What's Going on @SPNS

APRIL 2011

AN UPDATE FROM THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES, HEALTH RESOURCES AND SERVICES ADMINISTRATION, HIV/AIDS BUREAU, SPECIAL PROJECTS OF NATIONAL SIGNIFICANCE

Common Voices: SPNS Women of Color Initiative

Women of color (WOC) account for one-third of the female U.S. population but approximately 84 percent of the estimated number of women living with AIDS. The disparity is most egregious among Black/African-American* women, who comprise approximately 65 percent of all women living with AIDS.[1,2]

Most WOC contract HIV through heterosexual contact.[2] In fact, women are more biologically susceptible to HIV infection: Male-to-female transmission of HIV is 2 to 4 times more efficient (in the epidemiologic sense) than female-to-male transmission.[1,3] Many of the factors that render WOC especially vulnerable to HIV infection also serve as barriers to effective linkage to and retention in care. Moreover, lower retention and adherence rates for WOC in care translate to lower rates of response to treatment and survival.[4]

In response to these staggering statistics, the Health Resources and Services Administration's Special Projects of National Significance (SPNS) Program created the Enhancing Access to and Retention in Quality HIV/AIDS Care for Women of Color Initiative, a multisite demonstration and evaluation of HIV service delivery interventions. The initiative funds 11 demonstration sites for up to 5 years to design, implement, and evaluate innovative methods of HIV care delivery to WOC.

Interventions include community-based outreach, patient education, intensive case management, and patient navigation strategies that promote access to and retention in care. Albert Einstein College of Medicine in Bronx, New York, the evaluation and support center for the initiative, will provide technical assistance to the demonstration sites and assess the effectiveness of the selected models. The grantees are in the early stages of implementation, and outcomes will not be available until 2014. Still, preliminary efforts have given grantees valuable insight into the unique barriers facing WOC in various communities as well as a greater understanding of potential strategies for overcoming those obstacles.

This issue of *What's Going on @ SPNS* describes the early lessons from the 11 demonstration sites and highlights the work of 3 of those sites: the Medical College of Georgia HIV Clinic (Augusta, Georgia), the CORE Center (Chicago, Illinois), and Community AIDS Resource Inc. (Miami, Florida).

Common Ground: Barriers to Receiving and Benefiting From Care

All demonstration sites have noted significant barriers that prevent WOC from accessing and benefiting from care. Although each grantee faces some unique challenges, all recognize three categories of common obstacles facing WOC: sociodemographic, psychosocial and behavioral, and systemic.

Sociodemographic Barriers

Sociodemographic barriers across sites include poverty and unmet basic subsistence needs, lack of child care, financial dependence on men, low levels of education and health literacy, and a lack of insurance or underinsurance. For many WOC, their understanding of HIV and its treatment is based on the experience of family members with HIV who were treated before the advent of highly active antiretroviral therapy or who struggled with insufficient treatment and resources.

Psychosocial and Behavioral Barriers

Common psychosocial and behavioral barriers include gender inequality in sexual relationships, domestic violence, mental health issues, substance abuse, distrust of the health care system, lack of a social support network, and stigma. Grantees explain that many women clients face challenges in their interpersonal relationships that affect their ability to negotiate safe-sex practices with HIV-positive partners and protect themselves from repeated exposure to HIV and other sexually transmitted infections. Those relationships also impede their ability to safely take charge of their health and access care consistently over time. Grantees have reported that women exchange sex not just for drugs or money but

*Terminology for ethnic groups follows that of the data source.

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also to meet basic sustenance needs or to avoid physical abuse. More than one grantee has reported that its clients often lack a network of family and friends with whom they can share their HIV status and receive emotional and other support, a problem that may be even more acute for recent immigrants. Finally, WOC with mental health or substance abuse issues are perhaps the most challenging to engage in care.

Systemic Barriers

Grantees cite health care system barriers that include transportation, lack of cultural competency, and inadequate care coordination. WOC from all sites miss appointments because of a lack of reliable and affordable transportation, whether they live in urban, suburban, or rural areas. At least one site has noted that Hispanic women are more likely than other women to face legal barriers and language difficulties, perhaps because of unfamiliarity with immigration laws and available public services, leaving them unable to take advantage of necessary social service programs. Some immigrants may also avoid services or fail to adhere to providers' recommendations because they fear deportation. The specter of deportation—whether real or imagined—may coerce women into acting against their best interests, particularly if they are concerned for the well-being of their children. In addition, WOC, especially newly diagnosed women, often lack the skills and resources to navigate the complicated and often fragmented U.S. health care system.

The sections that follow describe what the Medical College of Georgia HIV Clinic (MCG), the CORE Center, and Community AIDS Resource Inc. (Care Resource) are doing to mitigate the various barriers HIV-positive WOC face in accessing and staying in care.

Medical College of Georgia

The MCG HIV clinic is a comprehensive, full-service clinic serving the Central Savannah River Area, which comprises 13 counties around Augusta, Georgia, and several communities across the border in South Carolina. MCG serves 1,200 clients and is the largest HIV care provider in this largely suburban and rural area. Nearly one-half (46 percent) of the clientele are female, 80 percent of whom are WOC. Among the WOC, the majority are African-Americans who contracted HIV through heterosexual contact. Many WOC in the MCG catchment area come from rural communities, populations traditionally marginalized in the health care system. "Some [of our patients] report that they don't have a close network of friends who know their story and can provide support. They feel alienated and isolated, which degrades self-esteem," explains Marie Denis-Luque, project director.

Approach

To improve the quality of life of WOC with HIV, MCG developed an initiative called Synchronizing Your Network Creates Positive (+) Smart Women Inspiring Mentors (SYNC [+] SWIM). MCG is in the process of conducting in-depth interviews with approximately 30 HIV-positive WOC to better assess the needs and concerns of this population. "We realized that we had developed this program based on what *we* thought the women's needs were. But we hadn't surveyed the women to find out what *they* perceived to be the most pressing needs," explains Cheryl Newman, principal investigator. These preliminary interviews will help inform the development of the program to ensure its effectiveness. SYNC (+) SWIM has three interconnecting components: peer mentors, a referral network, and life skills training.

LifeGuards Peer Mentoring Program

MCG is interviewing candidates for its LifeGuard program, in which three HIV-positive peer women will be employed as program peer specialists. The goal of the LifeGuard program is to equip HIV-positive WOC with the skills and support they need to effectively self-manage their disease, including identifying and overcoming barriers to care. The long-term goal is to create an extensive peer mentorship program over time by training clients as "LifeGuards."

The LifeGuards will provide rapid HIV testing and education and will assist newly diagnosed women and women who are inconsistently in care with navigating the health system and accessing social and medical services through the MCG referral network. The LifeGuards will support and guide patients through the care process by offering reminders about appointments and medication schedules, following up with them after appointments, and helping to resolve any issues that emerge. For example, LifeGuards will help clients who face transportation and other logistical barriers come up with ways to keep their scheduled appointments.

Each client will get to know two different LifeGuards to ensure coverage in case one is sick or absent. "We knew that peers were

SPNS WOC Initiative Grantees

- Albert Einstein College of Medicine, Bronx, NY (evaluation and technical assistance center)
- Center for Human Services, Bethesda, MD
- Community AIDS Resource, Inc., Miami, FL
- CORE Center, Chicago, IL
- Health Services Center, Inc., Anniston, AL
- JWCH Institute, Inc., Los Angeles, CA
- Medical College of Georgia, Augusta
- New North Citizens Council, Inc., Springfield, MA
- Research Foundation of the State University of New York, Brooklyn
- Special Health Resources for Texas, Inc., Longview
- University of North Carolina at Chapel Hill
- University of Texas Health Science Center at San Antonio

essential because there is so much stigma. We hope our clients will feel really comfortable knowing this peer worker has been through it herself and will not judge," says Denis-Luque. LifeGuards serve as a role model for how to overcome obstacles and live a full life with HIV. Newman adds, "These are women who know how to successfully navigate the system."

Referral Network

To ensure that WOC get the medical and social services they need across the care continuum, MCG is working to strengthen its referral network of community-based organizations and service providers. "Our initial discussions have revealed that many organizations, including Goodwill Job Connections, are eager to help," says Denis-Luque. The next step is to formalize those nascent connections into established relationships. To that end, MCG is in the process of hiring a community service liaison, who will establish ties to a range of businesses and community agencies. "We want to hire someone who really knows the communities and has case management and social work experience," explains Newman. The hope is also to find untapped resources in the community. MCG will develop a newsletter and email list to keep community organizations up to date.

Life Skills Programs

MCG will offer clients life skills training to assist in addressing socioeconomic, emotional, and logistical barriers to care. The topics covered will be determined by the qualitative interviews. "As we move on, we may find that there are needs that have been overlooked, and we will have to reassess," says Newman. MCG anticipates that sessions will focus on financial planning, employment skills, housing assistance, self-esteem, treatment compliance, stigma, and basic health literacy. However, Denis-Luque explains that "the interviews are critical in designing the program. There is no point in setting up . . . a [particular] training only to find out that our patients aren't interested." Once topics are selected, MCG plans to tap into resources available through its growing community network. "Apart from the educational component, we want these sessions to be enjoyable. We want to provide women with fellowship and camaraderie in the context of learning something new. This is especially critical among a population with self-esteem issues," says Denis-Luque.

CORE Center

The Chicago-based Ruth M. Rothstein CORE Center provides prevention, care, and research in HIV/AIDS and other infectious diseases. Established in 1998 as a partnership between the Cook County Health and Hospitals System and Rush University Medical Center, the CORE Center is one of the largest HIV/AIDS clinics in the Nation. The center's "one-stop shopping" setup offers a full range of services to more than 1,200 HIV-positive women every year. CORE provides care for 75 percent of women who are known to be HIV infected and living in the Chicago Eligible Metropolitan Area. Of the center's female client population, 70 percent are African-American, 12 percent are Hispanic, 8 percent are White, and 10 percent are other.

Approach

The HIV System Navigation Program—Women Empowered to Connect and Remain Engaged in Care (Project WE CARE), the CORE Center's SPNS project—was designed to address individual-level barriers and facilitate access to and retention in care for WOC with HIV. The target population is WOC in Cook County who are newly diagnosed with HIV, lost to care, sporadically in care, or lost to follow-up. The program comprises two interventions:

1. The Patient Navigator (PN) program
2. The Diffusion of Effective Behavioral Interventions (DEBI) project's Healthy Relationships program, developed by the U.S. Department of Health and Human Services, Centers for Disease Control and Prevention (CDC).

The short-term goal of the initiative is to help patients access and navigate care at the CORE Center while giving them the skills and knowledge they need to cope with HIV/AIDS. Ultimately, the goal of the initiative is to reduce morbidity and mortality associated with HIV/AIDS by increasing earlier access to primary medical care, bolstering engagement and retention in care, and increasing treatment adherence.

Patient Navigators

The PN program is based on a model that has achieved great success in the treatment of breast cancer. CORE administrators are recruiting patients with demonstrated interpersonal and organizational skills; medical literacy in HIV treatment and prevention; and a willingness to work with culturally, racially, and ethnically diverse patients and staff. According to Marisol Gonzalez, principal investigator, ideal PN candidates are HIV positive; have been CORE clients for at least 1 year, and have graduated from the center's 5-week, 40-hour peer training program.

All WOC are offered a PN. Once a patient is diagnosed with HIV within the CORE Center or at a community partner location, a PN initiates contact during the posttest counseling session. The PN serves as an adjunct to the case manager and plays a critical role throughout the care continuum through the following activities:

- Accompanying the client to her first visit to the CORE Center and orienting her to services
- Connecting the client to a case manager, who conducts a risk assessment and develops a patient-specific service plan
- Helping the client understand and execute case management and medical service plans
- Reminding the client of upcoming appointments
- Addressing barriers to care and coordinating services with CORE Center staff and community-based organizations
- Ensuring that the client attends follow-up appointments

- Preparing the client for medication side effects and reiterating the value of treatment
- Communicating with the multidisciplinary care team about the client's needs and concerns
- Arranging for transportation to appointments as available
- Sharing knowledge and education about HIV
- Sharing their personal stories and how they have handled issues such as disclosure and medication side effects
- Acting as a positive role model by demonstrating healthy lifestyle behaviors.

The hope is that the PNs will help increase each patient's adherence to her care plan, as devised by case managers and medical staff, as well as serve as positive role models. The peer status of PNs is critical to the success of the program. "Meeting with a PN who has 'been there, done that' and who has been living with HIV disease can be very reassuring to a newly diagnosed woman and provide a real sense of hope. The client may say to herself, 'This PN seems OK so maybe I, too, will be OK," explains Gonzalez.

The PN may identify issues that are never raised with the case manager. The CORE Center has found that new clients are often more likely to open up with a PN they can relate to, sharing valuable information that could prompt timely referrals to needed services. For example, the client may feel comfortable enough to admit to the PN that she needs assistance with mental health or substance use issues. In addition, as a person who can elicit trust and camaraderie, the PN is in a prime position to dispel common myths and misconceptions about HIV transmission and treatment.

The CORE Center is providing information to all departments, including ancillary services, to make center staff aware of the duties and objectives of PNs and of the initiative in general. The hope is to avoid any confusion as to the role of PNs and make staff aware of how they are a psychosocial support—and do not replace—case managers and other social service providers. Rather, the PNs are paraprofessionals based on other models, such as community health workers or "promotoras de salud." They are vital bridges to medical–psychosocial services.

Healthy Relationships Program

The CDC-developed DEBI Healthy Relationships Program empowers clients with the problem-solving and decision-making skills needed to make informed decisions about disclosing their HIV status and negotiating with partners about condom use. The model also helps clients develop the coping skills they need to manage the stress associated with HIV/AIDS.[5] The intervention, which involves five 2-hour sessions, will be offered to all WOC enrolled in care at the CORE Center. According to Gonzalez, the Healthy Relationships Program works in conjunction with the PN initiative. "The Patient Navigator serves as a gatekeeper at the moment of crisis, but because clients will not have access to the PN for life, we need to give them the skills they need to live life with HIV." Clients will learn through modeling, role-playing, and motivational feedback.

Care Resource

Care Resource is South Florida's oldest and largest HIV/AIDS service organization. It offers clients "one-stop shopping" for a full range of HIV/AIDS services. The organization's SPNS initiative, Assertive Community Treatment for Women of Color (I–ACT for Women of Color) targets women in Miami–Dade County, particularly those living in the Liberty City, Homestead, Little Haiti, and Little Havana areas. Of the 67 counties in Florida, Miami–Dade has the highest rate of reported HIV/AIDS cases.[6] The county is also among the Nation's most ethnically and racially diverse, comprising many minority groups, including African-Americans and roughly 22 Hispanic subpopulations. More than one-half of Miami residents were born in other countries. The county is home to immigrants from a wide swath of countries across the Caribbean and South and Central America.[7] Miami–Dade has high poverty rates and large numbers of uninsured persons.[8,9]

Although Hispanics in Miami–Dade County are far less likely than Blacks to be affected by HIV/AIDS, Hispanics face unique language and legal barriers and continue to have rising HIV infection rates.[9]

Approach

I–ACT was adapted from a service delivery model that has proven successful in the mental health field. The program offers HIV tests with the hope of engaging at least 200 HIV-positive WOC within the first year. Activities will take place at the Care Resource office, the program's mobile testing unit, and client homes—wherever patients may be. Collaborating entities include community-based organizations, University of Miami/Jackson Memorial Medical Center, and Project Dress to Success.

In the I–ACT program, a team of professionals from a wide range of disciplines provides WOC with a range of intensive, culturally competent, comprehensive, coordinated, and client-driven services outlined in a highly individualized treatment plan. The team includes physicians, patient care assistants, case managers, psychosocial counselors, addiction specialists, outreach workers, HIV testing counselors, peer educators, and rehabilitation workers. Services are provided both onsite and through referrals to other providers. "We are taking a very holistic approach to engaging and retaining women of color in care. If I–ACT staff can work together to address needs and overcome barriers to care, women

*Assertive Community Treatment, considered an evidence-based practice for the treatment of serious mental illness, involves an interdisciplinary team that provides intensive services and support in the community. For more information, see http://mentalhealth.samhsa.gov/cmhs/CommunitySupport/toolkits/community/default.aspx and http://mentalhealth.samhsa.gov/features/surgeongeneralreport/chapter4/sec5.asp#assertive.

For More Information . . .

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of color are more likely to make treatment a priority," says Carolyn McKay, Care Resource's director of information, evaluation, and quality assurance service.

An early and thorough understanding of each client's individual needs and barriers to care is critical to developing an effective treatment plan. To that end, I–ACT has established two new positions designed to take case management to a new level: the access and evaluation supervisor and the access and evaluation assistant. During the intake process, the supervisor and assistant conduct a comprehensive needs assessment, including administering a questionnaire designed to identify not only the client's needs but also any barriers she faces. Using this assessment, the supervisor develops an individualized care plan while the assistant provides any supplemental support in executing this plan. They also provide essential case management services, including client enrollment, referrals, and counseling on issues such as domestic violence and treatment adherence. In the I–ACT program, however, the supervisor provides more individualized services than would a general case manager. "Traditionally, a case manager will help *direct* a client to various services. But the supervisor [actively] helps them *access* these services," explains McKay.

The I–ACT program has underscored the multiple challenges WOC face in Miami–Dade County. "We try to help with transportation. We subcontract with a child care provider to babysit during group meetings," McKay explains. I–ACT works to remove the immediate barriers to care so women can more readily focus on their health and develop strategies for improving their management of HIV.

To identify effective interventions and processes and any gaps in services or unmet needs, the I–ACT multidisciplinary team participates in two kinds of bimonthly meetings: a data meeting and a case staffing (or case review) meeting. Through these meetings, team members discuss a sampling of patients, particularly those who are newly tested, partially engaged, and lost to care, as well as any emerging issues of concern.

The team identifies and dissects the barriers that each client is facing and explores ways to improve the client's adherence to care as well as the quality of services provided. "We also look at fully engaged [clients] as models of success," says McKay. By examining effective cases, I–ACT can more readily ascertain what strategies should, perhaps, be replicated with their hard-to-reach clients.

McKay believes the SPNS initiative will provide Care Resource with a valuable opportunity to improve care coordination and quality for all clients: "The multidisciplinary meetings will give us an opportunity to look at what we are offering women of color and discuss how we can make those services operate more efficiently. Sometimes things don't work as cohesively as they should; we need better coordination. With its strong evaluation focus, the SPNS program will provide the impetus for real change that lasts beyond the SPNS time frame," Although Care Resource does not yet have outcomes data on I–ACT, anecdotal evidence suggests that many WOC are more comfortable and more engaged at Care Resource than before the SPNS initiative took effect.

Conclusion

Although the SPNS demonstration sites are located in very different geographic settings with their own subset of unique challenges, many of their clients face remarkably similar barriers to care. Whether they use LifeGuards, I–ACT teams, or PNs, the various approaches chosen by the grantees are designed to provide more individualized support and care to WOC.

As these SPNS grantees implement their intervention models and work with clients to help them address the myriad challenges of living with HIV disease, the demonstration sites acknowledge that they must continue to learn from and work closely with their clients. This strategy is instrumental in successfully engaging and retaining WOC in treatment, care, and support services. Ultimately, the goal of all sites—and for all participants—is improved patient health outcomes and quality of life.

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