Tailoring HIV Care for Black Populations

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Abstract

Background: Research has shown integrating community health workers (CHWs) into the formal healthcare system can improve outcomes for Black people living with HIV (BPLH), yet the standard of care continues to be delivered through the traditional clinic-based framework.

Objective: Herein, we discuss the design and feasibility of a clinic-embedded CHW strategy to improve ART adherence among BPLH in Miami-Dade County, a designated priority region for the U.S. Department of Health and Human Services' Ending the HIV Epidemic Initiative (EHE).

Methods: From December 2022 – September 2023, three CHWs were trained and integrated into the hospital workflow as members of the clinical team. Ten Black adults with an HIV viral load over 200 copies/mL were enrolled to received three-months of CHW support focused on navigating the health system and addressing poor social determinants of health. Intervention feasibility was based on four criteria: recruitment rate, demographic composition, study fidelity, and qualitative feedback on implementation from the CHW team.

Results: Participants were recruited at a rate of 5.7 per month, and the sample was evenly distributed between men and women. Retention was moderately strong, with seven of the ten of participants attending more than 75% of CHW sessions. Qualitative feedback reflected CHW perceptions on clinical interactions and intervention length.

Conclusions: Outcomes indicate a clinic-integrated CHW approach is a feasible and acceptable methodology to address adverse social determinants and improve HIV treatment adherence among BPLH. By offering targeted social and clinical support, CHWs may be a promising solution to achieve sustained viral suppression and care engagement for BPLH.

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ABSTRACT

Background: Research has shown integrating community health workers (CHWs) into the formal healthcare system can improve outcomes for people living with HIV (PLH), yet there is limited literature exploring this framework among marginalized minority populations. Objective: Herein, we discuss the feasibility of a clinic embedded CHW strategy to improve ART adherence among Black PLH in Miami-Dade County, a designated priority region for the U.S. Department of Health and Human Services' Ending the HIV Epidemic Initiative (EHE). Methods: From December 2022 – September 2023, three CHWs were trained and integrated into the hospital workflow to provide support as members of the clinical team. Ten Black adults with an HIV viral load over 200 copies/mL were enrolled to received three-months of CHW support focused on navigating the health system and addressing poor social determinants of health. Intervention feasibility was based on four criteria: recruitment rate, demographic composition, study fidelity, and qualitative feedback on CHW perceptions. Results: Participants were recruited at a rate of 5.7 per month, with the sample evenly distributed between men and women. Retention was moderately strong, with seven of the ten (70%) of participants attending more than 75% of CHW sessions. Qualitative feedback reflected CHW perceptions on clinical interactions and intervention length. Conclusion: Outcomes indicate a clinic-integrated CHW approach is a feasible and acceptable methodology to address adverse social determinants and improve HIV treatment adherence. By offering targeted social and clinical support, CHWs may be a promising solution to achieve sustained viral suppression and care engagement for BPLH.

Tailoring HIV Care for Black Populations

INTRODUCTION

Advances in antiretroviral therapies (ART) have led to significant improvements in HIV treatment and management, transforming the disease from a fatal diagnosis to a manageable chronic illness. Despite this, Black populations are disproportionately impacted by poor HIV outcomes, and the incidence rate among the Black communities of in Miami-Dade is among the highest in the Nation. Accounting for 15% of the region’s population, Black Miamians comprise nearly 70% of the region’s AIDS-related deaths, highlighting vast underutilization of HIV resources. [1, 2]

The complex determinants of health and health behavior that contribute to HIV disparities stem from systemic discrimination that has historically limited access to services and diminished continuity of care for marginalized populations.[3] The legacy of such discriminatory care continues to impact these communities, as those who were barred from equitable health services are often the same to face the greatest burden of poor HIV outcomes.[4] As innovative HIV treatment and prevention modalities continue to emerge, underutilization of such advances by Black Miamians have become even more prominent, highlighting the need for evidence-based HIV interventions that are tailored to reach those suffering the greatest HIV burden.

Community health worker (CHW) interventions have emerged as an efficacious strategy to improve HIV outcomes in Black populations.[5] Trusted members of the community, CHWs have the capacity to deliver patient-centered care using culturally-adapted strategies tailored to the populations they serve.[6] As the interface between the formal health care system in highly vulnerable communities, CHWs facilitate collaboration among healthcare providers, patients, and social supports, such as family and friends – an integral factor in improving health and promoting wellness among people living with HIV (PLH). Further, by focusing on the delivery of HIV services that “meet people where they are”, CHWs are able to facilitate the communities of greatest need in navigating the social and structural barriers to engagement in care, such as stable housing, food security, drug assistance, and immigration status.

For example, CHWs in our formative studies assessed risk behaviors, provided peer-education on treatment adherence, and navigated patients to the appropriate social support services, including food banks, cultural groups, churches, and HIV support groups. Functioning as peers, HIV educators, and liaisons to the healthcare system, CHWs provided BPLH with the multifaceted support needed to improve medication adherence and significantly reduce their HIV viral loads.

Building upon the CHW framework, research suggests integrating CHWs into the formal healthcare system could further improve access to treatment and preventive services for people living with HIV (PLH).[7, 8] However, there is limited literature on clinic-integrated CHW models for minority populations, and less so on their unique consideration of the cultural nuances and social barriers that diminish access to care among marginalized communities of color.[9, 10] To this end, we developed the **I**ntegrated **N**avigation and **S**upport for **T**reatment, **A**dherence, **C**ounseling, and **Re**search (INSTACARE) intervention: a CHW strategy to improve ART adherence and reduce HIV viral loads among Black PLH. Herein, we discuss the design and examine the feasibility, fidelity, and acceptability of the intervention within a clinical setting, and the potential impacts of the intervention in achieving the identified objectives.

METHODS

From December 2022 – May 2023, we conducted a pilot feasibility study aimed at determining the fidelity, acceptability, and potential impact of a CHW intervention for Black adults in care at an outpatient HIV clinic at a large safety net hospital in Miami-Dade.[11] Prior to study onset, this research was reviewed and approved by the University’s Institutional Review Board (IRB # 20201234).

Study Design

Utilizing the Social Ecological Model, CHWs delivered three-months of patient support informed by the formative qualitative research for this study.[12] Specifically, this clinic-integrated intervention focused on challenges to viral suppression and the complex multilevel barriers to care experienced by Miami’s BPLH, including restrictive HIV policies, logistical hurdles to navigating care, and stigma across clinical and community-based settings.

CHW Intervention

CHW integration into the Outpatient Clinical Care Team involved CHWs shadowing the HIV providers. Shadowing was an on-site learning process in which the CHWs observed and followed clinic staff during patient interactions to learn about the wide range of medical, mental health, and social support resources available through the clinic. CHWs established a rotating schedule to ensure at least one person was stationed in the clinic daily to network with providers, encourage collaboration with clinic staff, and facilitate immediate study eligibility screening for walk-in patients. CHWs also accompanied patients to appointments to facilitate communication between patients and providers, as well as aid in with scheduling appointments and referrals. When available, CHWs also attended Case Manager meetings when their patients were being discussed. At these meetings, CHWs helped to inform the healthcare team of areas of concern and contribute to the development of intervention plans inclusive of the information CHWs learned through interacting with their patients. These clinical activities were conducted in addition to the home visits and off-hours communication CHWs traditionally provide to their participants as part of their patient-centered approach to care delivery.

For the first 30 days of enrollment, CHWs meet with participants on a weekly basis to discuss their challenges and develop an action plan on how to address those barriers. For example, if employment was the concern, CHWs would offer to help the participant identify a job placement agency and schedule an interview. After the first 30 days of enrollment, meetings were reduced from weekly to biweekly. Some participants, however, were kept on a weekly meeting schedule depending on the complexity of support needed.

Study team meetings with the CHWs, research associates, and the data manger occurred weekly. In team meetings, CHWs were encouraged to share documentation on any barriers they encountered in adhering to the protocol or in securing services and resources for their patients.

CHW Characteristics

Three community health workers were selected for pilot implementation. All three CHWs were Black women born and raised within the high priority jurisdictions in which our participants reside. One CHW was of Haitian descent and fluent in both English and Creole. All three women had prior professional experience in social work, and two were considered “senior CHWs” with more than 20 years of experience in HIV care and 15-years of experience as community health workers. All CHWs completed HIV counseling coursework provided by the Florida Department of Health, which introduces learners to standardized information regarding the basics of HIV as it pertains to risk reduction, testing, and linkage. CHWs also completed human subjects research training provided by the Collaborative Institutional Training Initiative (CITI Program), including the development of human subject protections, ethical considerations for vulnerable populations, and current regulatory and guidance information.

Participant Recruitment

Eligible participants included English-speaking, Black patients 18 years of age or older, living with an unsuppressed HIV viral load, as indicated by more than 200 copies of HIV per mL of blood. From December 2022 – May 2023, participants were recruited through referral by the case manager (CM) or charge nurse on shift, who would identify eligible participants on the clinic’s appointment schedule. The Nurse/CM briefly described the study to potential participants. Those who expressed interest in participating were then referred to a CHW to learn more about the study. CHWs then met potential participants directly in the clinic or called them at a later time to provide additional study details. Permission was given during the informed consent process to allow for CHWs to access each patient’s viral load data.

Feasibility Measures

Intervention feasibility was based on four criteria: recruitment rate, demographic composition, study fidelity, and qualitative feedback on CHW perceptions.

Recruitment Rate**:** Participant recruitment rate was calculated by dividing the total number of participants enrolled by the number of months in which recruitment occurred. A target recruitment rate was derived from our prior research studies examining the impact of CHW support on HIV outcomes for PLH. Based on recruitment data from our prior research, a four–person team of full-time CHWs could recruit approximately fourteen participants per month. Scaling this value to align with the three-person team employed in this study, a recruitment rate of ten participants per month was selected.

Demographic Composition**:** We sought to recruit an equal distribution of men and women within our eligibility criteria. Characteristics of the sample, including frequencies and descriptive statistics, are displayed in *Table 1*.

Table 1. Baseline characteristics of patients enrolled in the INSTACARE feasibility pilot (*n*=10)

Characteristics	
Sex (female): n (%)	5 (50%)
Age (years): median, (IQR)	55 (45-58)
Ethnicity (Haitian): n (%)	3 (30%)
HIV Viral Load (copies/mL): range	214 – 343,000
Primary Barrier to Care	
Basic Physiological Needs, n (%)	5 (50%)
Social Support, n (%)	3 (30%)
Healthcare Navigation, n (%)	2 (20%)

Study Fidelity**:** Study fidelity, calculated by the number of successful patient visits over the number of visits attempted,[13] was abstracted from CHW case notes. Literature on acceptable retention rates for pilot interventions suggest “at least 70% of participants in each arm should attend at least 70% sessions.” [14, 15] During the three-month intervention period, CHWs kept case notes and weekly activity logs to document their patient encounters and attempted visits.

***CHW Experience*:** CHWs participated in a semi-structured focus group at the close of the pilot. Guided by the Consolidated Framework for Implementation Research, a research associate queried CHWs for their perceptions of the successes and failures in protocol implementation, acceptance of CHWs within the clinical framework, and suggestions for improving the approach. Data from the CHW focus group were analyzed by two graduate-level researchers trained in qualitative data analysis. A rapid thematic approach was employed, in which each analyst independently summarized the focus group recording down to its key points and reviewed their summary for emerging themes. The analysts then met to compare their findings, discuss any edits, and finalize the list.

Preliminary Efficacy Measures

Three survey instruments were examined to assess ease of delivery and ability to capture patient experiences pre- and post-intervention. The measurements – collectively called the INSTACARE Health Survey (INSTACARE-HS) – combined three validated assessments based on the barriers and challenges previously identified in our formative research: the Medical Outcome Study HIV Health Survey (MOS-HIV), the Doctor-Patient Communication Questionnaire (DPC), and the Everyday Discrimination scale (EDS).

The HIV Medical Outcomes Survey (MOS-HIV) is a 30-item assessment with 11 domains for quality of life.[16] MOS domains were scored by summing the item responses after recoding for reverse scored items. The scales for each domain were then transformed to a scale of 0–100, with a higher score representing better health status.[16] The EDS is an 8-item survey on a 4-piont scale that assesses how often participants experienced mistreatment within the past year.[17] The DPC questionnaire is a 13-item survey also rated on a 4-point Likert scale that examines the relationship between how well a doctor communicates with their patients and the patient's outcomes.[18] Lower scores on the EDS indicate low perceived discrimination, while a higher score on the DPC suggests strong communication between patients and physicians. As with the MOS-HIV, scores for both assessments were averaged and transformed to a scale of 0-100. All three assessments were reviewed by key community and health system stakeholders prior to implementation.

Data Analysis

The sociodemographic factors of the sample were characterized using descriptive statistics. Data were collected on paper forms and entered into a REDCap database by a member of the research team. Data were analyzed using SPSS Version 28. Continuous variables were expressed using median and interquartile range (IQR) and categorical variables were expressed as frequencies.

RESULTS

Participants were evenly distributed by gender (i.e., 5 women and 5 men), and ages ranged from 26-64 years with a median age of 55 (IQR 46-58) years. Three participants (two men, one woman) were of Haitian descent; the remaining identified as African American or reported no ethnic identity. Baseline viral load levels ranged from 214 copies/mL to 343,000 copies/mL. Half of participants identified their greatest barrier to adherence as an unmet basic need, most commonly food and shelter. Three participants identified healthcare related barriers, such as adverse medication side effects or identifying covered providers; and two indicated social barriers, such as a limited support network.

Intervention Feasibility

Participant recruitment rate was projected to be 10 participants within one month based on prior research by the investigative team.[8] Turnover in clinic staff and an institutional hiring freeze led to initial delays in recruitment from December 2022 to March 2023, resulting in three participants enrolled via direct provider referral from December 2022 to February 2023. Due to the unusual administrative disruption in the recruitment strategy, these three cases were treated as outliers in the data. Thus, a more accurate recruitment rate was inferred from the remaining data.

From April to May 2023, the remaining seven participants were enrolled into the

INSTACARE pilot. Twenty-four patients were identified as potential participants by the charge nurse and referred to the study team for screening before the target sample size was achieved. As shown in *Figure 1*, 17 excluded potentials were removed due to inaccurate contact information (n=9) or updated labwork indicating viral suppression (n=8). Thus, CHWs were able to recruit seven participants within five weeks, resulting in a recruitment rate of approximately 60%. All eligible participants who were approached about the study agreed to participate.

Participant fidelity in the INSTACARE intervention was moderately strong in this small sample, with seven of the ten of participants attending more than 75% of their CHW sessions. Notably, participants who were disengaged with the intervention became more involved within their last few weeks, and the majority asked to participate if a larger intervention became available.

Table 2. INSTACARE Health Survey Assessments, Scoring, and Average Pre-Post Results among a Sample of Black People Living with HIV in Miami, FL.

Assessment	**No. of Items**	**Scoring Range**	$\bar{x}$ **Pre-Int.**	$\bar{x}$ **Post-Int.**
Medical Outcome Survey-HIV	**30**	***0-100***	***68***	***67***
General health	1	1-5	60	66
Pain	2	2-15	71	68
Physical function	6	6-18	71	72
Role function	2	2-4	83	85
Social function	1	1-6	59	67
Emotional Wellbeing	5	5-30	66	63
Vitality	4	4-24	66	62
Health distress	4	4-20	61	69
Cognitive function	3	4-24	56	58
Quality of life	1	1-5	78	62
Health transition	1	1-5	78	66
Everyday Discrimination Scale	**8**	**8-32†**	**48**	**48**
Doctor Patient Communication	**13**	**13-52†**	**78**	**80**

†Final scores scaled out of 100.

Preliminary Efficacy

As a pilot feasibility study with a small, nonrandomized sample size, this study was not adequately powered to identify statistically significant differences between baseline and exit assessments. Thus, the INSTACARE-HS instrument was evaluated on its efficacy as a data collection tool, and pre-post survey responses were reviewed for potential preliminary trends among survey responses. CHWs reported the 55-question survey took, on average, 60- to 90-minutes to complete. As shown in *Table 2*, no changes were observed between baseline and exit scores for the Everyday Discrimination or Doctor-Patient Communication assessments. The average EDS score was 48, suggesting moderate levels of perceived discrimination among patients. The average DPC score was 79, indicating good communication between patients and provider. Some improvement was observed across several HIV-MOS domains between pre- and post-intervention, including general health, health distress, and social functioning (*Figure 2*).

Changes in HIV viral load were also reviewed. At study exit, four of the ten participants had achieved viral suppression within the three-month study timeframe, and one experienced a clinically significant reduction in viral load, though they did not reach viral suppression. Of the five remaining participants, four did not complete their scheduled lab work, including one who refused ART treatment. Finally, one participant maintained high intervention compliance but experienced worsening HIV outcomes due to the advanced progression of their HIV and an excess of social and structural barriers, including homelessness, unemployment, limited literacy, recent traumatic injury.

CHW Perspectives

Emergent themes from the focus group reflected CHW insights on the challenges surrounding study implementation and acceptability of the intervention within the clinic environment. A theme reiterated throughout the group discussion was the need for more time with participants. While the CHWs believed they could help participants overcome their barriers to HIV treatment, they also felt they were “just starting to peel the layers” for many of their difficult cases. This is further reflected in CHW case notes, which highlight how the participants missed less CHW check-ins leading up to their exit date.

CHWs further indicated that many of the resources that participants needed for adherence were social services that could not be addressed within the pilot timeframe. For example, some social services, such as housing or food assistance, require specific documentation that is often unavailable to the most vulnerable of members of the population. This was the case for one houseless participant, who needed to replace their state ID and social security card to apply for disability benefits. Receipt of this documentation can take up to two weeks from the point of submission, and this paperwork must then be brought to the appropriate city office for processing. Further, these estimates do not account for the time potentially needed to locate a transient individual once the documentation arrives. As one CHW shared,

> *"Getting HIV under control is a priority, but it's not the Number 1 priority […] it's housing or it's some sort of income. So, it becomes difficult because of […] the timeframe that it takes to get those resources. We['re] not only working with the individual and their HIV – we're working with the individual and their HIV and the a-million other things that come with that."*

CHWs also noted variability in participant engagement with the intervention. Half of the sample was actively engaged in consistent communication with their CHW, attending 100% of CHW sessions and freely opening up about their barriers to care. Others, however, were more hesitant to establish open dialogue, while some seemed to avoid CHW contact for the majority of the intervention. As one CHW described, "I felt like [the] FBI!", highlighting the challenges to locate some of her patients and provide the resources they discussed. Despite limited engagement, the CHWs noted that nine of ten participants showed increased communication and engagement in the final weeks of the intervention and believed they could develop a rapport with each patient in time. CHWs also highlighted the INSTACARE-HS as a beneficial rapport-building tool. When asked about potential As some clients were less forthright with their need for assistance compared to others, the baseline survey provided CHWs with valuable insight on the social barriers and experiences of the clients. All participants reported interest in continued CHW support if another study became available, suggesting they were able to establish a connection with their CHW during the intervention timeframe. These findings are further supported throughout CHW-focused research, as several publications reflect “trust cannot be earned overnight.” [19]

CHWs held mixed views on their relationships with clinic staff. They perceived the nurses and physicians as having “bought-in” to the Clinic CHW model, as many of them have participated in CHW interventions in the past. As a result of these prior experiences,

> *“They know the benefit of having a CHW […] a one-on-one individual that helps [patients] not only navigate the healthcare system, but [also] to better understand and identify issues in their environment.”*

With regard to social services and support staff, however, CHWs felt their role was met with “resistance,” largely due to misperceptions surrounding the role of a CHW within the clinical setting. “Individuals who render services to the same scope of patients that we target, they don’t necessarily see us as an ally – they see us as repetitive resources.” The group also believed that this barrier could be overcome with time as staff witnessed CHW work in action and distinguished their services from those of traditional case management.

> *“Our line of work is different from a regular case manager, so people don’t fully understand [because] they see us as case management.”*

DISCUSSION

This was a prospective pilot study examining the feasibility of a clinic-integrated CHW intervention designed to help BPLH achieve viral suppression. Specifically, this study evaluated feasibility across four criteria: 1) an estimated recruitment rate of 10 participants per month; 2) a balanced sample composition recruited from the existing clinic population; 3) intervention fidelity among study participants; and 4) CHW perspectives on study implementation. The findings of this study suggest clinic-integrated CHWs are a feasible and acceptable approach to facilitate greater access and communication between patients and the health system, and thus may improve patient outcomes along the continuum of care.

Approximately half of Miami's BPLH have fallen from HIV care. Despite increased use of antiretroviral medication, and an overall increase in sustained viral suppression among the general population, less than 41% of Black adults have achieved viral suppression,[20] highlighting the significant barrier social determinants can create beyond access to care. This is further supported by our data, as the most common barriers to viral suppression for this sample were basic physiological needs, such as food and shelter. As a resource with an established presence in clinical and community settings, CHWs can help PLH address these factors and prevent them from falling through the cracks in the healthcare system.

Aligned with the literature, results from this intervention highlight the importance of both internal and external stakeholder buy-in when establishing a clinic-focused CHW system.[21] While CHWs felt they created a collaborative relationship with the majority of nurses and physicians, support from hospital case managers and social workers was difficult to obtain during pilot implementation, as many felt the CHW role was a replacement for the services social workers currently provide. Future studies should prioritize the development of a research advisory board during the study design phase to ensure the perspectives of all key stakeholders are included prior to implementation.

When considering generalizability, this study was focused on a small sample of patients at a single outpatient HIV clinic. As a result, these findings may not be generalizable to other settings or populations, such as individuals that are lost to care or in treatment at private facilities. However, as the largest public hospital in Miami-Dade County, and the third largest safety-net hospital in the Nation, this health center serves as a primary entry point to obtain HIV care among underserved minority populations. While the broader applicability of this sample is limited, patients seeking care at this institution are often those that lack the resources to obtain services elsewhere and, similarly, may reflect Miami's PLH who would most benefit from CHW support.

Our assessment of CHW fidelity to the intervention was also limited in its results. While all

CHWs were trained in HIV counseling, research file management, and human subjects research strategies, our assessment of CHW fidelity to intervention delivery would have benefit from additional quality control procedures, such as randomized files reviews and client audits. Case notes and other documentation on participant interactions were handwritten by CHWs and reviewed by the Research Coordinator for completion. However, verification of these interactions would have strengthened our evaluation of CHW interventions and limited the influence of potential moderators. As described by the Conceptual Framework for Implementation Fidelity [22], complex interventions, such as sociobehavioral studies, have greater scope for variation in their delivery, and thus are more susceptible to deviations from the protocol. As such, more rigorous recording, reporting, and verification of implementation delivery are needed to ensure the accuracy and replicability of complex intervention methods, and such strategies should be incorporated into future efficacy studies.

Finally, the study activities involved in this CHW intervention are designed for a one-year implementation period. Our previous research on CHW strategies for treatment adherence among BPLH found intervention delivery must last at least 24 weeks to achieve significant improvements in adherence. While this study was not powered to identify statistically significant differences in patient outcomes, many of our survey domains were trending in a positive direction despite the limited timeline, and greater improvements may have been observed if the intervention were implemented for longer. To better determine the efficacy of this intervention, a fully powered randomized trial is necessary.

An often underutilized resource in the healthcare system, CHWs are a valuable asset to healthcare teams due to their unique bond with the population of interest. Our study demonstrates that a clinic-embedded CHW intervention is a feasible strategy with the potential to improve treatment adherence by addressing adverse social determinants of health. By offering targeted social and clinical support, this research shows CHWs may be a promising solution to achieve sustained viral suppression and care engagement for BPLH.

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Supplementary Files

Figures

Flowchart Depicting the Enrollment Process for Participants in the INSTACARE Pilot Study in Miami, FL.

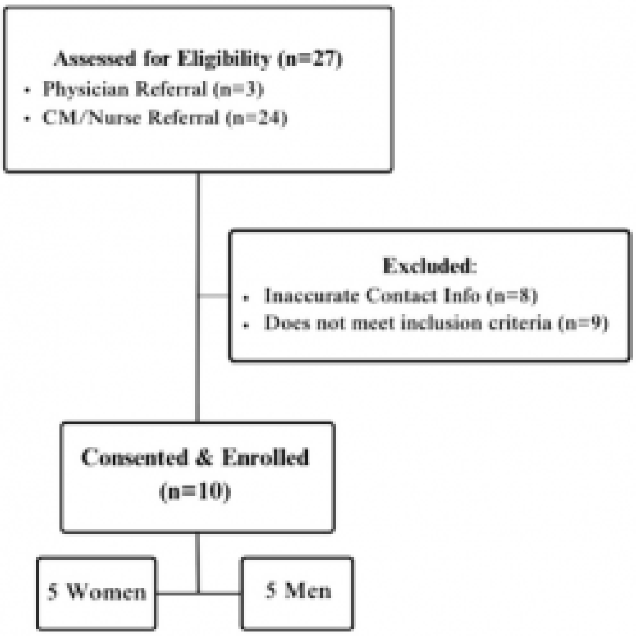

Figure 1. *Flowchart Depicting the Enrollment Process for Participants in the INSTACARE Pilot Study in Miami, FL*

Average Pre- and Post-Intervention Results on the INSTACARE Health Survey among a Sample of Black People Living with HIV in Miami, FL.

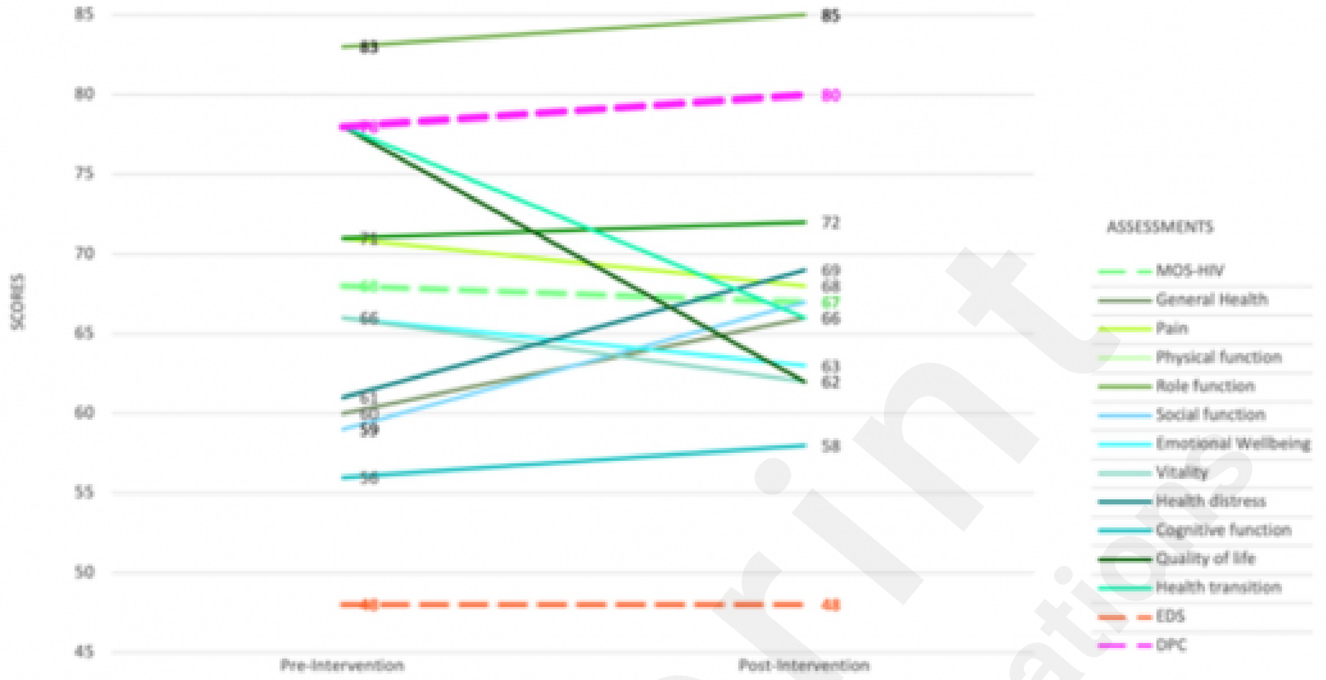

Figure 2. *Average Pre- and Post-Intervention Results on the INSTACARE Health Survey among a Sample of Black People Living with HIV in Miami, FL*