.

## Results

### Participants

Between 2/1/09 and 7/31/11, 502 participants were interviewed, of whom 493 had sufficient data available on the primary outcome of interest. Of these, data were available on whether a break or delayed entry into HIV care of  $> 1$  year was experienced by 479 (97.2%) participants and they were included in this analysis. Nearly a third (30.0%) reported a break or delayed entry into HIV care  $> 1$  year. As shown in Table 1, the majority of the sample was male (53.4%), 30 years or older (86.8%), and African American (79.3%). Seventeen per cent of participants (17.4%) reported they were infected as a result of men having sex with men exposure (MSM) and 51.5% via heterosexual contact. Three-quarters (77.5%) reported that they were currently taking antiretroviral treatment, 11.6% reported that they had a CD4 count of  $< 200$  in the last 6 months, and 33.3% reported that they had an undetectable viral load in the last 6 months; 31.0% indicated poor or fair "health in general." Individual stigma component scores indicate that there is a modest degree of stigma experienced by participants, with overall score on the Internalized Stigma Scale of 29 [IQR 23–36]; 47.4% of participants reported having elevated internalized stigma based on this score.

As shown in Table 1, when assessing bivariate associations between reporting a break in care and independent variables of interest, we found that persons under 30 were significantly less likely to report a break (7.8% vs. 15.4%,  $p < 0.03$ ) and that those with a history of homelessness were more likely to report a break (29.8% vs. 17.5%,  $p < 0.01$ ), though no other demographic characteristics were associated with this primary outcome of interest. Persons with a CD4  $< 200$  in the last 6 months were more likely to have had a break (14.9% vs. 10.1%,  $p < 0.05$ ), as were those reporting having a recent viral load that was not undetectable (44.0% vs. 28.4%,  $p < 0.001$ ); this was consistent with those who experienced a break being less likely to report currently taking antiretroviral treatment (66.7% vs. 81.7%,  $p < 0.001$ ). Persons reporting a break were more likely to report negative experiences with doctors or nurses not always listening carefully to them (20.7% vs. 14.2%,  $p < 0.08$ ), not always explaining things to them (17.9% vs. 11.8%,  $p < 0.08$ ), and big challenges in getting HIV care (9.3% vs. 4.1%,  $p < 0.05$ ). Likewise, they reported higher component scores for the Internalized Stigma Scale, including society looks down on HIV-infected persons, feeling like an outsider, feeling that the provider was uncomfortable because the participant was HIV positive and preferred to avoid or refused to serve the participant ( $p < 0.05$ ). Stigma scores were significantly higher among those persons as well [median (IQR) 31 (23–36) vs. 28 (22–35),  $p < 0.05$ ].

After adjustment for other characteristics, as shown in Table 2, women were more likely to have an elevated stigma score ( $p < 0.01$ ), as were participants over 30 ( $p < 0.01$ ), while

those with a gay or bisexual sexual orientation ( $p < 0.05$ ) were less likely to have an elevated stigma score. As shown in Table 3, after adjustment for confounders, having a break in care was significantly associated with perceiving that the doctor or other health professionals listen carefully less than most or all of the time ( $p < 0.01$ ), having an elevated stigma score ( $p < 0.05$ ). In addition to the dichotomized Kinsler score, evidence from the data suggested the need to also include the single variable regarding whether participants perceived that healthcare providers disliked caring for HIV-infected people: presence of any response on the Kinsler questions was not associated with reporting a break in care, while this one question was highly associated ( $p < 0.01$ ) and altered the outcome's relationship to the rest of the variables when it was omitted ( $> 10\%$  change in coefficients). Those with a break in care were less likely to have Medicaid ( $p < 0.05$ ) and to be under 30 years of age at the time of interview ( $p < 0.01$ ).

## Discussion

Nurses and physicians play a key role in the retention of HIV-infected persons in care; this, in turn, is a critical component in improving individual-level outcomes, as well as slowing the epidemic on the community level. We found that comparing a sample of HIV-infected persons who had experienced a break in care with those who did not allowed us to have greater insight into what keeps patients from falling out of care. Patient perception of provider willingness to care for patients with HIV and their sense of overarching shame and stigma were significantly associated with prior breaks in care. Understanding how provider attitudes and behaviors perceived as stigmatizing can negatively impact patients' connection to a health care provider and altering practices to improve the interpersonal interactions to reduce stigma forms a strong foundation for increasing durable care relationships for persons living with HIV.

We found that women and older patients may be at elevated risk of perceiving stigma in the HIV healthcare setting, and that stigma is clearly associated with reporting significant breaks in HIV care. In particular, people who felt their healthcare providers did not listen to them or that their providers did not like caring for those who are HIV-infected were more likely to report a break. In a longitudinal study of newly identified HIV-infected persons, Naar-King et al.<sup>20</sup> found that those reporting stigma at 12 months based on their measures were less likely to be retained than those not reporting such stigma. Their sample, however, may not have had adequate power to fully evaluate this question, and also focused on a sample of newly diagnosed persons, differing from our participant sample. Reassuringly, our findings are consistent with those of other authors,<sup>8–17</sup> but they also provide an important addition to the literature because the participants were all drawn from the same clinical environments, allowing perceptions of patients from the same settings to be compared.

There are several limitations to this study. As an interview-based study, clinical data were based on self-report, which can be of limited accuracy. While this will not impact our understanding of participant perceptions, it may reduce our ability to adequately adjust for clinical covariates in the multivariable models. Patients may not have experienced as long (or a short) a lapse in care as they recall and their clinical

TABLE 1. CHARACTERISTICS OF SAMPLE (N=479)

	All participants (%) N=479	Reports no break in care (%) N=338	Reports break in care (%) N=141
Demographics			
Male gender	53.4	46.8	54.6
Black/AA	79.3	77.8	82.3
Medicaid <sup>a</sup>	49.1	50.0	46.8
< 30 years of age*	13.2	15.4	7.8
Mode of HIV acquisition			
MSM	17.4	18.3	14.2
Heterosexual	51.5	51.2	52.5
IDU	10.7	9.8	12.8
High school diploma/GED or less	81.2	81.1	81.6
Homeless last 6 mo***	20.9	17.5	29.8
Health care utilization (self-report)			
Prescribed ART last 6 mo	80.7	82.3	75.2
Currently taking ART***	77.5	81.7	66.7
Hospital visits last 6 mo**	19.9	16.6	27.0
Emergency visits last 6 mo	35.9	33.7	40.4
Seen healthcare provider visits last 6 mo**	94.7	96.8	89.4
Clinical status (self-report)			
Most recent CD4 count <200 last 6 mo*	11.6	10.1	14.9
Most recent RNA PCR last 6 mo (viral load) not undetectable***	33.3	28.4	44.0
Health in general poor/fair*	31.0	26.0	17.8
Perception of care quality			
How often did doctors/health professionals listen carefully to you in the last 6 mo			
Not always	16.5	14.2	20.7
How often did doctors/health professionals explain things to you in a way you could understand in last 6 mo			
Not always	14.0	11.8	17.9
How often did doctors/health professionals show respect for what you had to say with you in last 6 mo			
Not always	13.2	11.2	15.7
How often did doctors/health professionals spend enough time with you in last 6 mo			
Not always	18.9	15.4	21.4
Stigma			
Internalized stigma component questions			
Society looks down on HIV-infected persons**			
Most/all of the time	55.3	51.3	65.8
People blame me for having HIV			
Most/all of the time	23.2	21.4	28.8
Medical providers assume people with HIV sleep around			
Most/all of the time	23.2	21.7	26.0
People think you can't be a good parent if you have HIV			
Most/all of the time	20.0	17.9	24.7
People treat me as less than human now that I have HIV			
Most/all of the time	16.2	15.5	16.4
I am concerned that, if I go to an AIDS organization, someone I know might see me			
Most/all of the time	19.2	18.5	19.9
I am concerned that, if I am sick, people I know will find out that I have HIV			
Most/all of the time	18.6	17.6	20.6
People I am close to are afraid they will catch HIV from me			
Most/all of the time	13.0	12.6	14.4
I feel like I am an outsider because I have HIV			
Most/all of the time	19.0	17.0	23.2
I feel ashamed to tell other people that I have HIV			
Most/all of the time*	23.2	21.1	29.5
My family is comfortable talking about my HIV			
None/a little of the time	49.1	46.2	54.8
It is important for a person to keep HIV a secret from co-workers			
Most/all of the time	43.5	43.7	44.5

(continued)

TABLE 1. (CONTINUED)

	All participants (%) N=479	Reports no break in care (%) N=338	Reports break in care (%) N=141
Nurses and doctors treat people who have HIV as if they are contagious			
Most/all of the time	7.9	7.3	8.2
Nurse and doctors dislike caring for patients with HIV*			
Most/all of the time	4.8	3.5	8.2
Elevated internalized stigma score*	47.4	44.8	55.0
Median [IQR] stigma score*	29 [23–36]	29 [22–35]	31 [24–39]
Kinsler scale items			
Since you've had HIV, any healthcare provider has been uncomfortable with you*	13.4	10.7	18.4
Since you've had HIV, any healthcare provider has treated you as inferior or in an inferior manner	11.4	9.5	14.9
Since you've had HIV, any healthcare provider has preferred to avoid you**	9.1	5.9	15.6
Since you've had HIV, any healthcare provider has refused to serve you**	7.7	5.6	12.8
Any one of the Kinsler et al items above	17.8	15.3	21.9

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$  for comparison between break and no break in care; <sup>a</sup>participants having Medicaid; participants could respond with multiple insurers. Referent is not having Medicaid.

status may have been recalled incorrectly. As a cross-sectional study, we are unable to infer causality or temporality from these findings. This may have affected our findings in several ways, most saliently in that patients experiencing negative health outcomes may be more likely to attribute negative perceptions to their physician and the healthcare setting. In this way, it is a challenge to disentangle which experience came first. Lapses in care may have influenced views of care (or introduced poor recall) or, conversely, positive experiences at care re-entry could have introduced bias into participant responses. We attempted to minimize the potential effect of the visit itself on response through ensuring that all interviews took place prior to the provider visit, but longer term influences would be challenging to minimize. Another limitation may be the “ceiling effect” in that the majority of the responses, even for those with breaks in care, were always at the top of the positive range, indicating strong satisfaction

with the providers and system, which may overshadow other opportunities for improvement. It is important to note that we cannot definitively link clinic location to perception of stigma or barriers to care: patients utilize services at many locations and care settings. In view of this, we cannot determine that their positive or negative perceptions of care are linked with any one clinic or set of providers. Comparing people who were in clinic to people lost-to-care would be the ideal comparison, enabling us to focus on barriers to clinic attendance. However, this is rarely possible and was not possible for this study. Instead, however, this study allowed us to replicate the population of out of care persons through selecting those who had been out of care themselves. Inclusion of a scale (dichotomized presence/absence of response on the scale questions) as well as one question from the scale itself could present multicollinearity as a challenge. However, with the scale dichotomized, we found that it alone did not inform the research question and was subject to confounding that the addition of just one question eliminated—while providing important information about not only retention in care but the questions when used in this population. Inclusion of this variable could potentially have attenuated associations between breaks in care and the dichotomized scaled score, but sensitivity analyses and substantial data diagnostics did not suggest this was the case. In addition, although statistically significant, many of the variables we found associated with breaks in care were not highly prevalent. As a result, it may be that the stigma variables account for relatively little variance in the outcome of interest. Still, for those that are affected, this may provide important insight into factors that place HIV-infected persons at risk of falling out of care. Finally, the interview was intended by CAPS to be computer administered, but due to participant request and discomfort using the computer interface, the vast majority of interviews were administered face-to-face instead. Limitations of this are mitigated by the fact that nearly all were administered in this fashion, reducing heterogeneity of the sample.

This study also has several strengths. It is the first study of its kind to be conducted in Louisiana in response to the introduction of the LaPHIE system and to compare a sample of

TABLE 2. ADJUSTED ODDS RATIOS (OR) AND 95% CONFIDENCE INTERVALS (CI) ASSOCIATED WITH HAVING AN ELEVATED STIGMA SCORE (N=479)

	Adjusted <sup>a</sup> OR (95% CI) associated with having an elevated stigma score
<b>Demographics</b>	
Female gender	1.73 (1.17–2.57)**
Black/AA	1.04 (0.59–1.84)
<30 years of age	1.47 (1.13–1.91)**
Medicaid insurance	0.96 (0.71–1.32)
Currently homeless	1.32 (0.50–3.48)
High school diploma/GED or less	1.16 (0.96–1.38)
Gay or bisexual	0.56 (0.32–0.95)*
Non-MSM mode of HIV transmission	1.05 (0.98–1.12)
Diagnosis of AIDS	1.17 (0.98–1.41)

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ ; <sup>a</sup>adjusted for all other variables in the column.

TABLE 3. ADJUSTED ODDS RATIOS (OR) AND 95% CONFIDENCE INTERVALS (CI) ASSOCIATED WITH HAVING DELAYED ENTRY INTO CARE >1 YEAR OR A BREAK IN CARE >1 YEAR (N=479)

	<i>Adjusted<sup>a</sup> OR (95% CI) associated with having delayed entry into care &gt;1 year or &gt;1 year break in care</i>
<b>Demographics</b>	
Female gender	0.78 (0.58–1.05)
Black/AA	1.86 (0.62–5.54)
Medicaid insurance	0.72 (0.43–0.99)*
<30 years of age	0.43 (0.25–0.75)*
<b>Perception of care quality</b>	
Doctors/health professionals did not always listen carefully to you in the last 6 mo	1.76 (1.21–2.55)**
Doctors/health professionals did not always explain things to you in a way you could understand in last 6 mo	0.78 (0.43–1.42)
Doctors/health professionals did not always show respect for what you had to say with you in last 6 mo	0.71 (0.27–1.92)
Doctors/health professionals did not always spend enough time with you in last 6 mo	1.66 (0.87–3.15)
<b>Stigma</b>	
Elevated internalized stigma score	1.02 (1.01–1.05)*
Nurse and doctors dislike caring for patients with HIV	1.19 (1.02–1.38)*
Any one of the Kinsler et al items	1.22 (0.59–2.54)

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ ; <sup>a</sup>adjusted for all other variables in the column.

patients with breaks in care to those without breaks in care. Because it is statewide, we had representation from multiple parts of the state, not only the urban centers of New Orleans and Baton Rouge; adjusting for clinic location in the multivariable models allowed us to adjust for the effect of differential sample sizes at multiple clinics and similarities of patients seen within clinics. Conducted over five 6-month intervals, we were able to ensure engagement of a breadth of participants, not just those who may have been affected by seasonal needs (e.g., cold/flu season) or secular trends (e.g., changes in appointment availability) that could have discouraged or encouraged them to seek medical care. This also allowed us to evaluate time trends because of the repeated cross-sectional samples. The sample was invited from persons seen within one healthcare system; thus, we can assume that the force of structural barriers to care was exerted similarly on each of the patients, allowing a more refined view of factors associated with having a break or delayed entry into care of a year or more. Finally, use of a survey instrument developed by experts at CAPS and drawing from validated tools such as the Internalized Stigma Scale provides a greater basis for confidence in the measures.

This study corroborates the findings of other authors of the importance of health care provider reduction in stigma and improvements in ensuring patients feel welcomed and comfortable with clinic staff. Provision of care within a framework in which providers make patients comfortable with the staff appears to be highly associated with whether or not patients are retained in care. Future interventions should be developed to identify individual-level patient experiences of discomfort with provider staff or stigma within the healthcare setting, followed by interventions in order to reduce them. Such innovative approaches will enable us to engage and retain HIV-infected persons more effectively in care, having a positive impact on the epidemic, and improving care overall.

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## Author Disclosure Statement

No competing financial interests exist.

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