



HHS Public Access

Author manuscript

Curr HIV/AIDS Rep. Author manuscript; available in PMC 2019 September 03.

Published in final edited form as:

Curr HIV/AIDS Rep. 2012 December ; 9(4): 313–325. doi:10.1007/s11904-012-0136-6.

Interventions to Improve Retention in HIV Primary Care: A Systematic Review of U.S. Studies

Darrel Higa¹, Gary Marks², Nicole Crepaz¹, Adrian Liau³, Cindy Lyles¹

¹Prevention Research Branch, Division of HIV/AIDS Prevention, CDC, Atlanta, GA

²Epidemiology Branch, Division of HIV/AIDS Prevention, CDC, Atlanta, GA

³Indiana University School of Medicine, Indianapolis, IN

Abstract

Retaining HIV-diagnosed persons in care is a national priority, but little is known on what intervention strategies are most effective for promoting retention in care. We conducted a systematic search and qualitatively reviewed 13 published studies and three recent conference presentations to identify evidence-informed retention strategies. We extracted information on study design, methods, and intervention characteristics. Strengths-based case management that encourages clients to recognize and use their own internal abilities to access resources and solve problems offered strong evidence for retention in care. Other evidence-informed strategies included peer navigation, reducing structural- and system-level barriers, including peers as part of a health care team, displaying posters and brochures in waiting rooms, having medical providers present brief messages to patients, and having clinics stay in closer contact with patients across time. Opportunities for additional intervention strategies include using community-based organizations as a setting for engaging HIV-infected persons about the importance of regular care and involving patients' significant others in retention in care interventions.

Keywords

HIV; Care; Retention; Intervention

INTRODUCTION

It is estimated that 1,178,350 people are living with HIV infection in the US, of whom 941,950 (80%) have been diagnosed and are aware of their seropositive status [1]. Helping HIV-diagnosed persons enter and remain in primary care are major goals in the U.S. National HIV/AIDS Strategy (NHAS)[2]. Retention in care plays a pivotal role in the spectrum of engagement in care which begins with the diagnosis of HIV infection through HIV testing, entry into and retention in HIV medical care, access and adherence to antiretroviral therapy (ART), and ideally concludes with complete viral load suppression[1,

Correspondence/Reprints: Darrel H. Higa, PhD, 1600 Clifton Road, NE, Mail Stop E-37, Atlanta, GA 30333, dhiga@cdc.gov.

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the U.S. Centers for Disease Control and Prevention.

3]. Several studies have demonstrated the clinical benefits of regular HIV care. Patients retained in care have decreased likelihood of developing HIV opportunistic infections [4], greater viral load suppression [5], and increased survival rates [6–8]. On the other hand, poor retention is associated with higher viral loads and lower CD4 counts [6, 9], increased HIV risk behavior [10], and more hospitalizations [11]. It is clear that retention in care is a critical piece in promoting health outcomes for HIV-diagnosed persons [12, 13].

Despite the importance of retention in care, many HIV-diagnosed persons struggle with consistently attending primary care appointments or fall out of care entirely. A recent national HIV surveillance report using data from 13 jurisdictions in the U.S. estimated that only 45% of HIV-diagnosed persons had 2 or more viral load tests at least 3 months apart in the previous 12 months [14]. A recent meta-analysis estimated that 54% (95% CI 51–56%) of HIV-diagnosed persons had 2 or more HIV medical care visits in a 12-month interval [15]. Thus, there is an urgent need to improve retention in HIV primary care.

Studies have identified several factors correlated with enhanced and diminished retention in care rates. These studies provide insight into the factors that may be important in interventions to improve retention. Lower retention in HIV care is associated with the following client-level factors: being female [16], being younger [17], ethnic and racial minority status [17, 18], lower CD4 count at study entry [18], not having an AIDS diagnosis [16, 19], little social support [20], competing caregiver responsibilities [16, 21, 22][16, 21, 22], having mental health or substance abuse issues [16, 17, 19, 23], the misperception that health insurance coverage is needed [24, 25], discomfort in talking to health care providers [18, 26, 27], feeling stigmatized [22, 28], and negative perceptions of the health care system [29, 30]. Structural factors such as unstable housing [31, 32], having public health insurance vs. private insurance [7], lack of child care or transportation [33], and fragmented HIV prevention and care services [22, 34] may also contribute to low retention in care. The roles of provider and agency factors in retention have received less attention but may include practitioner communication skills, appointment scheduling and tracking systems, and clinic access issues [35]. These findings indicate that interventions need to focus on client-, provider-, agency-, and structural level factors to effectively address the multi-level challenges of retaining HIV-diagnosed persons in HIV care.

Herein we provide a systematic review of U.S.-based studies that evaluated interventions for improving retention in HIV primary care. We qualitatively summarize evidence from those studies, describe the methodological characteristics and the focus of the interventions (e.g., factors or barriers addressed), identify emerging intervention strategies, and offer recommendations for research and practice to improve retention in HIV care.

METHODS

Search Strategy

We used the Center for Disease Control and Prevention (CDC)'s HIV/AIDS Prevention Research Synthesis (PRS) (<http://www.cdc.gov/hiv/topics/research/prs>) project's cumulative HIV/AIDS/STI prevention database [36] to identify relevant citations. Two subject-experienced librarians annually update the PRS database with automated and manual

searches. The automated search was conducted in October, 2011 and then updated in May, 2012 for capturing those citations due to publication gaps. It consisted of searching in MEDLINE, EMBASE, CINHALL, and PsycINFO by cross-referencing multiple search terms (i.e. index terms, keywords, and proximity terms) in three areas: HIV-positive persons; prevention/intervention/evaluation; and health care utilization descriptors (e.g., health care access, case management, health services, linkage, retention) for citations available in these electronic databases between January 1996 and December 2011. The on-going manual search consisted of checking reference lists of pertinent articles, examining HIV/AIDS Internet listservs (i.e., adherence@ghdonline.org; www.RobertMalow.org) and other government funded projects and programs such as those located on the Health Resources and Services Administration (HRSA) website devoted to Special Projects of National Significance (SPNS) (<http://hab.hrsa.gov/abouthab/special/spnsproducts.html>). Additionally, we hand-searched 2010–2012 conference abstracts presented at the International Conference on HIV Treatment and Prevention Adherence (herein referred to as “Treatment and Adherence Conference”) and at the Conference on Retroviruses and Opportunistic Infections (CROI).

Inclusion Criteria

Studies were included in this review if they met all of the following criteria: (1) U.S.-based studies of interventions designed exclusively to improve retention or interventions that included retention as part of a broader intervention focusing on HIV-diagnosed persons; (2) studies that included tests of statistical significance of the intervention effect or provided descriptive data (without statistical tests) that could be used to interpret whether the intervention improved retention; and (3) measured retention in care which was operationally defined as having multiple HIV medical care visits within specified time intervals. The number of visits and the time intervals could vary across studies [15, 37, 38]. Studies were excluded if they focused only on initial entry into HIV care or if they focused on medical care other than care for HIV infection.

Classification of Study Characteristics

Due to the heterogeneity among studies in target population, study design, measurement, and analysis, we conducted a qualitative review instead of a meta-analysis. We extracted information on study characteristics such as study dates, location, and target sample. We treated reports that provided data from the same project (e.g., HRSA SPNS outreach project) as independent studies even though some may have used pooled data from different sites. We also extracted information on study characteristics such as analytic sample size, data collection method, measures used, study design, and findings. We described how studies measured the outcome (e.g., self-report, medical records), the type of retention in care outcome that was used (e.g., multiple visits over time, gaps in care), and the study design. The studies had a variety of designs including randomized controlled trials (RCTs), comparisons to a historical control group, 1-group pre-post designs, and 1-group post-only designs that collected retention data after implementation of the intervention but not before the intervention started. For these 1-group post-only studies, we compared the post-intervention data to findings from a recent meta-analysis [15] that found an aggregated

retention rate of 54% for 2 or more visits in a 12-month period. We assessed the strength of intervention findings based on study design (e.g., RCTs offer the strongest evidence).

We also extracted information on select intervention characteristics (e.g., goals, settings, deliverers, duration, and strategies). For intervention duration, we abstracted the number of sessions and the length of the intervention. Intervention strategies were classified into 10 categories: (1) ancillary services other than case management (e.g., child care, emergency financial assistance, housing, drug treatment, and mental health services) (2) appointment accompaniment (i.e., taking the client to the medical provider and in some cases being with the client during the medical exam), (3) appointment coordination (e.g., making or helping clients make medical care appointments), (4) case management or making referrals to case management or helping access and coordinate social services, (5) cognitive-behavioral strategies (e.g., establishing rapport, counseling, motivational interviewing, social support), (6) co-location of services (e.g., having medical care and social services in the same agency), (7) home visits or home-based services, (8) media (e.g., brochures and posters in exam rooms), (9) outreach, and (10) transportation services (e.g., providing transport to medical appointments).

RESULTS

We screened a total of 9415 abstracts. Of these, we obtained and reviewed 167 full reports. We identified 13 studies that met eligibility criteria (see Table 1). The majority of studies (n=11; 85%) were multi-site investigations that reported pooled data from different sites or reported data from a single site. Studies were conducted most frequently in the Midwest (n=9, 69%) followed by the South (n=8, 62%) and West (n=7, 54%). Target populations were diverse but most studies focused on groups that historically experience barriers to health care use such as ethnic/racial minorities, men who have sex with men, youth, and persons with unstable living conditions. Two studies (15%) specifically targeted newly HIV-diagnosed individuals [39, 40] and 3 (23%) focused on HIV-diagnosed persons who were not fully engaged in care or were out of care [33, 41]. Two studies (15%) targeted both newly diagnosed and previously HIV-diagnosed persons not fully engaged in care [42, 43]. Two studies (15%) reported patients who had recently enrolled in HIV care or had a history of receiving HIV care [44, 45]. The remaining 4 studies (31%) did not specify the care histories of their participants [46–49]. Sample sizes ranged widely from 43 to 8535; the median was 104.

In terms of study design and measurement characteristics, 4 studies (31%) were RCTs [39, 45, 48, 49], 2 studies (15%) collected post-data only but used a historical control for comparison [42, 46], 5 studies (38%) were 1-group pre-post study designs [33, 41, 44, 47], and 2 studies (15%) used 1-group post-data without a comparison group [40, 43]. The majority of studies assessed retention outcomes using medical records (n=6, 46%) [40, 42–45, 47] or self-reports (n=5, 42%) [33, 41, 48, 49]. One study (8%) used medical records and self-report [39] while another study used medical and administrative records [46]. Retention in care was operationalized as having multiple HIV primary care visits (n=10, 77%) [39–44, 46–49], missed appointments (n=2, 15%) [33] or gaps in care (n=2, 15%) [45, 46] during specified time intervals.

Intervention Goals, Settings, Deliverers, Durations, and Strategies

Studies in this review reported similar intervention goals but reported different intervention settings, deliverers, durations, and strategies to help keep HIV-diagnosed persons in care (see Table 2). Eleven (85%) studies reported retention in care as a primary intervention goal and 1 of these studies focused primarily on initial entry into care but also assessed whether the intervention improved clinic attendance after the initial linkage [39]. The remaining two studies [48, 49] reported a broader intervention focus such as reducing HIV transmission or stabilizing housing but also included retention in care as an outcome. Interventions were conducted in various settings; the most common setting was medical clinics (n=10, 77%), followed by community-based organizations (CBOs; n=5, 33%), patient residences (n=2, 15%), research offices (n=2, 15%) and community outreach (n=1, 8%), not mutually exclusive. Studies also reported diverse intervention deliverers including case managers (n=5, 38%), peers (n=4, 31%), and health care providers (e.g., nurses, physicians) (n=4, 31%). For intervention duration, studies reported a range from 2 to 30 intervention sessions. A couple of studies reported offering services on an “as needed” basis such as providing transportation [33]. The most common length for an intervention was 12 months (n=6; 46%). The majority of studies (n=10, 77%) used multiple intervention strategies to facilitate retention in care. The most common intervention strategies were cognitive-behavioral approaches (n=10, 77%), case management (n=10, 77%), co-location of services (n=3, 23%), and appointment accompaniment (n=3, 23%). Less common strategies included appointment coordination, transportation services, home-based services, providing ancillary services, outreach, and media.

Published Intervention Findings

Of the 13 studies reviewed, 10 (77%) found evidence that interventions improved retention in care. Table 1 describes the findings and how this outcome was operationalized in the studies. The strongest evidence comes from the Antiretroviral Treatment and Access Study (ARTAS) intervention [39], an RCT that primarily focused on promoting initial entry into care, but also assessed retention in care for recently diagnosed persons. The intervention tested a strengths-based case management model compared to a passive referral to medical care. Findings from ARTAS indicated that 64% in the intervention group and 49% of the passive referral group had care visits in each of the two consecutive 6-month periods; adjusted relative risk = 1.41, p=0.006).

Significant intervention effects were seen in studies that used less rigorous designs. For example, young ethnic-minority MSM who received a comprehensive retention in care intervention (e.g., outreach, case management, appointment coordination, and co-locating medical and social services) reported a higher percent of having 3 or more visits within the first year of enrollment compared to a historical control group [42]. Another study found that ethnic-minority youth who received HIV care from adolescent-specialist care providers and received enhanced services such as youth-focused psychosocial and educational services (e.g., improving self-efficacy, teaching health care navigation skills) were significantly less likely to have gaps in HIV care compared to youth who received HIV care from adolescent specialists without enhanced services [46]. No significant differences were found, however,

when retention in care was operationalized as visit constancy (e.g., having 3 or more quarters with at least 1 visit in a year) [46].

Intervention effectiveness was also seen in 1-group pre-post study designs. One study used patient navigators to accompany clients to appointments, guide clients through the complex health care system and teach skills in communicating with providers [41]. Participants having 2 or more primary HIV care visits significantly increased from 64% pre-intervention to 87% at 6 months and 79% at 12 months post-intervention. A recent study found that clinic-wide brief messages from physicians, brochures given to patients, and posters in clinic waiting rooms significantly improved appointment keeping for primary care compared with appointment keeping at the clinic during the 12 months preceding onset of the intervention [44]. Another study found that the number of annual HIV specialty clinic visits for Spanish-speaking patients significantly increased from 2.81 to 5.30 when a bilingual/bicultural health care team was added to a medical clinic [47]. Although no statistical tests were reported, the two studies that included providing transportation as a major intervention component showed considerable increases in the relative percentages of participants who did not miss any HIV medical appointments in the past 6 months [33]. In the transportation-only intervention, the relative percentage increases for the first and second 6-month periods were 63% and 66% respectively. For women with mental health and/or substance abuse problems who received transportation and case management, the relative percentage increases for the first and second 6-month periods were 80% and 83% respectively.

Studies with only post-intervention data also reported promising findings when compared to the aggregated retention rate of 54% for 2 or more medical visits over a 12-month period based on Marks et al's [15] meta-analysis of observational studies. As one example, one study provided intensive outreach services (e.g., using a mobile van in the community to offer HIV education and help with accessing resources) and reported 81% of their sample had a medical appointment in both 6-month periods over a 1 year interval [40]. Another study implemented a youth-focused case management intervention and found 70% of young ethnic minority MSM had attended 2 or more HIV care appointments in the past 6 months [43].

Two studies did not find positive intervention effects. Both studies were RCTs. One study tested the impact of peer mentoring training on HIV care use and risk reduction with intravenous drug users (IDUs) and found no significant increases in use of HIV care compared to a video discussion control [48]. This study did not exclusively focus on retention in care but included it as one of the outcomes. Similarly, the other study assessed the effect of immediate housing rental assistance on multiple outcomes, including retention of unstably housed persons in HIV medical care. No significant effects were found for retention in HIV care [49].

The remaining study [45] was a RCT but did not test an intervention to decrease gaps in care against a control group. Instead, the researchers tested motivational interviewing delivered by peers versus professionals for reducing gaps in care for newly HIV-diagnosed persons. The findings indicated no significant differences between the groups, suggesting that both types of intervention deliverers did equally well on the outcome.

Recent Conference Presentations

A few papers presented at recent Treatment and Adherence Conferences (2011, 2012) focused on retention in care interventions. None were identified at CROI from 2010–2012. Zinski et al. (2011) presented a systematic review of peer interventions indicating that peers working independently or as part of a care team promoted access to and retention in HIV primary care [50]. Effective peer-related intervention strategies included frequent contact with the HIV-diagnosed person, life skills development, appointment accompaniment, counseling and education related to treatment, and comprehensive assessment and help with unmet needs. Konkle-Parker et al. (2012) reported on a test of a multi-dimensional intervention targeting both medication adherence and retention in care using HIV education, motivational interviewing, training on medication adherence strategies, and patient-provider communication versus a standard of care [51]. Using an analytic sample of patients who had less than 1 visit per quarter, the study found significantly more patients fully retained in care (at least 1 visit per quarter) if they had at least 3 contacts with an interventionist. Gardner et al.'s (2012) preliminary results of an RCT conducted at 6 U.S. HIV clinics indicated that patients who received enhanced contact across a period of 12 months (reminder calls, interim visit call, missed visit call) had significantly higher primary care appointment adherence (proportion of scheduled appointments kept) and visit constancy (care visit in each of three consecutive 4-month periods) compared with patients who received the clinic's standard of care [52].

DISCUSSION

The primary aim of this review was to qualitatively synthesize published studies of retention in HIV care interventions conducted in the U.S. and highlight newer unpublished studies on this topic. Only a small number of studies were available and, thus, the evidence shown in this review should be considered cautiously. Furthermore, several of the studies used multi-component interventions and it is difficult or impossible to disentangle the independent effects or interactions among various components. Nevertheless, several encouraging outcomes were observed and the findings are consistent with engagement in care guidelines from the International Association of Physicians in AIDS Care (IAPAC) [53].

Intervention-Related Issues

There is evidence that interventions can improve retention in care among HIV-diagnosed individuals. Interventions that focus specifically on engaging and retaining patients in care may produce more favorable outcomes than interventions that target multiple issues or include broader prevention goals such as risk reduction. Findings from this review also suggest that using multiple intervention strategies within a single study may be effective. Using multiple retention strategies appears to be necessary to effectively address the multiple barriers to accessing and consistently using HIV primary care. In terms of specific intervention strategies, case management approaches that utilize patients' strengths and help patients navigate increasingly complex health care systems seem to be especially beneficial in retaining persons in care. These approaches tend to involve the HIV-diagnosed individual as a partner in his or her own health care. Other evidence-informed interventions reduce or remove barriers to health care access such as accompanying patients to medical

appointments, providing transportation, co-locating services, conducting intensive outreach (e.g., using a mobile van to provide services in the community), and providing bilingual and culturally competent care. Although time and resource-intensive, these strategies may be necessary to engage persons who are multiply diagnosed (e.g., HIV-diagnosed and substance abuse problems) or who are often marginalized in the health care system. Practical strategies that help patients remember appointments or the importance of keeping appointments such as reminder calls and brochures/posters in clinic waiting rooms also facilitate retention in care. Strategic messaging via health care providers and printed materials may be useful in health care clinics with limited resources. Additionally, including peers as advocates, outreach workers, and navigators/case managers on the HIV-diagnosed person's health care team may be a crucial component to increase retention in care. In particular, HIV-diagnosed youth may benefit from working with trained peer interventionists.

Our review also identified areas where intervention strategies for retaining persons in care could be improved. For example, most strategies were targeted at the individual. A few structural- or system-level interventions, such as co-locating services, adding a bilingual/bicultural health care team to a medical clinic, or displaying posters in waiting rooms were assessed, but these strategies were infrequently utilized. Intervention strategies that address structural- and system-level barriers such as appointment tracking systems, flexible clinic hours, using health department surveillance data to track persons missing in care, and reducing HIV-related stigma were given little attention. Our review also found that relatively few interventions were being implemented in non-medical settings such as CBOs. CBOs may be underutilized in efforts to promote retention in care. For example, CBOs may play a role in communicating messages about the importance of staying in care and provide or make referrals to medical care or to critical ancillary services that may enhance retention in care. Finally, we found a lack of intervention strategies that intervened with health care providers and significant others of the HIV-diagnosed individual (e.g., family, partners, friends). Intervening with health care providers and involving significant others to improve retention in HIV care remains largely understudied and may be a critical piece in keeping HIV-diagnosed persons in care.

Methodological Issues

There were several studies that did not use a comparison group to test the intervention. Although having a comparison group may not always be feasible in CBOs or smaller health care clinics, researchers should strive for including comparison groups in their study designs to advance the field. When RCTs cannot be feasibly implemented, study designs such as historical and pre-post designs offer alternative methods, especially when used to evaluate operational research and program implementation. Another methodological issue is that almost half of the studies relied on self-reported measures of retention in care which may be prone to recall and social desirability bias. Although medical records are not without error, these records may provide a more accurate assessment of retention, especially when the outcomes are being monitored across long periods of time. State surveillance systems of viral load and CD4 laboratory testing results are also becoming available and could be put to use by researchers, program evaluators, and public health personnel for monitoring retention in care and conducting re-engagement activities. An additional methodological issue was

that the majority of the studies in this review relied on a single measure of retention. Recent research suggests using multiple measures of retention may be important [54]. For example, measuring visit constancy (e.g., number of consecutive quarters seen for primary care) captures something slightly different than appointment adherence (proportion of scheduled appointments kept). A patient can have perfect appointment adherence, but only be seen at a clinic once a year, which is not optimal. To help address methodological issues for retention in care interventions, the CDC's Prevention Research Synthesis (PRS) team are developing criteria to evaluate linkage and retention in care interventions, strategies, and programs.

CONCLUSION

Our review identified several intervention strategies for improving retention in HIV care and provides some preliminary recommendations (see Table 3). Overall, more attention should be given to the development of interventions specifically focusing on retention in HIV care rather than interventions that include retention as only part of a larger intervention that seeks to impact several types of behaviors. These retention-specific interventions should ideally be multi-level and focus not only on the individual and his or her immediate environment but also address system- and structural-level factors associated with barriers to retention in care. Interventions need to be further evaluated in real world settings at a larger scale to improve the quality and consistency of health care for HIV-diagnosed individuals. Finally, attention is also needed for the other aspects of engagement in care including testing efforts to reduce the prevalence of unrecognized HIV infection, linkage to care, and provision of and adherence to ART so that a greater number of HIV-infected persons achieve viral suppression.

Reference List

1. CDC. Vital signs: HIV prevention through care and treatment--United States. *MMWR Morb Mortal Wkly Rep* 2011;60(47): 1618–1623. [PubMed: 22129997]
2. Office of National AIDS Policy. National HIV/AIDS strategy for the United States. Washington, DC: Office of National AIDS Policy Available at: <http://www.whitehouse.gov/sites/default/files/uploads/NHAS.pdf>. Accessed December 13, 2010.
3. Gardner EM, McLees MP, Steiner JF, Del Rio C, Burman WJ. The spectrum of engagement in HIV care and its relevance to test-and-treat strategies for prevention of HIV infection. *Clin Infect Dis* 2011;52(6):793–800. [PubMed: 21367734]
4. Bani-Sadr F, Bedossa P, Rosenthal E et al. Does early antiretroviral treatment prevent liver fibrosis in HIV/HCV-coinfected patients? *J Acquir Immune Defic Syndr* 2009;50(2):234–236. [PubMed: 19155771]
5. Mugavero MJ, Amico KR, Westfall AO et al. Early retention in HIV care and viral load suppression: implications for a test and treat approach to HIV prevention. *J Acquir Immune Defic Syndr* 2012;59(1):86–93. [PubMed: 21937921]
6. Giordano TP, Gifford AL, White AC Jr., et al. Retention in care: a challenge to survival with HIV infection. *Clin Infect Dis* 2007;44(11):1493–1499. [PubMed: 17479948]
7. Mugavero MJ, Lin HY, Willig JH et al. Missed visits and mortality among patients establishing initial outpatient HIV treatment. *Clin Infect Dis* 2009;48(2):248–256. [PubMed: 19072715]
8. Park WB, Choe PG, Kim SH et al. One-year adherence to clinic visits after highly active antiretroviral therapy: a predictor of clinical progress in HIV patients. *J Intern Med* 2007;261(3): 268–275. [PubMed: 17305649]

9. Berg MB, Safren SA, Mimiaga MJ, Grasso C, Boswell S, Mayer KH. Nonadherence to medical appointments is associated with increased plasma HIV RNA and decreased CD4 cell counts in a community-based HIV primary care clinic. *AIDS Care* 2005;17(7):902–907. [PubMed: 16120506]
10. Metsch LR, Pereyra M, Messinger S et al. HIV transmission risk behaviors among HIV-infected persons who are successfully linked to care. *Clin Infect Dis* 2008;47(4):577–584. [PubMed: 18624629]
11. Fleishman JA, Moore RD, Conviser R, Lawrence PB, Korthuis PT, Gebo KA. Associations between outpatient and inpatient service use among persons with HIV infection: a positive or negative relationship? *Health Serv Res* 2008;43(1 Pt 1):76–95. [PubMed: 18211519]
12. Aberg JA, Gallant JE, Anderson J et al. Primary care guidelines for the management of persons infected with human immunodeficiency virus: recommendations of the HIV Medicine Association of the Infectious Diseases Society of America. *Clin Infect Dis* 2004;39(5):609–629. [PubMed: 15356773]
13. Cheever LW. Engaging HIV-infected patients in care: their lives depend on it. *Clin Infect Dis* 2007;44(11):1500–1502. [PubMed: 17479949]
14. Hall HI, Gray KM, Tang T, Li J, Shouse L, Mermin J. Retention in care of adults and adolescents living with HIV in 13 U.S. areas. *J Acquir Immune Defic Syndr* 2012;60(1):77–82. [PubMed: 22267016]
15. Marks G, Gardner L, Craw JA, Crepaz N. Entry and retention in medical care among HIV-diagnosed persons in the United States: a meta-analysis. *AIDS* 2010;24(17):2665–2678. [PubMed: 20841990] A study which meta-analyzed 28 findings on retaining patients in HIV care.
16. Cabral HJ, Tobias C, Rajabiun S et al. Outreach program contacts: do they increase the likelihood of engagement and retention in HIV primary care for hard-to-reach patients? *AIDS Patient Care STDS* 2007;21(Suppl 1):S59–S67. [PubMed: 17563291]
17. Ulett KB, Willig JH, Lin HY et al. The therapeutic implications of timely linkage and early retention in HIV care. *AIDS Patient Care STDS* 2009;23(1):41–49. [PubMed: 19055408]
18. Magnus M, Jones K, Phillips G et al. Characteristics associated with retention among African American and Latino adolescent HIV-positive men: Results from the outreach, care, and prevention to engage HIV-seropositive young MSM of color special project of national significance initiative. *J Acquir Immune Defic Syndr* 2010;53(4):529–536. [PubMed: 19755914]
19. Marx KA, Malka ES, Ravishankar J, Schwartz RM. Measurement of retention in care among adults infected with HIV in an urban clinic. *AIDS Care* 2011;23(10):1298–1304. [PubMed: 21939407]
20. Catz SL, McClure JB, Jones GN, Brantley PJ. Predictors of outpatient medical appointment attendance among persons with HIV. *AIDS Care* 1999;11(3):361–373. [PubMed: 10474634]
21. Stein MD, Crystal S, Cunningham WE et al. Delays in seeking HIV care due to competing caregiver responsibilities. *Am J Public Health* 2000;90(7):1138–1140. [PubMed: 10897195]
22. Williams B, Amico KR, Konkle-Parker D. Qualitative assessment of barriers and facilitators to HIV treatment. *J Assoc Nurses AIDS Care* 2011;22(4):307–312. [PubMed: 21277804]
23. Tobias CR, Cunningham W, Cabral HD et al. Living with HIV but without medical care: barriers to engagement. *AIDS Patient Care STDS* 2007;21(6):426–434. [PubMed: 17594252]
24. Goldstein RB, Rotheram-Borus MJ, Johnson MO et al. Insurance coverage, usual source of care, and receipt of clinically indicated care for comorbid conditions among adults living with human immunodeficiency virus. *Med Care* 2005;43(4):401–410. [PubMed: 15778643]
25. Turner BJ, Cunningham WE, Duan N et al. Delayed medical care after diagnosis in a US national probability sample of persons infected with human immunodeficiency virus. *Arch Intern Med* 2000;160(17):2614–2622. [PubMed: 10999975]
26. Bakken T Constitutional and social equality: legacies and limits of law, politics and culture. *Indian J Gend Stud* 2000;7(1):71–82. [PubMed: 12322598]
27. Kinsler JJ, Wong MD, Sayles JN, Davis C, Cunningham WE. The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. *AIDS Patient Care STDS* 2007;21(8):584–592. [PubMed: 17711383]

28. Beckerman A, Fontana L. Medical treatment for men who have sex with men and are living with HIV/AIDS. *Am J Mens Health* 2008;3(4):319–329. [PubMed: 19477739]
29. Cunningham CO, Sohler NL, Korin L, Gao W, Anastos K. HIV status, trust in health care providers, and distrust in the health care system among Bronx women. *AIDS Care* 2007;19(2): 226–234. [PubMed: 17364403]
30. Kalichman SC, Graham J, Luke W, Austin J. Perceptions of health care among persons living with HIV/AIDS who are not receiving antiretroviral medications. *AIDS Patient Care STDS* 2002;16(5): 233–240. [PubMed: 12055031]
31. Aidala AA, Lee G, Abramson DM, Messeri P, Siegler A. Housing need, housing assistance, and connection to HIV medical care. *AIDS Behav* 2007;11(Suppl 6):101–115. [PubMed: 17768674]
32. Smith MY, Rapkin BD, Winkel G, Springer C, Chhabra R, Feldman IS. Housing status and health care service utilization among low-income persons with HIV/AIDS. *J Gen Intern Med* 2000;15(10):731–738. [PubMed: 11089717]
33. Andersen M, Hockman E, Smereck G et al. Retaining women in HIV medical care. *J Assoc Nurses AIDS Care* 2007;18(3):33–41. [PubMed: 17570298]
34. Mugavero MJ, Norton WE, Saag MS. Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care Delivery System. *Clin Infect Dis* 2011;52(Suppl 2):S238–S246. [PubMed: 21342913]
35. Giordano TP. Retention in HIV care: what the clinician needs to know. *Top Antivir Med* 2011;19(1):12–16. [PubMed: 21852711]
36. DeLuca JB, Mullins MM, Lyles CM, Crepaz N, Kay L, Thadiparthi S. Developing a comprehensive search strategy for evidence-based systematic review. *Evid Based Libr Inf Pract* 2008;3(1):3–32.
37. Horstmann E, Brown J, Islam F, Buck J, Agins BD. Retaining HIV-infected patients in care: where are we? where do we go from here? *Clin Infect Dis* 2010;50(5):752–761. [PubMed: 20121413]
38. Mugavero MJ, Davila JA, Nevin CR, Giordano TP. From access to engagement: measuring retention in outpatient HIV clinical care. *AIDS Patient Care STDS* 2010;24(10):607–613. [PubMed: 20858055]
39. Gardner LI, Metsch LR, Anderson-Mahoney P et al. Efficacy of a brief case management intervention to link recently diagnosed HIV-infected persons to care. *AIDS* 2005;19(4):423–431. [PubMed: 15750396] A study which demonstrated the efficacy of a brief strengths-based case management intervention for initial entry and retaining patients in HIV care.
40. Naar-King S, Bradford J, Coleman S, Green-Jones M, Cabral H, Tobias C. Retention in care of persons newly diagnosed with HIV: outcomes of the Outreach Initiative. *AIDS Patient Care STDS* 2007;21(Suppl 1):S40–S48. [PubMed: 17563289]
41. Bradford JB, Coleman S, Cunningham W. HIV System Navigation: an emerging model to improve HIV care access. *AIDS Patient Care STDS* 2007;21(Suppl 1):S49–S58. [PubMed: 17563290]
42. Hightow-Weidman LB, Smith JC, Valera E, Matthews DD, Lyons P. Keeping them in “STYLE”: finding, linking, and retaining young HIV-positive black and Latino men who have sex with men in care. *AIDS Patient Care STDS* 2011;25(1):37–45. [PubMed: 21162690]
43. Wohl AR, Garland WH, Wu J et al. A youth-focused case management intervention to engage and retain young gay men of color in HIV care. *AIDS Care* 2011;23(8):988–997. [PubMed: 21390879]
44. Gardner L, Marks G, Craw J et al. A low-effort clinic-wide intervention improves attendance for HIV primary care. *Clin Infect Dis*. In press 2012.
45. Naar-King S, Outlaw A, Green-Jones M, Wright K, Parsons JT. Motivational interviewing by peer outreach workers: a pilot randomized clinical trial to retain adolescents and young adults in HIV care. *AIDS Care* 2009;21(7):868–873. [PubMed: 20024744]
46. Davila JA, Miertschin N, Sansgiry S, Schwarzwald H, Henley C, Giordano TP. Centralization of HIV services in HIV-positive African-American and Hispanic youth improves retention in care. *AIDS Care*. In press 2012.
47. Enriquez M, Farnan R, Cheng AL et al. Impact of a bilingual/bicultural care team on HIV-related health outcomes. *J Assoc Nurses AIDS Care* 2008;19(4):295–301. [PubMed: 18598904]
48. Purcell DW, Latka MH, Metsch LR et al. Results from a randomized controlled trial of a peer-mentoring intervention to reduce HIV transmission and increase access to care and adherence to

- HIV medications among HIV-seropositive injection drug users. *J Acquir Immune Defic Syndr* 2007;46(Suppl 2):S35–S47. [PubMed: 18089983]
49. Wolitski RJ, Kidder DP, Pals SL et al. Randomized trial of the effects of housing assistance on the health and risk behaviors of homeless and unstably housed people living with HIV. *AIDS Behav* 2010;14(3):493–503. [PubMed: 19949848]
 50. Zinski A, Wahl T, Mugavero M. Peer interventions for adherence to HIV clinical care: a systematic review. Oral presentation at: IAPAC 6th International Conference on HIV Treatment and Prevention Adherence; May 22–24, 2011; Miami, FL Abstract 69909.
 51. Konkle-Parker D, Amico KR, McKinney V. A multi-dimensional intervention improves retention to HIV care. Poster presented at: IAPAC 7th International Conference on HIV Treatment and Prevention Adherence; June 3–5, 2012; Miami, FL Abstract 79991.
 52. Gardner L, Marks G, Craw J et al. Preliminary findings from CDC/HRSA retention in care project. Oral presentation at: IAPAC 7th International Conference on HIV Treatment and Prevention Adherence June 3–5, 2012; Miami, FL Available at: http://www.iapac.org/AdherenceConference/presentations/ADH7_Invited_Gardner_Marks.pdf. Accessed June 29, 2012.
 53. Thompson MA, Mugavero MJ, Amico KR et al. Guidelines for improving entry into and retention in care and antiretroviral adherence for persons with HIV: evidence-based recommendations from an International Association of Physicians in AIDS Care Panel. *Ann Intern Med* 2012;156(11): 817–833. [PubMed: 22393036]
 54. Mugavero M, Westfall A, Zinski A et al. Measuring retention in HIV care: the elusive gold standard. Oral presentation at: IAPAC 7th International Conference on HIV Treatment and Prevention Adherence; June 3–5, 2012; Miami, FL Abstract 79956.

Table 1:

Study characteristics and findings of studies in qualitative review

1 st Author (Year)	Study Dates	Location	Sample (n ^a)	Design	Data Collection Method	Measure	Findings
Anderson 1 (2007)	Not reported	Detroit, MI (1 out of 10 HRSA-SPNS sites)	Women not fully engaged in care (61)	1-group prepost	Self-report	% participants did not miss any HIV medical appointment in past 6 months ^b	Pre-intervention: 21% 57% in first 6-month period 61% in second 6-month period No significance tests conducted
Anderson 2 (2007)	Not reported	Detroit, MI (1 out of 10 HRSA-SPNS sites)	Women not fully engaged in care and who report heroin use and/or mental health issues (51)	1-group prepost	Self-report	% participants did not miss any HIV medical appointment in past 6 months	Pre-intervention: 10% 51% in first 6-month period 58% in second 6-month period No significance tests conducted
Bradford (2007)	10/03–6/06	Boston, MA, Portland, OR Seattle, WA Washington, DC (4 out of 10 HRSA-SPNS sites)	Not fully engaged in HIV care (437)	1-group prepost	Self-report	% participants had 2 or more HIV medical appointments in past 6 months	Pre-intervention: 64% 87% at 6 months, pre-post change: p<0.001 79% at 12 months, pre-post change: p<.0001
Davilla (2012)	1/02–8/08	Houston, TX	Young African American & Hispanic patients (174)	3-group historical comparison	Administrative & medical records	% having 3 or more quarters with at least 1 visit in 12 months (adequate visit constancy) % having 180 days between 2 consecutive HIV primary care visits in 12 months (gaps in care)	Adequate visit constancy OR ^c (95% CI) No youth services: 0.42 ^d (0.17–1.03), ns ^e Youth services: (reference) Enhanced youth services: 1.18 ^d (0.55–2.53), ns Gaps in care OR (95% CI) No youth services: 1.37 ^d (0.46–4.17), ns Youth services: (reference) Enhanced services: 5.56 ^d (1.20–25.0), p<0.05
Enriquez (2008)	3/05–3/07	Kansas City, MS	Hispanics (43)	1-group prepost	Medical records	# of HIV specialty clinic visits in a year	Pre-intervention mean: 2.81 (SD=2.34) Post-intervention mean: 5.30 (SD=2.69) (t[42], = 6.29, p<0.05)
Gardner (2005)	3/01–5/02	Atlanta, GA Baltimore, MD Miami, FL Los Angeles, CA	Newly diagnosed (273)	2-group, randomized	Medical records used to confirm self-reports	% participants visited HIV clinician at least twice in a 12-month period	64% vs. 49% (intervention vs. control); Adjusted relative risk = 1.41, p=0.006
Gardner (in press)	5/08–5/10	Baltimore, MD Boston, MA Birmingham, AL Brooklyn, NY Houston, TX Miami, FL	HIV patients who had appointments for primary care (8535)	1-group prepost	Medical records	% participants who kept two consecutive primary care appointments following exposure to the intervention (anchor visit) compared with patients with	Pre-intervention period: 48.6% Intervention period: 52.2% ^c , p<0.001

1 st Author (Year)	Study Dates	Location	Sample (n ^a)	Design	Data Collection Method	Measure	Findings
Hightow-Weidman (2011)	6/06–8/09	Bronx, NY Chapel Hill, NC, Chicago, IL Detroit, MI Houston, TX Los Angeles, CA Oakland, CA Rochester, NY (7 out of 8 HRSA-SPNS sites)	Newly diagnosed or out of care young African American or Latino MSM (89)	2-group historical comparison	Medical records	% participants had at least 3 HIV care visits within the first year after enrollment with at least 1 visit in the first 6 months	Intervention vs. historical control (80% vs. 67%, t statistic = 2.16, p=0.03)
Naar-King (2007)	Not reported	Detroit, MI Los Angeles, CA Portland, OR Washington, DC (4 out of 10 HRSA-SPNS sites)	Newly diagnosed (104)	1-group post only	Medical records	% participants had a medical appointment in both 6-month periods over a 12 month assessment	81% had a medical appointment in both 6-month time periods over 12 months No significance tests reported
Naar-King (2009)	03–06	Detroit, MI	Adolescents and young adults enrolled in medical care (83)	2-group, randomized (peer vs. professional delivered)	Medical records	Gap in medical appointments (e.g., no appointment in a 3-month period). A 4-point gap score was calculated based on number of gaps over 12 months (e.g., 0= no gaps; 1=1 gap or appointments in 3 of 4 quarters)	Peer-vs. professional-delivered 1.34 vs. 1.52, F=0.54, ns Peer-delivered (pre vs. post) 2.76 vs. 1.33, no significance tests reported Professional-delivered (pre vs. post) 2.53 vs. 1.52 (no significance tests reported)
Purcell (2007)	8/01–3/05	Miami, FL New York, NY San Francisco, CA	Injection drug users (795)	2-group, randomized	Self-report	% participants who used HIV care 2 or more times in past 6 months	71% vs. 72% (intervention vs. control); adjusted OR=0.81, 95% CI = 0.57, 1.14, ns at 6 months 69% vs. 64% (intervention vs. control); adjusted at OR=1.14, 95% CI =0.82, 1.58, ns at 12 months
Wohl (2011)	4/06–4/09	Los Angeles, CA	Newly diagnosed or out of care African American or Latino MSM (61)	1-group post only	Medical records	% participants attended 2 or more HIV care appointments in past 6 months	70% at 6 months for whole sample 82% at 6 months for 33intermittent HIV care users No significance tests conducted
Wolitski (2010)	7/04–1/07	Baltimore, MD Chicago, IL Los Angeles, CA	Persons in unstable housing conditions (630)	2-group, randomized	Self-report	% participants had 2 or more HIV medical visits in past 6 months and being on ART	37% vs. 38% (intervention vs. control) at 6 months, ns 47% vs. 41% (intervention vs. control at 12 months), ns 49% vs. 46% (intervention vs. control at 18 months), ns

^a Analytic sample size

^b The number of missed visits or “no shows” during an observed period of time is one of the most common ways of measuring retention (Mugavero et al., 2010). We assumed many patients would have at least 2 appointments based on current medical recommendations.

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript

^cOdds ratio

^dAdjusted for age, sex, race, mode of transmission, and previously in care at another clinic

^eAdjusted for changes across time in viral load, age, and health insurance

^fNot statistically significant

Table 2:

Intervention characteristics of studies in qualitative review

1 st Author (Year)	Intervention Goal(s)	Intervention Setting	Intervention Deliverer(s)	Intervention Duration (# of sessions/length of contact)	Intervention Strategies
Anderson 1 (2007)	Increase retention by eliminating access-to-care barriers	Nursing outreach clinic	Transportation staff	Weekly as needed/12 months	Provide transportation to HIV medical appointments ^j
Anderson 2 (2007)	Increase retention by eliminating access-to-care barriers	Nursing outreach clinic	Transportation staff Nurse case manager	Weekly transportation as needed; at least 1 home visit and 1 accompaniment to medical provider visit by nurse/12 months	Accompany client to doctor visit to help interpret medical treatment plan ^b Accompany to mental health appointments ^b Make referrals to drug treatment ^d Provide counseling to address concerns with a focus to improve well-being ^e Visit client at home ^g Provide transportation to HIV medical appointments ^j
Bradford (2007)	Improve retention through patient navigation services	Community-based organization Community-health center Community-based clinic	Patient navigator (non-clinical staff)	NR ^k /12 months	Accompany client to appointments as needed ^c Coordinate appointments and other services ^c Help navigate health and social service systems ^d Address barriers to care ^d Provide health care referrals ^d Help develop skills in provider interactions (e.g., modeling behaviors, rehearsing conversations) ^e Provide social support ^e Provide HIV information ^e Establish rapport ^e
Davila (2012)	Improve retention by offering youth specific services	Medical clinic	Adolescent health care providers Youth-focused social workers and case managers	NR/NR	Co-location of services ^f Provide youth specific support groups and educational activities ^e Use motivational interviewing to improve self-efficacy ^e Teach health care navigation skills ^e Encourage HIV disease management
Enriquez (2008)	Better serve Hispanic patients at a medical center by using bilingual/bicultural health care providers	Medical clinic	Nurse practitioner Ryan White case manager Peer educator	NR/12 months	Refer clients for sub-specialty care as needed ^d Assess social and psychological needs ^d Provide information and referrals to community resources ^d
Gardner (2005)	Facilitate linking and retention using brief, strengths-based case management	Research study offices in community	Case manager	5 sessions/3 months	Identify and address needs and barriers to health care ^d Establish rapport ^e

1 st Author (Year)	Intervention Goal(s)	Intervention Setting	Intervention Deliverer(s)	Intervention Duration (# of sessions/length of contact)	Intervention Strategies
Gardner (in press)	Improve retention in care through clinic-wide intervention	University-based HIV clinics	Medical providers	Providers asked to give messages at each visit; attempt made to give brochure to every patient; posters continually displayed/12 months	Encourage contact with a HIV primary care clinic ^e Accompany client to HIV primary care clinic ^b Present brief messages ^e Offer brochure emphasizing importance of regular care ^h Display posters in waiting and exam rooms ^j
Hightow-Weidman (2011)	Improve retention through social marketing, outreach, and medical-social support networks	University-based medical clinic Health department clinic	Peer outreach worker Case manager Infectious diseases-board-certified physician	NR/24 months	Provide ancillary social support services (case management and support groups) ^{a,d,f} Offer medical appointment within 72 hours ^b Assist with appointment scheduling or answer medical questions ^{ce} Co-location of medical services ^f
Naar-King (2007)	Address stigma and helping with accessing resources to increase use of HIV care by providing outreach services	Community-based organization Community-based clinic Nursing outreach clinic	Not reported	Average of 19 contacts within a year/12 months	Address stigma ^d Advocate and help with accessing resources to address financial and structural barriers ^d Offer HIV education and support ^e Provide intensive outreach ^h
Naar-King (2009)	Reduce gaps in HIV care by using motivational interviewing	Clinic Outreach center Community outreach	Peer outreach worker Masters level staff	2 sessions/6 months	Elicit clients' view of keeping HIV medical appointments ^e Express empathy ^e Boost self-efficacy ^e Develop discrepancy between clients' values and attending HIV medical appointments ^e Complete change plan focusing on client goal ^e Explore possible barriers to achieve goal ^e
Purcell (2007)	Increase use of HIV care and reduce HIV transmission risk through peer mentoring training	Community-based organization	Research staff	10 sessions/5 weeks	Provide information on local services for medical care, support groups, drug treatment, and prevention resources ^d Train clients in peer mentoring skills ^e Increase knowledge in utilization of HIV primary care and adherence ^e Increase knowledge on sex and drug risk behaviors ^e Review and reinforce motivation and skills for behavior change ^e
Wohl (2011)	Improve retention by using youth-focused case management	Clinic	Case manager	Participants met weekly with case manager for first 2 months; monthly for next 22	Conduct comprehensive assessment to evaluate medical, physical, psychosocial, environmental, & financial needs ^d

1 st Author (Year)	Intervention Goal(s)	Intervention Setting	Intervention Deliverer(s)	Intervention Duration (# of sessions/length of contact)	Intervention Strategies
Wolitski (2010)	Improve medical care access and use, improve HIV-medication adherence, improve physical and mental health, and reduce HIV-transmission risk through immediate rental assistance	Rental assistance agencies	Housing referral specialist Case manager	months; average of 5.1 sessions attended/24 months	Develop an individualized treatment plan to address identified barriers ^d Make referrals for necessary services ^d Evaluate readiness to initiate utilization of HIV care using the stages of change model ^e
				2 sessions/18 months	Help initiate immediate rental assistance and locate housing ^{a,d}

^a Ancillary services

^b Appointment accompaniment

^c Appointment coordination

^d Case management

^e Cognitive-behavioral strategies

^f Co-location of services

^g Home-based services

^h Outreach

ⁱ Media

^j Transportation services

^k Not reported

Table 3:

Recommended Intervention Strategies to Enhance Retention in HIV Care

Recommended Intervention Strategies to Enhance Retention in HIV Care
<ul style="list-style-type: none">• Strengths-based case management• Patient navigation approaches• Appointment accompaniment to medical appointments• Transportation to medical appointments• Co-location of services (i.e., ancillary services and medical care)• Outreach services• Bilingual/bicultural health care teams• Consistent reminder calls• Brief messages from health providers during medical visits• Posters and brochures in waiting rooms• Peers as part of the health care team

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript