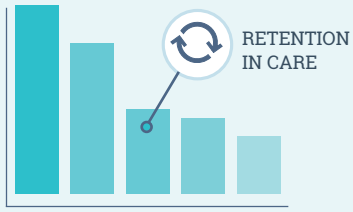
Enhanced Patient Navigation for HIV-Positive Women of Color

DISSEMINATION OF EVIDENCE-INFORMED INTERVENTIONS

Intervention Summary



The Enhanced Patient Navigation for HIV-Positive Women of Color intervention is designed to retain HIV-positive Women of Color (WoC) in HIV primary care after receiving support, education, and coaching from a patient navigator. Patient navigators are critical members of the health care team focused on reducing barriers to care for the patient at the individual, agency, and system levels. While engaging with patients, patient navigators lend emotional, practical, and social support; provide education on topics related to living with HIV and navigating the health care system; and support both patients and the health care team in coordinating services. In this intervention, patient navigators will work with HIV-positive WoC who are experiencing at least one of the following challenges: have fallen out of care for 6 months or more, have missed 2 or more appointments in the prior 6 months, are loosely engaged in care (have cancelled or missed appointments),[1] are not virally suppressed, and/or have multiple co-morbidities.

This intervention is intended for organizations, agencies, and clinics considering integrating a structured patient-navigation model to increase retention of HIV-positive WoC to ultimately improve health outcomes.

Professional Literature

Reaching, linking, and retaining people living with HIV (PLWH), including Women of Color (WoC) in health care, are federal priorities and are integral steps of the HIV Care Continuum due to their importance in increasing viral load suppression (the main goal of HIV treatment and a key factor in prevention). Pecoraro et al. (2013) found, "patients dropped out of care because of multiple factors such as substance abuse, unstable housing, psychiatric disorders, incarceration, side-effects from HIV medication, denial about diagnosis, relocation, stigma, forgetfulness, and problems with the patient's medical home."[2] Higa et al. found, "Patients retained in care have decreased likelihood of developing HIV opportunistic infections, greater viral load suppression, and increased survival rates [and] poor retention is associated with higher viral loads and lower CD4 counts increased HIV risk behavior, and more hospitalizations."[3] According to Higa et al., lower retention in HIV care is associated with client-level factors including:

- being female;
- ethnic and racial minority status;
- minimal social support;
- having competing caregiver responsibilities;
- having mental health or substance abuse issues;
- lack of understanding regarding health insurance;
- discomfort in talking to health care providers;
- stigma; and
- negative perceptions of the health care system.[4]

Defining "out of care" and identifying out-of-care patients is complex. Patient engagement in care (i.e. attending medical visits and adherence to treatment) is fluid and requires a proxy measure (e.g. viral load test, appointment attendance, etc.) to use for patient evaluation and assessment. PLWH do not stay on one point of the care continuum throughout their lifespan, and movement along the care continuum is not linear.[5] PLWH can also cycle in and out of care. Successful retention in care can break this cycle and improve patient health outcomes.

Underserved and marginalized populations, including many racial or ethnic minority communities, face numerous structural, financial, and cultural barriers to linking to, re-engaging in, and being retained in care.[6] Women of color, especially African American women, "currently represent the majority among women living with HIV/AIDS … and face numerous social and economic factors that both increase their vulnerability to HIV infection and decrease their access to care."[7] Subsequent negative outcomes are largely due to the inequitable distribution of power, money, and resources.[8] Linkage and re-engagement in care leads to improved health outcomes[9] and retention in care is an independent predictor of survival.[10,11] Mugavero et al. found, "patients with missed visits in the year after establishing initial outpatient HIV care had more than twice the rate of subsequent mortality, compared with patients who did not miss visits, even when controlling for baseline CD4 count and antiretroviral receipt within the first year." [12] Giordano et al. found, "Patients out of care for as little as 3 months beginning in the first year of therapy had worse survival after adjusting for age, CD4 count, plasma HIV concentration, hepatitis C virus co-infection, and other comorbid conditions."[13]

Women of color currently represent **the majority** among women living with HIV/AIDS.

Navigation services in health care have been shown to improve HIV treatment outcomes, patient satisfaction, and mental health outcomes, and to increase patient self-management.[14] Findings from a patient navigation program among African-American/Black women living with HIV suggest that patient navigators provided patients with necessary knowledge, skills, and access to resources to be able to manage their HIV.[15] Additionally, participants in this study felt more hopeful about successfully living with HIV and identified the value of the emotional support provided by the nurse patient navigator.[16]

The patient navigation model originally evolved as a strategy to eliminate barriers to cancer care among vulnerable populations by supporting the patient in moving through a complex and fragmented health care system.[17] The work of patient navigation is guided by the principles of disease management and cultural sensitivity,[18] and enhancing the ability to connect patients with care while establishing trust. Core patient navigation activities are meant to remove patient and system barriers so that patients may better receive health care services.[19,20,21,22] Parker et al. (2010) divided core activities of patient navigators into two categories: tasks and networks. Task categories include navigation, facilitation, maintaining systems, and documenting activities. Patient navigation work encompassed in the network category included engagement with patients, clinical providers, nonclinical staff; formal and informal support; and documenting in medical record systems (and subsequent communication with team members).[23] Navigators come from various backgrounds, experiences, and education levels. There is no clear evidence to support the required background of a navigator. Patient navigators share many qualifications, skills, and responsibilities as other support service providers in the clinic setting (advocates, health educators, and case managers) yet their work has a "predetermined endpoint" which is dependent on the parameters intervention.[24]

Theoretical Basis

A theory is a combination of, "interrelated concepts, definitions, and propositions that present a systematic view of events or situations by specifying relations amount variables, in order to explain or predict the events or situations."[25] By grounding an intervention in theory, the component parts are intentionally sequenced to build off of one another to facilitate a change in health behavior.

The Enhanced Patient Navigation for HIV Positive Women of Color intervention is based on the conceptual framework presented in the 1993 Institute of Medicine report *Access to Healthcare in America.*[26] The framework presented by the IOM includes four categories: barriers, uses of services, mediators, and outcomes. Barriers are categorized as being structural (availability, organization, transportation), financial (insurance coverage, reimbursement, public support), and personal (acceptability, cultural, language, attitudes, education/income). Uses of services included visits and procedures. Mediators included appropriateness, efficacy of treatment, quality of providers, and patient adherence. Outcomes included health status (mortality, morbidity, well-being, functioning) and equity of services.

Bradford et al. (2007) found that an adapted patient navigation model was effective among patients who were loosely engaged in care or who had fallen out of care in reducing barriers (e.g. lack of insurance, lack of information related to services available), increasing mediators (e.g. linking to case management, engagement with health care providers), and improving health outcomes (e.g. viral load suppression, health-related quality of life).[27]

Intervention Components and Activities

This Enhanced Patient Navigation for HIV-Positive Women of Color intervention targets HIV-positive WoC 18 years and older who meet the following criteria: have not been seen at the clinic in the prior 6 months; have missed 2 or more appointments in the prior 6 months; are loosely engaged in care (have cancelled or missed appointments in the prior 12 months); are not virally suppressed; and/or have multiple co-morbidities. The intervention focuses on providing enhanced services in addition to the clinic's existing case management standard of care and support to patients, building patient trust, meeting patient priorities first (putting the patients priorities ahead of service provider priorities), increasing patient health literacy, strengthening patient health beliefs, and developing patient self-efficacy in managing their care. Services are tailored to the individual patient and typically include appointment scheduling, transportation, accompaniment, referrals, health education, and counseling. The goal of the Enhanced Patient Navigation for HIV-Positive Women of Color intervention is to better understand patient needs, help patients to optimize care, to ultimately develop patient autonomy for their care and to retain patients in HIV primary care.

Intervention components and activities that occur at the patient level include:

- Contact eligible patients and initiate a process of developing rapport and providing support to patients using motivational interviewing[28] and trauma informed care principles through:
  a. Assessing patient barriers, needs, and acuity;
  b. Developing a patient action plan with the patient;
  c. Implementing the action plan; and
  d. Monitoring the patient action plan.

- Conduct structured sessions on health education topics including:
  a. HIV transmission and the life cycle of HIV;
  b. Understanding lab values;
  c. HIV medications;
  d. Drug resistance and adherence;
  e. Understanding and managing side effects;
  f. Effective communication and self-advocacy;
  g. Disclosure and stigma;
  h. Mental health;
  i. Substance use; and
  j. Harm and risk reduction.
- Support patients in obtaining referrals for needed services (including transportation, housing, etc.).[29]
- Offer accompaniment to internal and external appointments.
- Work in tandem with standard case management throughout the intervention time period.
- Conduct the transition to the standard of care (standard case management) using a standard transition protocol.

Patient navigators will work with patients for a minimum of 6 months and a suggested maximum of 12 months. After 6 months, patients will be reassessed every 3 months using an acuity based system to determine if they still need the support of the navigator. If a patient reassessment shows that they still need patient navigation services after 12 months, the patient will still be eligible for enhanced navigation services. Patients who are transitioned to the standard of care after receiving the enhanced patient navigation intervention and are subsequently lost to care will be eligible to receive services from a patient navigator.

Intervention components and activities that occur at the agency and systems level include:

- Creation of a monthly eligible patient list using both electronic systems and local public health data;
- Use of clinic team members to identify patients who meet the eligibility criteria for participating in the intervention;
- Assign eligible patients to patient navigators;
- Provide navigators with access to electronic medical record system(s) to document activities and keep informed about their clients progress;
- Incorporate navigators into the clinical team to facilitate communication between clinicians and navigators to best meet the patient's needs;
- Facilitate ongoing, consistent, and bidirectional communication between intervention staff and community partners (who provide support services); and
- Facilitation of weekly administrative supervision sessions and monthly clinical supervision (both group and individual) for the navigator provider.

Staffing Requirements

The following staff positions need to be developed and filled in order to successfully implement the intervention.

STAFF TITLE	DESCRIPTION
Linkage staff	
PATIENT NAVIGATOR	Patient navigators in the HIV Patient Navigation intervention will have a bachelors (or equivalent) level of education, training in a related social service or human service field, and experience working in the community and with co-morbidities. The patient navigator is responsible for: ▸ Engaging eligible patients; ▸ Providing patient education sessions; ▸ Documenting services to patient in the electronic health record and updating the patient care plan; ▸ Connecting patients to services (care coordination); ▸ Accompanying patients to appointments; ▸ Providing reminder phone calls; ▸ Arranging transportation; ▸ Assisting with medication and adherence support; ▸ Assisting with arranging child care (where applicable); ▸ Explaining information from medical providers; ▸ Developing a patient action plan to help patients achieve their goals; and ▸ Transitioning patients to standard of care. The Patient Navigator is expected to attend weekly conferences with the health care team and case conferences. Patient navigators will receive regular administrative and clinical supervision.
ADMINISTRATIVE NAVIGATION SUPERVISOR	The Administrative Navigation Supervisor is responsible for: ▸ Providing weekly administrative supervision of navigator(s); ▸ Supervising the creation of a monthly eligible patient list; ▸ Conferring with clinical team to finalize monthly eligible patient list; ▸ Assigning eligible patients to the patient navigator.
CLINICAL NAVIGATION SUPERVISOR	The Clinical Navigation Supervisor is responsible for: ▸ Ensuring compliance with program and clinical standards of practice; ▸ Ensuring implementation of department-level quality assurance protocols and activities; ▸ Participating in case conferencing (as needed); ▸ Providing of monthly or as requested individual clinical supervision patient navigator(s); ▸ Providing of monthly group clinical supervision to intervention team.
DATA MANAGER	The Data Manager is responsible for: ▸ Creating monthly out-of-care lists to identify eligible patients (may need to work with other staff to create list); ▸ Collecting and submitting data required for multi-site evaluation; and ▸ Coordinating the collection of patient surveys, encounter forms, basic chart data abstraction, and implementation measures, and reporting them to the Dissemination and Evaluation Center (DEC).

Staff Characteristics

There are additional clinic staff who are important to the success of the intervention. These positions may not be considered "intervention staff," yet their training, support, and engagement is essential. All staff need to demonstrate:

- culturally sensitive services to reduce stigma;
- ability to provide trauma-informed care;
- commitment to support the aims and activities of the intervention;
- a team-based, inter-professional approach;
- genuine desire to work with women of color (which includes meeting patient priorities first, be able to engender patient trust, and be welcoming and accessible); and
- thorough and documented communication under HIPAA requirements.

Programmatic Requirements

The following are programmatic requirements that need to be addressed prior to implementation in order to facilitate a successful implementation:

- Determine methods for identifying patients population based on the intervention inclusion criteria;
- Train patient navigators;
- Establish relationships with community based agencies and clarify the mechanisms to generate referrals;
- Determine when and how to transition patients to the standard of care;
- Customize existing or design new assessment and transition protocols;
- Identification of who will provide administrative and clinical supervision to patient navigators;
- Train patient navigator supervisors (both clinical and administrative);
- Establish administrative, programmatic, and clinical support for intervention-related training of patient navigators; and
- Ensure patient navigators have access to patient information to both record their activities and review record for pertinent information prior to meetings with patients.

The following are programmatic requirements that need to be addressed throughout implementation in order to facilitate a successful implementation:

- Weekly administrative supervision of patient navigators by the administrative supervisor;
- Monthly and as requested clinical supervision of patient navigators by the clinical supervisor;
- Inclusion of patient navigators in team case conferencing meetings;
- Grant navigators access to patient EMR information;
- Create open lines of communication between patient navigators, case managers, and clinical staff; and
- Implementation of policies that address safety and boundary issues.

Costs

Estimated costs for navigation-like interventions with the goal of linking HIV patients to care ranged from $97 to $536 per month per patient from a provider perspective and $44 to $545 per month per patient from a societal perspective.[30] For interventions with the goal of retention in care the cost per patient per year ranged from $207 to $531 from a provider perspective.[31] These interventions used a variety of approaches including peer/patient navigation, motivational interviewing, community health workers, and care coordination.

Unpublished results of the SMAIF Peer Re-Engagement study, found the cost per patient per month was $289. The intervention included re-engaging and retaining newly diagnosed and patients who had fallen out of care in the prior 4 months.

Resources

OVERVIEW OF PRIOR SPNS INITIATIVES

- Targeted HIV Outreach & Intervention Models for Underserved HIV-positive Populations Not In Care www.hab.hrsa.gov/abouthab/special/outreachandintervention.html.
- The Costs and Effects of Outreach Strategies that Engage and Retain People with HIV/AIDS in Primary Care: www.hab.hrsa.gov/abouthab/files/outreachstrategiesmar10.pdf.
- Outreach: Engaging People in HIV Care: Summary of a HRSA/HAB 2005 Consultation on Linking PLWH into Care www.hab.hrsa.gov/abouthab/files/hivoutreachaug06.pdf.

IMPLEMENTATION/REPLICATION MATERIALS

- Making the Connection: Promoting Engagement and Retention in HIV Medical Care Among Hard-to-Reach Populations https://careacttarget.org/library/making-connection-promoting-engagement-and-retention-hiv-medical-care-among-hard-reach.
- Innovative Approaches to Engaging Hard-to-Reach Populations Living with HIV/AIDS into Care
  - Training Manual: https://careacttarget.org/library/innovative-approaches-engaging-hard-reach-populations-living-hivaids-care-training-manual.
  - Curriculum: https://careacttarget.org/library/innovative-approaches-engaging-hard-reach-populations-living-hivaids-care-curriculum.

BACKGROUND INFORMATION

- Brief Report: Predictors of Optimal HIV Appointment Adherence in Minority Youth: A Prospective Study. www.jpepsy.oxfordjournals.org/content/35/9/1011.long.
- The Association Between Life Chaos, Health Care Use, and Health Status Among HIV-infected Persons. www.ncbi.nlm.nih.gov/pmc/articles/PMC2219764/.
- Retention Challenges for a Community-based HIV Primary Care Clinic and Implications for Intervention. www.ncbi.nlm.nih.gov/pmc/articles/PMC4062571/.

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