

REVIEW

Interventions that can improve the retention in care among patients with HIV: A review

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ABSTRACT

Introduction: Despite the transformation in healthcare outcomes with the availability of effective antiretroviral therapy, retention in human immunodeficiency virus (HIV) care remains a challenge. Patients with poor retention have higher rates of HIV-related complications and death.

Materials and Methods: We conducted a literature search on PubMed, including articles that reported on the adult population in the United States and published between 2002-2022. The keywords used included HIV, retention in care, intervention, support services, missed appointments, barriers to care, text messages, mobile health, telehealth, and telemedicine.

Results/Discussion: We found that interventions implementing supportive services such as patient navigators, counseling, HIV education, and providing transportation led to an increase in retention in care. Technological interventions have also improved retention in care and include patient portals, appointment reminders, telehealth, and clinic-based smartphone apps. Lastly, visual, and verbal messages that

emphasize the importance of retention in care are easy, low-cost interventions to implement in the HIV clinic.

Conclusion: Overall, higher levels of patient retention are needed to secure improved healthcare outcomes in patients with HIV. The diversifying population of people with HIV (PWH) calls for additional research that aims to address unmet patient needs.

INTRODUCTION

In the United States, only 57.9% of PWH were retained in care in 2018.¹ Although the introduction of antiretroviral therapy (ART) has allowed providers to manage HIV as a chronic disease, patients who face difficulties maintaining follow-up appointments cannot maintain access to ART, and therefore, acquire its benefits. Expectedly, higher retention in HIV care has a markedly positive effect on patients' health, including decreased mortality.^{2,3} Higher retention is also associated with undetectable viral levels which decreases the risk of HIV transmission, thereby benefiting public health.⁴ On the other hand, poor retention in care is associated with negative clinical outcomes, such as detectable viral loads,

AIDS-defining CD4 counts, higher rates of ART failure, and overall reduced survival.^{5,6}

Identifying key factors associated with poor retention in HIV care may be useful in informing the interventions that intend to improve retention. Common predictors of poor retention in developed countries were active substance use, younger age, and physical and psychiatric comorbidities.⁷ Studies aiming to identify existing disparities in retention in care found that non-Hispanic Black and African Americans, younger persons, men who have sex with men (MSM), people who inject drugs (PWID), and individuals born outside of the United States had disproportionately poor retention in care.⁸ These results provide us with information about potential barriers to care and the subgroups by which targeted interventions may particularly make an impact.

Numerous studies have highlighted the challenges patients face in retaining in care. These challenges can be categorized into issues at the individual, community, healthcare system, and policy level.⁹ Barriers to retention in HIV care have been identified in the literature and include: distrust in the medical system, privacy issues, mood/somatic symptoms, disbelief in HIV status, stigma associated with having HIV, substance use disorder (SUD), and unmet needs (transportation, housing, childcare, and financial needs).⁹⁻¹² In this narrative review, we summarize the interventions that have been published in the last two decades that have aimed to increase retention in care for PWH.

MATERIALS AND METHODS

An extensive literature search was conducted on PubMed. Articles that were published between 2002-2022 were included. We restricted the focus of our research on adults with HIV in the United States and only

reviewed articles written in English. The keywords that were used included HIV, retention in care, intervention, support services, injection drug use, substance use disorder, sexual risk behavior, mental illness, missed appointments, barriers to care, text messages, mobile health, telehealth, and telemedicine. The articles that we report included quality improvement (QI) studies, retrospective analysis, single-arm prospective studies, non-randomized single arm and control trials, randomized control trial (RCT), and meta-analysis.

Currently, there is no standardized measure to evaluate various interventions on outcomes such as retention in care. A commonly noted problem is that the definition for “retention in care” is variable and inconsistently used among studies which makes comparing interventions challenging.^{13,14} The Centers for Disease Control and Prevention (CDC) defines retention in HIV medical care as documentation of at least two CD4 cell count or viral load tests performed at least 3 months apart during the year of evaluation.¹ Other commonly used measures of retention in HIV care include missed visits, appointment adherence, visit constancy, and gaps in care.¹⁵

DISCUSSION

Support services

Support measures that aim to address the diverse needs of patients are associated with improved retention and health outcomes. One observational study evaluated the effect of providing services, such as case management, mental health services, transportation, or substance abuse management, to those with unmet needs.¹⁶ Patients who received one of these services

were more likely to receive regular care compared to those who needed but did not receive that service. These support services resulted in a 15-18% increased retention in primary care, in addition to decreased viral loads, improved medication adherence, and higher likelihood of receiving ART. This study illustrated the importance of providing comprehensive care for PWH and showed that a multidisciplinary approach can successfully address patients' unmet needs.

In a non-randomized clinical trial, patients were enrolled in outreach initiatives that involved appointment reminders, aid in rescheduling appointments, service coordination, relationship building, transportation, counseling, and HIV education.¹⁷ There was an overall increase in retention in care at 12 months ($p=0.01$) and those with more than 9 program contacts in the first 3 months had a 50% increase in the likelihood of not experiencing a 4-month gap in care compared to those with 0-8 contacts ($p=0.03$). In this study, novel information about the relationship between outreach program contacts and retention in care promoted engagement and retention in HIV primary care.

Although most initiatives focus on science-based interventions for PWH, there is a limited amount of data available to interpret the significance of behavioral interventions for PWH and injection drug use. In one study, PWH and a history of injection drug use received either a peer mentoring (PM) or a video discussion (VD) intervention to evaluate the utilization of medical care and adherence to HIV medications.¹⁸ In the PM group, participants developed plans based on their individual risks, in addition to learning problem-solving skills for behavioral change. In the VD group, participants watched and discussed documentaries about prejudice, discrimination, obtaining a job, incarceration, and overdose prevention. They were also

given community resources and risk reduction tools. Both groups had a slightly increased adherence to appointments ($p<0.01$), post-intervention, compared to baseline. However, there was no significant difference in adherence between the PM and VD intervention. Both interventions led to decreases in risk behaviors such as drug injection and sexual transmission. This trial can be used as a model for other researchers to design more effective health promotion and disease prevention interventions for this patient population.

Similarly, researchers targeted PWH with concomitant SUD and mental illness by providing substance-use counseling and referral for treatment with buprenorphine.¹⁹ Participants were also connected with services such as counseling, housing, and transportation according to individual need. The results demonstrated that the participants with these support measures attended more medical visits than the HIV general clinic population ($p<0.001$). Addressing the needs of patients with SUD and mental illness was associated with an increase in appointment attendance.

In the realm of supportive services, patient navigation focuses on individualized assistance and guidance for the patient. Navigators interact directly with individuals instead of the healthcare system. In a 3-arm randomized study implementing patient navigation programs, participants received one of three interventions: enhanced contact with interventionist (EC) only, EC with other skills, or appointment reminder calls only (standard of care).²⁰ EC only consisted of in-person meetings, interim visit calls, appointment reminder calls and missed visit calls, while EC with other skills included education on problem solving and communication skills. Results demonstrated an increase in visit adherence for each intervention compared to standard of care

($p < 0.01$), but no difference between EC and EC with other skills was observed.

In another study, staff received training in motivational interviewing and performed a needs assessment for patients.²¹ Motivational interviewing consisted of skills to celebrate milestones. They helped patients navigate health and social service systems, drove them to their appointments, and guided patients to address other barriers of care. At the end of 12 months, there was an increase in the number of visits compared to pre-intervention ($p < 0.001$). This approach of amplifying patient-provider interactions improved consistency of patient visits.

Technology

More recently, technology has been utilized in various forms to improve health outcomes in HIV care, such as engagement with patient portals, delivering appointment reminders, and smartphone apps. One QI project worked to increase the enrollment of women with HIV who were at risk of disengaging in care into a clinic patient portal system.²² After their clinic visit, interested patients met with a medical case manager who helped them enroll into the portal system and review the portal features. Patients who were between 40 to 59 years had the greatest proportion of participation, which supports the use of mobile technology in this age group. The aggregate no-show rate decreased from 32% to 22% ($p = 0.539$) from pre-enrollment to 90-day post-enrollment.

Another QI study in an inner-city HIV clinic used multiple interventions including patient-centered reminders that patients chose to receive by email, phone call, or text message. These reminders were delivered 2 weeks before and again within 24-48 hours of the scheduled appointment.²³ In addition, patients who were characterized as medium or high risk of missing their next HIV appointment received further support

from a case manager or a home visit from a patient-peer navigator, respectively. Though phone call reminders were the overall preferred method of appointment reminders, 52% of patients between 19 and 29 years of age preferred text message reminders. Overall, in the first 5 months of implementation, these interventions resulted in a 3.8% decrease in the no-show rate, although statistical analysis was not reported. Because this study utilized multiple interventions, it is difficult to interpret whether appointment reminders or support services (case manager or patient navigator) had the largest impact on the outcome. Other studies have shown that text message reminders are a beneficial tool to improve different aspects of HIV-related compliance, including decreased rates of non-attendance ($p = 0.01$), improved medication adherence, and CD4 count or viral load.²⁴

An innovative study conducted in a nonurban population developed and piloted a clinic-based mobile intervention called PositiveLinks.²⁵ During development, the authors made modifications according to the clinic population and involved patients in the development process to identify features that they desired. This smartphone app connected patients to their health and local community with features that included appointment reminders, educational resources, messaging with the program coordinator, a community message board, and daily queries of mood and medication adherence. Compared to baseline, there was a significant increase in retention in care at 6 months ($p < 0.0001$) and 12 months ($p = 0.0003$). Moreover, participants reported that the app helped break through some of the barriers to accessing HIV care, such as social and geographic isolation. This technological intervention was unique since it incorporated “warm technology,” which accentuated emotion and human connection, in contrast to “cold technology” interventions that mainly

functioned to deliver reminders. The use of warm technology helped patients make sustained connections with their health care and build a virtual community.

Telehealth (or telemedicine) in the form of telephone or videoconference appointments serves as an alternative to in-person appointments and has been available in some clinics before the COVID-19 pandemic in 2020. A QI study that took place between 2015-2016 in the Veterans Affairs health systems studied the effects of telehealth in HIV care.²⁶ Primary care clinics were assigned to either the intervention group, which immediately initiated HIV telehealth visits, or the control group, which implemented telehealth visits 1 year later. Patients who resided in areas where telehealth were made available could then decide to receive HIV care through telehealth visits in a nearby primary care clinic or continue to travel to the HIV specialty clinic. Though telehealth intervention clinics were associated with slightly improved rates of viral suppression compared to control clinics, this study did not find a statistically significant difference in retention in care between groups ($p=0.10$). Still, the option of telehealth visits is beneficial for those who travel long distances to the clinic or have limited transportation options.

Due to social distancing recommendations, the COVID-19 pandemic led to widespread implementation of telehealth appointments for HIV care. In a safety-net clinic in San Francisco, in-person HIV visits were transitioned to a telemedicine model during the pandemic.²⁷ The pre-transition period had 1287 of 4153 visits that were no-shows (31%), while the post-transition period had 599 of 1997 that were no-shows (30%). There were fewer no-shows that occurred for telephone visits compared to in-person visits. Younger individuals (age < 35 years) had higher rates of retention in care post-transition, which

may be attributed to their familiarity with technology in general. However, the clinic experienced overall lower viral suppression rates during the pandemic, which suggests that telemedicine may fall short in compensating for the loss of clinic-based social support services that are vital to vulnerable groups. Another retrospective study in a safety-net infectious disease clinic in a large urban area investigated appointment adherence in patients who received telehealth appointments versus in-person HIV medical care visits.²⁸ Researchers found that overall appointment attendance, regardless of MSM, SUD or housing status, was significantly higher for telehealth appointments ($p<0.001$). PWID was the only risk category that did not show this trend, though the authors note this may be due to the small sample size for PWID. In conclusion, HIV clinics should provide patients with the option of telehealth visits in addition to in-person visits as it may be a strategy to help patients stay retained in care.

Visual and verbal reminders

The interventions of using visual and verbal messages that emphasize the importance of care retention have not been rigorously studied. In one study, six HIV clinics participated in an intervention that observed the effect of systematic messages on clinic attendance.²⁹ Specifically, the intervention consisted of print materials including brochures, examination and waiting room posters, and verbal messages that were used by all clinic staff. The verbal and written messages stressed the importance of keeping all appointments. An example of a verbal message was: “We have good evidence that PWH who come to their appointments do better than those who don’t. When you miss your appointments, we can’t work together to keep you healthy.” Compared to the pre-intervention period, there was a 7% increase

in attendance for keeping 2 consecutive visits ($p < 0.0001$) in the post-intervention period. Not only does this intervention increase retention in care, but it also has the added benefit of being low-effort and low-cost.

Future direction

Despite the interventions that we described above, there are gaps in research that need to be addressed. More rigorous methods, such as RCTs, are necessary to evaluate existing interventions.^{13,14} Research is needed to evaluate the efficacy of risk stratification tools to identify patients who are more likely to miss appointments.²³ Furthermore, telehealth has the potential to address many of the factors identified as barriers for retention in HIV care, such as transportation barriers and reaching communities where specialist care is limited.³⁰ However, it is not an option for every patient and few studies have targeted underserved populations using these interventions including those identifying as MSM, individuals with a mental health disorder, and those in rural communities. Interventions that use support groups for PWH are not ideal for MSM with HIV because in group settings, MSM encounter additional discrimination and isolation.³¹ Patients who have less resources, such as those living in rural areas with limited network coverage or patients who are unable to afford technology compatible with telemedicine, would have difficulty accessing telehealth services.³² In addition, telemedicine requires a basic knowledge base to navigate technology, therefore making it difficult for some patients. Thus, further studies are needed to improve the accessibility and experience of telemedicine.³³

CONCLUSION

In conclusion, the consistency of patient visits is essential to maximize healthcare outcomes in PWH. Retention of care reduces mortality, comorbidities, and rates of HIV transmission which benefit the health of current patients and the prevention of new infections. PWH are confronted with multifaceted barriers to achieving optimal medical management and continuity of care in the outpatient clinic. Our review paper highlights the various interventions that have improved the retention in care for PWH. Supportive services have demonstrated the benefit of addressing patients' unmet needs. Using text messages for appointment reminders, telehealth visits, or patient engagement through phone applications utilizes the widespread dissemination of technology. Lastly, systematic messages reiterate the importance of keeping appointments and is a low-effort, low-cost strategy for patient retention. Further studies and interventions that are tailored to individual needs and clinic patient demographics are needed to optimize advancements in HIV care.

Notes

Notes

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