

“Getting Me Back on Track”: The Role of Outreach Interventions in Engaging and Retaining People Living with HIV/AIDS in Medical Care

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ABSTRACT

This qualitative study investigated the process of engagement in HIV medical care from the perspective of people living with HIV/AIDS (PLWHA). In-depth interviews were conducted with 76 participants in six cities. All participants were considered underserved because of histories of substance use, mental illness, incarceration, homelessness, or cultural barriers to the traditional health care system. A semistructured interview guide elicited narratives related to health care and the role of program interventions in facilitating access to care. Data analysis revealed that participants cycled in and out of care, a process that was influenced by (1) their level of acceptance of being diagnosed with HIV, (2) their ability to cope with substance use, mental illness, and stigma, (3) their health care provider relationships, (4) the presence of external support systems, and (5) their ability to overcome practical barriers to care. Outreach interventions played a role in connecting participants to care by dispelling myths and improving knowledge about HIV, facilitating access to HIV care and treatment, providing support, and reducing the barriers to care. The findings suggest that outreach programs can interrupt this cyclical process and foster sustained, regular HIV care for underserved PLWHA by conducting client-centered risk assessments to identify and reduce sources of instability and improve the quality of provider relationships; implementing strategies that promote healthy practices; creating a network of support services in the community; and supporting adherence through frequent follow-ups for medication and appointment keeping.

INTRODUCTION

RETENTION IN HIV medical care improves adherence to antiretroviral therapy, slows

progression to AIDS, and increases survival.¹⁻³ Federal clinical guidelines recommend that all people living with HIV/AIDS (PLWHA) see an HIV health care provider to monitor their clin-

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ical status at least once every 3–6 months, and more frequently depending on medication regimen and disease progression.⁴ However, many PLWHA do not receive this level of care and thus cannot benefit from current advances in treatment. This qualitative study explores the underlying attitudes, beliefs, and practices that affect the regular use of HIV care among PLWHA considered to be hard to reach and underserved by the health care system and identifies strategies that encourage engagement and retention in care.

Quantitative studies have identified factors associated with poor utilization of HIV medical care and treatment including competing needs, substance use, youth, higher CD4 counts, incarceration, mental illness, lack of trust, negative provider attitudes, and previous experience with illness.^{5–14} Most quantitative studies examine care status from a health care utilization viewpoint and thus do not adequately capture the nuances of health care seeking behavior for PLWHA. Few studies have comprehensively examined barriers and facilitators to HIV medical care from the perspective of PLWHA.¹⁵ A few qualitative studies have examined factors associated with retention in care from the perspective of economically and socially vulnerable PLWHA. McCoy¹⁶ examined patient/physician relationships and found that interaction styles that reduce social distance with patients, provide information that improves patient comprehension, and acknowledge challenging life circumstances enhanced patients' use of HIV medical care. Mallinson et al.¹⁷ found that stigma, obstacles (substance use, transportation, food, and other competing priorities), health literacy, and the ability to connect with health care providers affected HIV care retention among sporadic users of medical care in an urban clinic. Weiss et al.¹⁸ found that substance users' perceived positive and negative experiences with health care providers were determinants of consistent utilization of health care. Although these studies yielded important insights they were limited to small samples or settings, or only explored a specific dimension of engagement in HIV care such as provider relationships.

There is little published literature about effective approaches for addressing these barriers and facilitators, and engaging PLWHA in HIV med-

ical care "in their own words." The current literature suggests that ancillary services such as case management, transportation, housing and drug treatment are associated with access to and retention in HIV medical care,^{19–21} but the measures used in these studies do not explain the role of these services in the complex lives of PLWHA. The primary aim of this qualitative study was to investigate participants' experiences with HIV medical care from a first-person perspective in order to understand how outreach interventions influence engagement and retention in care. The findings describe a cyclical model of engagement in HIV care, and suggest strategies that service providers can implement to promote retention in HIV care.

MATERIALS AND METHODS

Interview data were collected between June 2004 and June 2005 from seven sites that participated in the Health Resources and Services Administration (HRSA)-funded Outreach Initiative.²² The sites were located in six cities in the northwest, midwest, mid-Atlantic, and northeast regions of the United States. Purposive sampling techniques were used to recruit 76 HIV-positive participants to achieve variation in gender, race/ethnicity, age, sexual orientation, income, and length of time involved with the program. Sites oversampled for participants who were considered at high risk for dropping out of medical care or with limited access to the traditional health care system. Each site recruited between 8–16 participants.

A multisite research team consisting of staff with expertise in HIV/AIDS and qualitative research from each site and the multisite coordinating center was responsible for the study design, data collection, and analysis. A standard, semi-structured interview guide was developed that explored participants' experience testing HIV positive and seeking initial HIV treatment; past experience with HIV medical care; current HIV medical care and barriers/facilitators to retention in care; future plans for living with HIV and medical care; and the role of outreach interventions in their HIV care. Interviews were conducted in English or Spanish, audiotaped, and varied in length from

45–75 minutes. All participating sites received approval from local Institutional Review Boards for the study.

Analytic methods

Participant interviews were transcribed verbatim and assigned a pseudonym. Data were managed and analyzed using QSR Nvivo® software version 2.0 (QSR International Pty Ltd., Victoria, Australia). A grounded theory approach was used for data collection and analysis.^{23, 24} Analysis began by coding words and passages, and then collapsing codes into conceptual categories. Coding schemes were developed to identify the history of care-seeking behavior and experience with the health care system, barriers and facilitators to care, and the role of outreach interventions in facilitating engagement and retention in care. A pair of researchers including one from each study site and one from the multisite-coordinating center independently coded each narrative and reviewed and validated the emerging coding schemes through a process of discussion and consensus building. Individual summary profiles were developed to characterize each participant's level of engagement. Once the coding was validated, emerging patterns in the data were identified and relationships between conceptual categories and participant profiles were underscored. This led to a model illustrating the process of client engagement and retention in HIV medical care. To increase the trustworthiness of the findings, each narrative was reappraised by the multisite research team to assure its compatibility with the overarching model.

RESULTS

Sample

Table 1 describes the demographic characteristics of the sample. Slightly more than half the participants were male ($n = 39$) and primarily African American or Latino ($n = 53$). Thirty participants identified as being gay, lesbian, or bisexual. Fifty-three participants were living with HIV for more than 5 years. Age ranged from 18 to 55 years (mean, 39 years). Fifty participants reported being unemployed. Most participants had a history of substance use, incarceration, mental illness, or homelessness.

Model of engagement in care

Despite a high level of substance use, mental illness, incarceration and homelessness, almost all of the participants in this study reported seeing a health care provider for HIV medical care since testing positive. However, more than half the participants described periods of being out of HIV care ($n = 58$), and there was a broad spectrum in their level of engagement in care. Four categories of engagement emerged from the participant profiles: (1) people who had been in care since the time of their HIV diagnosis despite multiple risk factors and external challenges ($n = 18$); (2) people who described significant periods with no HIV medical care but were currently engaged and stable in care ($n = 23$); (3) people who were tenuously connected to care, reporting a HIV medical visit in the past six months, but described risk factors and a history of inconsistent HIV care ($n = 31$); and (4) people who had no HIV medical visits in the past year ($n = 4$).

The process of engagement in care was originally hypothesized as a linear process, whereby participants who were unstable in care would engage and stay in care once cer-

TABLE 1. DEMOGRAPHIC PROFILE OF PARTICIPANTS (N = 76)

	n (%) ^a
Gender	
Male	39 (51)
Female	35 (46)
Transgender	2 (3)
Race/ethnicity	
African American	39 (51)
Hispanic	14 (19)
Mixed race	10 (13)
White/Caucasian	9 (12)
Native American	3 (4)
Asian	1 (1)
Sexual orientation	
Heterosexual	44 (58)
Homosexual (gay/lesbian)	20 (26)
Bisexual	10 (13)
Undecided/not identified	2 (3)
Mean age	38.9 years
Employment status	
Unemployed	50 (66)
Unemployment due to disability	19 (25)
Housing	
Temporary/transitional housing or homeless	22 (29)
Mental illness	32 (42)
Current or past substance use	61 (80)

^aPercentages may not add to 100%.

tain barriers were overcome. However, most participant profiles revealed a cyclical pattern of engagement: connecting to care for a period of time and then falling out of care and sometimes reentering care again (Fig. 1). Five main themes emerged as affecting the engagement process: (1) level of acceptance of HIV; (2) coping with substance use, mental health, and stigma; (3) health care provider relationships; (4) presence of external support; and (5) ability to address external barriers to care.

Comparative analysis of these themes across the four categories of engagement revealed those participants who were always in care since being diagnosed with HIV and those who became engaged after periods of no care approached these themes differently from the other two groups: those who were tenuously connected to care or those who were not in care. In following section, the first two groups are referred to as the in-care group ($n = 41$) and the second two groups as being unstable-in-care ($n = 35$). Table 2 summarizes these themes and the differences reported by the in-care and unstable in-care groups. Additional analyses of these themes

found they were not related to gender, race/ethnicity, or time living with HIV, but rather with a participant's level of engagement in care.

In the following section these themes are described using direct quotes from participant interviews to elucidate the differences between the in-care and unstable in-care groups that lead to the cycling in and out of care. The role of outreach interventions in helping participants to address these themes and become connected and stay in HIV care is described. The cyclical model of engagement suggests pivotal points in the engagement cycle where programs can implement interventions to connect with unstable-in-care participants and keep in-care participants retained in HIV medical care.

Themes related to the process of engagement

Level of acceptance of HIV. Participants' ability to accept their HIV diagnosis affected their engagement in HIV care. Unstable-in-care participants denied their diagnosis, "I didn't go to the [clinic] for about 4 years. . . . because I didn't want to be reminded about

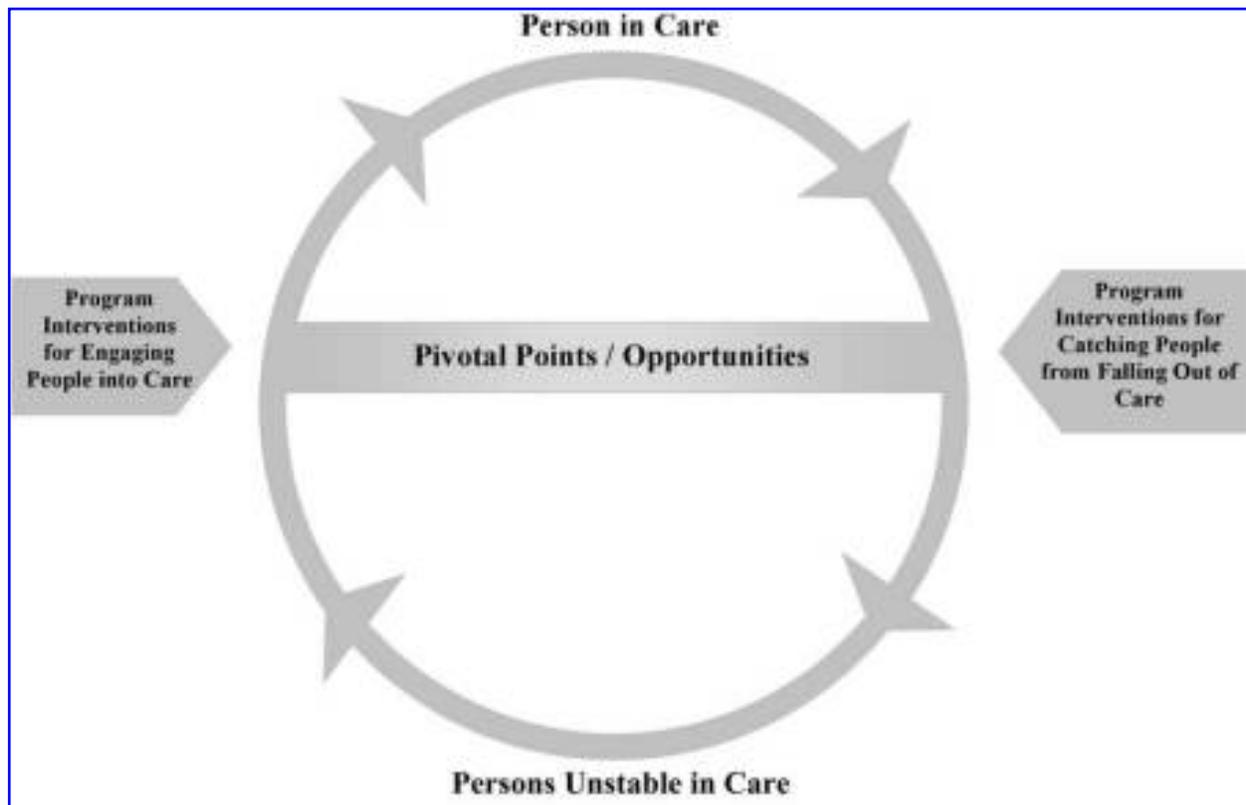


FIG. 1. Program interventions and engagement in care.

TABLE 2. CATEGORIES DESCRIBING THE IN CARE AND UNSTABLE IN CARE

	<i>In care</i>	<i>Out of care</i>
Level of acceptance	Participants have an acceptance about HIV and self-awareness and reliance to living with HIV currently and in the future	Participants expressed a state of dissasociation or denial; due to ignorance, a belief they are too healthy; or other priorities
Ability to cope with stigma, substance use, and mental health	Able to address these issues, and often the key to becoming engaged in care	Participants have barriers to entering care related to disclosure of their HIV status or treatment, current drug use, or mental health issues
Health care provider relationships	Participants have strong healthy positive relationship with provider; knows what he/she wants from the provider	Participants have a history of or currently experience poor provider relationships; no consistency
Presence of external support	Able to form in the past and currently has positive healthy relationships with family, friends, partners, or external groups. Participants have a strong sense of faith or beliefs either through religion or personal spirituality.	Ambiguous—not mentioned by participants as playing a role in their HIV experience.
Addressing system barrier	Participants have personal assets or, through relationships, able to address other needs; innate sense of resourcefulness; have strong connections to program interventions and providers to get needs met.	Participants have other obstacles preventing them from seeking HIV care such as housing, transportation, or ability to pay for care

my HIV," or stated that HIV was a low priority in their lives. They delayed care for many reasons: they did not feel sick, they did not want to be reminded of their disease, they did not want to feel sorry for themselves, or they had other priorities in life such as employment or housing.

... I don't even know my T-cell count ... I just feel fine ... It don't bother [me], if it was up or it was low, I wouldn't know what it means cause I think it hasn't hit me that I'm positive ...

In contrast, the in-care participants expressed a desire to be proactive in managing their illness. They were optimistic about treatment and reported a desire to be updated and informed about new treatments.

Ability to cope with substance use, mental health, and stigma. Many participants from both the in-care and unstable-in-care groups described struggles with substance use, mental health, stigma and discrimination. However, their dif-

ferences in managing these personal challenges affected their ability to access HIV care and services. Participants who were unstable-in-care often stated that substance use or depression kept them from seeking care, "I wasn't always going to the doctors as I should because my depression sat in. I stopped taking meds. So I start self-medicating, again, dipping and dabbing with drugs."

Other participants struggled with depression and anxiety related to living with HIV. One young man who did not have a medical visit in 6 months and refused medications attributed his interruption in care to "getting tired emotionally and physically" from managing the disease.

Stigma and discrimination related to HIV, substance use and homelessness also affected engagement in HIV medical care for unstable-in-care participants.

When I went to the hospital, I told them I was HIV ... he (the doctor) said, 'So you are HIV and you use Crystal (meth).' 'Yes.' And he looked down on me. And so he caused me a complex ... he didn't want to touch me. ...

In contrast, in-care participants were better able to cope with their substance use or mental health needs and focus on obtaining HIV medical care. For some, sobriety was a first step while for others controlling or managing drug use or mental illness was critical. One participant who struggled with homelessness and mental illness describes her decision to seek care:

In the beginning I didn't get help, I was confused, I wasn't caring about to live or die but then I seen the way my kids were suffering. I started getting counseling and stuff at the mental hospital. I started going to groups and counseling, so that helped me know that no matter that you're HIV+ you can get some counseling, get some treatment, have another chance at life. There was support for my kids and the people there were really good. I realized a lot of stuff.

In-care participants also had effective coping strategies for managing stigma. They expressed little concern for others' perceptions and developed a self-reliant attitude, "I have to live my life and I can't live my life around how does somebody else feel about me being positive."

Health care provider relationships. Participants' relationships with their HIV health care provider were critical in the process of engagement and retention. Across the narratives, unstable-in-care participants described negative experiences with health care providers. They felt their providers were controlling their health decisions without considering their other life issues or respecting their desires. In response, participants were less likely to seek medical care.

In contrast, many in-care participants described positive relationships with their HIV health care providers. These relationships were valued and sustained the participant's ability to engage and continue with medical care. Participants characterized positive relationships by feelings of being in control and perceiving that one's provider was accepting and responsive to the participant's particular life circumstances.

Presence of external support. In-care participants acknowledged the importance of external support from friends, partners, or family in living with HIV. They described how these allies provided ongoing motivation to take care of their health or address challenges such as

substance use. Spirituality was another source of support for in-care participants and helped many individuals develop feelings of self-worth, gain acceptance of their disease, and a reason to stay in care.

HIV is one thing, but it's not the end. It's just the beginning of a new life because you know you got to really take care of yourself. It's a wake up call . . . He [God] has put me into the hands of so many caring wonderful people at [the outreach program] . . .

In contrast, unstable-in-care participants made no explicit mention of external support or spirituality.

Addressing external barriers to care. All participants faced external barriers to care such as a lack of insurance, unstable housing or homelessness, or lack of employment. Unstable-in-care participants reported being overwhelmed by these needs. More than half of the unstable-in-care participants described how experiences of homelessness or unstable housing directly led to a gap in care. "I was just moving around and didn't have and still don't have care; But you know I don't really see the point in getting health care, if you don't have a place to live."

Several participants relayed how the fragmented service system contributed to gaps in care. One homeless participant described trying to get reconnected to HIV care after her belongings were stolen on the street:

. . . we waited nearly two months to get back on the medication . . . because we had to make this appointment in advance, like six weeks in advance to see the case worker . . . and then we still had to wait, there was a backlog a couple of weeks, and then you get your intake and then you have to wait a week to see a doctor who finally prescribes you your medication.

However, in-care participants were more likely to describe an ability to overcome these barriers by seeking outside support services, through a personal relationship, or their own self-reliance.

Interventions that facilitate the process of engagement

Participants were asked directly about the role that outreach programs played in helping

them with HIV care and described how the programs helped them become connected to care or stay in care. The analysis revealed five main interventions that contributed to engagement and retention in care: (1) dispelling myths and improving knowledge; (2) helping people physically obtain HIV care; (3) building participants' skills and ability to manage their HIV; (4) providing services to reduce barriers to HIV care; and (5) providing support networks (Table 3). Successful relationship-building and the development of trust between program staff and participants were the foundation for all of these interventions.

Dispelling myths and improving knowledge. Several participants credited the interventions with helping to erode denial and increasing their knowledge about HIV. They said that prior to joining the outreach program they were ignorant and believed they "were going to die" or worried that they would "give HIV to others." The programs helped participants obtain information on treatments, learn about transmission and disease progression, and gain a better understanding about living with HIV. Interventions directly addressed the beliefs and stigma and gave participants the reassurance that they could live with HIV:

I went to one of the groups at [the outreach program] and I thought I was going to see a lot of sick people and older people that had it and there was a lot of younger people, people full of life that had [HIV] . . . I had the wrong impression from what negative people had said filling my head and the stigma. And it wasn't like that and that is what changed my whole perspective on it [HIV] . . .

Helping to obtain HIV care. Outreach programs used multiple strategies to help participants obtain HIV medical care including appointment reminders, assistance with medications, finding doctors or clinics, obtaining health insurance, and accompaniment to med-

ical appointments. Most importantly, program staff facilitated communication between participants and their doctors. As one participant described, "She goes with me to my doctors visits and explains things to me I don't know . . . She gets the information for me . . ."

Receiving phone calls or other simple reminders of a pending appointment made a difference to participants. As one woman reported, "I will get the call and that makes a lot of difference. The difference is you have somebody that cares as opposed to someone who is just getting paid." The outreach programs also supported HIV medication adherence by offering reminders and helping participants incorporate HIV treatment into their daily routine. One homeless participant described how the program staff sought him out to encourage HIV medication adherence:

They keep me straight on making sure I got my meds with me . . . [outreach worker] is always asking me how I'm doing. Am I on my meds and stuff like that . . . Being reminded definitely . . . we don't talk everyday, but when I'm here he's more or less asking "Do you have, do you need a refill, what's going on with your meds, have you been taking them?"

Building skills and ability to deal with HIV. Over time, program staff taught many participants new skills to manage their disease, including coping with stress, addressing competing needs, disclosing to partners and families, and managing perceived stigma. Some participants learned to be self-advocates and how to take better care of themselves.

One participant who struggled with depression described how the program helped her to organize her life and reconnect with care.

[The doctor] would be telling me [what I needed to do]. I just wouldn't listen to her. There was a lot of other stuff I had to worry about. I took a break so long that I got sick. The [outreach program] helped me a lot. Got me back on track-medications, places I had to be . . .

As they gained new skills several participants described their intentions to share their knowledge with others. The outreach programs encouraged participants to become leaders.

[I gained] information about HIV; problems with learning how to deal it; how not to stress over it . . .

TABLE 3. STRATEGIES TO FACILITATE ENGAGEMENT TO HIV CARE

Dispelling myths and improving knowledge
Helping with HIV care
Building skills and ability to deal with HIV
Providing services to reduce barriers
Providing support networks

I feel like I can share my experience. When I was pregnant with my daughter, I went out to mentor teenagers . . . I wanted to help them and [the outreach program] has helped me and given me more encouragement to go help somebody else.

Providing services to reduce other barriers to HIV care. Interventions provided services such as transportation, food, clothing, identification cards for benefits, and housing to reduce the needs that compete with health care for attention. Programs helped participants better utilize the service system by matching participant needs with available resources. One participant with a history of abuse and mental illness described the help he received on a consistent basis:

He [outreach worker] comes over to [AIDS organization] every Tuesday. So we sat down and talked and stuff. And he just asked me, "What do you need help with?" "One—to have a doctor, Two—I want to see a therapist and somebody to help me with housing." And, from there, I see him every Tuesday. He's trying to help me work on getting a social worker, a therapist, and stuff like that.

Providing support networks. The interventions played an important role in providing external support for many participants, filling the gaps where partners, families, or friends failed or were nonexistent.

Patient advocates, social workers, [everyone in this program] it's good to have. Because I go through a lot of situations, like I said, I got fired . . . And it's good to have someone you can call to help you. They're patient. They will actually sit down and talk to you. They will not blow you off. I think if it weren't for [the outreach program] I'll probably still be out here in the streets, doing the same thing, if it weren't for this organization . . .

The programs also connected participants with HIV positive peers who could link them to a community or serve as role models through support groups or by employing peers as staff. Peers provided participants with resources and made them aware that there were others trying to solve similar problems while living with HIV. One Spanish-speaking participant described his experience with a peer staff member:

He [outreach worker] gave me lots of information about HIV. He told me not to think I was going to die because I was infected, that was something that maybe used to happen but there are lots of medi-

cines now, lots of treatment now and while it may not have a cure, you can still live a normal life . . . he [outreach worker] told me his story. And that helped me a lot because he told me he had many years with [HIV], and he looks good.

DISCUSSION

A key finding of this study is that participants' descriptions of their engagement and retention in HIV care do not match neatly with health care utilization measures used in quantitative studies. Many participants in this study described a tenuous connection to health care despite having seen an HIV health care provider in the recent past. This study develops a new classification for understanding how participants engage in care and suggests strategies that can enhance their connection to care and subsequent long-term, optimal health maintenance. Consistent with the literature, the model of engagement in care presented in this paper highlights the important roles of stigma, personal relationships and support, and experiences with HIV care providers.^{16–18,26,27} However, this model expands the understanding of engagement in HIV care by demonstrating that transition into care is a cyclical, rather than linear, process for underserved PLWHA. Depending on their acceptance of HIV, life circumstances, external support systems, and the quality of provider relationships, many PLWHA cycle in and out of the health care system. In this sample of hard to reach individuals, "fall-out-factors" existed independently of differences in gender, race, and culture.

The model also identifies several approaches to address the factors that inhibit engagement and retention in HIV care. While other studies have found that ancillary and support services help connect people to care,^{19–21,28–30} when PLWHA were asked directly about services that helped them receive care they also mentioned the role of outreach program staff in improving their knowledge about HIV care and treatment, building skills to incorporate HIV into their daily routine, and providing support networks. These services helped to interrupt the cyclical process of engagement and led to sustained care.

The findings also suggest that in addition to connecting people to care, services must also pre-

vent tenuously connected PLWHA from falling out of care. One potential strategy is to conduct periodic client risk assessments to identify sources of instability in peoples' lives, including homelessness, unemployment, history of substance use, and mental health needs. The assessments can also examine personal support networks and the perceived quality of provider relationships to obtain insight into client needs and identify risk factors for falling out of care.

Second, service providers can help clients establish a network of support services in the community. Participants in this study struggled with caretaker responsibilities, finding or balancing work, reintegrating into society after incarceration, coping with mental illness and substance use, and challenging family relationships. These competing needs often prevented clients from seeking regular HIV care. While a single program may not have sufficient resources to address all these challenges, linking clients with other community resources and with peers can help address potential challenges and prevent clients from postponing health care.

Third, programs may adopt strategies, such as motivational interviewing and education for promoting healthy practices that maintain health rather than just treating disease.³¹ These techniques can be used to identify points of resistance, such as beliefs about treatment, perceived stigma, or poor provider relationships that prevent optimal engagement in HIV care.

Finally, having program staff available to help manage periods of instability was key to preventing people from falling out of care. Reminder calls and periodic check-ins can help clients focus on improving their adherence to medications and appointments. "Knowing that someone cares" was a motivator for staying connected to HIV care.

CONCLUSION

This study examined the process of engaging hard to reach PLWHA in HIV care and program interventions that facilitate this process. Most intervention studies examine services over a brief period of time, usually 6 months. The findings in this study suggest that sustaining care may require longer term investments of human and financial resources. Hav-

ing interventions designed to address the "fall-out factors" is critical. A shift in program practices towards client-centered interventions may promote better health. Simply addressing short-term treatment problems (such as medication issues or symptoms of disease) does not recognize the larger context of clients' lives, nor does it build a mutually beneficial client-provider relationship. Outreach interventions can help clients understand that HIV is a long-term partnership between them and the health care system, which can lead to longer, healthier lives and improved quality of life for underserved PLWHA.

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