



What's Going on @ SPNS



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❖ The Power of Peers on Engagement and Retention in Care among People of Color

Underserved and marginalized populations, including many racial/ethnic minority communities, face numerous structural, financial, and cultural barriers to care.¹ Such barriers have contributed to disproportionately high rates of HIV-related morbidity and mortality in these traditionally hard-to-reach populations because, as studies show, engagement in care leads to improved health outcomes² and retention in care is an independent predictor of survival.^{3,4} For example, one study showed that mortality rates were significantly lower among patients seen 3 or 4 times per year versus once or twice annually.^{5,6} And in another study, attending all medical appointments during the first year of HIV care doubled survival rates for people living with HIV/AIDS (PLWHA) for years afterwards, regardless of baseline CD4 cell count or use of antiretroviral therapy (ART).⁷

A majority of HIV-infected individuals, however, consistently fail to engage in regular HIV care. Research by Dr. Edward Gardner and colleagues illustrates the severity of that lack of engagement. They estimate that of the more than 1 million people living with HIV/AIDS in the United States:⁸

- 1 in 5 do not know their HIV status
- 2 in 5 have not seen an HIV primary care doctor
- 3 in 5 don't regularly see their doctor, and
- 4 in 5 are not viral load suppressed.

Lack of proper engagement in HIV care is particularly acute in many racial/ethnic minority communities. In general, people of color continue to experience worse access to health care and worse health outcomes than their White counterparts, and those disparities result in billions of dollars in additional medical care costs.⁹

The Impact of Peer Integration

In the quest to overcome those disparities, some providers are turning to peers to help with engagement and retention efforts. Integrating peers into the health care team is supported by research demonstrating that peers can motivate attitudinal and behavioral change in PLWHA.¹⁰ Using peers also can prove effective because the process relies on existing social networks, and hard-to-reach populations may be more likely to trust peers. What's more, the peer education process can empower not only clients but also the peers themselves.¹¹

As a result, the Health Resources and Services Administration (HRSA), HIV/AIDS Bureau's (HAB's) Special Projects of National Significance (SPNS) program has funded several initiatives over the past decade designed to test implementation of peer integration. For example, a SPNS intervention launched in 2005 trained more than 850 HIV-positive individuals from 21 states to serve as peers supporting HIV care and treatment.¹² Several best practices emerged and many of the participating providers were successful in establishing ongoing peer programs and integrating peers into the care team.¹² A full report on that initiative is available at <http://peer.hdwg.org/lessons/>. An earlier SPNS initiative also involved recruiting and training peers—in the form of specially trained health “coaches” who came from the communities they served. Follow-up data on clients showed reductions in structural, financial, and personal barriers to HIV care, as well as increased utilization of case management services.¹³

More recently, SPNS is administering a project funded through the Minority AIDS Initiative (MAI) to enhance access to and quality of HIV clinical care and support services for people of color living with HIV/AIDS, especially those who also require support with housing, mental health, or substance abuse problems. This 2-year MAI Retention and Re-Engagement in HIV Care Project was launched on September 30, 2011, and its efforts to reduce health disparities and inequities among minority populations are designed to support one of the primary goals of the National HIV/AIDS Strategy (NHAS).¹⁴

What Is the MAI Retention and Re-Engagement in HIV Care Project?

This new SPNS initiative focuses on facilitating re-entry into care and preventing vulnerable clients from dropping out of care through the use of peer interventions. It is different from other SPNS initiatives in several key ways.

First, the Health and Disability Working Group (HDWG) at Boston University School of Public Health, which is serving as the Coordinating Technical Assistance Center (CTAC) for this project, was able to select the demonstration sites. The CTAC worked collaboratively with the three sites to design, implement, evaluate, and disseminate findings on innovative and potentially replicable integrated care models. The site selection parameters specified that the sites had to be Ryan White HIV/AIDS Program grantees providing a continuum of HIV primary care, as well as mental health services, outpatient substance abuse treatment, and housing services (via a central location or through a network of service providers). The parameters also specified that the CTAC should focus on three underserved communities in which the proportion of racial/ethnic minorities living with HIV disease is increasing: Miami, Florida; San Juan, Puerto Rico; and New York City.

Second, the same peer-based intervention was implemented across the three sites, resulting in a Randomized Controlled Trial (RCT). Thus, half of the enrollees have received or are receiving the service intervention, which includes peer services, while the other half has received or is receiving the standard level of care.

Baseline data collection began in March 2012 and concluded after one year. During that time, 349 patients were enrolled across these three sites:

- PR CoNCRA in San Juan, Puerto Rico;
- Care Resource in Miami, Florida; and
- The PATH Center, part of The Brooklyn Hospital Center, in New York City.

Baseline findings revealed that among enrolled patients:

- 42 percent report that they have been homeless in the past;

- 43 percent report that they have been incarcerated in the past;
- 77 percent are not currently working;
- 35 percent saw a mental health counselor in the past six months;
- 18 percent reported currently taking medications for depression; and
- 35 percent report that they tried to cut down on substance abuse within the past 6 months.

“We have really hit on the core group of people that need to be targeted with this sort of intervention,” says Jane Fox, principal investigator for the CTAC.

The overall intent of the project is to determine if the addition of a peer intervention to the standard of care makes a difference in engaging and retaining the target population in HIV primary care and support services. Changes in patient outcomes related to clinical markers—such as CD4 cell count and viral load, number of completed HIV primary care visits, and quality of care—will be measured. In addition, intervention measures will include changes in the participants’ HIV knowledge, self-efficacy, quality of life, stigma, and dose response. Finally, process measures will include methods of identification of target populations, organizational and structural characteristics of successful incorporation of the intervention, and the level of effort to engage or re-engage participants in care.

Hiring and Training the Peers

The first step in implementing the initiative was for each demonstration site (with support from the CTAC) to hire and train two full-time peers. Peers were selected who were adherent to their medication regimens, were fully engaged in their HIV primary care, and had been able to maintain viral load suppression. Potential recruits also had to have a desire both to help others and to be employed on a full-time basis.

To assess peer readiness, the demonstration sites considered the following issues:

- Is this individual ready to become fully employed?
- Is this job likely to bring negative consequences to the individual, such as straying from treatment regimens, relapse for those with a history of substance abuse, or mental health problems?
- Does this individual feel comfortable disclosing his or her HIV status?

- Does this individual demonstrate empathy and compassion?
- Does this individual seem motivated to serve as a role model to others living with HIV?
- Will this individual's benefits package be affected because of full-time employment?

The CTAC provided five days of onsite peer competency training. Extra attention was paid to the challenge of integrating peers into the health care team, specifically defining what their roles are in relation to case management. A full training curriculum—that includes all notes, handouts, and PowerPoint slides—will be available on the HDWG Web site at www.hdwg.org by the end of October 2013. Materials that provide support for peer supervision also will be available on the site.

The Intervention Model

The demonstration sites targeted two groups of patients for the intervention: 1) patients who were new to care, and 2) patients who had fallen out of medical care for 4 or more months. The sites identified newly diagnosed patients through local public health department referrals, as well as through internal testing promotions.

The sites generated initial lists of out-of-care patients from their internal electronic medical records (EMRs), as well as their support services database. However, those lists tended to contain many inaccuracies because of the transient nature of the targeted population. “There was a considerable amount of outdated contact information,” says Fox. “Also, many patients had not actually fallen out of care,” she adds. “In some cases, the patients didn’t need to be seen every 4 months. And in other situations, they already had an upcoming appointment scheduled, or their most recent appointments just never made it into the system.”

Reviewing these lists was a cumbersome process. “Case managers and clinicians actually sat down with the peers to discuss each individual left on the list, asking, ‘What do you know about this person?’” Fox explains. Once the lists were whittled down, the peers reached out to the remaining individuals via phone calls, field work, and home visits.

The focus of the intervention was structured peer-client sessions, informal check-ins, and extra support—all designed to promote behavioral change and increase retention. Topics for the structured educational sessions included:

- Introduction and assessment,
- HIV transmission and viral life cycle,
- Effective communication and self-advocacy,

- Understanding lab values,
- The varying classes of HIV medications and how they attack the virus,
- Drug resistance and adherence; understanding and managing side effects,
- Disclosure and stigma, and
- Harm and risk reduction.

Interim Lessons Learned

While the MAI Peer Project has only recently completed enrollment, CTAC evaluators say that several interim lessons have been gleaned.

Better Identification Protocols Are Needed

It’s important to streamline the process of developing accurate “out of care” lists. Thus, the CTAC will likely make recommendations about how to execute and cull through what are often large initial lists.

The first step is to make better use of data systems, according to Fox. “Right now, folks frequently are transitioning their EMRs, and not everyone is as well trained as they could be on how to use these systems,” she explains.

Providers Have Embraced the Peer Concept

Because of the peer intervention, team members at all three sites have adopted a more preemptive approach to keeping people engaged in care. The CTAC’s final analysis will examine the kinds of systemic changes that have occurred.

“Typically, someone [at the sites] is now calling a patient to say, ‘Don’t forget you have an appointment coming up,’” explains Fox. “And many of the clinicians now are going to the peers and saying, ‘Hey, I haven’t seen so-and-so in a while. Can you look up their file and find out if they need to be found?’”

Peers Gain Personally

Several of the peers have indicated that the process of providing education and support to patients is motivating them to engage more in their own health care. “Right now, this improvement is

“My experience as a peer educator has been wonderful. I never thought I would have a job . . . [because of the stigma] of my HIV status. Today, I am grateful that PR CoNCRA has given me the opportunity to grow and get by that stigma. Now, I am able to show others and myself that I can do and be more in life. Now, I am able to encourage clients, so they can see that living with HIV doesn’t mean we can’t live a productive, healthy, and meaningful life.”

—Nathania Garcia, Peer Educator at PR CoNCRA

based on anecdotal evidence,” says Fox. “But we are hoping that the [final] data will support it.”

Defining Peer Roles and Responsibilities Is Critical to Success

Initial findings show that it is helpful to develop job descriptions for peer educators and share them with members of the clinical and case management team. The descriptions should explicitly state how other staff members will be expected to work with the peers, as well as outline the expectation for communication.

It is also important to train staff members who will be responsible for supervising peer educators. One issue that supervisors must carefully consider is the implications of managing peers who are also clients. As mentioned previously, sample job descriptions and supervisory materials will be available on the HDWG Web site.

Establishing Boundaries With Case Management Is Important

The peers at the demonstration sites have built strong relationships with their case managers, making sure to work in tandem to meet patients’ needs. “It’s good to understand where the boundaries are so no one steps on any toes,” explains Fox. “A case manager simply doesn’t have time, however, to accompany patients to appointments or to track people down at their homes, so having the peers available to do that is a luxury that they have learned to appreciate.”

PATH Center case managers certainly appreciate the commitment that one of their peers showed recently. “A New York City peer is very dedicated to visiting people in their homes; she calls it ‘Feet in the Street Day,’” says Fox. “The peer tells this great story about how she went to a patient’s home and knocked on the door, but no one answered. She knocked again and still no one answered. So, the peer pulled out her cell phone and called the patient. When he answered the phone, she asked ‘Hey, where are you?’ The patient responded, ‘I’m at home.’ So the peer said, ‘Great, answer your door!’” shares Fox. “She’s ridiculously persistent.”

Final Results: What to Expect

The original intention of the project was to assess the impact of peers on patients’ health outcomes after at least 6 months of exposure to the intervention. The project, however, has been extended for an additional year.

“That will allow us to analyze a full 12 months of data for all enrollees, as well as 18 months of data for those enrolled at the beginning of the study, to better measure retention,” explains Fox.

Ultimately, the hope is that the data will prove that integrating peers into the care team provides measurable improvement in engagement and retention in care for people of color living with HIV/AIDS. What’s more, the project should produce a replicable service delivery model through the dissemination of practical training and implementation guidance. The result will be improved health outcomes for our Nation’s most vulnerable communities.

For More Information

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