Improving Health Outcomes

Moving Patients Along the HIV Care Continuum

INTERVENTION GUIDE

SPNS Demonstration Model on Guide to Healing:
Enhancing Access to Care for HIV+ Women in the Rural South

SEPTEMBER 2018

HRSA
Health Resources & Services Administration

U.S. Department of Health and Human Services
Health Resources and Services Administration
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Improving Health Outcomes

Moving Patients Along the HIV Care Continuum

INTERVENTION OVERVIEW & REPLICATION TIPS

Guide to Healing: Enhancing Access to Care for HIV+ Women in the Rural South

University of North Carolina at Chapel Hill

This intervention guide examines a patient navigation intervention focused on linkage to and retention in care, and provides information on key components of the intervention and the capacity required by organizations/clinics to conduct this work.

This intervention guide is part of a training series entitled, "Improving Health Outcomes: Moving Patients Along the HIV Care Continuum," and is published by the Special Projects of National Significance (SPNS), under the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration (HRSA), U.S. Department of Health and Human Services (HHS). The purpose of this intervention guide and others featured as part of the *Translation of SPNS Findings and Technical Assistance Support to Implement New Models of Care* project is to highlight interventions along the HIV care continuum and support replication of these evidence-informed innovative models of care. The HIV care continuum refers to the fluid nature of HIV health care delivery and client experiences, and research has demonstrated the importance of moving clients along the continuum with the goals of being fully linked, engaged, retained, and virally suppressed. This framework has received attention as research has demonstrated the importance of these activities. Therefore, finding programs that help clients move along the stages of the continuum are particularly important.

About SPNS

The Health Resources and Services Administration (HRSA), an agency of the U.S. Department of Health and Human Services, is the primary federal agency for improving health care to people who are geographically isolated, economically or medically vulnerable. The Special Projects of National Significance (SPNS) Program is a part of the HRSA HIV/AIDS Bureau (HAB). The SPNS Program supports the development of innovative models of HIV care and treatment in order to quickly respond to emerging needs of clients served by HAB. SPNS advances knowledge and skills in the delivery of healthcare and support services to underserved populations living with HIV. Through its demonstration projects, SPNS evaluates the design, implementation, utilization, cost, and health-related outcomes of treatment models while promoting the dissemination and replication of successful interventions.

About the Enhancing Access to Retention in Quality HIV Care for Women of Color Initiative

The featured evidence-informed intervention was part of the SPNS "Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative." For this initiative, SPNS supported 10 demonstration sites (five urban sites and five rural sites) for five years to design, implement, and evaluate innovative methods for enhancing access to and retaining women of color living with HIV in primary medical care and support services. Interventions included community-based outreach, patient education, intensive case management, and patient navigation strategies. The demonstration sites also participated in a robust multi-site evaluation. Populations of interest include HIV-positive women of color who are not retained in care or who may benefit from additional support to improve access to services. The study evaluation design assessed the effectiveness of the selected models in enhancing access to and retention in HIV care for women of color. To learn more about this initiative, visit: **https://hab.hrsa.gov/about-ryan-white-hivaids-program/spns-women-color**.

Guide to Healing: Enhancing Access for HIV+ Women in the Rural South

University of North Carolina at Chapel Hill

Why This Intervention?

The Guide to Healing: Enhancing Access for HIV+ Women in the Rural South (Guide to Healing) intervention links women of color living in the rural South to HIV primary care services. It also connects them with a Nurse Guide, who helps them develop autonomy to support their continued engagement in care. These are critical steps in achieving viral suppression, which is directly linked to improved health outcomes and decreased risk of transmitting HIV to others. Among a hard-to-reach population who suffers medical fragility and high rates of HIV stigma, the intervention retained 77 percent of clients and had 88 percent viral suppression.

At-a-Glance

The table below provides a general overview of the intervention so readers can assess the necessary steps required for replication.

Model at-a-Glance	
Step 1	**Client Referred to Guide to Healing Intervention** The Nurse Guide receives referrals from staff and providers treating women of color who are newly seeking care or struggle to remain retained in care.
Step 2	**Rapid Intake Appointment Made and Phone Call with Nurse Guide** Clients referred to the intervention are quickly given appointment times. The Nurse Guide reaches out within one to two days of receipt of the referral and provides an initial orientation about the program, answers questions the client may have, and helps prepare them for their first day at the clinic.
Step 3	**Orientation and First Provider Visit** The first time the client attends the clinic they meet with the Nurse Guide to receive the rest of their orientation as well as obtain their orientation pamphlet (with HIV basics, contact numbers, information on what to expect, and FAQs). The client then meets with the HIV primary care provider for her first medical appointment.
Step 4	**Provide Patient Navigation and Care Coordination Services** Over the next six to eight months, the Nurse Guide provides patient navigation services along with care coordination and system navigation services. This includes developing a care plan, connecting women to necessary resources, answering medical questions, providing medication adherence counseling, and helping run a support group for the women.
Step 5	**Client Transition** The Nurse Guide develops client transition plans, educates the clinic nurse or social worker about the client who is entering their care, and conducts a warm transition. At this point, clients should be able to manage self-care.

Source: University of North Carolina at Chapel Hill. Guide to Healing: Enhancing Access for HIV+ Women in the Rural South. [Final report.] November 30, 2015.

Resource Assessment Checklist

Prior to implementing the Guide to Healing intervention, organizations should walk through a Resource Assessment (or Readiness) Checklist to assess their ability to conduct this work. If organizations do not have these components in place, they are encouraged to develop their capacity so that they can successfully conduct this intervention. Questions to consider include:

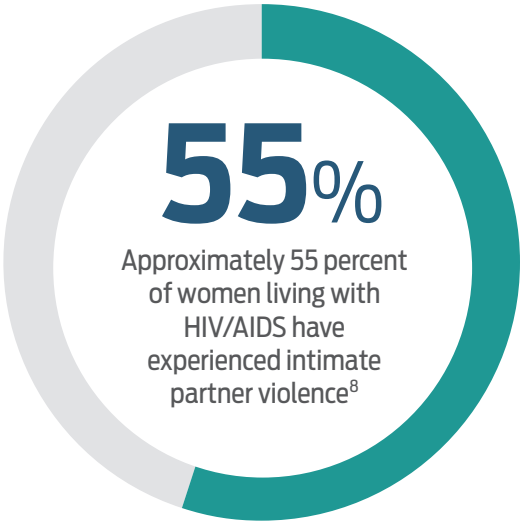
- ☐ Does your organization have access to the target population? If not, do you have a partnership in place with an organization that does?
- ☐ Does your organization provide HIV primary care?
- ☐ Do you have a nurse or nursing staff who can devote time to patient navigation services? The nurse navigation piece is a critical component to this intervention. Clients targeted by this intervention require more time intensity.
- ☐ Does your staff or organization have any experience with Motivational Interviewing? Motivational Interviewing is a goal-oriented, client-centered counseling approach that facilitates behavior change.* If not, are they able to be trained and certified in this counseling technique?
- ☐ Is the proposed Nurse Guide trained in Self-Determination Theory, strengths-based case management, trauma, and health literacy? If not, are you able to provide this training?
- ☐ Is transportation a challenge for your target populations. If so, are clients able to access a Medicaid van or are you able to supply gas cards or transportation vouchers of some kind to facilitate their travel to your clinic?

*To learn more about Motivational Interviewing, visit the Motivational Interviewing Network of Trainers at: **http://www.motivationalinterviewing.org**

Setting the Stage

The Southeast region of the United States bears a disproportionate burden of HIV/AIDS.[1] Southerners are more likely to be diagnosed with HIV, receive an AIDS diagnosis, and die from AIDS-related complications than counterparts in other regions of the country.[2] In the South, stigma is particularly rampant and factors such as lack of transportation, poverty, and health workforce shortages are more common and create additional structural barriers to entering care.

HIV-infected Black women in the U.S. experience twofold greater mortality compared with non-Black women,[3] suggesting they experience greater delays entering care and less sustained retention in care.[4] Retention-in-care rates are critical as they are associated with better viral suppression and improved survival.[5,6]



Women of color, the focus of the Guide to Healing intervention, face additional unique and complicated barriers to accessing and engaging into HIV care. The intersecting epidemics of substance use disorder, violence, and HIV/AIDS (known as the SAVA syndemic) contribute to disproportionate burden of disease among people of color.[7] This is particularly acute among women of color. Approximately 55 percent of women living with HIV/AIDS have experienced intimate partner violence.[8] A history of violence, trauma, and abuse has been shown to correlate with decreased medication adherence, decreased engagement in care,[9,10,11] and increased viral load as well as increased mental health disorders/ mental duress.[12,13] Structural and social determinants exist as well. Among interviews with 141 women of color living in the Southeastern United States, long distances and transportation, work-related difficulties, and confidentiality were all cited as barriers with community stigma and personal finances among the most frequently cited barriers to engagement in care."[14] It is also worth noting that social support from both formal and informal networks have been shown to contribute to engagement in

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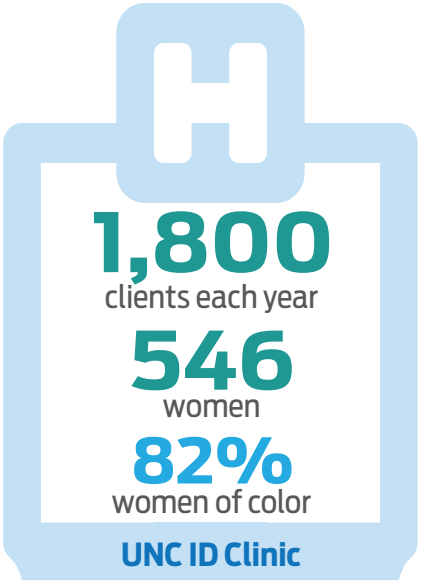
[1] Centers for Disease Control and Prevention (CDC). *HIV Surveillance Report, 2015*; vol. 27. **http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html**. Published November 2016. Accessed February 10, 2017.
[2] CDC. *HIV Surveillance Report, 2015*; vol. 27. **http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html**. Published November 2016. Accessed February 10, 2017.
[3] Murphy K, Hoover D, Shi Q. The Association of Race with Death from AIDS in Continuous HAART Users: WIHS. 19th Conference on Retroviruses and Opportunistic Infections. Seattle. Abstract 1045.
[4] Quinlivan EB, Messer LC, Admire AA, et al. Experiences with HIV Testing, Entry, and Engagement in Care by HIV-Infected Women of Color, and the Need for Autonomy, Competency, and Relatedness. *AIDS Patient Care and STDs*. 2013;27(7):1–8.
[5] Giordano TP, Gifford AL, White AC, Jr., et al. Retention in Care: A Challenge to Survival with HIV Infection. *Clin Infect Dis*. 2007;44:1493–99.
[6] Mugavero MJ, Davila JA, Nevin CR, et al. From Access to Engagement: Measuring Retention in Outpatient HIV Clinical Care. AIDS Patient Care STDs. 2010;24:607–13.
[7] Sullivan KA, Messer LC, Quinlivan EB. Substance abuse, violence, and HIV/AIDS (SAVA) syndemic effects on viral suppression among HIV positive women of color. *AIDS Patient Care and STDs*. 2015;29 (Suppl 1).
[8] Machtinger EL, Wilson TC, Haberer JE, et al. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS Behav*. 2012;16:2091–2100.
[9] Dae S, Cohen M, Weber K, et al. Abuse and resilience in relation to HAART medication adherence and HIV viral load among women with HIV in the United States. *AIDS Patient Care STDs*. 2014;28:136-143.
[10] Lopez EJ, Jones DL, Villar-Loubet OM, et al. Violence, coping, and consistent medication adherence in HIV-positive couples. *AIDS Educ Prevent*. 2010;22:61.
[11] Cohen MH, Cook JA, Grey D, et al. Medically eligible women who do not use HAART: the importance of abuse, drug use, and race. *Am J Public Health*. 2004;94:1147.
[12] Machtiner EL, Wilson TC, Haberer JE, et al. Psychological trauma and PTSD in HIV-positive women: a meta-analysis. *AIDS Behav*. 2012;16:2091–2100.
[13] Rose R, House AS, Stepleman LM. Intimate partner violence and its effects on the health of African American HIV-positive women. *Psycholog Trauma Theory Res Pract Policy*. 2010;2:311–317.
[14] Toth M, Messner LC, Quinlivan EB. Barrier to HIV Care for Women of Color Living in the Southeastern US are Associated with Physical Symptoms, Social Environment, and Self Determination. *AIDS Patient Care and STDs*. 2013; 27(11): 613–20.

HIV care, particularly among African American women. Conversely, the lack of social support can serve as a deterrent or barrier to care.[15,16]

The need for enhanced services to engage and retain women of color was clear.

UNC's Infectious Disease (ID) Clinic nurses and nurse practitioners had begun working on a small project with women with low CD4 counts, providing appointment reminders, conducting education around lab work and side effects and were seeing some initial success with retention when the **SPNS Enhancing Access to and Retention in Quality HIV Care for Women of Color (WOC) Initiative** funding became available. The WOC Initiative enabled UNC to bring their work to scale and fully test their model.



UNC was also well positioned to do so. The Clinic is within an academic hospital-based setting with easy access to the hospital's outpatient laboratory, pharmacy and consulting pharmacist, and radiology departments, a dental clinic, onsite substance use disorder and mental health counseling, medical case management, benefits counseling, clinical trials, multidisciplinary support services (e.g., social work, financial counseling, health education, adherence counseling), and a twice-monthly obstetrics/gynecology clinic held at the main ID Clinic. The ID Clinic serves approximately 1,800 clients each year, 546 of whom are women. Of their female clients, 82 percent are women of color.[17]

Description of Intervention Model

CHALLENGE ACCEPTED

THE CHALLENGE: Develop, integrate, and implement a client-centered HIV program targeting women of color to improve their engagement and retention in care and personal autonomy using a nurse patient navigator.

Intervention Model: Guide to Healing

The Guide to Healing intervention is a clinic-based intervention grounded in Self-Determination Theory, which offers a framework to study human motivation and personality, as well as cognitive and social development. The theory explains that, "new behaviors may be changed in the presence of extrinsic motivators, but will not be sustained until there is intrinsic motivation and the behavior has value and meaning. Behaviors gain value and meaning when persons feel competent, autonomous, and connected."[18]

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[15] Catz SL, McClure JB, Jones GN, Brantley PJ. Predictors of Outpatient Medical Appointment Attendance Among Persons with HIV. *AIDS Care.* 1999;11:361–373.
[16] Gardner LI, Marks G, Metsch LR, et al. *Psychological and behavioral correlates of entering care for HIV infection: The Antiretroviral Treatment Access Study (ARTAS). AIDS Patient Care STDs.* 2007;21:418–425.
[17] University of North Carolina at Chapel Hill. "Guide to Healing: Enhancing Access for HIV+ Women in the Rural South." In *Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative: An Intervention Monograph*. 2014.
[18] Quinlivan EB, Messer L, Adimora A, et al. Experiences with HIV Testing, Entry, and Engagement in Care by HIV-infected Women of Color, and the Need for Autonomy, Competency, and Relatedness. *AIDS Patient Care and STDs.* 2013;27(7):1–8.

- *Autonomy.* This refers to a sense of independent will and the ability to make choices for oneself. The Nurse Guide provided orientation of the clinic and larger medical system to familiarize clients and reduce the feeling of being overwhelmed given the sheer size of the larger UNC medical system. Clients were engaged in the development and execution of their care plans and, over time, were asked to take on more and more responsibilities as they became more self-sufficient.
- *Competency and self-efficacy.* This is the belief that one can complete a task and has the ability to actually do so. Clients received educational information at the start of the intervention and also attended support group meetings that covered topics such as communication skills, stress management, building social support systems, and understanding medical forms. As the weeks went on, clients felt more comfortable with these topics as well as their abilities to navigate them.
- *Relatedness.* Clients feel a sense of relatedness when they are welcomed, respected, and develop a relationship/connection. The Nurse Guide was the bridge between the clients and the clinical staff. She was friendly and patient-centered in her approach and focused on building relationships and trust throughout each encounter. This also included recognizing that her priorities were not always the clients' priorities and she had to make room for both. Whenever possible, the Nurse Guide celebrated milestones—whether clinical or personal (e.g., birthdays, a wedding engagement) to foster connection.

The consistent use of health care services by the target population, especially for a chronic illness that is often asymptomatic is a new health behavior for many women of color with HIV in the South and, thus, requires both structural and provider-level interventions in early phases to reach, link, and engage these women.[19] The intervention also applies Motivational Interviewing, a client-centered, goal-oriented strategy to encourage goal setting and behavior change.

The intervention focuses on patient navigation, a patient-centered model of care coordination focused on reducing barriers to care and linking clients to and retaining them in HIV care. Unlike other patient and systems navigation programs, however, the Guide to Healing intervention specifically uses a registered nurse (RN) to serve as patient navigator (known simply as the "Nurse Guide").[20] At the time of the study, the Guide to Healing appeared to be the first published HIV nurse patient navigation program designed specifically for women.[21]

Unlike other patient and systems navigation programs, however, the Guide to Healing Intervention specifically uses a registered nurse (RN) to serve as patient navigator (known simply as the "Nurse Guide").

UNC chose a nurse to manage navigation services in order to facilitate improved care team communication and have an individual with increased education and familiarity with medical conditions, treatments, and side effects in this role. Given the multidisciplinary nature of HIV and the complexity of care needs among women of color, the Nurse Guide is well positioned to work with both clients and medical staff.

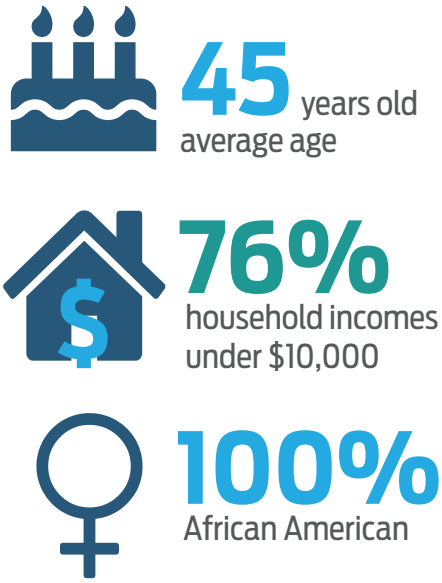
[19] University of North Carolina at Chapel Hill. Guide to Healing: Enhancing Access for HIV+ Women in the Rural South. [Final report.] November 30, 2015.
[20] Sullivan KA, Schultz K, Ramaiya M, et al. Experiences of women of color with a nurse patient navigation program for linkage and engagement in HIV care. *AIDS Patient Care and STDs*. 2015;29 (Suppl 1).
[21] Sullivan KA, Schultz K, Ramaiya M, et al. Experiences of Women of Color with a Nurse Patient Navigator Program for Linkage and Engagement in HIV Care. *AIDS Patient Care and STDs*. 2015;29(Suppl 1):S49–54.

The intervention provides Nurse Guide navigation support for up to six to eight months. Specifically, the nurse provides orientation to care, care coordination, and regular phone contact. The Nurse Guide also receives referrals from staff and providers treating women of color who are newly seeking care or struggle to remain retained in care. Clients are transitioned to full autonomy at the end of the intervention.

To promote recruitment, the Nurse Guide engaged providers so that they could refer qualifying clients to the intervention. Referrals were received from area health departments, emergency rooms (ERs), primary care physicians, local case management agencies, and disease intervention specialists. In particular, relationships with case managers helped foster rapid entry for newly diagnosed women. Flyers were also distributed around the larger UNC medical campus, although this was secondary to provider education and referrals.[22]

To be eligible, individuals needed to be HIV-positive, women of color, able to communicate in English, and at least 18-years-old. To support linkage and retention, clients are offered transportation support (e.g., gas cards, parking vouchers), communications support (e.g., cell phones), access to rapid appointments, and a women's support group (covering topics such as talking to providers, dealing with stress, HIV basics, money management, and more) to increase social support and health literacy. The women also receive expedited clinic appointments. Focus groups were held with HIV-positive women already receiving care at the UNC ID Clinic; the information from these groups helped refine the intervention and identify possible topics for the support group.

The women served through this intervention were an average age of 45 years old (ranging from 27 to 62), the majority (76 percent) had household incomes under $10,000, were Black/African American (100 percent),[23] and faced financial, psychosocial (e.g., depression, fatalism, internalized stigma), and structural barriers (e.g., longer distances from clinic, lack of transportation, and access to a consistent phone). In addition, they experienced external stigma in mostly small, rural, Southern towns.[24,25] Many experienced verbal, sexual, or physical abuse—receiving messages early on that undermine their sense of self-worth. Compounding this, the majority of women became HIV infected after some kind of trauma, such as betrayal by partners and in some cases rape, which exacerbate feelings of powerlessness and loss of autonomy and both their status and subsequent treatment can serve as reminders of their trauma.[26]



Without the Nurse Guide, many clients are overwhelmed with their HIV diagnosis and are unaware of the medications and long life expectancy they can have with treatment adherence and viral suppression. Clients are often navigating a health care system for the first time, which can be intimidating and confusing—especially a large one like UNC's. The one-stop-shop setting, however, facilitates referrals to other health care services that clients may need (e.g., mental health, OB/GYN, oncology).

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[22] University of North Carolina at Chapel Hill. "Guide to Healing: Enhancing Access for HIV+ Women in the Rural South." In *Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative: An Intervention Monograph*. 2014.

[23] Sullivan KA, Schultz K, Ramaiya M, et al. Experiences of Women of Color with a Nurse Patient Navigator Program for Linkage and Engagement in HIV Care. *AIDS Patient Care and STDs*. 2015;29(Suppl 1):S49–54.

[24] University of North Carolina at Chapel Hill. Guide to Healing: Enhancing Access for HIV+ Women in the Rural South. [Final report.] November 30, 2015.

[25] Messer L, Quinlivan EB, Parnell H, et al. Barriers and Facilitators to Testing, Treatment Entry, and Engagement in Care by HIV-positive Women of Color. *AIDS Patient Care and STDs*. 2013;27(7):1–10.

[26] Quinlivan EB, Messer L, Adimora A, et al. Experiences with HIV Testing, Entry, and Engagement in Care by HIV-infected Women of Color, and the Need for Autonomy, Competency, and Relatedness. *AIDS Patient Care and STDs*. 2013;27(7):1–8.

The Nurse Guide meets with clients to identify barriers to medical care and self-management and develops a written plan to support removal of those barriers and works with the women to build on their strengths and abilities in order to do so. The women also receive a new orientation booklet, which includes:

- ID Clinic general information
- Brief care team overview
- HIV basics
- Self-care information
- Tips for preparing for provider visits and what to expect during visits, including a checklist of items to bring to clinic
- Guidance for making appointments and what to do if clients need to reschedule (or miss an appointment)
- Guidance for obtaining medications and prescription refills
- The clinic billing policy
- Patient rights and responsibilities

Orientation materials also include a binder with note pages, slips to hold medical cards, and a calendar. Clients additionally receive an oral digital thermometer and instructions for use, condoms and lubricants, and an opaque zippered bag to use to bring materials to clinic visits, such as their medications.

The intervention initially sought to schedule the orientation with the Nurse Guide on one clinic day and a subsequent visit with the provider. Given the difficulty for some women in getting days off from work and arranging transportation to the clinic, they reported wanting the orientation visit with the Nurse Guide and the provider visit on the same day. To address this, UNC modified its procedure to enable the Nurse Guide to cover some orientation material by phone and the rest on the day of their first provider visit.[27]

The Nurse Guide teaches women critical information and skills, facilitates access to resources, and provides a safe and authentic experience for the women. The Nurse Guide stresses the importance of medication adherence and provides adherence support, and regularly checks in with clients about their medication. She also helps explain laboratory results to clients and clarifies confusing information clients may have received from other providers.

The Nurse Guide teaches women critical information and skills, facilitates access to resources, and provides a safe and authentic experience for the women.

The Guide to Healing intervention sought to give these women a voice by involving them in their own care to move them to full autonomy and along the HIV care continuum. "You want women to feel that they can build a life that HIV fits into," says Dr. Byrd Quinlivan, M.D., principal investigator for the UNC SPNS project. "That they don't need to build their life around their disease. HIV doesn't go away but they can have whatever it is they want, and that's the piece I was thinking of when I put 'healing' into the title of our program," Dr. Quinlivan explains.[28]

Indeed, for many Guide to Healing clients, the clinic and associated support groups may be the only place where they can safely disclose their HIV and other issues and feel truly comfortable being themselves.

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[27] University of North Carolina at Chapel Hill. "Guide to Healing: Enhancing Access for HIV+ Women in the Rural South." In *Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative: An Intervention Monograph*. 2014.

[28] U.S. Department of Health and Human Services, Health Resources and Services Administration, HIV/AIDS Bureau. *The Ryan White HIV/AIDS Program Progress Report 2012: Ahead of the Curve.* 2012. Rockville, Maryland: Author.

Logic Model

Guide to Healing Intervention				
Resources	Activities	Outputs	Outcomes	Impact
• Nurse Guide • Clinic staff • Experience/ Expertise • Funding • Referring providers • Large, multi-disciplinary medical center/ one-stop shop	• Assess women's barriers to care • Develop an engagement and retention plan • Provide or refer clients to additional medical and support services as necessary to overcome barriers • Provide transportation assistance, if needed • Empower clients to make behavior changes via Motivational Interviewing and Self-Determination Theory	• Clients are able to manage HIV care and navigate health system within six to eight months • Clients remain engaged and retained in care	• Improved retention in care rates among target population • Better health outcomes • Improved client confidence and autonomy • Decreased risk of transmitting HIV to others	• Improve client engagement in care • Improve client autonomy, competency, and confidence

Staffing Requirements & Considerations

Staffing Capacity

To replicate the UNC Guide to Healing intervention, the following positions and capacity are necessary.

Program Manager

- Responsible for day-to-day operations
- Coordinates the women's support group

Nurse Guide

- Provides clinical, systems navigation, health education, and outreach/follow-up services to women in the intervention to engage and retain them in care and support their development of autonomy
- Facilitates more clinical education sessions to support group

Psychologist/Mental Health Counselor

- Provides mental health support services
- Conducts any psychological support group sessions
- Ideally onsite, but services could be provided through a community partner, particularly if psychologist/counselor can come to clinic (particularly on days that coincide with the women's support group).

Transportation assistance is also particularly important. This may be accomplished via gas cards or bus tokens. Clinics may also be able to partner with an organization that offers transportation services or arrange Medicaid vans for their clients.

Staff Characteristics

- Willingness to work with target population
- Culturally sensitive and competent
- Trained in Motivational Interviewing, Self-Determination Theory, strengths-based case management, trauma and HIV, and health literacy
- Familiarity with social determinants of health, particularly among women of color
- Patient, supportive, and collaborative
- Clear communicator
- For Nurse Guide, must be an RN, ideally with some mental health training
- Nurse Guide must be friendly, genuine, and able to connect with target population
- For mental health professional, a registered psychologist or social worker with mental health focus

Source: University of North Carolina at Chapel Hill. Guide to Healing: Enhancing Access for HIV+ Women in the Rural South. [Final report.] November 30, 2015.

Replication Tips for Intervention Procedures and Client Engagement

This section provides tips for readers interested in replicating the intervention and, where applicable, includes grantee examples for further context.

Recommendations for getting started:

- *Secure buy-in and educate staff.* All clinic representatives from front desk staff, social workers, Nurse Guide, other nurses, providers, and case managers play an important role in making women feel safe and welcomed at the clinic. As such, it is important they are clear about the intervention, the target audience, and the necessity to get these women into appointments quickly. Nurses, case managers, and the Nurse Guide all receive trainings around strengths-based case management, health literacy, and trauma. The Nurse Guide also undergoes additional training in Motivational Interviewing.

  To encourage referrals, providers who interface with the target population should be educated about the intervention. This includes health departments, ERs, primary care physicians, OB/GYNs, local case management agencies, disease intervention specialists, and local child and family programs who help victims of violence.

- *Clarify roles and responsibilities.* To clarify the Nurse Guide role and avoid turf wars, it's important to address any overlap and to develop a plan from which all parties can work. This is particularly true for other nursing staff and clinical social workers who are apt to have some overlap with the Nurse Guide.

  For UNC, clinic nurses check clients in and show them to their exam rooms and the Nurse Guide is the client's designated contact for phone calls and addressing medical problems. Once a client graduates out of the intervention, they are transitioned to one of the regular clinic nurses or social workers

Getting Started At-a-Glance


Secure buy-in and educate staff


Clarify roles and responsibilities


Receive client referrals


Conduct rapid intake appointments


Conduct first client visit


Provide patient navigation and care coordination services


Lead support group meetings


Develop a transition plan and transition clients out of the intervention

based on need. The social workers previously made phone calls to new clients to assess barriers and identify immediate needs and help prepare them for the first visit. To reduce the number of new people engaging with the client, the Nurse Guide took over these responsibilities, but consulted social workers for specific guidance and about community resources (e.g., housing assistance).

- *Receive client referrals.* Within one to two days of receiving a referral, the Nurse Guide will call the client and conduct a brief phone orientation and answer any questions. This orientation call introduces women to the clinic, gives them a chance to ask questions, and makes the first provider visit less intimidating.

- *Conduct rapid intake appointments.* Front desk staff need to schedule rapid intake appointments. This requires they identify the women as participants of the intervention, schedule an appointment quickly, and that providers have some flexibility in their schedules to accommodate these appointments as they arise.

- *Conduct first client visit.* The first clinic visit is twofold: the client meets with the Nurse Guide to complete her orientation and then meets with her provider. During the Nurse Guide meeting, the nurse assesses the client's autonomy and conducts the needs assessment if it wasn't completed via phone. Armed with this information the Nurse Guide develops a customized care plan. The client signs a policy acknowledging her understanding of the short-term nature of the intervention and that at the end of six to eight months she will be transitioned out of the Guide to Healing program and, as such, any additional services provided under this program will also end (e.g., gas cards, cell phones). The Nurse Guide pre-programs important phone numbers in the client's cell phone (either that the client has brought or that the clinic has provided to her). This includes numbers for the Nurse Guide's phone, ID Clinic, general clinic, case manager, and medical transportation.

  Phones are used by the Nurse Guide to contact women about upcoming appointments, lab results, and to respond to questions and referrals. Women may use the phone to contact the Nurse Guide or clinic staff for questions and concerns related to symptoms, medications, appointments, lab results, and barriers to care. At UNC, they were able to purchase cell phones for intervention participants; however, phones were locked to only be able to call and receive calls from authorized numbers input into the phone and cell phone usage was monitored. For replicating sites, if cell phones are not being purchased, the Nurse Guide should solicit additional numbers and information to be able to reach the women in case their primary phone number changes or is turned off.

  The Nurse Guide also provides clients with the orientation booklet that outlines key information about the clinic and intervention. (**For a list of information included in this booklet see page 7.**)

  The client is then seen by the HIV care provider who will serve as their primary provider at the ID Clinic (during the intervention and thereafter).

- *Provide patient navigation and care coordination services*. The Nurse Guide will provide patient and systems navigation and care coordination services for the next six to eight months. This includes HIV education, medication education and adherence counseling, referrals to other services as needed

(e.g., community resources, mental health services, substance use disorder treatment, financial counseling), reminder calls about upcoming appointments and upcoming support group meetings, and touching base with the women to see how they're doing.

The Nurse Guide serves as a conduit between the women and the clinic staff. The Nurse Guide follows the plan developed in the initial meeting (modifying as necessary) to guide women in their receipt of healthcare and support autonomy; she applies Motivational Interviewing and Self-Determination Theory to support these efforts. During this time it is critical that the Nurse Guide creates a warm, welcoming environment and safe space for the women as their connection to staff—particularly the Nurse Guide—will affect their ability and interest in engaging in care.

- *Lead support group meetings*. Support group meetings should be setup at a time and day most convenient to the women participating in the intervention and ideally held at the same location each time for ease. To identify topics of interest, conduct focus group interviews with the intervention participants about what they are most interested in discussing and what topics they struggle with the most. At UNC, some of the topics the women identified included talking to providers, dealing with stress, HIV basics, money management, and relationships.

  The support group meetings are led by either the Nurse Guide (typically for more clinically specific topics) or by a psychologist/mental health counselor. Occasionally, a guest speaker may participate as well.

- *Develop a transition plan and transition clients out of the intervention*. Over the course of the intervention, the Nurse Guide reminds clients about its time-limited nature. This helps manage client expectations. The Nurse Guide praises the positive behavior changes the women have made and underscores the important skills they've developed. The Nurse Guide prepares an ID Clinic nurse or social worker to become the new primary point of contact for the client and introduces the two for a warm handoff. The client's successful graduation from the intervention is celebrated.

Securing Buy-In

The Guide to Healing team conducted qualitative interviews with providers and ID Clinic staff members to explore perceptions of implementing the intervention within the clinic prior to its implementation. Key to securing buy-in was having the Nurse Guide spend time getting to know staff members throughout the clinic and referring providers.

It is important to have support from clinic leadership in the planning and implementation phases, as well as an identified supervisor for the Nurse Guide to help ensure fidelity of the model and provide assistance to her as necessary. For example, UNC secured clinic staff buy-in from the Clinic Director and Associate Clinic Director and this facilitated the Nurse Guide being "embedded" within the clinic's operations as well as sharing office space with a social worker.

It's important to have support from clinic leadership in the planning and implementation phases, as well as an identified supervisor for the Nurse Guide to help ensure fidelity of the model and provide assistance to her as necessary.

To avoid confusion and a sense of competition, it's important to clarify roles and address any overlap of job functions between the Nurse Guide and existing staff. The Nurse Guide is not replacing any one member on the team but, rather, is a newly carved out role devoted to a specific hard-to-reach population who requires more intensive assistance.

Regularly scheduled meetings with the Nurse Guide and other stakeholders can also help ensure the intervention is proceeding as planned, meeting the needs of the women, not interfering with other clinic operations, and help identify any course corrections as necessary.

Overcoming Implementation Challenges

The intervention intended to have the Nurse Guide provide initial HIV education and clinic orientation *at the clinic* and *before* the client's first formal provider visit; however, in some cases, the women called the front desk to make appointments and the provider visit preceded the Nurse Guide visit. When this happened, the women viewed the Nurse Guide visit and orientation as an added burden, especially because they had already been to the clinic and many traveled long distances to get there. As mentioned earlier, some women struggled with getting time off of work and/or arranging transportation to the clinic so two visits were viewed as overly burdensome. As such, UNC modified its procedure to enable the Nurse Guide to cover some orientation material by phone and the rest on the day of the client's first provider visit.[29]

Other challenges included women meeting briefly with the Nurse Guide and then falling out of care and becoming unreachable. As such, modifications to the original intervention steps (e.g., orientation, engagement, maintenance, and discharge) were required. To help address this, a standardized set of phone call attempts over four to six weeks occurred. UNC also developed criteria to help the Nurse Guide better identify clients requiring even more intensive engagement and education upfront to try and prevent any drop-offs from care.

UNC experimented with the timing of transitions and handoffs. Initially the timeline for transitioning clients was six months; however, some women did not appear ready in that timeframe so the clinic extended this to 12 months. The longer timeframe proved challenging because women had developed not only a deep relationship with the Nurse Guide by then but, in some cases more reliance rather than the autonomy the intervention sought to develop. Thus, women felt hurt and rejected by having to say goodbye to the Nurse Guide, even though the short-term nature of the intervention was stressed. UNC modified this to six to eight months and found that to be an adequate amount of time and also offer flexibility for clients requiring more time. UNC also increased the frequency of conversations about the time-limited nature of the intervention and began discussing transition plans as early as three months into the intervention to begin to prepare them. As they discussed transitioning, the Nurse Guide focused on celebrating achievements and their graduation from the program.

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[29] University of North Carolina at Chapel Hill. "Guide to Healing: Enhancing Access for HIV+ Women in the Rural South." In *Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative: An Intervention Monograph*. 2014.

Because many providers are only in clinic part-time, one challenge was making time for them to learn about the intervention and the role of the Nurse Guide. If providers don't know about the intervention then they can't make referrals to it. To overcome this requires reviewing provider schedules to identify a time to meet with them, adding a brief overview of the intervention to meeting agendas where providers will be in attendance, and educating nurse and social support staff at these sites so that they can act as champions of the program and help with referrals. Informational pamphlets or flyers about the intervention in clinic waiting rooms can also help increase visibility among clients and encourage providers to take note.

Another challenge is the medical complexity of the women. A large number of the women had cognitive impairments and complex and urgent medical needs, requiring the Nurse Guide to additionally provide education and support to family members and conduct more system navigation services than originally planned. Where applicable, the Nurse Guide facilitated nursing home placements and used the longer timeframe afforded by the intervention in order to provide these additional services.

Promoting Sustainability

Discussions around sustainability occurred early and often. Refresher trainings around strengths-based case management, health literacy, and trauma were provided to staff to continue to enhance their ability to work with female clients and ensure new nurses and social workers had received these trainings.
The Nurse Guide discussed transferring a portion of her activities to staff and midway through the final year of the SPNS grant, began doing so. This enabled the Nurse Guide to provide direction as necessary, answer questions, and ensure a smooth transition of responsibilities as well as the continuation of her activities.

The orientation guide booklet was adapted to be more general and was subsequently adopted as a standard of care resource for all clients. Additionally, all new clients receive an orientation to care appointment with labs prior to their first provider appointment—something initiated during the Guide to Healing intervention and now sustained clinic-wide. This has helped decrease the number of no-shows.

Conclusion

The Nurse Guide provided a median of six indirect contacts (one and a half hours total) and 11 direct contacts (three hours total) to each woman. Findings from the study suggest that women's experiences with the Nurse Guide were overwhelmingly positive. Although women experienced a sense of loss when transitioning out of the program, clients described their interactions with the Nurse Guide as increasing their hope about successfully living with HIV and providing them with the knowledge, skills, confidence, and access to resources in order to do so.[30]

[30] Sullivan KA, Schultz K, Ramaiya M, et al. Experiences of Women of Color with a Nurse Patient Navigator Program for Linkage and Engagement in HIV Care. *AIDS Patient Care and STDs*. 2015;29(Suppl 1):S49–54.

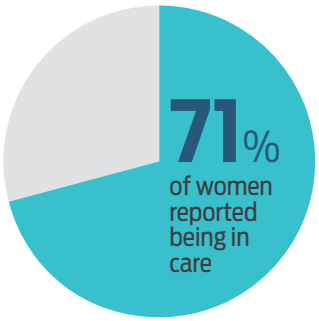
The findings suggest that a properly trained nurse can provide both critical medical as well as psychosocial support and successfully facilitate client HIV self-management, representing a promising approach to patient navigation for HIV-positive women of color.[31] This target population has medically complex conditions, a clustering of interacting epidemics of substance use disorder, violence, HIV, mental health, and sexual risk-taking. The high prevalence of these co-occurring—and mutually reinforcing—conditions suggest a need for comprehensive, multifaceted interventions, such as this one, to promote engagement into care and a need for a strengths-based approach that nurses are uniquely positioned to help support.[32,33]

The women served through the Guide to Healing intervention were high-need clients, but they achieved promising retention and viral suppression rates.

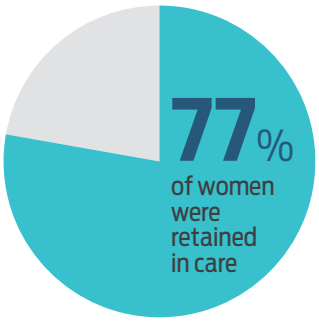
At recruitment,

- **20.5%** of Guide to Healing clients were homeless or fragilely housed and **2.5%** were in psychiatric or substance abuse treatment centers
- **35%** were disabled
- **30%** had income of less than $500 a month.

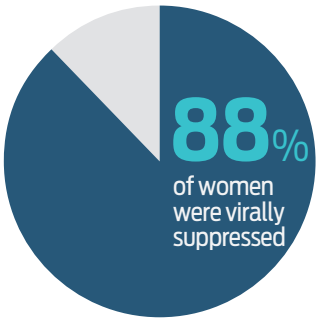
At baseline:



At project conclusion:



At project conclusion:



Source: University of North Carolina at Chapel Hill. "Guide to Healing: Enhancing Access for HIV+ Women in the Rural South." In *Enhancing Access to and Retention in Quality HIV Care for Women of Color Initiative: An Intervention Monograph*. 2014.

[31] University of North Carolina at Chapel Hill. Guide to Healing: Enhancing Access for HIV+ Women in the Rural South. [Final report.] November 30, 2015.
[32] Sullivan KA, Schultz K, Ramaiya M, et al. Experiences of Women of Color with a Nurse Patient Navigator Program for Linkage and Engagement in HIV Care. *AIDS Patient Care and STDs*. 2015;29(Suppl 1):S49–54.
[33] Sullivan KA, Messer LC, Quinlivan EB. Substance Abuse, Violence, and HIV/AIDS (SAVA) Syndemic Effects on Viral Suppression Among HIV Positive Women of Color. AIDS Patient Care and STDs. 2015;29(Suppl 1);S42–48.

Tested and Proven HIV Strategies

The Integrating HIV Innovative Practices (IHIP) project is an outgrowth of SPNS. HAB created IHIP to share knowledge gained from SPNS interventions, and to promote their replication. IHIP takes tested innovations and turns them into practice. IHIP is where training meets implementation, with the intended results being more informed providers, better care delivery and, ultimately, healthier clients and communities.

This intervention guide is part of a larger series of resources and capacity building assistance activities including webinars about the interventions, a dedicated IHIP listserv, and a help desk.

Tell Us Your Replication Story!

Are you planning to implement this intervention? Have you already started or know someone who has? We want to hear from you. Please reach out to **SPNS@hrsa.gov** and let us know about your replication story.

Other Resources

- SPNS Enhancing Access to and Retention in Quality HIV Care for Women of Color (WOC) Initiative: **https://hab.hrsa.gov/about-ryan-white-hivaids-program/spns-women-color**
- Chapter 5 in *Ahead of the Curve: Ryan White HIV/AIDS Program Progress Report:* **https://hab.hrsa.gov/sites/default/files/hab/data/biennialreports/progressreport2012.pdf**

Appendix: SWOT Analysis

SWOT is an acronym for Strengths, Weaknesses, Opportunities, and Threats. A SWOT analysis is a structured planning method that can be used to assess the viability of a project or intervention. By conducting a SWOT analysis in advance of an intervention, organizations can proactively identify challenges before they occur and think through how best to leverage their organizational strengths and opportunities to improve future performance.

UNC Guide to Healing Intervention	
Internal	**Strengths:** Nurse-led patient navigation services, inclusive of planning, evidence-based approach (e.g., Self-Determination Theory, Motivational Interviewing) within a large, multidisciplinary one-stop-shop medical facility
	Weaknesses: Delineating staff roles and responsibilities with other nurses and social workers. Educating providers about the intervention so they can refer clients.
External	**Opportunities:** Offers a model for other agencies to replicate. May have implications for other hard-to-reach populations.
	Threats: Lack of funding or staff time to support Nurse Guide activities. Lack of transportation support to facilitate client access to care.

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