



Comment on Project THANKS: Examining HIV/AIDS-Related Barriers and Facilitators to Care in African American Women: A Community Perspective

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Abstract

The aim of Project THANKS (Turning HIV/AIDS into Knowledge for Sisters) was to provide resources for African American women living with a dual diagnosis of HIV and associated comorbidities such as a chronic illness, and substance use disorder. HIV self-management is viewed within a larger context that addresses HIV and comorbidities concurrently. Project THANKS is an evidence-based, culturally competent curriculum that provides African American women with the necessary knowledge and tools to manage their complications associated with having multiple chronic diseases. The intervention was piloted in 2015 and later conducted in 2018 in 3 community-based health centers in New Jersey. Future interventions of Project THANKS will address the social support, mental health, and health literacy needs expressed by participants as well as incorporating a licensed social worker to further improve their physical and mental health outcomes.

Keywords

African America women, HIV/AIDS, comorbidities, community health, health equity, urban health, community-based intervention

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Summary of Project THANKS (Turning HIV/AIDS into Knowledge for Sisters)

This commentary will provide a brief summary of the project and highlight significant gaps in care for African American women living with HIV (WLWH) that Project THANKS (Turning HIV/AIDS into Knowledge for Sisters) aims to address. This commentary will provide a glimpse into the future direction of Project THANKS based on participant feedback and qualitative findings from the pilot project. Project THANKS is a community-based lifestyle management program for African American WLWH, and an additional chronic disease.¹ The premise of Project THANKS focuses on connecting WLWH to services within their communities in order to reduce the health disparity gap that disproportionately impacts this group. The intervention examines the unique intersection of HIV and co-occurring disorders such as substance abuse and mental disorders, nutrition-related chronic diseases, and socioeconomic status, and how these issues can impact the health

outcomes for African American women living in urban, under-resourced environments.¹

Project THANKS empowers participants to be involved in their health choices and outcomes. The program incorporates a culturally component curriculum that was developed using components that have been adapted from CDC's compendium

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What Do We Already Know about This Topic?

We already know that HIV+ women of color face unique stressors as it pertains to their health and health seeking behaviors.

How Does Your Research Contribute to the Field?

Our research contributes to the field by providing additional context to the lived experiences of HIV+ women of color and how to best address their healthcare and psychosocial needs.

What Are Your Research's Implications toward Theory, Practice, or Policy?

Our research's implications towards practice include resources for social workers, therapists and case managers to assist in the delivery of services for HIV+ women of color.

of evidence-based HIV prevention interventions for African American women, namely the Holistic Health Recovery Program (HHRP) and Sisters Informing Sisters on Topics about AIDS (SISTA). Project THANKS differs from HHRP and SISTA however, in that in addition to HIV and substance abuse, this curriculum aims to provide African American women with the necessary knowledge and tools to manage the complications associated with having multiple chronic diseases.

Project THANKS has 3 primary goals for women participating in the program: (1) prioritizing their health care needs given the dual diagnosis of HIV and another chronic disease and substance use disorder; (2) learning to recognize the symptoms of other chronic diseases early and seek appropriate care; and (3) learning to become an active participant in their own health care by adopting healthy behaviors. The intervention aimed to accomplish this goal by including components that enhanced each individual's problem-solving and decision-making skills, increasing self-efficacy, and building their sense of agency. Facilitators and peer leaders were responsible for implementing the curriculum and worked collaboratively with participants to reflect upon individual, sociopolitical, and environmental systems that have a direct impact on their nutrition, access to medical care, mental health resources, and supportive networks.

The success of Project THANKS partially stems from its theoretical foundation, as the socio-ecological model utilized highlights a comprehensive network which includes changes in perception and values at the individual level (knowledge, attitudes, and beliefs), interpersonal level (social support and size of social networks), and environmental level (availability of relevant information and educational resources), and

institutional (public health policies).¹ The program assumes that changes across all levels are most effective in producing systemic change in health outcomes and promoting health equity for women with HIV.² The aim is to contribute to the literature and science on community-based intervention research for African American WLWH and comorbid disorders.

The intervention was first pilot tested in 2015 with a group of 10 WLWH at Well of Hope Community Development Center Inc, a harm reduction agency that serves a high number of low-income WLWH residing in and around Paterson, NJ. Paterson, NJ, is an urban, under-resourced community and has one of the highest rates of HIV/AIDS in the state. In 2018, an intervention research study involving Project THANKS was conducted in 3 community-based health centers: North Jersey Community Research Initiative in Newark, NJ Camden Area Health Education Center in Camden, NJ and St. Clare's AIDS Resource Foundation Center in Newark, NJ. Newark and Camden were targeted cities to receive Project THANKS due to the high rates of HIV/AIDS cases in New Jersey.³ Project THANKS implemented 7 weekly group sessions which were approximately 2.5 hours long in each health center. There were 7 sessions included in the intervention: (1) Needs Assessment (focus group discussions to assess the specific needs of the African American WLWH in the program); (2) Personalized Goal Setting (motivating participants to set realistic goals for themselves using role plays and case scenarios); (3) Stress Management (learning how to manage stress caused by the intersection of race, gender, class, co-occurring disorders, and HIV status); (4) Nutritional Recovery (learning how to access healthy food options and nutritional importance); (5) Healthy Relationships (learning how to identify and maintain supportive and healthy relationships); (6) Healthcare Participation (teaching women how to be involved in their physical health care); (7) Media Advocacy (learning tools on community mobilizing and empowerment through advocacy of health care access and public health issues).³

The results of the group sessions are applicable to other communities that comprise women of color living with HIV/AIDS and related comorbidities. The findings add to the body of existing research on effectively providing care to WLWH. By aiming to "sustain and build upon the implementation of the intervention at harm reduction agencies across the state" and by creating new models of service, Project THANKS hopes to provide direct insight to the agencies and health care professionals from the communities they serve in order to provide meaningful and sustainable change.^{1,3}

The Need for Project THANKS for African American WLWH

Project THANKS is innovative in nature as it is designed to encourage women to set overall health and wellness goals while acknowledging environmental context. Women living with HIV have stated that identifying what is important in their life, which can vary depending on their circumstance,

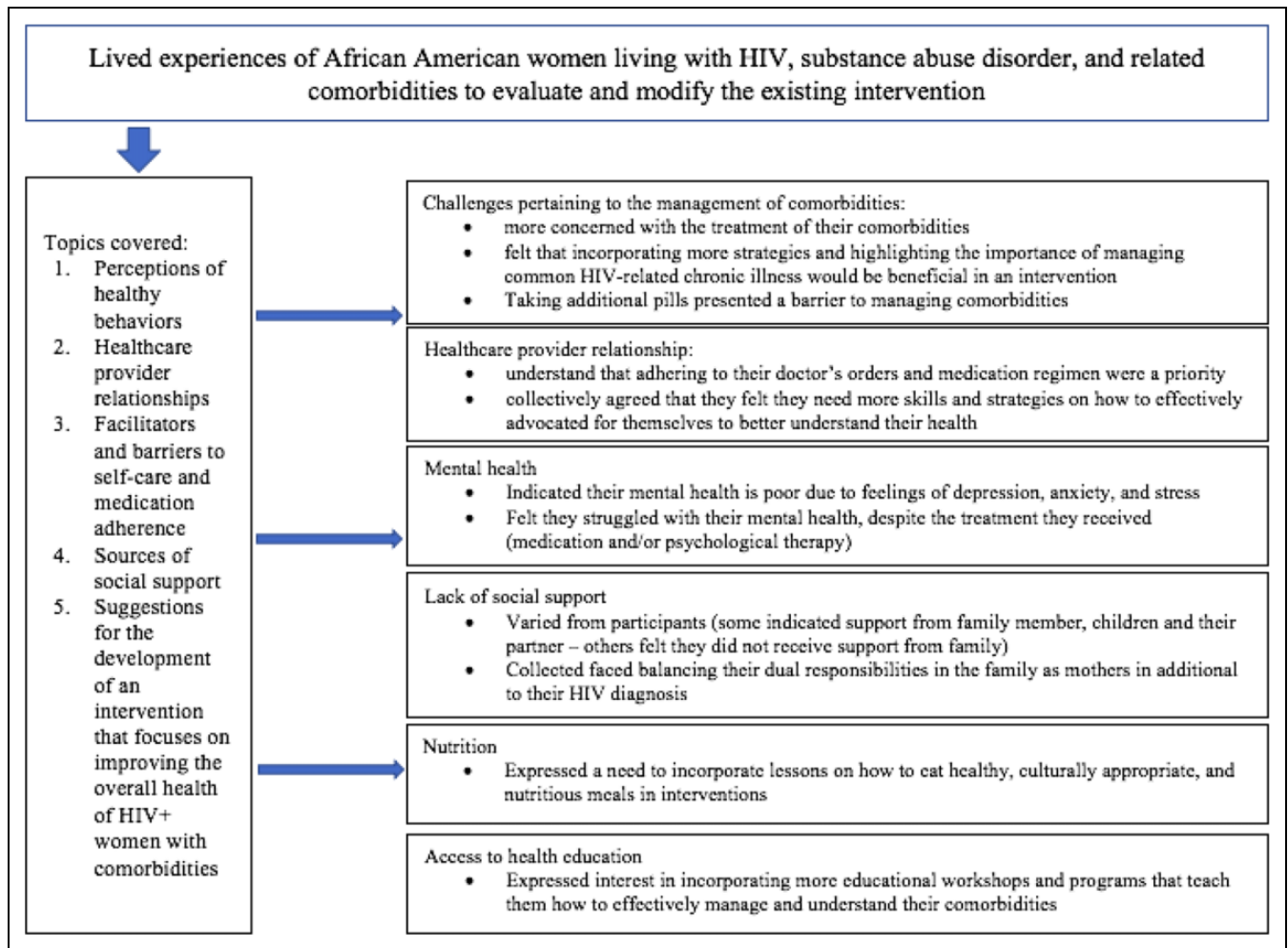


Figure 1. Major themes from qualitative study.

motivates them to adhere to treatment.^{4,5} Thus, interventions that incorporate goal setting help participants focus on what is important to achieve a sense of balance between the difficulties associated with managing HIV and comorbidities and other life responsibilities, such as caring for children.⁶ Project THANKS takes an individualistic approach by allowing the women to set goals that will ultimately motivate them to adhere to treatment.

Research has suggested that African American WLWH may be at a particularly high risk for psychological distress compared to African American men and white women and men.⁵ Project THANKS addresses the concerns of HIV-positive African American women who are dealing with multiple chronic conditions (ie, diabetes, hypertension, or heart disease), mental health disorders, and substance use disorder and have unique contextual needs. African American women as a whole are at an increased risk for poverty, are more likely to be unmarried and under or uninsured than whites, and often place their health care needs behind other family members, that is, spouses, children, and grandchildren.⁷⁻⁹

In our qualitative study, Project THANKS participants indicated experiencing feelings of depression, anxiety, and stress (see Figure 1). A systematic review by Lambert et al found that

social support was a valuable resource that improved ART adherence and retention in care.¹⁰ Similarly, Project THANKS participants indicated that it was comforting to connect with other WLWH. Social support was a major theme that arose from the qualitative study. Future interventions of Project THANKS will include a targeted focus on addressing mental health needs by incorporating meditation and providing referrals to mental health services.

Project THANKS participants indicated they wanted a better understanding of their health; including their laboratory tests results and the impact of medication on their treatment (see Figure 1). HIV care providers have stated the importance of patient education and counseling.⁴ Due to the findings from the qualitative study, future iterations of Project THANKS will incorporate more educational workshops to provide participants with the tools to better manage their health, including understanding lab tests and treatment and communicating better with their provider.

A strong patient–provider relationship can lead to better medication adherence and improved treatment outcomes among African American women with HIV.¹¹ In DeMoss et al's qualitative study among middle-aged African American WLWH in the Deep

South, participants indicated that a strong relationship with their provider was a contributing factor to taking their medication as prescribed. In another study, African American WLWH in the South said it was also important that their health care provider takes a genuine interest in their care.¹⁰ Project THANKS focus groups reinforced these findings.

Studies show that managing HIV in addition to other chronic conditions can affect treatment adherence (taking multiple medications for multiple conditions), retention in care, exacerbate stress and depression, increase side effects, and lead to worse health outcomes.^{10,12,13} In a series of focus groups conducted in Washington, DC, with HIV-positive African American women aged 52 to 65, comorbidities were perceived to be more difficult to self-manage than HIV.¹² Warren-Jeanpiere et al concluded that optimal HIV self-management (adhering to daily medication, eating well, exercising, doing something good for others and self, and engaging in spiritual activities) must be viewed within a larger context that addresses HIV and comorbidities concurrently.⁶

Next Steps, Insights, and Reflection

As Project THANKS looks to expand the curriculum that has been implemented previously, considerations that examine the most impactful way to address the evolving health and social support needs of WLWH are needed.¹⁴ African American WLWH represent a unique group that faces the compounded burden of being female, African American, and HIV positive. The intersection of race and sex requires a targeted and holistic approach to ensure that as African American WLWH age, they are able to be retained in care, practice medication adherence, and enjoy full and fulfilling lives.

Future iterations of Project THANKS will look to incorporate social support (ie, friends, family, and treatment-specific peer groups) into the program. The addition of a licensed social worker or therapist to assist the women in unpacking their feelings of guilt, shame, and stigma would be a powerful change to the existing curriculum. For the next implementation of the Project THANKS curriculum, we plan to increase critical health literacy in participants by delving deeper into the treatment and management of HIV and other chronic illness, such as diabetes, hypertension, and heart disease, to ensure that women fully understand and are able to properly manage their lives and advocate for themselves. Through replication and rigorous research, our ultimate goal is to ensure that all African American WLWH in the United States are able to benefit from the tenets of Project THANKS, and that their lives, families, and overall physical and mental health outcomes are vastly improved.


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