

Barriers and Facilitators to Retaining and Reengaging HIV Clients in Care: A Case Study of North Carolina

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Abstract

Retention in HIV care is critical to decrease disease-related mortality and morbidity and achieve national benchmarks. However, a myriad of barriers and facilitators impact retention in care; these can be understood within the social–ecological model. To elucidate the unique factors that impact consistent HIV care engagement, a qualitative case study was conducted in North Carolina to examine the barriers and facilitators to retain and reengage HIV clients in care. HIV professionals (n = 21) from a variety of health care settings across the state participated in interviews that were transcribed and analyzed for emergent themes. Respondents described barriers to care at all levels within the HIV prevention and care system including intrapersonal, interpersonal, institutional, community, and public policy. Participants also described recent statewide initiatives with the potential to improve care engagement. Results from this study may assist other states with similar challenges to identify needed programs and priorities to optimize client retention in HIV care.

Keywords

HIV/AIDS, retention, reengagement, health providers, social–ecological model

Introduction

In the United States, only half of the people diagnosed with HIV are estimated to be consistently retained in HIV care,¹ although large variations exist across states.² Retention in care is critical for access to antiretroviral treatment and, therefore, achieving and maintaining viral suppression.³ The HPTN 052 study in 2011 demonstrated the importance of viral load suppression in reducing the transmission of HIV within serodiscordant couples and has become a benchmark for defining prevention efforts around the world.⁴ Numerous studies have found that poor participation in HIV care is associated with adverse outcomes for persons living with HIV (PLWH). These include increased risks of HIV treatment failure and AIDS-defining illnesses, as well as increased chances for patient mortality,^{5–7} particularly for those who miss medical appointments.^{8–10} Thus, improving patient engagement in care has become a national priority, and targeted retention measures have been established by the National HIV/AIDS Strategy (NHAS) and the Health Resources and Services Administration (HRSA), Ryan White HIV/AIDS Program.^{11–13} Appropriately addressing patient HIV care engagement requires a better understanding of the facilitators and barriers to retention and reengagement across US states and regions.

The social–ecological model is a useful conceptual tool for examining patient engagement within an HIV care system. This framework posits that 5 levels of factors reciprocally interact to influence health behavior, moving from the individual (intrapersonal and interpersonal) to institutional, community, and, finally, public policy.¹⁴ Mugavero et al¹⁵ applied the social–ecological framework to a review of the literature

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examining the interaction of factors that impede the diagnosis, linkage, and retention of HIV clients in care, including the role of supportive services (eg, case management, substance abuse treatment, and housing assistance), infrastructure of clinical care (eg, hours of clinic, availability of appointments, and culturally sensitive medical care), and impacts of national and local policies on testing, linkage, and treatment (eg, funding and medical provider shortages and the fragmentation of testing and care provider networks). The authors also highlighted successful models from the literature to promote care engagement, including case management and patient navigation programs, and the integration of health care systems.

Other studies have examined barriers and facilitators at multiple levels within the health care system which influence HIV care engagement. Some have looked at individual factors on intrapersonal and interpersonal levels and have concluded that maintaining strong personal relationships, managing psychosocial issues, remaining committed to self-care, perceiving providers in a positive way, and developing autonomy are often associated with more consistent engagement in HIV care.¹⁶⁻²² Others have identified institutional-level barriers to care, such as long clinic appointment wait times and inflexible clinic hours.^{16,23} Lastly, community- and policy-level barriers to HIV care have been identified, including limited access to transportation, inadequate medical insurance coverage, and the high costs of care.^{16,20} Undoubtedly, salient barriers and facilitators to engagement in care vary across settings and individuals. Clarifying these context-specific factors within state and regional HIV care systems can inform efforts to reduce health disparities and improve public health.

One geographic area in which to examine these disparities and their impacts on HIV care systems is within the US Census Bureau-defined South,²⁴ a region that carries a disproportionate burden of the nation's HIV epidemic.²⁵ In 2011, 48% of US HIV diagnoses were from the South, although the area was only home to 37% of the national population.^{26,27} The South also has the highest adjusted death rate for PLWH among the Census regions.²⁸ To explain these disparities in HIV incidence and HIV-related mortality, the unique social, political, and demographic factors of the region are often cited, including higher levels of poverty, HIV-related stigma, and sexually transmitted diseases; fewer HIV providers; and more restrictive government policies, such as a dearth of needle exchange and comprehensive sex education programs.^{25,29} In addition, the vast majority of Southern states have opted not to expand Medicaid under the Affordable Care Act (ACA),³⁰ leaving many adults in the South without insurance coverage and thus access to affordable care. Living within these nonexpanding Southern states is especially problematic for PLWH, as they are more likely to be low income and childless and less likely to be privately insured; therefore, they would benefit from expanded Medicaid eligibility based on the ACA.³¹ Numerous studies have demonstrated that inadequate health insurance coverage can worsen patient retention in HIV care,³²⁻³⁵ and the expansion of safety net programs, such as Medicaid and the Ryan White HIV/AIDS

Program, can improve patient clinical outcomes and participation in HIV care.³⁶⁻³⁹

As a Southern state that has not expanded Medicaid, contains many uninsured residents, and possesses a large HIV disease burden,^{30,40,41} North Carolina represents a relevant case study among the South to explore the barriers and facilitators to retaining and reengaging HIV clients in care. In North Carolina, at the end of 2013, an estimated 28 101 people were living with HIV/AIDS, the vast majority of whom were male (71%). African Americans made up 65% of all diagnosed cases with HIV/AIDS, and African American females were the largest racial/ethnic group among women living with the disease (75%). Although rates of new HIV infections have been on the decline in recent years, in 2012, the state's HIV diagnosis rate ranked it eighth among all US states and dependent areas reporting HIV diagnoses to the Centers for Disease Control and Prevention (CDC).⁴² In addition, in 2013, 16% of North Carolinians lacked health insurance, a rate that was higher than the US average (13%) and was also one of the highest uninsured rates in the country.⁴⁰

North Carolina's sociodemographic landscape and disproportionate burden of HIV have created opportunities and challenges within the HIV prevention and care systems to meet the medical and support service needs of PLWH in the state. To deliver these services, North Carolina uses a regional network model, funded by the HRSA Ryan White Part B Program and overseen by the North Carolina Department of Health and Human Services (NCDHHS) AIDS Care Program. The state has 10 regional networks of care that cover 95 of the 100 North Carolina counties. The remaining 5 counties within the Charlotte metropolitan Transitional Grant Area receive direct funds from the Ryan White Part A Program. Within these regional networks, individual providers may receive additional funding for HIV medical and support services through other sources, such as Ryan White Parts C and D.⁴²

Health professionals working within the state's HIV networks of care possess unique opportunities to directly observe the implementation of programs and policies and, ultimately, their impacts on PLWH. Soliciting their input is therefore important to shape HIV policy priorities.⁴³ This valuable and often understudied perspective provides necessary insight to inform efforts to improve patient engagement in care.

Methods

This study used a qualitative approach to explore the perspectives of professionals working in the HIV field in North Carolina about the barriers and facilitators within the state's HIV prevention and care systems to test, link, retain, and reengage PLWH. Two researchers conducted in-depth interviews with 21 stakeholders from a variety of organizations in 2012. Written informed consent was obtained from all participants prior to in-person or telephone interviews, which lasted between 30 and 60 minutes. At the conclusion, each participant was offered a US\$25 gift card for his or her time. All study procedures were conducted with Institutional Review Board approvals from the

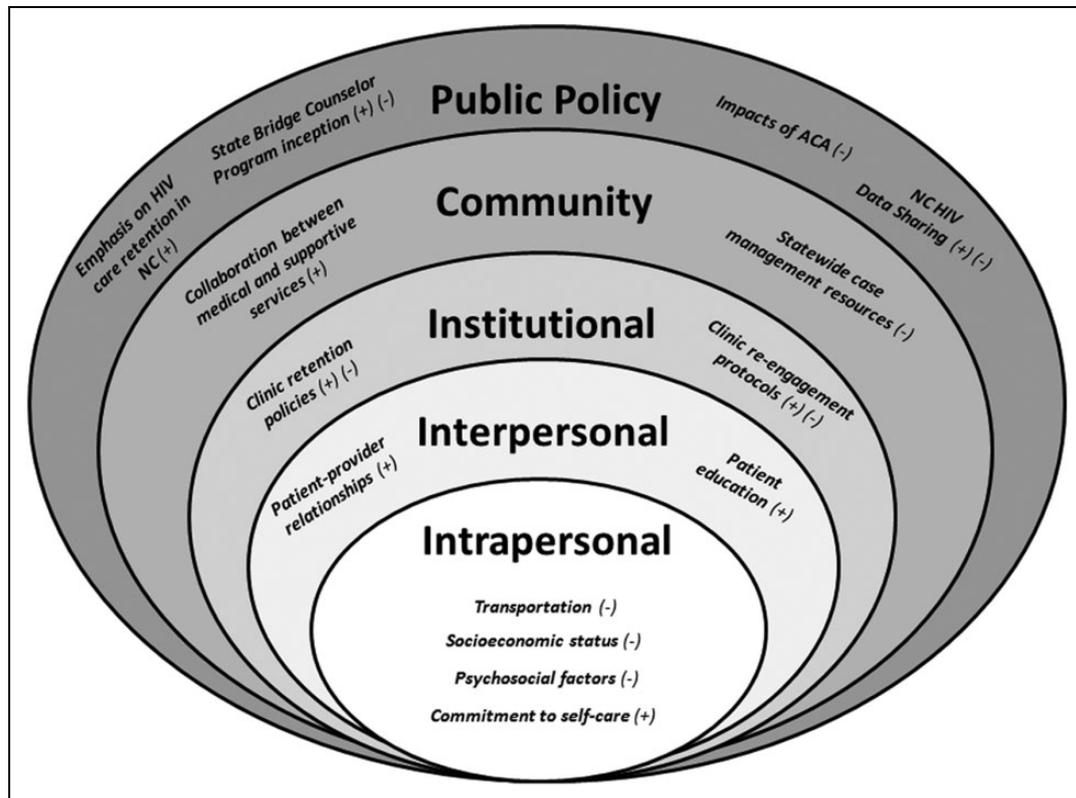


Figure 1. Summary of results, presented within the social–ecological framework, as described by participants. (+) indicates a facilitator to care engagement and (–) indicates a barrier to care engagement.

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Recruitment

Initial participant recruitment was conducted through purposive sampling of known professionals working within the HIV prevention and care systems in North Carolina to achieve participant variability in geographic location, employee position, and organizational type. Description of the recruitment of additional participants is described in Sullivan et al.⁴⁴ Inclusion criteria was being an adult professional working within the North Carolina HIV prevention or care system, being willing to discuss North Carolina’s HIV prevention and care systems, and speaking and reading English.

Data Analysis

Interview transcripts were double coded for emergent themes by 2 researchers using NVivo 10 software; discrepancies in coding were discussed until consensus was reached. Responses were compared within and across participants, with similarities and differences noted. Themes were then further examined and placed within the context of the social–ecological framework. Results from interview questions on the barriers to and facilitators of testing and linkage in North Carolina are described in Sullivan et al.⁴⁴ Analyses

included here focus on North Carolina’s barriers and facilitators to retention and reengagement in care on the individual, community, and policy levels.

Results

Participants

The 21-study participants represented a variety of organizations and positions throughout North Carolina. Most participants worked in clinical care settings, as HIV health care providers ($n = 8$, 38%), or in ancillary care and administrative support roles ($n = 5$, 24%). The remaining participants were employed by the NCDHHS ($n = 5$, 24%), and a few ($n = 3$, 14%) were employed at local AIDS service organizations or county health departments. Over half (57%) of the participants had worked in the North Carolina HIV prevention and care system for more than 10 years. A summary of the main themes as described by the respondents is included (Figure 1).

Retention in Care: Intrapersonal Factors

A majority of respondents described individual barriers that often impede full client engagement in HIV care. The most frequently mentioned obstacles included socioeconomic, transportation, and psychosocial issues.

Socioeconomic Barriers

Many respondents discussed client financial problems negatively affecting engagement in care. As one medical provider explained:

Many of them [our patients] are from low socioeconomic status and have other life issues that take priority over their health care, so you have women who have young children at home who need food in the cabinet.

Transportation

A lack of a reliable form of transportation was also cited numerous times as an obstacle for consistent HIV care, particularly for PLWH who live in rural regions of the state and must travel several hours to reach an HIV provider, often with limited transportation options. As one respondent described:

In metropolitan areas, [retention] percentages are better . . . In rural areas, you don't have providers in those areas and transportation poses a big problem and funding has been cut.

Psychosocial Factors

The vast majority of respondents who discussed client barriers described the adverse impacts of psychosocial factors on care engagement, particularly mental health and substance use issues, as was summarized by a medical provider:

People that are . . . found dealing with very active mental health issues can be very challenging to engage them into medical care . . . and I think our options for outpatient substance abuse treatment in the clinic setting are very limited.

Client Facilitators

Several respondents discussed the strength of clients who prioritized care engagement, which some attributed to client self-esteem and a commitment to self-care. As one respondent described:

Generally, the people that we see who . . . have confidence in us and they want to take care of themselves, and I think there may be . . . positive self-esteem. I think they want to really take care of themselves and realize they need to keep coming in and they'll do that.

Retention in Care: Interpersonal Level

Patient–Provider Relationships

Several respondents described the importance of PLWH forging strong relationships with staff members in the clinic. As a medical provider commented:

If they [patients] seem to have connected to staff in our clinic. . . . If we can get them on therapy and see that they're successfully taking meds, then we feel more positive about how we've engaged in them in care.

Patient Education

In addition, several respondents mentioned the need for providers to reinforce health education information to maximize client comprehension of HIV disease progression and the importance of consistent care engagement. As one respondent commented, providers should:

Educate the client on the importance of being in care other than just saying, 'You need to go to the doctor.' Having those tools to really be able to counsel the client and help them make that behavior change that's going to keep them in care.

Retention in Care: Institutional Level

Clinic Policies and Procedures

Standardizing client policies and procedures at the clinic level was cited by a few participants as a successful and critical component to help patients remain engaged in care. However, not all clinics and agencies possessed standardized policies for retention efforts. Variability in attempts to locate patients who miss medical appointments was described, depending on the structure and available resources at the clinic. As one respondent stated:

We don't have a really strong protocol for reengagement in any sense. Some regions, some providers, really go all out. Most can't do that, so they might make a call or 2, and then that's it—click—we're done. And we really haven't emphasized that that's just not good enough.

Retention in Care: Community Level

Coordinated and Collaborative Care

A majority of respondents who worked in medical or ancillary care settings discussed local collaboration with partnering agencies as a strength for retention efforts. A few respondents described the importance of co-located services (eg, medical providers working in the same location as case managers, financial counselors, psychiatrists, etc) to efficiently and comprehensively address complex client needs. In addition, the collaborative nature of relationships between medical personnel and case management teams was mentioned as important for client retention. However, the lack of resources to devote to case management was described as a limitation within the HIV care system. A few respondents mentioned that clinics were challenged to conduct case management activities with a paucity of staff. Thus, case managers were burdened to handle large client volumes and an array of complex client needs.

Retention in Care: Public Policy Level

Emphasis on HIV Care Retention in North Carolina

Several respondents stated that in recent years in North Carolina, there have been increased efforts dedicated to HIV care retention, as indicated by this respondent:

I think a lot of places are starting to . . . really focus on retention . . . and I think that's a huge factor in keeping them engaged. So, the fact that that's becoming a focus in more than just a few places is a good thing.

Some of these respondents attributed this emphasis to research, demonstrating the efficacy of early and continuous HIV therapy in preventing HIV transmission. A few respondents mentioned the HPTN 052 study,⁴ including 1 respondent who summarized the importance of the study for care retention:

It's not just about the individual's health. It's about the health of their partners as well. If they're out of care and off medication, your risk of transmission is so much higher. We have the science to prove that now.

A few respondents also expressed concerns regarding the impacts of the ACA on the health care system, specifically the potential for increased client loads for clinics, fragmentation of current health care networks, and inadequate insurance coverage to meet client needs.

State Bridge Counselors

Several respondents discussed the work of the State Bridge Counselors (SBCs), a new program within the NCDHHS that began in 2011. At that time, a few Disease Intervention Specialists (DIS) began to transition into positions as SBCs. The role of DIS was to link new HIV-infected patients to care, educate them about HIV disease control measures, and notify partners of potential HIV exposure. In contrast, the role of the new SBCs was to receive referrals from DIS and regional providers to locate and reengage patients deemed out of care.

Overall, the SBC program was described by several respondents as an innovative component of the North Carolina system to reengage HIV-infected patients. The experience of SBCs as former DIS allowed them to be resourceful at finding clients in the field when clinics lacked current client contact information and local reengagement efforts were unsuccessful. Several respondents stated that this was a strength in addition to the authority of SBCs to work with or on behalf of clients without special permission. A clinic staff member commented on this:

I . . . think it's a good thing that the bridge counselors, at least ours, are DIS, because they're trained to go find people and interview people. They're also empowered to do so, and they're empowered to call providers.

However, the large geographic territory and caseload for fieldwork was noted as a weakness of the program. Moreover, the transitioning of DIS to new positions as SBCs, and thus temporarily fulfilling 2 roles, was viewed as a limitation. A few participants felt that this challenged state personnel to simultaneously balance public health needs (preventing the spread of HIV to others) with client care needs (keeping clients in care). Consequently, a few respondents stated that the newly

transitioned SBCs needed clarification on what was required of them as SBCs in contrast to their previous work as DIS.

State HIV Data Sharing

In North Carolina, all Ryan White Part B-funded providers are required to use CAREWare—a free and scalable HIV software platform provided by HRSA—to enter their Part B client services and clinical data on the state's CAREWare server. Recently, the NCDHHS AIDS Care Program opened data sharing within the state's CAREWare server, allowing providers to determine whether clients receive services in other locations. A clinic staff member described the role of data sharing as helpful for client retention:

[Data-sharing] is a huge help because I can see if patients are getting case management in other areas besides mine. I think just that very even small piece of data sharing has helped immensely.

In addition, the NCDHHS expanded the use of a communicable disease surveillance database, North Carolina Electronic Disease Surveillance System (NC EDSS), to include HIV and syphilis case reports. This system was designed with the potential to monitor cases over time and includes a package for the DIS to make referrals to SBCs. Consequently, NC EDSS was mentioned as another potentially effective way to track HIV client retention in care. However, several participants stated that access to NC EDSS was restricted to state health department personnel; thus, a few respondents suggested the need for state-managed reports to offer clinical data to providers throughout the state, allowing clinics and agencies to more easily monitor client HIV care data. A medical provider elaborated on this:

I would love to see improved transfer of information amongst the different systems we have in the state It's sort of a one-directional flow at this time, other than receiving large aggregate quality data which is important, but doesn't address individual needs.

Discussion

This qualitative case study captures the landscape of the HIV prevention and care systems in North Carolina and the impact of state and local infrastructures on the retention and reengagement of HIV-infected persons in care. Study participants highlighted myriad factors that hinder or strengthen client engagement in consistent HIV care on individual, institutional, community, and public policy levels. Examining the strengths and barriers to retention and reengagement in HIV care as was discussed by participants through a social-ecological lens provides a needed framework to understand the complex issues that often influence care engagement.

This study contributes to the limited available literature on the application of the social-ecological model to HIV care engagement. One study by Olson et al⁴⁵ included a qualitative analysis of the underuse of Alabama's AIDS Drug Assistance

Program (ADAP) within a social–ecological model. Focus groups conducted with ADAP clients described barriers to full participation in the program and were then characterized into levels within the social–ecological model. This North Carolina study echoes the findings of Olson et al⁴⁵ that barriers and facilitators on the intrapersonal and interpersonal levels (eg, substance abuse, health literacy, and relationships with providers), clinic level (eg, presence of social workers and other providers in the clinic) as well as the policy level (eg, ADAP prescription dispensing and recertification processes), all have implications for care engagement. In addition, the findings from this study support Mugavero et al¹⁵ in their identification of promising approaches to improve retention in HIV care, namely, strong case management services and coordinated health service, as well as a need for increased integration of surveillance data into routine HIV care.

This case study also demonstrated how barriers at the intrapersonal level may impede client engagement in care, as identified in prior research.^{20,46–48} In this study, challenges discussed were namely socioeconomic, transportation, and psychosocial in nature, which are often difficult to address and which were also mentioned by the respondents as barriers to HIV testing and linkage, as described by Sullivan et al.⁴⁴ Nonetheless, they are important to consider, as they are impacted by policies such as health insurance premiums, mass transit planning, and funding of substance abuse and mental health treatment programs.

In addition, the presence of strong interpersonal relationships between patients and providers was mentioned by respondents as important for involvement in care, a point that has been documented in the literature.^{17,19,49,50} Flickinger et al⁵¹ found that PLWH were more likely to attend their appointments when they felt that their providers treated them with respect and explained information in an understandable way. Thus, assessing the quality of provider communication with their patients and providing skills-based training, as needed, may enhance client engagement.

Respondents also identified the new SBC program as promising to improve HIV care retention outcomes, particularly to employ dedicated personnel to actively search for out-of-care patients and assist clients to overcome barriers to care engagement. This echoes findings from the literature that the provisions of strengths-based counseling and patient navigation services, as well as the removal of individual and systems-level barriers, can yield improved client retention rates.⁵² However, some participants also noted that future efforts should continue to identify how the work of the DIS and SBCs can best complement one another. A key component of the NC-LINK project—a collaboration between the NCDHHS, Duke University, and University of North Carolina at Chapel Hill—is to standardize the distinct personnel roles of the SBCs and DIS and evaluate the effects of the SBC program on locating and reengaging lost-to-care clients.

Statewide HIV data-sharing policies and systems were also identified as a strength and an area in need of additional focus. Several participants noted the impetus for data systems that

allowed public health officials and care providers to obtain more complete pictures of patient retention in care. Recent initiatives in NC to share client data were mentioned as significant improvements; however, some participants suggested that allowing nonstate personnel to access surveillance data would further improve retention and reengagement efforts. The importance of using such surveillance data to monitor care has been documented in the literature.^{53,54} An evaluation of the information exchange system in Louisiana that integrated HIV surveillance data within HIV care clinics for out-of-care clients demonstrated improved client retention and reengagement in care.⁵⁵ In addition, the CDC recently created a national initiative, “Data to Care,” to standardize the use of state surveillance data to identify and engage PLWH who are otherwise not virally suppressed, which NC and other states are adopting to improve HIV care engagement.⁵⁶

This study also possesses some limitations to consider. Some of the respondents were involved with the planning and implementation of the NC-LINK project, of which this case study was a component. This may have biased their responses; however, due to their key roles in the delivery of HIV care in North Carolina, their contribution and perspectives were deemed important to include. In addition, only a small number of participants ($n = 3$) were interviewed from county health departments or AIDS service organizations. The sample size of 21, however, was within an appropriate range for qualitative research,⁵⁷ and a saturation effect was observed among participant responses.

Overall, this study provides important contributions to the literature about patient engagement in HIV care. First, many studies have examined the importance of clients remaining retained in care, but further research is needed within a Southern context to examine care engagement within ever-evolving HIV care landscapes. In addition, understanding system responses to the unique situations of patients who are inconsistently retained in care or who are lost to care is critical to realize the updated NHAS target of 90% of PLWH remaining engaged in HIV medical care by 2020.¹¹ Finally, these findings may offer insight into all states, especially those within the Southern United States, regarding the successes and challenges seen in North Carolina to engage and reengage HIV clients in care. This may ultimately assist other states with similar challenges to identify needed programs and priorities to optimize client engagement in care.

Authors' Note

This information, content, and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, the US Government, or the NCDHHS.

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